Running Head: Transfer of Young Adults

TRANSFER OF YOUNG ADULTS WITH TYPE 1 DIABETES FROM PEDIATRIC TO ADULT DIABETES CARE

By

Christina B. Whittaker

A Thesis Submitted to the Faculty of Graduate Studies in Partial Fulfillment of the Requirements for the Degree of

MASTER IN NURSING

Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba

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Transfer of Young Adults with Type 1 Diabetes from Pediatric to Adult Diabetes Care

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Christina B. Whittaker

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

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ABSTRACT

Young adulthood is a period of major transition in physical, psychological, and social development. Throughout this time, youth with Type 1 diabetes must continue to meet the extensive health and self-care demands of diabetes, during which they are transferred from pediatric to adult diabetes health care. Research indicates that many young adults with Type 1 diabetes do not continue with diabetes medical care and education upon transfer to adult health care, however research limitations and programmatic differences prohibit generalization of research. The purpose of this study was to examine the experience of young adults with Type 1 diabetes in Winnipeg as they moved from specialized pediatric diabetes health care to specialized adult diabetes health care.

Using the Health Belief Model as a conceptual framework, this exploratory five-year multi-site retrospective study used audits of the pediatric and adult diabetes health records to examine diabetes health, and follow-up with diabetes health care the year before and after transfer. A mailed self-administered questionnaire included standardized tools to examine the subjects' health beliefs, and a number of questions to explore the subjects' experiences and recommendations regarding the transfer process. Bivariate analysis was conducted to examine the relationship between health beliefs, metabolic control, and attendance at pediatric and adult diabetes health care. Content analysis was used to examine the self-report of the experiences of the 19 subjects, and to formulate major themes.

Close to half of the subjects reported having difficulty with their transfer. Their predominant recommendation for young adult care was for a specialized diabetes health care

team for those aged 18 to 25, consisting of both the pediatric and the adult diabetes team. The distribution of the total number of visits, and of the frequency of Hemoglobin A1C measurement pre and post transfer was significant. Metabolic control remained suboptimal. The subject's age at the last visit to pediatrics, self-report of the helpfulness of transfer information from the pediatric diabetes team, and visits to specific pediatric staff correlated to metabolic control or participation in adult health care. Further results, and recommendations for future research and for the development of a transition program are provided.

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CHAPTER 1: SIGNIFICANCE OF THE PROBLEM

Introduction

Literature concerning the diabetes-related health of young adults with Type 1 diabetes has demonstrated both increasing recognition of the importance of glycemic control in attaining long-term health, and uncertainty regarding the continued participation of young adults in diabetes medical care or education when they are transferred from their specialized pediatric diabetes health care team to specialized diabetes adult health care. The unequivocal acceptance of the research-based evidence by both the pediatric and adult diabetes health care teams of the importance of glycemic control and on-going participation in health care is in contrast to the limited research assessing the follow-up of young adult clients of the pediatric diabetes health care team when they are referred to adult diabetes health care.

Young adulthood is a period of major transition in physical, psychological, and social development (Newacheck, McManus, & Fox, 1991). Young adults may be dealing with issues such as employment, relationships, experimentation with alcohol, sex and drugs, parental conflict, and decision making in the areas of marriage, vocation, child-bearing and personal values, all in the context of declining parental influences (Ferguson, 1988). Young adults want to distance themselves from authority and become free from the perceived limitations that prevent them from attaining their aims and developing into independent adults (Kyngas & Hentinen, 1995). This natural strive for independence and freedom can translate into distance from diabetes education, medical care and self care.

Type 1 diabetes imposes extensive behavioural demands on the individual and family. Management entails a complex and unremitting regime involving decision-making

and self-care of insulin doses and injections, blood glucose monitoring and recording, meal planning, activity management, and prevention and treatment of hyperglycemia and hypoglycemia (Wysocki, Hough, Ward & Green, 1992). In a nine year study of 95 youth who entered the study between the ages 8 to 13 years of age, Kovacs, Goldston, Obrosky and Iyengar (1992) found that the ages of 17 to 19, more so than any other age group studied, was associated with the least amount of time participating in self-care behaviours, a factor that was directly associated with diabetes related rehospitalization and poor metabolic control. It is during this period between adolescence and adulthood that the young adult is forced to move from their pediatric health care team to an unfamiliar adult health care team.

Research indicates that many young adults with Type 1 diabetes opt out of medical care at the time of transfer to adult health care. They may resurface in the health care system several months or years later when they experience a diabetes-related crisis which otherwise might have been averted (Frank, 1996). A Canadian researcher demonstrated a 24 percent failure to engage in diabetes medical care three to four years after discharge at age 18 from pediatric care in a major referral centre in Toronto (Frank, 1996). Those who did not engage in medical care were significantly more likely to have been hospitalized for a diabetes-related problem prior to and after referral, have a higher mean glycated hemoglobin and have exhibited less frequent use of the pediatric diabetes clinic the year prior to discharge. Bartsch, Barnes, Jarret, and Lindsay (1989) found a high hospitalization rate of 28% the year following referral from pediatrics to adult health care, with only 38% of the sample seeing an endocrinologist for adult diabetes medical care.

Many possible factors influencing the lack of consistent follow-up with specialized adult diabetes care and education have been put forward in the literature. Reasons expressed

by clients are varied. A survey in Montreal, Canada, found that 13% of the respondents were not being followed medically. The majority of participants asserted that they should have been transferred when older than the clinics' mean age of referral of 18.5 years (Pacaud, McConnell, Huot, Aebi, & Yale, 1996). No Canadian research was found that addressed follow-up in adult diabetes education.

A landmark study, the Diabetes Control and Complications Trial (DCCT) demonstrated that maintenance of near-normal glycemic control delays the onset and slows the development of long-term complications of diabetes (DCCT Research Group, 1993). Subjects with type 1 diabetes with either no complications or mild retinopathy were randomly assigned to either intensive or conventional diabetes care and education. Over a six and one half year period, the mean risk for the development or progression of retinopathy, the occurrence of microalbuminuria and the occurrence of clinical neuropathy was reduced from 34% to 76%. Subjects enrolled in the DCCT at age 13 to 17 years had higher mean Hemoglobin A1C (Hgb A1C) values compared to adults. As indicated in the Clinical Practice Guidelines (CPG), Hgb A1C reflects glucose control over the preceding two to four months (Meltzer et al., 1998). This age group of 13 to 17 was "the most difficult to manage and required a disproportionate share of the supportive care provided by the diabetes treatment team" (DCCT Research Group, 1994). In response to the DCCT results, the 1998 Canadian Clinical Practice Guidelines reduced the acceptable glycemic control for adolescents over the age of 13 from a Hgb A1C < 150% of the upper limit of the normal to the same as the adult goal of <110% (Meltzer et al., 1998). In an evaluation of the DER-CA (Diabetes Education Resource for Children and Adolescents) by Anderson (1997) less than 17% of the self-selected sample surveyed age 13 to 17 years had a Hgb

A1C within the previous acceptable goal of Hgb A1C < 150% of normal, further underscoring the risks and needs of the age group.

The purpose of this study was to examine the experience of young adults with Type 1 diabetes in Manitoba as they move from specialized pediatric health care to specialized adult health care. This study has contributed to a greater understanding of the needs of young adults with Type 1 diabetes in Winnipeg during this time period.

Significance of the Problem

The number of Canadians aged 12 and over with diabetes is estimated at 1.2 to 1.4 million, with an annual incidence of 2.6 new cases per 1,000 people (Bureau of Cardio-Respiratory Diseases and Diabetes, Laboratory Centre for Disease Control, Health Protection Branch, 1999). Such statistics do not distinguish between the type of diabetes. The average annual incidence of Type 1 diabetes in children aged 0 to 14 years in Manitoba from 1985 to 1993 was 20.4 per 100,000. This incidence is double that in the 1970's of Montreal and Toronto, and similar to that of Prince Edward Island from 1975 to 1986 (Blanchard et al., 1997). Karvonen, Tuomilehto, Libman and La Porte (1993) compiled epidemiological data on Type 1 diabetes under 15 years of age from incidence data collected by nearly 70 registries in 40 countries in the late 1980's for the World Health Organization. Incorporating Manitoba statistics into this global picture would indicate that Manitoba has the ninth highest reported incidence of Type 1 diabetes in this age group.

The economic costs of diabetes in Canada may be as high as $9 billion in U.S. funds (Bureau of Cardio-Respiratory Diseases and Diabetes, Laboratory Centre for Disease Control, Health Protection Branch, 1999). A large portion of the costs of

diabetes relates to the care and treatment of long-term complications. As found in the Manitoba Burden of Illness study (Epidemiology Unit and Diabetes Unit, 1996), the rate of initiation of dialysis and lower limb amputations for persons with diabetes was approximately 10 times higher than for persons who did not have diabetes. The hospitalization rate due to cardiovascular disease and stroke was close to five times higher than for those who do not have diabetes (Epidemiology Unit and Diabetes Unit, Public Health Branch, Presentation, February 28, 1996).

Health care costs in Manitoba in 1995-96 for adults with diabetes related to inpatient hospital services, professional and medical services, dialysis services and personal care homes were estimated at $193 million. This amount represents approximately 18% of health care spending on adults for these services during one year, with the annual per capita cost for these services roughly twice as much for adults with diabetes than in the general population (Manitoba Diabetes Steering Committee, 1998). The aforementioned costs do not include indirect or social costs, or other direct health care costs such as pharmaceutical needs, home care, diabetes education, or public health. Lack of follow-through with diabetes care or education prevents the opportunity for education and early screening for prevention of complications, increasing the expenditures related to an increased risk of complications.

The "Clinical Practice Guidelines (CPG) for the Treatment of Diabetes Mellitus'' from the Canadian Diabetes Association (Meltzer et al., 1998) formally recognized the uniqueness and importance of the young adult moving from pediatric to adult health care by including a reference to transition for the first time in 1998: "Planning the transition from pediatric to adult diabetes care must be undertaken with sensitivity to the needs of

the adolescent and recognition of the factors that predict noncompliance with medical follow-up" (Meltzer et al., 1998, p. 18). In Manitoba, the Diabetes and Chronic Diseases Unit of Manitoba Health coordinated the development of a provincial diabetes strategy. The Manitoba Diabetes Strategy Committee (1998) recommended a "specialized integrated care program for young adults (age 18 to 25) with Type 1 diabetes" to "assist in transition from pediatric to adult care" (p. 28).

The terms "transition" and "transfer" are often used interchangeably, particularly in relation to the movement of adolescent clients from pediatric health services to adult services. It has become popular in recent health care nomenclature for programs to relate to their "transition" program, regardless of the program content. "Transfer" to adult health care has been described as an isolated event, and is not part of an anticipated, planned process (Sawyer, Blair, & Bowes, 1997).

In contrast, the concept of "transition" is illustrated by terms such as passage, bridge, progression, journey, and adjustment. In their conceptual analysis of transition, Schumaker and Meleis (1994) found three universal properties of transition that distinguish between "transition" and "nontransitional change." According to these authors, transition includes: 1) a process that occurs over time, 2) development, flow or movement from one state to another, or, have a sense of direction, and 3) change in fundamental life patterns. In the movement from pediatric to adult health care "transition" is a "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems" (Blum, Garell, Hodgman, Jorissen, Okinow, Orr, & Slapp, p. 570, 1993).

In Manitoba, data is lacking on the period of time between specialized pediatric

diabetes health care and adult diabetes care. Written documentation is not available as to whether the young adults maintain regular contact with adult health professionals regarding their diabetes, the form the contact takes, and the reasons for lack of follow-up. Among health care professionals opinions differ as to the nature or extent of difficulties during the referral process, potential solutions to these difficulties, and the role of the pediatric versus the adult health care team in young adult diabetes care. Currently, the only available evidence is anecdotal, based on individual case reports shared between the health care teams or provided by the client and family.

Diabetes Community Care and Education in Manitoba

In Manitoba, the Diabetes Education Resource for Children and Adolescents (DER-CA) provides initial and on-going diabetes education to children and adolescents with diabetes and their family up to 18 years of age. The DER-CA sees 95% of all children in Manitoba with Type 1 diabetes aged 0 to 14 years (Blanchard et al., 1997). The DER-CA is the centralized and specialized pediatric component of 12 province-wide diabetes education resources (DER). Clients of the DER-CA are predominantly from the population of Manitoba. The other 11 DER programs are distributed geographically throughout Manitoba, and focus primarily on diabetes health care and prevention in Type 2 diabetes, adults with diabetes, and community education and prevention.

The DER-CA education team (educators) consists of a social worker, dietician and nurse educator. Diabetes medical care is provided by 1) a pediatric endocrinologist, also Pediatric Medical Advisor to the DER program and Medical Director of the DER-CA, and 2) a clinical associate (pediatrician). Intense follow-up of the child and parent/caregivers occurs during the first year of diagnosis, after which follow-up at the DER-CA is

recommended a minimum of every six months.

The DER-CA is a provincially funded community program and is physically located within the facilities of Children's Hospital, Health Sciences Centre, Winnipeg, Manitoba. Children's Hospital is a university associated teaching facility and the only facility in the province that offers tertiary care in pediatrics. The DER-CA is currently under the administrative authority of the Winnipeg Regional Health Authority.

The DER-CA transfers clients to adult health care at the age of 17 years. Age is used as the criteria for transfer as: 1) The DER-CA medical director is not able to write prescriptions for people greater than 18 years of age; and 2) Children's Hospital policy prohibits admission of clients older than 17 years of age unless they have a chronic illness already being treated at Children's Hospital (Health Sciences Centre, 1996). This would exclude clients of the DER-CA who rarely require admission to hospital. A review of the practice of the DER-CA indicates that transfer to adult health care may occur at an earlier age at the clients' request, but is an infrequent occurrence.

The DER-CA referred a mean of 34.6 clients annually to adult diabetes care in Winnipeg from 1994 – 1998 inclusive for a total of 173 (Diabetes Education Resource for Children and Adolescents, 2001) (see Appendix A). Data from 1999 onward does not discriminate between those who left the pediatric program due to moving and those who were transferred to adult care. The transfer of young adults to adult diabetes care at the DER-CA begins with education of the client. The family may be included in education if available, however many clients at this age attend appointments alone. Ideally, education regarding referral to adult care begins at least one year prior to the final DER-CA appointment, allowing for education and preparation to proceed over a further two to four

visits. The desired recommended frequency of appointments at the DER-CA is not always maintained by the client, with discussion of the transfer to adult care prior to the final appointment not always possible. Educational content related to young adult health care issues such as smoking, pregnancy, drugs and alcohol are integrated into the regular diabetes education program beginning in the early adolescent period.

Any staff member of the DER-CA may initiate education of the client regarding the upcoming referral to adult health care. The client is verbally provided with a choice of both an adult diabetes education team and adult endocrinologist (see Appendix B: Options for Adult Diabetes Medical Care and Education in Manitoba), to which a written referral is then made. The adult health care provider contacts the client to arrange an appointment upon receipt of the referral.

Summary

The experience of young adults as they move from pediatric to adult health care in Manitoba was unknown. Anecdotal evidence was suggestive that many young adults did not consistently follow through with adult health care providers. This lack of health care utilization occurred at a time when glycemic control grows increasingly critical to their future health. Research to identify factors that impact on effective transfer to adult care may ultimately reduce health care morbidity, and the resultant health care costs. This research describes the nature of the follow-up with diabetes education and medical care in Winnipeg, and the factors associated with specialized adult diabetes follow-up of the participants. These results provide evidence on which future programs can be planned.

CHAPTER 2: CONCEPTUAL FRAMEWORK

Introduction

The Health Belief Model (HBM) is the framework to guide the development of this thesis. The review of the HBM will focus primarily on the literature as it applies to Type 1 diabetes and youth.

Health Belief Model

The HBM was developed within the field of social psychology in the 1950's by Rosenstock, Hochbaum, Kegeles and Leventhal as a conceptual framework to understand preventive health behaviour. Concerns about the failure of people to accept disease prevention, or screening tests for early detection of asymptomatic disease despite services being offered free of charge or at low cost stimulated the development of the HBM (Rosenstock, 1974).

The HBM states that the likelihood of undertaking health behaviour is related to the individual's beliefs or perceptions as they relate to the following dimensions:

1) Perceived susceptibility: one's subjective perception of the risk of experiencing a condition or problem.

2) Perceived degree of severity (threat): feelings concerning the seriousness or consequences of a disease or problem, social and physical; how threatening the condition is to the person.

3) Perceived benefits of the treatment: the perceived effectiveness of the various actions available to reduce the threat or severity of a problem.

4) Perceived barriers to care: the individual weighs the action's effectiveness against perceptions of any negative side effects or difficulties (Rosenstock, 1974; Janz & Becker,

1984).

The interrelationship of these dimensions was summarized by Rosenstock (1974). The combined levels of susceptibility and severity provide the impetus to act, and the perception of benefits minus the barriers provides a preferred path of action.

In addition to the four dimensions, stimuli are necessary to trigger the decision-making process. Such "cues to action" might be internal (e.g. symptoms) or external (e.g. media, reminders from healthcare providers, interpersonal interactions). The intensity of the cue that is required to stimulate behaviour is presumed to vary with the level of readiness to act (Mikhail, 1981). Diverse "modifying" factors, such as demographic, sociopsychological, and structural variables might affect an individual's perceptions of susceptibility, severity, benefits and barriers and thus indirectly influence health-related behaviour (Rosenstock, 1974). A schematic model of the HBM was developed by Becker, Drachman and Kirscht in 1974 and adopted by Rosenstock (1974).

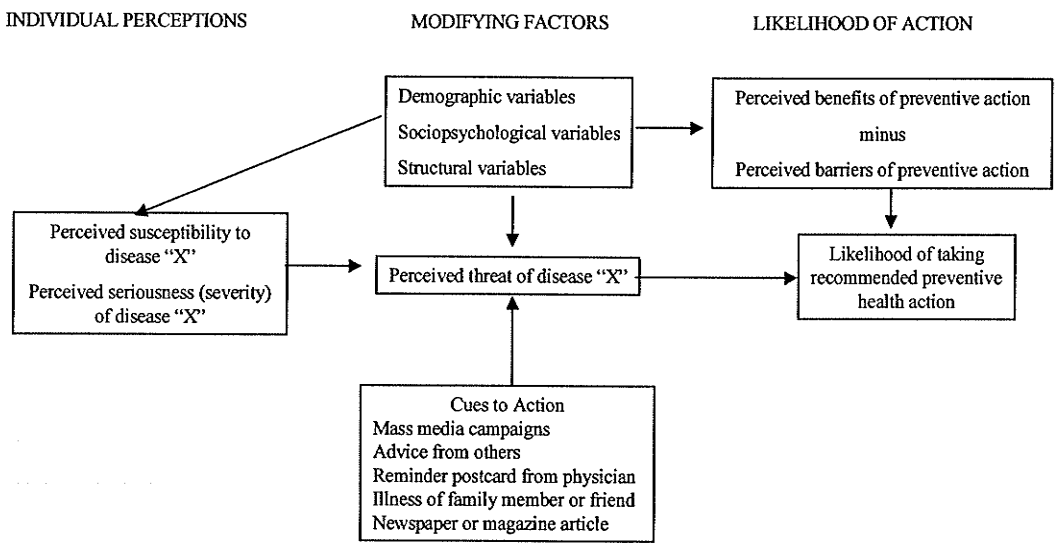

Figure 1

The Original HBM as Predictor of Preventive Health Behaviour (Rosenstock, 1974)

In 1985, Rosenstock proposed that the HBM be expanded to include a fifth dimension - the belief in one's "self-efficacy," or the conviction that one is capable of carrying out a health recommendation. The addition of self-efficacy followed the principles of social learning as espoused by Bandura in 1977. While people may believe in the efficacy of health recommendations, Rosenstock declared they would not comply if they believe the regimen is too difficult for them to follow. Rosenstock (1985) concluded that:

> ... an expanded HBM that incorporates perceived self-efficacy should provide a more powerful approach to understanding and influencing a health-related behaviour, and that such an exploration should rank high on any research agenda for studying and improving adherence (p. 610).

The HBM began to be applied beyond preventive health behaviours, and theorized as applicable to "sick-role" behaviour and chronic illness in the 1970's (Mikhail, 1981). Janz and Becker (1984) provided a comprehensive review of research incorporating the HBM, published from 1974 to 1984. The authors limited their review to research that involved adult subjects, medical conditions, all four core dimensions of the HBM, and that included at least one behavioural outcome. The authors confirmed the predominant use of the HBM was to explore preventive health behaviours via retrospective studies (Janz & Becker, 1984). The author's review of the 46 HBM studies determined that 18 studies were prospective and 28 retrospective. Twenty-four studies examined preventive health behaviours, 19 explored sick role behaviour, and three addressed clinic utilization. Three of the studies examining sick role behaviours pertained to diabetes.

One professed strength of the HBM is it's potential flexibility. The HBM allows for the individual to identify his/her own perceptions of health. It does not suggest a specific

approach for intervention, but provides for the implementation of specific, targeted strategies that can specifically apply to the population under study. As such, the model could be applied to a wide variety of health related behaviours (Mikhail, 1982). Application of the HBM to health-related behaviour may support the identification of specific predictors and motivators of health behaviour. The HBM may well serve as a logical basis for developing a set of guidelines in making an "educational diagnosis" that will allow the health care professional to focus educational interventions on identified health beliefs, behavioural skills, and self-efficacy (Janz & Becker, 1984; Rosenstock, 1985). Any one of the variables in the model, or a combination of them, can be altered or manipulated by a health provider as appropriate to the health behaviour and population under study.

The specific populations and disease entities researched to date have restricted the application of the HBM to a wider range of health-related activities and populations. As the HBM was not created specifically to apply to children or adolescents, research is needed to explore whether it can adequately explain or account for familial or developmental issues. The HBM has been evaluated as demonstrating greater explanatory power than predictive value in relation to chronic illness (Rosenstock, 1985; Becker and Janz, 1985). Evidence is also limited as to how much variance in individual health related behaviours can be explained by those particular attitudes and beliefs (Charron-Prochownik, Becker, Brown, Liang & Bennett, 1993; Rosenstock, 1985). In regard to adherence, the HBM has not consistently demonstrated predictive validity (Charron-Prochownik et al., 1993). This gap in research relative to the HBM and whether it can predict adherence with specific disease regimes in order to understand a variety of health related actions particularly behaviour related to chronic illness is beginning to be

addressed (Charron-Prochownik et al., 1993).

Health Belief Model and Diabetes

In 1985, Rosenstock confirmed the utility of the HBM as a conceptual scheme to understand behaviours related to diabetes. According to the HBM, individuals with diabetes will most likely participate in a "treatment" or diabetes self-care plan if they hold the following four beliefs to be true, undertaking a kind of cost-benefit analysis:

1) They are vulnerable or susceptible to problems due to diabetes or its consequences, such as complications.

2) Diabetes or its consequences could have a serious, negative impact on their lives. This dimension includes evaluations of both medical and/or clinical consequences (death, disability, pain), possible social consequences (effect of the condition on work, family life, social relations) and seriousness of leaving diabetes untreated.

3) Following health recommendations will be beneficial in reducing the threat of, or the severity of, diabetes-related problems. Health action is seen as feasible, available, and efficacious.

4) The barriers associated with following the health recommendations (e.g. economic cost, pain, convenience, effort, and side effects) are outweighed by the benefits.

Since the review by Becker and Janz in 1985, research has continued to expand into the areas of health behaviour related to acute and chronic illness. Diabetes has continued to remain an emergent focus of HBM research. The complexity of the diabetes regime and the required or recommended health related behaviours may explain the emergent focus of HBM research on diabetes as a chronic illness (Rosenstock, 1985).

The majority of the published research regarding the HBM and diabetes examined

adults with type 2 diabetes. One Canadian study that used the HBM in diabetes research by Pham, Fortin and Thibaudeau (1996) examined the relationship between health beliefs and self-reported adherence in adults with diabetes and lower limb amputations. A number of the published research studies examined the development of measurement tools for the HBM (Bradley, Brewin, Gamsu & Moses, 1984; Given, Gallin & Condon, 1983; Harris Linn, Skyler & Sandifer, 1987; Harris, Skyler, Linn, Pollack, & Tewksbury, 1982 and Hurley, 1990b). A frequent theme within the research was the examination of the HBM to predict or explain diabetes behaviours related to the outcome measures of "compliance" or "adherence," and to metabolic control (Bond, Aiken & Somerville, 1992; Brownlee-Duffeck et al., 1987; Cerkoney & Hart, 1980; Charron-Prochwonik et al., 1993; Harris, Skyler et al., 1982; Pham et al., 1996; Polly, 1992; Woolridge, Wallston, Graber, Brown & Davidson, 1992). The diversity in sample and methodology makes comparisons of research difficult. Most of the research examining diabetes and the HBM explored all four of the original core dimensions of the HBM, although the dimensions were frequently measured differently. The factors of "cues to action" and modifying factors were commonly discussed within descriptions of the model, but were not consistently measured in previous research, nor commonly incorporated in HBM scales (the exceptions found were the scales used by Cerkoney & Hart, 1980; Pham et al., 1996).

Few studies applied the HBM to samples of children or youth with Type 1 diabetes. Research relevant to children and youth was found within the fields of nursing, medicine and psychology. One of the difficulties encountered in the literature is the lack of differentiation between young adults, and adults in studies. Some researchers (Bradley et al., 1984 and 1987; Cerkoney & Hart, 1980; Coates & Boore, 1998; Given et al., 1983; Schlenk

& Hart, 1984) utilized study samples that combined young adults aged 17 and 18 with adults who were up to 50 or 70 years of age, thus assuming a homogeneity of variables within a very heterogeneous age group. A small but growing amount of research was restricted to children or to young adults (Bond et al., 1992; Brownlee-Duffeck et al., 1987; Charron-Prochownik et al., 1993; Wdowik, Kendall & Harris, 1997).

Application of the Health Belief Model to Transition

The use of conceptual models within transition research, and research in young adults with Type 1 diabetes is limited. No previous applications of the HBM to transition research or young adults with Type 1 diabetes were found. The following model was developed by the researcher based on previous research and the literature review.

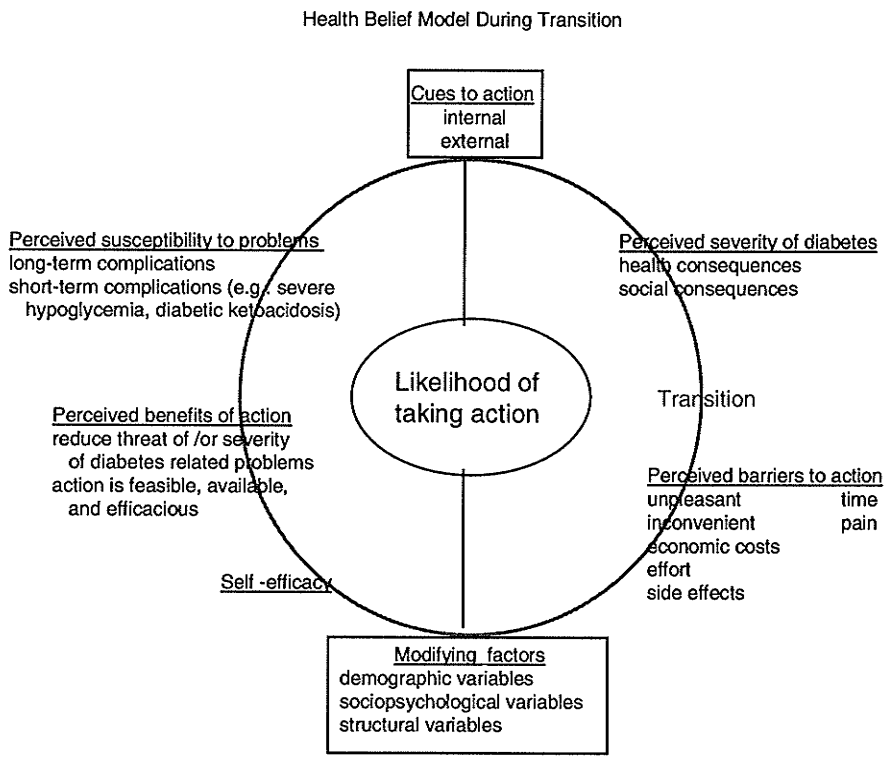

Figure 2:

Modification of the Health Belief Model as Applied to Transition

The schematic in Figure 2 represents the HBM and includes the core dimension of self-efficacy as recommended by Rosenstock. As with the original schematic by Becker, Drachman and Kirscht (as cited in Rosenstock, 1974), the core dimensions of the HBM, cues to action and modifying factors are conceptualized as impacting on the likelihood of taking health related action. The action or behaviour under investigation in this research is the behaviour related to transition, as symbolized by the connecting circle. The interrelationship of the components is consistent with the original model. Chapter four will describe the study variables that were incorporated into the HBM to examine young adults with Type 1 diabetes during transfer to adult care. The dimensions of the HBM as recommended by Rosenstock were applied in their entirety.

Summary

The HBM has evolved from the prediction of preventive health behaviour to the prediction of illness behaviours in diabetes and other chronic illnesses. Gaps in research related to specific age groups and disease entities are being addressed, however comparisons and generalizations in research are limited by variation in methodology. The next section describes the literature examining the transfer of youth with chronic illness from pediatric health care to adult health care.

CHAPTER 3: LITERATURE REVIEW

Introduction

The following review addresses the literature related to the referral of youth with chronic illness from specialized pediatric health care to specialized adult health care. Research related to young adult development and the transfer of young adults with Type 1 diabetes to adult health care is discussed and critiqued. The review is organized according to the Health Belief Model framework.

The body of literature regarding referral to specialized adult health care is growing in diabetes and other chronic diseases. An extensive search of the related literature of the past decade has revealed a dramatic escalation in the attention given to the issues associated with transfer to adult health care. Reasons for this growth have in part been attributed to the advances in medical care that have improved the survival rates of many childhood chronic illnesses (Blum, 1995; Newacheck et al., 1991). In addition, in diabetes, the results of the Diabetes Control and Complications Trial verified the importance of continuing care and education in diabetes health, with advances in blood glucose monitoring and measurement of Hgb A1C, allowing evaluation of metabolic control (DCCT Research Group, 1993). However, in many cases, the health care system has not changed in response to this success, with young adults lost to follow-up due to the lack of specialty services (Bronheim et al., 1989). The health of young adults with diabetes has received little attention in health care policy, as the population is small, difficult to research and difficult to locate.

The variability in the type and rigor of research was matched by the diversity in the health system programs or practices to enhance client transfer, limiting

generalizability. The developmental needs and health beliefs of adolescence were often generalized to young adults. Direct comparisons of reported attendance or follow-up at pediatric or adult clinics is made difficult by the absence of controlled studies, incomplete description of the clinic or transfer process, and inconsistent terminology or operational definitions, particularly in the operational definitions of attendance, follow-up and metabolic control (Johnson, 1992).

A variety of literature is available, including commentary of individuals or organizations, anecdotal experience with clients or programs (Ferguson, 1988), combined qualitative and quantitative studies (Eiser, Flynn, Havermans, Kirby, Sanderman, & Tooke, 1992; Frank, 1996), and testing of newly developed questionnaires (Pacaud et al., 1996; Wysocki et al., 1992). The majority of the literature reviewed was descriptive and addressed medical follow-up. Most publications date from 1990 onward. The variety of the literature confirms that the factors influencing transfer to adult health care are multi-faceted.

Factors Influencing Transition

Modifying Factors

As discussed in chapter two, diverse "modifying" factors such as structural, sociopsychological and demographic variables might affect an individual's perceptions of susceptibility, severity, benefits and barriers and thus indirectly influence health-related behaviour (Rosenstock, 1974). This in turn may influence the type of transition the young adult experiences between adolescent and adult care. Issues in the literature related to all three modifying factors are examined.

Structural Variables

The literature identified a number of variables related to the organization of health care that may impact on transfer to adult health care. The procedures, policies and practices of an organization impact on the type of transition program that an organization can or will implement, the specialty of the health care providers, and the decision-making process regarding movement of the young adult client from pediatrics to adult health care.

Types of models of transition. Various models of transition programs were described in the literature. The most fundamental theoretical and empirical models identified are reviewed.

The experience of young adults with Type 1 diabetes in the literature encompassed all four types of transition identified by Schumaker and Meleis (1994). The authors completed a conceptual analysis of the nursing literature on transition via a search of Medline from 1986 to 1992. The four types of transition models found were (a) developmental, (b) situational, (c) health-illness, and (d) organizational transitions. The "developmental" changes include the maturational changes of young adulthood. The "situational" changes include changes in education and profession, and in family or living situations. The "health-illness" transition occurs as the individual moves among levels of care within the health care system. The fourth type of transition, "organizational" transition, includes the reorganization and regionalization of health care.

Schumaker and Meleis also identified six conditions that characterized transition in the literature: 1) Meanings: the subjective appraisal of an anticipated transition and the likely effect on one's life, 2) expectations, 3) level of knowledge and skill relevant to the transition, 4) the environment, 5) the level of planning that occurs before and during a

transition, and 6) emotional and physical well being during the transition. Although empirical testing of their model was not found, elements of the authors' nursing model of transition were seen throughout the literature on transfer of youth with a chronic illness from pediatric to adult health care.

In an attempt to move models of transition services from a theoretical framework to one empirically derived, Scal, Evans, Blozis, Okinow, and Blum (1999) conducted a study of transition programs within a wide variety of health services and agencies in the United States. Upon analysis of the 122 returned completed surveys (44% response rate), Scal and associates found that program services could be empirically divided into only two primary categories: those that were (a) disease-focused, and (b) adolescent-focused. The authors found that the primary focus of all the transition programs was with medical follow-up. With few differences found between the services, Scal et al. concluded: "it makes little sense to talk about service types" (p. 263).

The most succinct and directly applicable models of transition from pediatric to adult health care were described by Court (1991): (a) pediatric care direct to adult care, (b) pediatric care to transition/young adult clinic to adult clinic, and (c) pediatric to adolescent care to young adult to general adult care. Literature was absent on this last model, theorized by Court as representing the establishment of sub-specialty adolescent clinics within the pediatric setting, and sub-specialty young adult clinics within the adult setting. The most commonly described model in the literature was of transfer from pediatric care direct to adult care. Transition programs varied widely in design, timing, and content. The actual mechanics of transfer depended greatly on the local circumstances and the people involved (Cameron, 1985). Discussion of the research regarding the first

two models, and of a newer model of joint service delivery by both pediatric and adult health care providers, follows.

Pediatric care direct to adult care. Frank, a diabetes nurse educator at the Hospital for Sick Children in Toronto was the first to publish a study about transfer to adult health care in Canada. Frank (1996) reported on patients discharged from the pediatric diabetes clinic in 1985 and 1986. Three to four years after their discharge, Frank investigated 41/56 eligible clients, using a phone survey, a mailed psychosocial questionnaire, and an audit of the pediatric chart. Frank defined compliance with medical follow-up as diabetes assessment within one year of leaving the pediatric facility and at least once a year thereafter. Compared to those subjects that did participate in medical follow-up, those that had not, judged themselves to be in poorer metabolic control, were more likely to have been hospitalized for diabetes related problems both prior to discharge and following discharge, have a higher mean Hgb A1C prior to discharge, attended the pediatric clinic on fewer occasions, and were less likely to seek post-secondary education. The anticipated transfer to adult medical care had not been routinely discussed during regular appointments with a pediatric endocrinologist. The pediatric diabetes educators did not see clients on a routine basis for anticipatory education. Acknowledged limitations to this research included recall bias, and interviewer bias. Frank had a therapeutic relationship with all of the subjects while a nurse in the pediatric diabetes clinic.

As follow-up to her research (1996), Frank developed a daylong transition workshop for parents and adolescents discussing issues such as complications, and the referral process. No formal evaluation was completed, but attendance from the young

adults was described as very low, despite intense educator effort at communication and invitation (personal communication, Marcia Frank, 1997).

In Montreal, Pacaud et al. (1996) noted that two pediatric diabetes clinics referred young adult clients to one of eight adult diabetes centres. While both of the pediatric diabetes teams functioned with multidisciplinary teams within diabetes education centres, the adult centres were described as more diverse, with less intervention from members of the multidisciplinary team other than the physician. Using a self-administered survey, 32.8% of the young adults surveyed post transfer, answered "yes" that they had a problem with the transition. In written comments regarding the experience, subjects noted the different approaches of the pediatric and adult health care providers.

Bartsch et al. (1989) attempted to contact all graduates over the age of 15 from their pediatric diabetes clinic in Salt Lake City within the previous five years. Forty percent of the graduates could not be contacted. Twenty-eight per cent of the subjects had a diabetes-related hospitalization the year following transfer to adult care.

In Finland, Salmi, Huupponen, Oksa, Koivula and Raita (1986) retrospectively analyzed the metabolic control of 61 consecutive adolescents with Type 1 diabetes one year before and one year after referral to an adult centre. The authors did not find any significant deterioration in metabolic control. Of note, were the acknowledged similar treatment methods between the pediatric and adult clinics. The process of referral was described as the physician informing the patient of the upcoming referral 12 months prior. A more comprehensive description of the clinics and staff would have aided in the comparison of their approach to those of other programs.

Pediatric care to transition/young adult clinic to adult clinic. In the United States, Orr, Fineberg and Gray (1996) prospectively examined glycemic control in clients from one year before to one year after referral to a young adult clinic for 82 clients, ages 17 until 23 to 25 years of age. In this young adult clinic, an adult health care practitioner provided care in the familiar pediatric setting. The clinic took place within a single, university setting, whose pediatric and adolescent/young adult diabetes programs shared a similar philosophy. The authors did not find any significant deterioration in glycemic control. Orr noted that compared to Salmi et al. (1986), the duration of diabetes was longer, with better glycemic control, prior to transfer. All clients attended the young adult diabetes clinic at least once within one year of referral.

Eiser et al. (1992) surveyed 69/101 clients to assess the efficacy of a young adult "under-25" diabetes clinic in the United Kingdom. Clients transferred from the pediatric clinic from 12 to 20 years of age, with a mean of 15.9 years. Forty-one of the sixty-nine respondents had attended both the pediatric and the under-25 clinic. Overall, those respondents recalled little difficulty transferring clinics. Patients considered that it would be helpful to visit the under-25 clinic before transfer; if there was greater co-ordination between pediatricians and adult physicians and if a nurse from the under-25 clinic visited the pediatric clinic. Data was not available regarding how many clients did not follow-up with adult diabetes care. Information regarding the staffing, program site, and referral process would have aided comparisons between their results and the results of other such programs.

Also in the United Kingdom, Ferguson (1988) described an attempt to increase young adult attendance at a diabetes clinic, by initiating a new evening diabetes clinic for

clients age 15 to 25. Access to this clinic was made more flexible by supporting "drop-in" visits, as well as formal appointments. Although no formal evaluation had been made of the new format, the author described the attendance as "encouraging." Although consistent staffing in the clinic was recognized as important for rapport, it was not clear if staff were from the adult or the pediatric service. The impetus for this change in service delivery was an assessment that existing diabetes services for this age group had been deemed inadequate during a review of diabetes services in the region.

Joint pediatric and adult health care. Joint clinics, where health care is provided to young adults by members of both the pediatric and adult diabetes health care team, were seen as the ideal model in which to provide health care to young adults, and address the problem of transition in numerous commentaries and policy statements (American Academy of Pediatrics, 1996; Adolescent Medicine Committee Canadian Pediatric Society, 1994a, 1994b & 1994c; Court, 1993; Rosen, 1995). Joint clinics were regarded as bridging the cultural, philosophical, care and practice gaps between pediatrics and adult health care teams, but were considered to require respect, communication, time, financial support and close collaboration between the teams.

Despite the assumption that joint clinics would be the most advantageous model in which to provide care and education to young adults, no evidence of such a model within diabetes care was found. The only description found of a joint pediatric/adult transition clinic was found within the field of Rheumatology (Rettig & Athreya, 1991). The aim of that program included enhancing the transfer of confidence to a new physician, and minimizing client and family anxiety related to the new physician not knowing any past history. The program and program development were thoroughly described. The adult

rheumatologist was introduced to the patient and his/her family by the pediatric team, at the adult rheumatology centre. The adult and pediatric rheumatologists then saw the patient. After this, the pediatric nurse and social worker continued to be involved with the now adult client. Strengths of the program were described as a "strong" pediatric team with a common philosophy in how to effect transition, close proximity to the pediatric and adult health care team, an active teen group in the centre, and most importantly, funding for a nurse and social worker to function as key members of the transition program.

The program demonstrated a marked improvement in follow-up in comparison to the previous referral process. During the first three years of the transition program, only 2/36 clients were lost to follow-up. The authors acknowledged methodological difficulties with the comparison group used from a previous, ten-year retrospective study of 144 persons transferred to other medical centres. In that first study, only one patient referred had remained at the adult centre.

The program was subsequently revised such that the adult rheumatologist would see the adolescent patient jointly with the adolescent team, at the pediatric site, during several appointments. The increased frequency of joint visits over one to two years "allowed us to focus on the transition process rather than on one transition visit, as with our initial program" (Rettig & Athreya, 1991, p. 178). The interest and commitment of an interested adult rheumatologist was seen as crucial.

The ability to conclude which is the optimal model for transfer is prevented by the limited research into models other than pediatric care direct to adult care, the variety and number of factors that influence the implementation of any model, and the absence of controlled studies. The problems associated with the most commonly used model, referral

directly from pediatric to adult care, is provided as an indication of the need to improve upon established transfer procedures. Other influences, upon the transfer process, or transition program, are discussed.

Health care providers. As the developmental period of young adulthood received increasing recognition as a unique area of health care delivery, questions arose as to the optimum setting and staffing for this age group. Clinics for young adults could be staffed by the pediatric team, the adult team, or be jointly run. While the literature raised the question of differences between the philosophy, care and setting of adult and pediatric health care programs and providers, research into this area was notably absent. Bronheim, Fiel, Schidlow, Magrab, Boczar and Dillon (1988) viewed the feelings and beliefs of both the pediatric and adult health care providers as impediments to successful transition. Conflicting opinions were evident as to the appropriateness of either pediatric and/or adult health care providers in the young adult period. Suggestions by other health professionals of the deficiency or inappropriateness of care provided to young adults provoked intense emotions in professionals, further hindering communication and collaboration between teams, and hence successful transition. Blum et al. (1993) clearly summarized the one agreement in the available literature: "All individuals, whether receiving primary preventive care or tertiary care, deserve services that are appropriate for their age and developmental stage" (p. 572).

Pediatric health care team. Bronheim et al. (1988) summarized the perceptions of youth of the different health care teams. The pediatric caregiver was alleged to possess strong emotional bonds with the patient and family and might not have confidence in the ability of their adult colleagues to care for their patients. The pediatric caregiver would

view the transfer to adult health care with apprehension or ambivalence, inadvertently communicating their reservations to the client and family, further impairing the transfer to adult care. The pediatric team could also overestimate its ability to care for an adult population, and be distrustful of the adult team's ability to adequately care for their clients (Bronheim et al., 1988; Nasr, Campbell, & Howatt, 1992). Additional disadvantages to continuing in the pediatric clinic were depicted as the potential for reinforcing dependence and delaying the assumption of responsibility for self-care (Komp, 1991). Reluctance to transfer their pediatric patients for fear of losing their economic base was another reason cited in the literature (Schidlow, 1999), however the regulations for economic reimbursement for medical care vary.

A contrasting view was that the pediatric team might be more likely to have developed a relationship with the client and family, and thus be in the best position to encourage a sustained relationship with health care (Ferguson, 1988). Eiser et al. (1992) surveyed participants of an "under-25 clinic," 40% of who had transferred to this young adult clinic from pediatric care. Respondents found that in comparison to adult practitioners, staff in pediatric clinics placed greater emphasis on family and social life, school or work progress. However, pediatric health care professionals were considered to have less expertise in medical areas such as pregnancy and complications, and psychosocial issues such as living alone, university and relationships with a significant partner.

Adult health care team. Adult practitioners were believed to possibly feel uncomfortable spending time acquiring the specialized knowledge needed for the young adult (Sawyer et al., 1997). Adult practitioners could have heightened expectations for the

young adult's self care, knowledge, abilities and maturity (Schidlow & Fiel, 1990). Adult practitioners were criticised as possibly being less familiar with, and less tolerant of, adolescent attitudes, behaviours, and self-management practices than their pediatric counterparts (Frank, 1992). The focus of adult practitioners was on prevention and/or modification of risk factors that promote the development of long-term complications (Frank, 1992).

An adult care setting in diabetes was anticipated by young adults to represent older patients with complications and Type 2 diabetes. This was theorized by the authors as possibly inhibiting or frightening to the young adult, who may feel out of place and resent identification with the elderly and disabled (Court, 1991). Ferguson (1988) also reported that his adolescent patients indicated that they did not fit into the adult clinic where they would sit next to people with obvious complications. Respondents of the survey by Eiser et al. (1992) reported that adult physicians were perceived to stress the risk of long-term complications, importance of exercise and need to maintain strict levels of glycemic control. In contrast, an adult setting has also been described as the most appropriate place to provide care, promoting adolescent independence and self-sufficiency (Russell, Reinbold & Maltby, 1996). Conflicting views on an adult and more independent approach were also noted by the subjects of Pacaud et al. (1996), where this approach was viewed both as motivating maturity and self-motivation, and lacking in needed care, sensitivity and education.

Recruitment of a skilled adult specialist with an interest in young adults has been identified as being difficult. Many an effort in establishing a transition program has been aborted at this stage because of frustration, lack of interest, or dearth of individuals in the

adult setting (Schidlow & Fiel, 1990). Adolescent and young adult specialists are evolving as a recognized speciality (Council on Child and Adolescent Health, 1988; American Academy of Pediatrics, 1982). Perhaps due to the limited amount of literature on transition and the evolving nature of adolescent or young adult care as a health care specialty, no literature was found on this type of care provider within a transition program.

Organization of health services and policy. In their global analysis of transition services Bowes, Sinnema, Surís and Bühlmann (1995) demonstrated that transition services are influenced by the organization and financing of health care. A review of outcome measures used in diabetes education research as part of the American Association of Diabetes Educators Research Summit (Glasgow, 1999) determined that little attention has been paid to effects at system levels. Rosenstock included modification of the system as one strategy within the Health Belief Model for enhancing compliance (Rosenstock, 1985). Administrative support of a transition program was considered essential to effective transition programs, as administration would be interested in all aspects of financing, and resource allocation (Bronheim et al., 1988).

Financial impact of diabetes on health care services. The Diabetes Control and Complications Trial, as discussed in chapter one, demonstrated the dramatic effect of glycemic control on delaying or preventing the development or progression of the long-term complications of diabetes. In the DCCT, subjects were randomized into two groups to receive either intensive therapy, or conventional therapy. The intensive group received multiple daily injections or subcutaneous insulin infusion with a goal of achieving blood glucose levels as close to normal as possible. The goal in the conventional group was to

remain clinically well, and symptom free. The annual cost of intensive therapy using US figures was $4,000 to $5,800 per year compared to $1700 per year for the conventional group, not including research costs (DCCT Research Group, 1995). The largest proportion of the cost difference between intensive and conventional therapy was related to differences in the frequency of outpatient visits, with the nurse educator the primary provider of care in almost all clinics.

Replication of the financial and staff resources of the DCCT within the current health care environment is an acknowledged challenge. Although the financial costs were not broken down for the sub-set of the 13 to 19 year olds, as indicated earlier, this age group required a disproportionate share of the supportive care provided by the diabetes treatment team (DCCT Research Group, 1994). The health care resources necessary to impact substantial change in the diabetes health of the young adult age group are demanding. Although the risk of client problems with transfer to specialized adult health care may include an increased hospitalization rate, poor metabolic control, and increased risk of long-term complications, the costs of a transition program may be considered to be prohibitive within a health management environment that focuses on short term cost restraint.

Position and policy statements. The increase in recognition of the needs of the adolescent with chronic illness when transferring to adult care is reflected in the release of a number of policy statements by the Adolescent Medicine Committee, Canadian Pediatric Society (1994a, 1994b, 1994c), the American Academy of Pediatrics Council on Child and Adolescent Health (1996) and Committee on Children with Disabilities and Committee on Adolescence (1988), and the Society for Adolescent Medicine (1993). The majority of the

committee members authoring the position statements were from a pediatric professional background. The only disease specific transition position statement was found in the Manitoba Diabetes Strategy, as described in chapter one.

All of the position statements reflected the growth in size of this population of young adults with chronic illness, and their unique and multiple needs, including vocational, developmental, educational, social and medical. The position statements by the American Academy of Pediatrics (1988) and the Canadian Pediatric Society (1994) regarding the age limits of pediatric care recommend referral to adult health care based on social and developmental assessment of readiness. The Adolescent Medicine Committee of the Canadian Pediatric Society (1994a) favours a more functional definition of age limits and adolescence based on the biopsychological readiness of young people to enter adulthood, stating that "a definition of adolescence based solely on chronological age is unjustified and impractical" (p. 1).

Referral process. Two studies identified a deficiency in the formal referral process by the pediatric team to adult health care providers. Bartsch et al. (1989) found that of the young adults they were able to contact, only 38% had received a referral for an adult physician. Frank found that subjects who did not participate in health care follow-up within one year of leaving pediatric care were significantly less likely to have a medical referral documented on their medical chart than those who did attend for follow-up (40% vs. 87%).

Criteria for referral to adult health care. Regardless of the recommendations of the position statements, the most frequently described criteria used by health care providers and programs to determine the time to transfer clients from pediatric health care

to adult health care was the chronological age of the pediatric client. As discussed further in this chapter, additional criteria such as client or family readiness, completion of developmental tasks, and absence of other life transitions, continued to be cited as essential components to the decision to move from the pediatric program.

Age as criteria for transfer. A specified age or age range may be used to determine referral to adult care due to institutional policy, assumption of developmental stage, or as an arbitrary criterion. Although the literature and policy statements consistently recommended flexibility with regard to the age of transfer to adult health care, the majority of diabetes health care programs described in the literature continued to utilize a set age as the indication to refer clients to adult care. The age of transfer occurred predominantly between the ages of 17 and 19 (Bartsch et al., 1989; Orr et al., 1996: Pacaud et al., 1996; Frank, 1995). The exception noted in the research was of Eiser et al. (1992), where the mean age of referral from pediatric care was 15.9 years, ranging from 12 to 20 years.

Research investigating the optimal age for transfer utilized client questionnaires to explore the experience or recommendations. In 1991, Court sent anonymous questionnaires to 100 young adults with Type 1 diabetes who had left the pediatric diabetes department within the last 1 to 5 years. In 1993, he surveyed those (n = 105) who at 16 to 18 years of age were due for referral to adult care. The results were comparable. Respectively, the response rates were high at 70% and 69%. Fifty-three and 44.8% of the respondents felt that the ideal age for referral to adult care was 17 to 20 years. Thirty-five and 44.8% indicated that up to the age of 25 years was ideal, emphasizing the clients readiness to transfer, rather than age as the indication for transfer. The content, reliability

or validity of Court's tools was not available.

In Montreal, Pacaud et al. (1996) received a 36% return rate on questionnaires sent to 372 graduates of 2 pediatric clinics. Fifty percent of respondents either expressed difficulty with transition or had a delay or loss of follow-up during transition, with 65% indicating that they should have been transferred later than age 18 years. The majority (50%) of subjects who indicated that they did have a problem with transition felt that they should have been transferred at a later age, or never, as compared to only 20% who indicated that they did not experience a problem,

Knowledge and maturation as criteria for transfer. Due to the difficulties of adolescence and young adulthood, pediatricians in one facility reportedly did not refer clients to adult care until cessation of statural growth, full pubertal development, and some degree of social maturation (Orr et al., 1986). Despite these criteria, the mean age of admission to the adult clinic was consistent with most other programs at 17.5 +/- 0.5 years (range 16.5 to 18.8). This age of referral was later than the traditional age of referral to adult clinics in Finland, reported by the authors to be at 15 years.

In their pioneering manual for developing transition programs, Bronheim et al. (1988) recommended an assessment of client readiness for transfer as one indicator of time for referral. This assessment was recommended to include responsibility for self-care; disease knowledge; infrequent hospitalizations; acquisition of career and personal goals; client not experiencing an acute loss of relationship with a particular team member; and ability to communicate directly with the health care team. Preparation for transfer should include a complete re-education of disease as part of a transition program.

Despite the expressed importance of individual assessment of the timing for

referral to adult care, no programs were found that demonstrated such flexibility. Despite their theoretical importance, those criteria were not noted in any program descriptions to exhibit a practical influence in decision making regarding the timing of the referral to adult health care.

Sociopsychological Variables

Developmental stage. The concept of transition has regularly been used to describe the movement from childhood into adulthood (Gortmaker, Perrin, Weitzman, Homer & Sobol, 1993; Reynolds, Morton, Garralda & Postlethwaite, 1993). The process of transfer from pediatric to adult health care traditionally occurs during a time when the individual is experiencing many maturational changes, such as in lifestyle, the role of the family, vocation, education, relationships and psychosocial development. Given that numerous transitions are occurring simultaneously, existing coping strategies may be insufficient to deal with the many changes. The elements of discontinuity, disruption and risk in transitions are most likely to occur when one experiences multiple and simultaneous demands. The multiple and simultaneous transitions are typical for any young adult, regardless of the additional transition needs related to a chronic illness (Schulenberg, Maggs & Hurrelmann, 1997). Although the challenges of adolescence have prompted much research into adolescence and diabetes, less research is available on the normative developmental processes of young adulthood, and even less on young adults and diabetes.

> "Populations included in studies have typically been families who have regular access to health care services and whose children are school age and preteen. Minimal attention has been devoted to … the developmental periods of early childhood and late adolescence" (Brandt, 1998, p. 63).

Little research has been done to determine whether the adequacy of coping with diabetes during adolescence is predictive of coping in the young adult period (Wysocki, Hough, Ward & Green, 1992). Research that does include the late adolescent or young adult period infrequently controls for age. This approach assumes without empirical evidence that the developmental tasks, needs and challenges of the young adult are the same as those of the adolescent (Hanson, Henggeler & Burghen, 1987; Standiford, Turner, Allen, Drozda, & McCain, 1997; Anderson, Miller, Auslander & Santiago, 1981). This next section examines the research regarding the young adult period and Type 1 diabetes.

The change to university life or employment is a major developmental milestone in which discontinuity in life and the opportunity for risk behaviours are increased. Changes in life circumstance such as moving away from home leads to dramatic changes in the physical context and in normative expectations for behaviour. Within these new environments, adults in positions of authority over the young adult, such as employers or educators, do not extend the same degree of concern for the individual to the same extent such individuals would when the client was younger. Significant changes occur in the situational affordances and opportunities in many domains, increasing the opportunities to experiment and participate in high-risk behaviour (Maggs, 1997). Risk taking thus serves both constructive and potentially destructive functions, as negotiating autonomy from parents is a key part of developing a sense of identity (Schulenberg, Maggs & Hurrelmann, 1997).

During the time period of transfer from pediatric to adult health care, the young adult moves through two of the psychosocial stages, as described by Erikson. From the

age of 11 years through the end of adolescence, the young person struggles to develop their identity, in the stage known as "Identity vs. Role Confusion." Youth are preoccupied with appearance, hero worship, ideology, group or peer identity. They are in danger of role confusion, with doubts about sexual and vocational identity. According to Erikson, in the next stage from ages 19 to 40 years, the young adult must develop intimate relationships with others, facing conflict over "Intimacy vs. Isolation." If the young adult does not resolve this conflict, the young adult is left feeling isolated. To succeed in this stage, the young adult must be willing to be open and committed to another individual (Cramer, Flynn, and LaFave, 2000)

To differentiate between health behaviours in the different age groups, Hanna and Guthrie (1999) examined non-diabetes related health-related behaviours in 107 adolescents and young adults with Type 1 diabetes from 12 to 24 years of age. Health behaviours were analyzed within the age ranges of 12 to 14 years, 15 to 17 years and 18 to 24 years. The highest levels of health-compromising behaviours such as smoking, alcohol use, and sexual activity, although relatively low, occurred in the oldest age range.

Wysocki et al. (1992) tried to fill the gap in research related to Type 1 diabetes between adolescence and adulthood. A comprehensive cross-sectional study of health and adjustment looked at predictors of health status, treatment adherence, and health use, and a retrospective evaluation of the persistence of diabetes specific adjustment from earlier through late adolescence. Eighty-one people (60% response rate) between the age of 18 and 22 were recruited by telephone, mail or answered a newspaper advertisement. Subjects and their parents completed 11 self-administered scales investigating stress, social support, self-efficacy, diabetes knowledge, psychological adjustment, treatment

compliance, health care utilization and previous adjustment to diabetes. A combination of previously used tools, and tools developed for this study was used. Validity and reliability were strong, and thoroughly described. Scores measuring resistance to life-style changes and denial of disease were significantly elevated, with a low number of social supports and less satisfaction with available social supports than on a previous study with college students. The subjects' social, behavioural and affective adjustment to diabetes during the ages of 13 to 17 years was measured retrospectively using the Teen's Adjustment to Diabetes Scale, constructed specifically for this study. A comparison of these results to those from measures of current adjustment indicated that poor adjustment to diabetes in early adolescence persists into the transition to adulthood.

In Canada, Pless, Heller, Belmonte and Zvagulis (1988) were able to contact 225 (70% response rate) former campers of a diabetes camp in Quebec, now 18 to 34 years of age. A structured phone interview was used to assess education, work, social and family life, diabetes care during childhood, and social and emotional adjustment. No relationship was found between level of diabetes control expected by the physician and emotional functioning. This unusual measure of control was presumed to indicate the level of effort from the subject to attain good control. In her interview of people with Type 1 diabetes aged 17 to 22, Myers (1992) found that respondents overwhelmingly viewed diabetes as a secondary condition, having little impact on their life. These subjects were more likely to live at home while still studying; not to travel away from home; and reported less dating than controls. These results were similiar to those of Kokkonen, Lautala, and Salmela (1994) in Finland. Compared to a non-diabetes control group, subjects aged 19-25 years were more likely to have always lived at their parental home or to have returned to live

with their parents, and a smaller percentage were married or financially independent. A poorer score on an overall social maturation index was correlated with the presence of diabetes, but not with duration of disease or family background. The overall score on social maturation was lower for those with diabetes, than for the non-diabetes control group.

Burroughs, Pontious and Santiago (1993) assessed six psychosocial domains, age, health care adherence and metabolic control in 21 parent and youth dyads, with youth from ages 13 years to 17 years. Eight measurement tools were used to assess adherence, family knowledge, family cohesion and adaptability, supportive behaviours, stress, social competence and Locus of Control. Some of the analyses were separated into the age group of < 16 years of age. The more knowledgeable youth were older, but were less likely to follow their meal plans. Parents less accurately predicted glycemic control for youths older than 16 years than for youth less than 16 years old. A negative relationship was exhibited between strong self-concept, high knowledge of diabetes, parental support and poor metabolic control. The results were not stratified for age.

Grey, Cameron, and Thurber (1991) investigated the influence of age on coping behaviour and psychosocial adaptation in children with Type 1 diabetes from 8 to 18 yrs (mean age of 12.9 years). Preadolescents and adolescents differed significantly in the manner in which they coped with illness. Younger children were more likely to cope by ventilating feelings through yelling and arguing, while older children were more likely to cope by avoidance and risk taking behaviours such as drinking, smoking or staying away from home. Metabolic control and psychosocial adjustment worsened with increasing age. The lack of normative data on late adolescence, and the lack of a comparison group,

precludes the conclusion that these differences are due to development rather than living with diabetes. As emphasized by Grey and Sullivan-Bolyai (1999) in their review of chronic illness research in children with diabetes, the duration of the disease may be a further time-related influence on the psychosocial adaptation to diabetes. The duration of disease may impact differently related to the developmental stage of the child at diagnosis, the natural course of the disease state itself, such as the increase in endogenous insulin production in the first year of Type 1 diabetes, and what may be critical periods in adjustment to chronic illness that vary with time since diagnosis.

Demographic Variables

The influence of gender. Only one research study identified a difference in gender in regards to young adults and/or transition. Using changes in metabolic control twelve months after referral compared to the first visit as an indicator of the success of transition, Salmi et al. (1986) deduced that males coped better than females with the transition period ($p < 0.01$). In both groups, the Hgb A1C improved. The A1C for males one year after transition was 10.0 +/- 1.7, compared to the metabolic control of females after referral improving to 10.3 +/- 1.9 with $p < 0.005$. The norm for the A1C was 4.5 to 8.0 %. Orr et al. (1996) also noted the better glycemic control of males in their prospective cohort study with measurement of A1C one year before and after transfer to adult diabetes health care. Of note was that the males did not demonstrate greater improvement in their metabolic control compared to women, but that both genders maintained their level of control, and the metabolic control of males was better pre-transfer. Young adult females reported more diabetes mismanagement behaviours such as missing meals and snacks, and adjusting their insulin to cover eating foods not part of their meal plan, and falsifying glucose results, than

males, but no difference was found in behaviours of alcohol, sex and smoking (Hanna and Guthrie, 1999).

Hanna and Guthrie (2001) also surveyed 107 youth with Type 1 diabetes aged 12 to 24 years in an exploration of health-compromising behaviour. Again, being female was related to diabetes management problems and poor metabolic control. Williams' (1999) explorations of the impact of gender on self-care, via interviews of ten young men and ten young women with Type 1 diabetes aged 15 to 18 in England also suggested that gender impacts on self-care and parental care.

Core Dimensions of the Health Belief Model and Other Factors

The following section reviews the literature on the transfer of young adults with Type 1 diabetes from pediatric to adult health care as it relates to the four core dimensions of the Health Belief Model (perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers), "cues to action" and other modifying factors. These variables are discussed jointly as it is difficult to distinguish between them in the literature.

Young adults reported a number of reasons why they participated in diabetes follow-up. Those who participated in follow-up reported that they did so for assessment (Frank, 1996), or to please a parent (Eiser et al. 1993; Frank, 1996). In Court's surveys in 1991 and 1993 the most common reason cited to follow-up with care was to receive information on new developments (78%). Other reasons, mentioned in descending frequency, were to learn about the condition, emergency care, phone in for advice, help with personal problems, contribute to research, and meet others. Respondents in a study by Eiser and colleagues (1993) also reported that attendance was motivated by the desire to avoid complications, but added the increased likelihood of getting a driver's license.

Only one study was found within the diabetes literature that investigated the reasons of young adults for not participating in health care follow-up. Reasons for lack of follow-up included "feeling fine" (perceiving no need) (70%), and not yet ready to comply with physician demands (30%) (Frank, 1996).

Many researchers reported on the difficulty in contacting the graduates from pediatric care for research purposes. Pacaud et al. (1996) sent questionnaires to the last known address from a pediatric clinic, with a repeat questionnaire at three months to non-responders. Of the 372 patients, 64 or 17% were returned with an unknown address. Pless, Cripps, Davies, and Wadsworth (1988) similarly sent two letters to the most recent known addresses. From a population of 431, 23% of the clients had either moved outside of the province or could not be traced. Methodological issues not withstanding, questions can be raised as to the mobility this age group, and its impact on health care provision.

The framework of the HBM was used to specifically explore the barriers and psychosocial issues of college students with diabetes via focus groups (Wdowik et al., 1997). Participants were recruited from students with diabetes who attended student health services and from those who answered advertisements in the university paper. All subjects were participating in formal health care follow-up. Five most salient barriers to successful diabetes management were identified: (a) Scheduling and time management, (b) stress, (c) hypoglycemia, (d) diet, and (e) inadequate finances. In addition to barriers to diabetes self-care, three dominant psychosocial issues were identified and categorized: (a) Inconveniences of diabetes management, (b) motivators to managing diabetes, and (c) social support issues.

Self-efficacy

Only one published research study was found that incorporated self-efficacy into an evaluation of the HBM and diabetes, as recommended by Rosenstock (1985). Charron-Prochownik et al. (1993) explored the relationship between the HBM and self-efficacy in six to nine year olds with Type 1 diabetes as discussed below. The literature found pertaining to self-efficacy and young adults with Type 1 diabetes primarily studied self-efficacy in relation to locus of control or self-esteem. The research by Charron-Prochownik et al. (1993), as well as research regarding self-efficacy and adolescents with Type 1 diabetes follows.

Three measures of self-efficacy were found in the literature that specifically measured self-efficacy in diabetes, and had been applied in children or young adults with Type 1: (a) the Self-Efficacy Diabetes (SED) by Grossman (Grossman, Brink & Hauser, 1987), (b) the Insulin Management Self-Efficacy Scale (IMDES) by Hurley (Hurley & Shea, 1992), and (c) a self-efficacy scale developed for research regarding the relationship of self-efficacy and bingeing to adherence to diabetes self-care among adolescents at the Hospital for Sick Children in Toronto (Littlefield et. al., 1992). The latter scale was not discussed due to limited information available in the literature.

Grossman and Brink (1984) briefly describe the use of the SED in a cross sectional study of self-efficacy with ten pre-adolescents and adolescents matched on age and sex comparing insulin pump and non-pump users. The age of the subjects was not identified. The authors also looked at self-esteem and locus of control. Metabolic control was assessed using Hgb A1C. Findings relating metabolic control with self-efficacy were not available. The highest self-efficacy was seen in those using insulin pumps, and those who were on

pump therapy, but later discontinued. Starkman, Grossman and Reavill (1984) made brief reference to further using the SED in an evaluation of a pilot wilderness canoe camping program for adolescents with diabetes.

Grossman et al. (1987) further developed and tested the SED scale when measuring self-efficacy in diabetes campers, age 12 to 16 years of age. The 35-item self-efficacy scale included three sub-scales: diabetes specific situations, medical situations, and general situations. Content validity was established using a panel of experts. The SED was then pilot tested on campers in an earlier camp session. Answers on a six point Likert scale ranged from "very sure I can't" to "very sure I can" do the activity stated in each item. The authors also investigated relevant demographics, measures for metabolic control and administered a self-esteem questionnaire. The camp setting prohibited the evaluation of Hgb A1C for all campers. As such, four indices of metabolic control available at camp were utilized over a four-day period: (a) Average blood glucose levels, (b) average urine glucose levels, (c) urine ketones, and (d) twenty-four hour glycosuria. Results were pooled into a three point rating scale of metabolic control. The total self-efficacy score was able to predict the total index of metabolic control with an intercorrelation of $r = .25$, and $p < .05$. Girls had the closest correlation between self-efficacy of diabetes score and metabolic control with $P < .025$, and intercorrelation of .25. The weak correlations, the broad and unusual measurement of metabolic control and the specific setting limit the generalizability of the outcomes.

Hurley (1990b) modified a self-efficacy scale for use with persons taking insulin, from one developed in 1986 by Crabtree. Crabtree's scale was developed for a doctoral thesis, and was unable to obtained. The scale was developed for use by adults with

diabetes, regardless of the type of diabetes or whether insulin was used. Hurley reports that Crabtree constructed this tool with the input of Dr. Albert Bandura, the developer of the Self-efficacy theory. Examination for reliability and validity was comprehensive in design and description. Hurley and Shea (1992) further tested their modification of the scale on a convenience sample of 142 subjects age 18 to 73 years. The subjects had all knowingly selected a specialized tertiary care diabetes referral centre for care and education, well known for advocating tight glycemic control. Self-care was measured by a newly developed self-report measure, the Insulin Management Diabetes Self-Care Scale (IMDSCS) and by Hgb A1C. Subjects rated their degree of capability for carrying out a diabetes-related activity on a six-point Likert scale. Within the acknowledged limitations of self-report, the IMDSCS demonstrated high internal consistency, and stable mean test retest scores in pilot testing. Upon discharge from the diabetes program, self-efficacy was predictive of diabetes self-care behaviour one-month later. Neither demographic nor diabetes variables predicted self-care. The IMDSES was the only self-efficacy scale found in the research to have been used in transition research (Pacaud et al., 1996).

A literature review relating to Type 1 diabetes and the HBM would be incomplete without reference to Charron-Prochownik et al. (1993). The self-efficacy of children aged 6 to 9 with Type 1 diabetes was incorporated into a Health Belief Scale. The Diabetes Health Belief Pictorial Instrument for School-Age children consists of a 11 item paired pictorial scale, with the child choosing which of the two pictures of diabetes related behaviour most represents themselves. They modified the Becker and Janz 16 item HBM scale to develop a Parental scale of Health Beliefs. A four-item scale scored from one to ten, ranging from "not at all confident" to "very confident" measured parental self-efficacy. The researchers

incorporated parents' self-efficacy as a predicator variable in their study of health beliefs with children. Validity was thoroughly examined in all three tools. The reliability of the parental scales was described as marginally acceptable for self-efficacy, benefits and barriers. The authors reported moderate to very strong health beliefs about susceptibility, severity, and benefits, and high levels of self-efficacy. Parents had stronger health beliefs and higher self-efficacy. Children's beliefs were not significantly associated with those of their parents. Among children, better metabolic control was best predicted by stronger beliefs in severity and higher socio-economic status. These variables explained 18% of the variance in metabolic control. The best predictive model of observable adherence was with greater self-efficacy and higher socio-economic status, explaining 21% of the variables in adherence. Greater perceived barriers to treatment were related to greater nonadherence; and greater self-efficacy was associated with greater adherence. In conclusion, the authors noted that the children's health beliefs were found to "have little correlations with outcome variables" of metabolic control and observed adherence, with only perceived severity significantly associated with A1C.

Likelihood of Taking Action

The purpose of diabetes education is to facilitate client self-management of diabetes, and in turn, empower behaviour change to improve health status and/or quality of life (Peyro, 1999). The research related to adherence with diabetes self-care, and metabolic control as a reflection of self-care, is explored in the following section.

Diabetes and Adherence

The measurement of the concept of "adherence" in diabetes as in other chronic diseases research raises many problems. Such problems begin with the most basic issue of

variation in the operational definition of "adherence." Additional problems include the lack of specific treatment plans, the reliance on self-report, a lack of standardized or objective measures of compliance, an insufficient number of measures to adequately reflect the complexity of self-care, the differences between Type 1 and Type 2 diabetes, and inadvertent non-compliance related to patient-provider miscommunication. Comparison and evaluation of published diabetes adherence research is further complicated by the rapid changes over the last decade in recommended self-care strategies, available tools, options for care, and changes in diabetes medical and educational/behavioural philosophy. The type and number of instruments used in the literature to measure adherence and self-care also varied widely, although all researchers used multiple methods to minimize measurement error. Instruments were administered using a number of different methods, including self-administered questionnaires, self-report, and report by parents or physicians. Adherence measures included the frequency of specified diabetes self-care activities, attendance at health care appointments, and metabolic control (Glasgow, 1999; Johnson, 1992).

Two studies were found that specifically related the Health Belief Model to adherence in young adults with Type 1 diabetes. The earliest and the most comprehensive research found regarding the HBM, Type 1 diabetes, and children or youth was that by Brownlee-Duffeck et al. (1987). Brownlee-Duffeck et al. compared and contrasted a group of younger adults from one diabetes clinic (mean age 18 years) with an older group from another diabetes clinic (mean age 37 years). Diabetes health beliefs were assessed via the Diabetes Health Belief Questionnaire (DHBQ). This 27-item questionnaire, scored on a scale of one to five, measured perceived severity of diabetes, perceived susceptibility,

perceived benefits of adherence, perceived costs of adherence, and cues for adherence. Adherence was measured via a 15-item self-report Diabetes Treatment Compliance Questionnaire (DCTQ). The DTCQ assessed whether specific diabetes behaviours are performed on time. Responses, as measures of frequency, were scored from one to five. The researchers found that overall, perceived severity and perceived benefits were associated with greater self-reported adherence. However, in the younger group, perceived severity and susceptibility were related to metabolic control but not adherence. In the older group, self reported adherence and control was predicted by perceived benefits to treatment, while in the younger group, reported adherence was predicted by cost. The HBM accounted for 41 to 52% of the variance in reported adherence in the combined sample.

As one component of their study, Wysocki et al. (1992) utilized the Diabetes Treatment Compliance Questionnaire (DCTQ) from the research by Brownlee-Duffeck et al. (1987) to assess the relationship between knowledge and health behaviours in 18 to 22 year olds. The results revealed that adequate diabetes knowledge, as assessed by a 75 item Test of Diabetes Knowledge did not ensure acceptable maintenance of the assessed health-related behaviours.

In an infrequent example of replication in HBM research, Bond, Aiken and Somerville (1992) modeled their research after that of Brownlee-Duffeck et al. (1987). The same Diabetes Health Belief Questionnaire (DHBQ) was applied to a self-selected younger age group with a mean age of fourteen years. In addition to Hgb A1C, the adolescent, and the parent most involved with their child's diabetes were interviewed as a measure of the adolescent's compliance. Bond et al.'s younger subjects of 10 to 19 years demonstrated that

greatest reported compliance was achieved with low perceived threat and high perceived benefits-costs, and that compliance was positively associated with cues to action. Furthermore, as age increased, reported adherence to the exercise, injection, and frequency of eating and blood glucose monitoring decreased.

The majority of subjects evidenced suboptimal diabetes management in the follow-up of graduates by Bartsch et al. (1989). Bartsch and colleagues attempted to contact all graduates from their pediatric diabetes clinic within the previous five years. The researchers used the frequency of blood glucose monitoring, frequency of Hgb A1C tests, following of a meal and exercise plan, frequency of hospitalizations and frequency of medical follow-up as indicators of diabetes self-management. Twenty-eight percent of the respondents had a diabetes-related hospitalization, with forty-two percent of the respondents not seeing the adult physician for whom they had received a referral.

In a rare example of longitudinal research, Kovacs, Goldston, Obrosky and Iyengar (1992) assessed 95 consecutive families from the child's initial diagnosis with Type 1 diabetes at 8 to 13 years of age for up to nine years. The authors looked at the prevalence and predictors of noncompliance among youth with diabetes. Behaviours related to insulin administration, blood glucose monitoring and dietary behaviour were assessed in order to define noncompliance. Noncompliance was defined according to parent and child's reports, the clustering and persistence of behaviours, clinical data and alternative explanations for management problems, and determined by consensus among clinicians. Noncompliance typically started at about 15 years of age, with years three to four after diagnosis with diabetes to be a particularly high-risk period. The late adolescent period was associated with the most amount of time noncompliant. Neither social

competence, self-esteem, family functioning at diagnosis nor initial psychiatric status predicted compliance. The distinction between compliance and noncompliance, as an all-or-nothing concept was a major problem in this study.

Attendance at Diabetes Clinic

Attendance at health care follow-up is often referred to in adherence literature as one measure of "adherence." As with other measures of adherence, the operational definition of attendance at a specialized diabetes clinic in the literature varied widely. The minimum period for attendance ranged from once every four months (Bradley et al. 1984; Bradley et al. 1987) to once per year (Frank, 1996). No Canadian research was found that used the recommendations of the 1998 Canadian Diabetes Association Clinical Practice Guidelines of diabetes care a minimum of every two to four months. Only one study was found that investigated the relationship between the HBM and attendance at diabetes clinics, but many studies reported on the statistics related to attendance at adult follow-up.

Coates and Boore (1998) used the HBM in their comparison of 18 to 35 year olds, with appointments made for diabetes medical care, to appointments that were actually attended. A scale to measure the HBM developed specifically for persons with Type 1 diabetes during feasibility studies of insulin pump use (Bradley, Brewin, Gamsu & Moses 1984; Bradley, Gamsu, Moses, Knight, Boulton, Drury & Ward, 1987) was administered to 263 clients (58% response rate) in two diabetes clinics in Northern Ireland. Data on clinic attendance was obtained through a chart review of a time span of six clinic visits, over approximately a two-year period. Only 23% of the sample attended all six of the appointments made for them. Nineteen percent of the sample attended clinic less than three times during this time period, less than half as often as recommended by the clinic.

Although the respondents indicated that the benefits of following treatment were greater than any barriers, neither of these factors, nor any others examined, were predictive of metabolic control or clinic attendance.

A number of studies provided statistics regarding the rate of participation in adult diabetes health care following transfer from pediatric. Of those young adults contacted by Bartsch et al. (1989) the overall dropout rate from specialized diabetes health care was 69%. Eiser et al. (1992) found that the non-attendance rate at an "under 25" clinic was 18.9%. Eiser et al., as with many other researchers, compared responders to non-responders, with non-responders to the survey on more insulin/kg, having more emergency hospitalizations, and demonstrating worse glycemic control as indicated on a chart audit.

In Montreal, Pacaud et al. (1996) found that 27.5% of the young adults experienced a delay of more than 6 months between the last visit in pediatrics, and the first visit to adult diabetes clinic, and that 13% of the respondents were not being regularly followed medically, from one to six years after referral. Pacaud found that two variables were linked with the subjects perceived problem with transfer: (a) the difference between the actual age at transfer and the ideal age suggested by patient, and (b) and number of physicians seen by the patient before establishing regular follow up.

Frank (1996) found that 24% of the young adults indicated a failure to engage in medical follow-up three to four years after discharge from pediatrics in one facility in Toronto. Frank (1996) as previously discussed, found that those who did not participate in diabetes follow-up were more likely to have attended clinic on fewer occasions in the last year before transfer. Additionally, those who did not attend adult care were more likely to have been hospitalized for a diabetes-related problem prior to discharge and post discharge;

have a higher mean glycated hemoglobin; and were less likely to have attended pediatric clinic without a parent the year prior to discharge (non-significant finding). The only difference in sociodemographic variables between those who participated in follow-up and those who did not, was that those who did were more likely to have gone beyond high school education.

A comparison between participation in pediatric health care and adult diabetes education was found in only one study. In the first of the studies by Wysocki et al. (1992) exploring health and adjustment in adulthood, a sample of 18 to 22 year olds was recruited from medical records and multiple methods of publicity. Only 51.8% of the sample reported receiving subspecialty multidisciplinary diabetes care and education during early adolescence. For the purpose of the study, multidisciplinary diabetes care was defined as management by a pediatric endocrinologist and two of either a nurse educator, dietician, social worker or psychologist. In the only research found that examined diabetes education, participation in diabetes education was noted to be less than with diabetes medical care. Unfortunately, data regarding multidisciplinary adult care was not available. More favourable frequency and continuity of health care was reported by persons with a longer duration of diabetes and more favourable history of adjustment to diabetes, accounting for 24% of the variance in health care utilization.

Metabolic Control

The importance of glycemic control to the prevention or delay in progression of long-term complications has been clearly demonstrated by the Diabetes Control and Complications Trial (DCCT) as introduced in chapter one. A subgroup of 125 adolescents in the Diabetes Control and Complications Trial aged 13 to 17 at study entry, was

followed for a mean of 7.4 years. Those subjects who did not have retinopathy at study entry and who received intensive diabetes therapy had a 53% decreased risk of having retinopathy compared to those who received conventional diabetes therapy. In those who had mild retinopathy at study entry, intensive therapy decreased the risk of progression of retinopathy by 70% and the occurrence of microalbuminuria by 55%. The decrease in complications and rate of progression of retinopathy, microalbuminuria and neuropathy for the adult population were similarly impressive, and have been thoroughly reported and reviewed elsewhere (Diabetes Control and Complications Trial Research Group, 1993).

Bond et al. (1992) and Brownlee-Duffeck et al. (1987) also explored the relationship between the HBM, youth with Type 1 diabetes, and Hgb A1C or metabolic control. Hemoglobin A1C (Hgb A1C) is a blood test that reflects overall glycemic control over the previous two to four months. The above researchers found findings contradictory to the HBM regarding the influence of threat and fear, when looking at the relationship between metabolic control and the HBM. They found an inverse relationship between threat and metabolic control when cues to action were high. While the poorest metabolic control was associated with high threat and high cues, the best metabolic control was found when threat was low, and cues to action were high.

To explore for possible selection bias in the findings relative to the HBM and metabolic control, Brownlee-Duffeck et al. (1987) explored the difference in metabolic control between responders and non-responders. The response rate was 65% in the younger group, compared to 82% in the older group. In the younger group, non-responders had a significantly higher Hgb A1C than younger responders. No difference

was found in the older group. Overall, perceived severity and perceived benefits were associated with greater self-reported control, with perceived costs associated with poorer metabolic control. For the older group, metabolic control was predicted by perceived benefits whereas for the younger group, perceived severity and susceptibility predicted metabolic control. For the younger group, perceived severity and susceptibility were related to metabolic control but not adherence. Overall, the HBM accounted for 19 - 20% of the variance in metabolic control.

Contrary to the tenants of the HBM, in the younger group, greater perceived susceptibility to complications was associated with poorer metabolic control. Brownlee-Duffeck et al. (1987) interpreted this result as follows:

> This may simply reflect a realistic appreciation by subjects who are in poor metabolic control that they are more susceptible to complications. However, it may alternatively indicate that young patients react to their susceptibility with denial, and subsequently, even poorer control... High fear messages are often ineffective and may even be counterproductive in eliciting preventive health behaviours (p. 142)

The possibility of such contradictory findings to the original HBM was hypothesized earlier in the literature. Mikhail (1981) explained this possible counterproductive reaction to the perception of threat in that "fear messages may motivate avoidance behaviour or denial rather than control if the person lacks the knowledge of feasible ways of coping with the threat or believes that coping may incur a high cost" (p. 74).

Glycemic control was typically poor to moderate in 76.5% of the sample, with a

glycosylated hemoglobin greater than 10%. Of the 21 subjects who provided urine samples, 21 had evidence of early diabetic nephropathy (Wysocki et al., 1992).

Summary

The application of the Health Belief Model to health related behaviours in chronic illness has been most prevalent and accepted in diabetes research. Additionally, there is an expanding body of literature regarding the transfer of young adults from specialized pediatric health care to specialized adult health care. The limitations of research in this area include the primarily descriptive nature of the research, the small sample sizes, the wide variety of instruments, the lack of attention to nursing or non-physician follow-up, and the unique characteristics of each setting and clinic. Such breadth in the research and in the nature of each setting limits the ability to generalize the nature of the problems, or potential solutions, from one setting to the next.

The next chapter addresses the research design and methodology to address the issue of the transfer of young adults from specialized pediatric diabetes health care to specialized adult diabetes health care in Winnipeg.

CHAPTER 4: RESEARCH METHODOLOGY

Introduction

Based on the knowledge gained from a review of the literature related to young adult development and the transfer of young adults with Type 1 diabetes to specialized adult diabetes care, the research methodology follows. After a presentation of the purpose of the research, and research questions, the design including the sample, variables, instrumentation and analysis is reviewed.

Purpose

The purpose of this study is to examine the experience of young adults with Type 1 diabetes in Winnipeg as they move from specialized pediatric diabetes care to specialized adult diabetes care. It is hoped that this study contributes to a greater understanding of the transition needs of young adult clients with Type 1 diabetes in Winnipeg. Ultimately, this research is intended to provide a foundation for the development of a developmentally appropriate program for the young adult with Type 1 diabetes in Winnipeg, as recommended by the Manitoba Diabetes Strategy Committee (1998). A letter of support for this research by Dr. Dean, Director of the DER-CA is included in Appendix C.

Research Questions

1. What is the nature of client follow-up with specialized adult diabetes medical care and education after referral from specialized pediatric diabetes health care for persons with Type 1 diabetes in Winnipeg?
2. What is the reported experience with diabetes health care services of young adults with Type 1 diabetes in Winnipeg who have been referred from specialized pediatric

diabetes health care to specialized adult diabetes health care?

3. Is there a change in diabetes health within one year after referral to specialized adult diabetes health care, in particular metabolic control and diabetes-related hospitalizations, of individuals with Type 1 diabetes?
4. What factors are associated with attendance at specialized diabetes adult medical care within the first year after referral, in particular, health beliefs, when controlling for other variables?
5. What factors are associated with attendance at specialized diabetes education within the first year of referral, in particular, health beliefs, when controlling for other variables?
6. What factors are associated with attendance at specialized diabetes health care (combined medical and educator) within the first year of referral, in particular, health beliefs, when controlling for other variables?

Design

An exploratory retrospective design was used to answer the research questions. Multiple methods of data collection included an audit of pediatric and adult diabetes health records and a mailed self-administered questionnaire. The questionnaire consisted of two standardized tools and a transition instrument that included several demographic questions and open-ended questions. The three instruments included a transition tool examining the transition between pediatric and adult services for people with Type 1 diabetes (see Appendix D); the Diabetes Health Belief Scale (DHBS) (see Appendix E); and the Insulin Management Diabetes Self-efficacy Scale (IMDSES) (see Appendix F). The questionnaire and consent were mailed to the subjects for self-administration.

Study information, consent forms, and a questionnaire were sent to the last known address of the 95 eligible persons by the Research Assistant (RA) #1 from the Diabetes Research Group (DRG). The material was accompanied by a cover letter by Dr. H. Dean, Medical Director of the DER-CA (see Appendix G), and included a stamped envelope for return. The return address on the envelope was the Transition study, c/o Diabetes Education Resource for Children and Adolescents. Completed surveys were forwarded to the researcher by the DER-CA. Upon receiving consent, the researcher confirmed the eligibility of consenting individuals and conducted an audit of the subject's pediatric diabetes health record at the DER-CA. An ID number was used to identify each subject on the audit form to ensure anonymity of participants.

Recruitment of the Sample

In an attempt to increase the response rate, the research assistant (RA #2) contacted non-respondents three weeks after the initial mailing (Polit and Hungler, 1995) (see Appendix H: Telephone script). Telephone contact was used to assist in identifying those who did not respond to the surveys due to relocation of the subjects. The number of phone calls to each potential subject and the outcome of that phone call was recorded on a phone record sheet.

The response rate in previous transition research using a similar retrospective time frame of five years, and questionnaire distribution is reported as low. Pacaud et al. (1990) similarly sent two separate mailings to the subject's last known address at the pediatric clinic. The overall response rate was 36 %. Pless, Heller, Belmonte, and Zvagulis (1988) attempted to personally contact and interview 431 former diabetes campers, up to fifteen years after camp. Forty-five percent could not be located, died or failed to reply. Joffe,

Radius, and Gall (1988) distributed a questionnaire regarding health beliefs and habits to all freshman university residents living in residence with a completion rate of 25%. The young adult population is known to be highly mobile, with the inability to locate individuals a source of loss for subject follow-up (Pacaud et. al., 1990; Roos, Nicol & Cageorge, 1987).

All clients of the DER-CA who met the inclusion criteria were contacted for participation in the study, using a non-probability convenience sampling technique. The names of clients of the DER-CA who would be between the ages of 19 and 24 at the time of data collection were retrieved by the Medical Director of the DER-CA from the DER-CA database. A research assistant (RA #1) screened the diabetes health records to ensure potential subjects met the inclusion and exclusion criteria. The names of eligible subjects were then given to the research assistant (RA #1) for the mailing of study information, consent form, and questionnaire. A five year time span for sample selection was chosen to enable comparisons with the research design and sampling of Frank (1996) and Pacaud et al. (1996), to provide an adequate sample size, and to minimize threats to internal validity related to history, maturation, and recall.

The population was derived from the DER-CA client list of people who were transferred from the DER-CA to adult diabetes educators and physicians in Winnipeg over a five-year period. The DER-CA transferred 173 clients to adult diabetes care who continued with diabetes care in Winnipeg from 1994 to 1998 inclusive, a mean of 34.7 persons per year (see Appendix A: DER-CA statistics). Based on this, the potential sampling frame of clients who were transferred to adult care in Winnipeg from June 1994 to June 1999 consisted of 173 people. The purpose of inclusion of clients only up until June 1999 was to eliminate those subjects who were diagnosed within the year prior to

transfer, and who thus may have remaining endogenous insulin production, a confounding variable that may impact separately on the adjustment to diabetes (Grey, 1999).

Envelopes returned to the DRG due to address unknown were returned to RA #1 for further investigation. The facility's computerized records were checked to identify an alternate or updated address. If this method did not produce an alternate address, or the envelope was returned a second time, RA# 2 from the DER-CA, proceeded with attempts to contact the potential subjects, starting with phoning the last known phone number.

Questionnaire Return

Methods to increase the rate of participation, including the nature and number of attempts to contact each potential subject by the Research Assistants (RA) were recorded by the RAs on a spreadsheet. This information was later translated to SPSS by the researcher, and analyzed using descriptive statistics. Each attempt by RA #2 to contact subjects other than the initial mailing was counted as a unique contact. All contacts occurred via the phone, mail or computer. The types of contacts included: leaving messages on answering machines for the individual to call; speaking with the individual; speaking with a person at the last known phone number, such as a parent; re-mailing surveys to the same or a new address; and contact with directory assistance. Attempts to contact potential subjects occurred over a two-month period, and were discontinued on an individual basis, based on variables such as number and type of contacts and success at directly contacting the potential subject.

Inclusion Criteria

Clients were included in the study if they met the following criteria:

1. Diagnosed with Type I diabetes as per the DER-CA Medical Director, or the DER-CA attending physicians. Diagnosis of diabetes is made by the symptoms of diabetes plus a casual plasma glucose value greater than 11.1 mmol/L. The classic symptoms of diabetes include fatigue, polyuria, polydipsia and unexplained weight loss. Casual is defined as any time of the day, without regard to the interval, since the last meal (Meltzer et al., 1998). Confirmation of Type 1 diabetes is made clinically and documented on the DER-CA charts.
2. Referred by the DER-CA to adult diabetes physicians and diabetes educators in Winnipeg between June 1994 to June 1999.
3. Ability to read and understand English.

Exclusion Criteria

Clients were excluded from the study if they met the following exclusion criteria:

1. Attendance at pediatric diabetes education or pediatric diabetes medical care elsewhere than the DER-CA.
2. Diagnosed with other chronic physical conditions requiring specialized referral to an adult physician such as cystic fibrosis, or with mental health disorders. The diagnosis of a mental health disorder will be identified as per the chart.
3. Client was transferred to adult diabetes care due to pregnancy.

Measurement of Variables

The operationalization of variables selected for this study is summarized in Appendix I: Operationalization of Variables. The selection and measurement of the

independent variables and outcome variables were based on the review of the literature. The Health Belief Model (HBM) was used to organize the variables according to health beliefs, self-efficacy, cues to action, likelihood of taking action and modifying factors.

Independent Variables

Health Beliefs

Diabetes Health Beliefs were measured using the Diabetes Health Belief Scale (DHBS), more commonly known as the HBM 11, developed by Hurley (1990a) (see Appendix E). Given et al. (1982) were the first to develop a scale to test the HBM on subjects with diabetes. This original 76-item Diabetes Health Belief Scale (HBM 76) was developed predominantly with subjects with Type 2 diabetes. Becker and Janz (1985) later revised the HBM 76 to a 16-item scale - the HBM16. Four items each were selected to represent each of the four core dimensions of the HBM, perceived susceptibility, severity, benefits and barriers. The original content validity of the HBM 76 was felt by the researchers to be maintained when the scale was shortened, as each item was matched to one of the four core dimensions (Hurley, 1990a).

Hurley (1990a) examined the HBM16 for reliability and validity, using a sample of 127 adults on insulin, 71% with Type 1 diabetes. The mean age of this sample, and the sample used to test the HBM11, as below, was 45.6 years. Analysis of the HBM16 resulted in two items being discarded due to very low discriminating power, and two others with negative item-to-related-item correlations. After further testing of the reduced scale (HBM12) one further item was eliminated due to poor factor loading.

The final HBM11 measures three dimensions of the Health Belief Model: benefits (items 1, 6, and 7), barriers (items 8 to 11), and seriousness (items 2 to 5). The HBM 11

was shown to have concurrent, criterion-related and predictive validity. Concurrent validity was examined and proven using perceptions of diabetes severity and metabolic control. The association between perceptions of previous metabolic control and A1C validated criterion validity. The predictive capacity of the HBM11 was supported by the correlation between the HBM and diabetes self-care, as measured by the Diabetes Self-care Scale total score (r = .36, $p < .001$), and between the HBM and three diabetes self-care subscales of general, diet and insulin ($p < .001$; r = .33 general; r = 28 diet; r = .26 insulin)

The revised 11-item scale represents three of the four core dimensions of the Health Belief Model: severity, benefits and barriers, and uses an ordinal level of measurement. A five-item Likert scale ranges from strongly agree to strongly disagree. Items numbered 1, 3, 4, 5, 6 and 7 are negatively worded and were reverse coded prior to analysis. The final score is a sum of all questions for a maximum total score of 55. A high score is equated with psychological readiness to undertake diabetes health actions. For this study, the HBM11 was mailed to all potential subjects, and returned completed along with the signed consent.

The HBM11 was modified for this study by the researcher to replace the word "diet" with "meal plan" to reflect current diabetes education practices. The total score, mean, median and scores of the sub-scales of benefits, barriers and severity were used for analysis of Health Beliefs, and for the evaluation of relationships to the outcome variables.

Internal consistency of the Health Belief Scale. For this study, the internal consistency of the HBM 11 and subscales was tested by using Cronbach's alpha. The barrier subscale had the highest internal consistency at .76, followed by .62 for benefits

and .28 for seriousness, suggesting that while the items included in the barrier subscale measured the same characteristic, there was little homogeneity among items measuring benefits, and no relationship among the items measuring seriousness. The combined internal consistency of all eleven items was low at - .08. The reliability of the scale was likely affected by changes in the goals and philosophies of diabetes health, health care and education, since the development of the scale, and by the impact on diabetes of the unique developmental issues of young adults.

Factor analysis of the Health Belief Scale. Confirmatory factor analysis was utilized to determine the presence of subscales that were similar to those developed by the researchers who used the HBM 11 in the past. The factors that emerged did not correspond with those developed by the authors of the tools. Therefore, the sub-scales suggested by the authors of the scale were used. All eleven items were strongly correlated, ranging from .66 to .79. Four dimensions were isolated, however they were not similar to the three identified by the previous research: benefits, seriousness and barriers. Thus, the original sub-scales developed by the researcher were used for analysis for this study.

Self-efficacy

Self-efficacy is the fifth component of the Health Belief Model. Self-efficacy was measured by the Insulin Management Diabetes Self-efficacy Scale (IMDSES) (see Appendix F). The IMDSES was developed for use with subjects on insulin by Hurley (1990b), based on the version by Crabtree and Bandura. Hurley and Shea (1992) further modified the IMDSES in a study of 142 adults using insulin aged from 18 to 73 years, with a mean age of 45.

Each of the 28 items of the IMDSES consists of a statement of diabetes activities and circumstances. Subjects rate their degree of capability for being able to carry out the activity on a six point Likert scale, using an ordinal level of measurement ranging from one (strongly agree) to six (strongly disagree). As recommended by Hurley (1990b) "non-applicable" answers were initially recorded as missing data. The 18 positively worded items were reverse scored before analysis.

Examination of the IMDSES by Hurley in 1990(b) in 127 adults who used insulin revealed adequate content validity. The internal consistency ($\alpha = .82$, N = 79, items = 28) of the combined subscales of the IMDSES was considered to be above the norm of .70 for a new scale. Due to low discriminating power, two items about taking insulin were removed from the IMDSES. The resulting 26-item IMDSES ($\alpha = .86$) has three internally consistent sub-scales: general (6 items, $\alpha = .67$), diet (7 items, $\alpha = .78$) and insulin (9 items, $\alpha = .77$). Scale total scores or sub-scales can be used. The maximum total score is 168 with higher scores indicating a higher level of self-efficacy. Two items each related to exercise and foot care were too small in number to have subscales for those behaviours. The diet subscale had the highest alpha coefficient of .78. The insulin subscale had the lowest alpha coefficient, described as due to the range and complexity of behaviours that constituted that subscale (Hurley, 1990b). Construct validity of the IMDSES was supported by the positive correlation of the IMDSES and the A1C, and Diabetes self-care scale. Convergent validity of the IMDSES was supported. The IMDSES is currently being used in a randomized trial of diabetes transition with young adults in London, Ontario (personal communication, Dr. Beth Mitchell, April, 2000).

The IMDSES consists of three internally consistent sub-scales: diet, general and

insulin, and two items each related to exercise and foot care.

Internal consistency of the self-efficacy scale. For this study, Cronbach's alpha was used to test the internal consistency of the Self-efficacy Scale and subscales. The diet subscale had the highest internal consistency at .91, followed by .75 for general and .67 for insulin. The combined inter-item reliability of all 28 items was high at .92 suggesting that items in the Self-efficacy scale correlated highly with each other.

Factor analysis of the self-efficacy scale. The Self-efficacy Scale was also analyzed via confirmatory factor analysis using SPPS. All 28 items on the Self-efficacy scale were strongly correlated, ranging from .74 to .94. Eight dimensions were isolated by factor analysis, however none corresponded with the three identified by the previous research. Thus, the total score and original sub-scales of the original authors were used for analysis. In this study, the mean and total score of the IMDSES and the sub-scales were calculated, and used in the analysis of the subjects' health beliefs, and for correlation with the outcome variables. Higher scores indicate a higher level of self-efficacy.

Scoring of the self-efficacy scale. The responses on the Self-efficacy scale provided an option of "non-applicable." The "non applicable" choice on the Self-efficacy scale was initially recorded as missing data, as per the instructions of Hurley (1992). Missing values were then replaced with the subject mean for that sub-scale, and total scores calculated. For items not included in a sub-scale, the mean of the total score was used for that subject. The item in the self-efficacy scale most frequently answered as non-applicable by the subjects was the following: "I can routinely apply the recommended lotion to my feet."

Cues to Action

The following variables measured the cues to action, or stimuli that are necessary to trigger the decision-making process, according to the Health Belief Model. The first three variables measuring cues to action were found in the pediatric diabetes medical record, and transcribed onto the Pediatric Chart Audit form developed by the researcher:

Discussion of transfer prior to last visit with pediatric diabetes physician. Discussion of transfer with the subject by the diabetes physician, prior to the last visit to the pediatric diabetes physician was measured by evidence of documentation of such a discussion on the DER-CA chart. Documented words that were considered to represent discussion of transfer included "referral," "transfer," "adult care" and "transition."

Discussion of transfer prior to last visit with pediatric diabetes educators. Discussion of transfer with the subject by the diabetes educators, prior to the last visit to the pediatric diabetes educators was measured by evidence of documentation of such discussion on the DER-CA chart. Documented words that were considered to represent discussion of transfer included "referral," "transfer," "adult care" and "transition."

Frequency of diabetes-related hospitalization the last year of specialized pediatric diabetes health care. The frequency of diabetes-related hospitalizations the last year of specialized pediatric diabetes health care is recorded on the DER-CA chart. Documentation of diabetic ketoacidosis, or severe hypoglycemia, within one year to the last appointment with the DER-CA, was recorded on the Pediatric Chart Audit Form.

The two remaining variables that measured cues to action were obtained from the transition questionnaire mailed to the subjects. The "Questionnaire on transition between pediatric and adult services for people with Type 1 diabetes" (see Appendix D) was

modified with permission from Pacaud, McConnell, Huot, Aebi, and Yale (1996). The original questionnaire was pre-tested and revised, and verified for face validity. Modifications were recommended by Pacaud to reflect local variations in the process of transfer from pediatric to adult health care (D. Pacaud, March 2000, personal communication). It contains a combination of closed and open-ended questions utilizing nominal, ordinal, interval and ratio measures.

Information regarding transfer to adult care. Two questions on the self-administered transition questionnaire examined the information that the subjects recalled receiving regarding their upcoming transfer to adult diabetes health care. The first question examined whether subjects received any information as follows: "Did you receive any information from your pediatric diabetes team about the adult diabetes clinic or adult diabetes education team?" with yes = 1, and no = 2.

An open-ended question examined what education or information the subjects recall being given about the upcoming transfer as follows: "Could you describe the kind of information that you were given?" A four-point Likert scale further examined how helpful the subjects found this education: 1 = To a Great Extent; 2 = Somewhat; 3 = Very Little; 4 = Not at All helpful; and 9 = No response. For analysis, this was collapsed to a dichotomous variable, comprising of "to a great extent" and "somewhat" as one value, and "very little" and "not at all" as the second.

Modifying Factors - Sociopsychological Variables

The variable "living arrangements" reflected the modifying variable of sociopsychological variables, according to the Health Belief Model.

Living arrangements. Who the subject lives with was obtained from self-report

via the transition questionnaire using the following format: 1 = Lives on their own; 2 = Lives with parents; 3 = Lives with spouse; 4 = Lives with friends; 5 = Other; and 9 = No response.

Modifying Factors – Structural Variables

The following variables reflect the structural variables of the modifying factors of transfer to adult care, which according to the Health Belief Model, might affect an individual's perceptions of susceptibility, severity, benefits and barriers and thus indirectly influence health-related behaviour. The following data measuring modifying factors - structural variables, were obtained from the transition questionnaire mailed to the subjects.

Experience with transfer. The subject's experience with transfer to adult care was examined qualitatively, using an open-ended question on the self-administered transition questionnaire. A forced choice question examined whether the subject experienced any problems or difficulties with their transfer (dichotomous choice where 1 = yes and 2 = no). This was followed by an open-ended question for the affirmative respondents, "If so, in what way?"

Factors the subjects feel should determine the time for transfer. The factors that the subjects identify that should determine the time for transfer from pediatric to adult health care were examined qualitatively on the self-administered transition questionnaire using the following question: "In your opinion, how should the time for transfer from pediatric to adult health care be determined?"

Ideal age for transfer. The subjects' opinion of the ideal age for persons with type 1 diabetes to transfer from specialized diabetes pediatric health care to specialized adult

diabetes health care was obtained in the self-administered transition questionnaire via the following question: "If age was used to determine the time of transfer from pediatric diabetes care to adult diabetes health care, in your opinion, what would be the ideal age be?"

Ideal health care team. The subject's opinion of who they felt would be the ideal members of the diabetes health care team for young adults with Type 1 diabetes from age 18 until age 25 was obtained via self-administered transition questionnaire via the following question: "Regardless of where the diabetes clinic was, who do you feel would be the ideal health care members of your diabetes health care team from age 18 until age 25?" 1 = The pediatric team; 2 = The adult team; 3 = A mix of the two, some familiar pediatric staff and new adult staff; 4 = other; and 99 = no response.

Ideal setting for young adult health care. The subject's opinion of the preferred setting for young adult diabetes care was obtained via self-administered transition questionnaire via the following question: "What setting do you feel would be preferable for the diabetes care and education of young adults (18 to 25 years)": 1 = Stay with pediatric diabetes team, and move to adult care at about age 25; 2 = A clinic for people 18 to 25 year old only, then move to adult care; 3 = Move straight to adult care at the age of 18; 4 = other; and 99 = no response.

Problems with transfer. The subject's perception of problems related to the transfer process was examined using a forced choice, dichotomous question, and qualitatively, using an open-ended question on the self-administered transition questionnaire, via the following questions:

"Did you experience any problems with your transfer?" Yes/No; and "If so, in what

way?"

Recommended changes in transfer process. The subject's recommendations for changes to the transfer process were examined via the following open-ended question: "If you could change anything about how you were educated about, or referred to the adult diabetes care, what would you change?"

The remaining variables measuring cues to action were found in the pediatric diabetes medical record, and transcribed onto the Pediatric Chart Audit form developed by the researcher.

Age at final visit to specialized diabetes pediatric care / Age at transfer to adult diabetes health care. The date of the last documented visit to the DER-CA was found on the subject's record at the DER-CA. The last visit documented was used, regardless of whether the visit was to the physician or the educators. The date of this visit was then subtracted from the date of birth.

Date of referral letter to adult diabetes medical care. As per DER-CA practice, a dated copy of the referral letter from the pediatric diabetes physician to the adult diabetes physician was available on the subject's record at the DER-CA.

Date of referral letter to adult diabetes educators. As per DER-CA practice, a dated copy of the referral letter from the pediatric diabetes education team to the adult diabetes education team was available on the subject's record at the DER-CA.

Location of adult diabetes physician referred to. The location of the adult diabetes physician that the subject was referred to by the pediatric diabetes physician was indicated in order to perform the adult chart audit. The location was obtained via a chart review of the DER-CA chart, and transcribed on to the Pediatric Chart audit form as follows: Winnipeg

Clinic = 1; St. Boniface Hospital = 2; Health Sciences Centre = 3; Diabetes specialist outside of Winnipeg = 4; Diabetes specialist outside of Manitoba = 5; Other: = 6; and not found = 9.

Location of adult diabetes educators referred to. The location of the adult diabetes education team that the subject was referred to by the pediatric diabetes educators was indicated in order to perform the adult chart audit. The location was obtained via a chart review of the DER-CA chart, and transcribed to the Pediatric Chart audit form. as follows: 1 = St. Boniface Hospital; and 2 = Health Sciences Centre; 3 = Rural DER; 4 = Youville DER; 5 = Outside of Manitoba; 6 = Other; and not found = 9.

Modifying Factors - Demographic Variables

The following variables reflected the modifying demographic variables, which according to the Health Belief Model, might affect an individual's perceptions of susceptibility, severity, benefits and barriers and thus indirectly influence health-related behaviour. The following variables measuring modifying factors were found in the pediatric diabetes medical record, and transcribed onto the Pediatric Chart Audit form developed by the researcher: age, gender, date of diagnosis with Type 1 diabetes, and length of diagnosis with Type 1 diabetes prior to referral to adult care. If unavailable on the chart, the length of diagnosis was calculated by subtracting the date of diagnosis from the subject's age at referral to adult care.

The following four variables measuring modifying factors were completed by the subjects in the transition questionnaire:

Educational status. The subjects' highest level of education was obtained using the following measure: Did not complete high school = 1; High school completed = 2;

Currently in university or college = 3; Completed university or college = 4; Other = 5; and Not answered = 9.

Employment status. The subject's employment status was obtained via the following format: Currently working full time = 1; Currently working part time = 2; Unemployed = 3; Other = 4; and Not answered = 9.

Living arrangements. The subject's living arrangements were obtained via the following question: Who do you live with? The responses were obtained using the following format: live on your own = 1; live with parents = 2; live with spouse = 3; live with friends = 4; Other = 5.

Marital status. The subject's marital status was obtained using the following format: 1 = Single; 2 = Living with partner; 3 = Married; 4 = Separated/Divorced; and 9 = No response.

Likelihood of Taking Health-Related Action

The following variables measured the subject's likelihood of taking health-related action, as per the Health Belief Model. The first three variables were found in the pediatric diabetes medical record, and transcribed onto the Pediatric Chart Audit form developed by the researcher.

Number of visits in the last year of specialized pediatric diabetes medical care.

The subject's attendance at specialized pediatric diabetes medical care during the last year of pediatric diabetes health care was determined via a review of the pediatric chart. It was measured as the number of visits in the last year.

Number of visits in the last year of specialized pediatric diabetes education.

The subject's attendance at specialized pediatric diabetes education during the last

year of pediatric diabetes health care was determined via a review of the pediatric chart. It was operationalized as the number of visits to any of the diabetes educators.

Metabolic control (pediatric). The subject's metabolic control was determined via measurement of Hgb A1C. The measure of Hgb A1C during the last year at specialized pediatric diabetes health care included all results the year prior to and including, the subjects final visit to specialized diabetes pediatric care. Results were obtained from the record of the DER-CA. The number of Hgb A1C results within that time period, and the normal values for that assay were also recorded.

To allow for comparison of results from different assays, each Hgb A1C result was converted to percentage of normal, using the following formula: Hgb A1C value/assay upper limit x 100. The mean result during the last year at specialized pediatric diabetes health care was then calculated from those individual values.

The remaining variables measuring the likelihood of taking action were obtained from the transition questionnaire mailed to the subjects.

Reasons for attendance or non-attendance at diabetes appointments with the pediatric diabetes team and physician. The subject's reasons for attending or not attending pediatric diabetes medical care or education during the last year of pediatric diabetes health care was assessed via the transition questionnaire, using the following two open-ended questions: "If you did attend diabetes appointments with the pediatric diabetes team and physician, what made did you decide to go?" and "If you did not attend or book regular appointments, why didn't you?"

Outcome Variables

The outcome variables for this research were:

1. Follow-up with specialized adult diabetes health care the first year after referral
2. Number of diabetes-related hospitalizations during the first year of specialized adult diabetes care
3. Metabolic control during the first year of specialized adult diabetes care.

The following outcome variables were found on the adult diabetes medical record, and recorded on the Adult Chart Audit form, developed by the researcher.

Number of Visits in the First Year of Specialized Adult Diabetes Medical Care

The subject's attendance at specialized adult diabetes medical care during the first year of adult diabetes health care, and dates of visits, were determined via a review of the adult chart. It was to be measured as a dichotomous variable, attendance vs. non-attendance, however the number of visits that would define acceptable attendance was not able to be determined due to the sample size and lack of variance in attendance. Similarly, the small sample size precluded the use of the dates of visits and a determination of the interval of visits.

Number of Visits in the First Year of Specialized Adult Diabetes Education

The subject's attendance at and dates of visits to specialized adult diabetes education during the first year of adult diabetes health care were determined via a review of the adult diabetes charts. Attendance at visits was operationalized as the number of visits to any of the adult diabetes educators. It was to be measured as a dichotomous variable, attendance vs. non-attendance. However, the number of visits that would define acceptable attendance was not determined due to the small sample size and lack of variance in attendance. Similarly, the small sample size precluded the use of the dates of visits and a determination of the interval of visits.

Metabolic Control (adult)

Metabolic control was measured using the results of Hemoglobin A1C documented on adult diabetes medical record. The adult record was that of the referred facility or community clinic.

The mean Hgb A1C during the first year of specialized diabetes health care included all Hgb A1C results from one year after the subjects last visit to pediatric diabetes health care to one year later. The number of Hgb A1C results within that time period, and the normal values for that assay were also recorded. The mean result during the first year at specialized adult diabetes health care was then calculated from those individual values.

To allow for comparison of results from different assays, the Hgb A1C results were converted to percentage of normal, using the following formula: Hgb A1C value/assay upper limit x 100.

Number of Diabetes-related Hospitalization During the First Year of Specialized Adult Diabetes Care

The dates of diabetes-related hospitalization the first year after referral to specialized adult diabetes health care was determined via a review of the adult health record and recorded on the Adult Chart audit form. The first year of specialized adult diabetes care was defined as one year following the last appointment at the DER-CA. The number of diabetes-related hospitalization utilized a ratio unit of measurement.

The following are the outcome variables that were transcribed from the transition questionnaire.

Reasons for Attendance at Adult Diabetes Care

The subjects reasons for attending adult diabetes care were examined qualitatively, using an open-ended question on the self-administered transition questionnaire as follows: "If you attended diabetes appointments with the adult diabetes team or physician, what made you decide to go?"

Reasons for Not Attending Adult Diabetes Care

The subject's reasons for not attending adult diabetes care were examined qualitatively, using an open-ended question on the self-administered transition questionnaire as follows: "If you did not attend or book all of the recommended appointments, why didn't you?"

Chart Audits

Audit forms developed by the researcher were used to obtain selected demographic and medical information from the pediatric and adult diabetes medical records (see Appendices J and K), as discussed above. The researcher completed the audit forms during an audit of the subjects' pediatric and adult diabetes health records, after written consent was obtained. Demographic information included: gender, date of birth, town of residence, date of and age at diagnosis with Type I diabetes, the date(s) of visits to DER-CA physician and educators the last year prior to transfer, and the subject's age at final visit to DER-CA.

Medical information obtained from the chart audits was not of a sensitive nature. Medical information was restricted to: confirmation of diagnosis with Type 1 diabetes; Hemoglobin A1C results within one year prior to, and one year following transfer to adult health care; frequency of diabetes related hospitalization(s) one year prior to, and one year following transfer to adult health care; dates and presence of referral letters to adult diabetes

health care (physician and educators); the date(s) of documented discussion by pediatric educators or the pediatric diabetes physician of the upcoming transfer within one year prior to the last visit to pediatric diabetes health care and the location of the adult diabetes health care agencies which patients were referred to.

The appropriate facility/hospital chart was used to complete the chart audit. The pediatric health records were found at the Diabetes Education Resource for Children and Adolescents. The adult chart records were found at the site of the specialized adult diabetes physicians and adult diabetes education teams (Winnipeg Clinic, St. Boniface Hospital, Health Sciences Centre and Youville Clinic).

Data Analysis

Data were analyzed using the Statistical Program for Social Sciences version 8.0 (SPSS for Windows) and Microsoft Excel 2000, version 9.0. Descriptive statistics were obtained on all participants. Variables were screened for skewness and outliers. Bivariate analysis, comparing those who attend adult diabetes health care services to those who do not, was conducted. Non-parametric tests were utilized because of the small sample size and the non-normal distribution of the variables. A linear logistic regression model to determine which independent variables were associated with attendance was not possible due to the small sample size.

Options for analyzing follow-up in adult diabetes medical care and education included, a) the Clinical Practice Guidelines of the Canadian Diabetes Association (1998) recommendation of follow-up every two to four months, b) attendance within the first and/or second six month period after transfer as per other researchers (Pacaud et al., 1996), or c) attendance within the first year after transfer as per Frank (1996). The final

decision to measure and analyze attendance within the first year after transfer was determined by the limited sample size and small number of visits.

Content analysis was used to examine the responses to the open-ended questions in the self-administered questionnaire. Categories and subcategories were developed by the researcher based on the key words or ideas noted after reading each question and verified by the Thesis Chair. Each of the open-ended questions was analyzed independently, and addressed according to the research questions.

Ethical Considerations

The University of Manitoba, Faculty of Nursing, Ethics Committee, granted approval of this study (see Appendix L: Ethics approval). Informed consent was obtained from subjects. Subsequently, the proposal was approved by the participating agencies, Health Sciences Centre, St. Boniface Hospital, Youville Clinic and Winnipeg Clinic, for access and impact (see Appendix M: Access and impact). To ensure the anonymity of each center, the sites were coded for analysis. Access to subject chart records, and names and addresses was obtained according to the Personal Health Information Act, and agency policies.

The researcher was the nurse educator at the DER-CA from October 1993 to May 1999 inclusive, providing pediatric diabetes education to eligible subjects. To minimize bias due to social desirability, insider bias, interview bias, and prevent any perception of coercion or a power imbalance (Polit and Hungler, 1995), the research methodology did not include any direct contact between the researcher and the subjects. The research was introduced with a cover letter from the Medical Director of the DER-CA. Mailed questionnaires and chart audits were chosen to minimize the potential for interviewer

bias, experimenter effect and bias due to social desirability (Polit and Hungler, 1995). The researcher does not have any future plans to engage in a professional relationship with the subjects.

The Manitoba Legislature assented to the Personal Health Information Act (PHIA), Chapter P33.5, on June 28, 1997. The design and ethical considerations for this research are in accordance with section 24 of PHIA as follows:

> Section 24 Health research: Conditions for approval
>
> 24(3) An approval may be given under this section only if the health information privacy committee or the institutional research review committee, as the case may be, has determined that
>
> (a) the research is of sufficient importance to outweigh the intrusion into privacy that would result from the disclosure of personal health information;
>
> (b) the research purpose cannot reasonably be accomplished unless the personal health information is provided in a form that identifies or may identify individuals;
>
> (c) it is unreasonable or impractical for the person proposing the research to obtain consent from the individuals the personal health information is about;
>
> (d) the research project contains:
>
> (i) reasonable safeguards to protect the confidentiality and security of the personal health information, and
>
> (ii) procedures to destroy the information or remove all identifying information at the earliest opportunity consistent with the purposes of the project.

Eligible individuals were determined via a review of the pediatric diabetes chart by a research assistant (RA #1) from the Diabetes Research Group. A list of potential participants by date of transfer was provided by the DER-CA medical director, and generated from the DER-CA database. The research assistant sent to eligible individuals an information package including a letter explaining the study, a consent form, a cover letter by a third party, Dr. Heather Dean, Medical Director of the DER-CA (see appendices N, O, and G), and questionnaires. This mailing was sent to the subject's last known address from the pediatric diabetes clinic, and included a stamped addressed envelope for the return of the consent and instruments. All mailings were returned to the researcher, care of the DER-CA. Subjects were invited to contact the researcher or the thesis chair with any concerns. As per the requirements of two of the facilities, a contact person at those facilities was also included in the letter

The researcher informed the research assistants which potential subjects responded. Facility B granted access based on the condition that any contact with potential subjects other than mailing be from a Research Assistant internal to the DER-CA. Thus, a second Research Assistant, RA #2, was hired to further participate in tracing and recruiting potential subjects. If after three weeks, individuals had not responded, they were telephoned by the second research assistant (see Appendix H: Telephone script) to assist in identifying those who did not respond to the surveys due to relocation. The researcher was not informed of the identity of the non-respondents.

The anonymity and confidentiality of subjects were maintained throughout the entire course of the research study. The instruments were assigned a code number prior to mailing. To determine the outcomes for the client of the transfer process, it was necessary

to link subject chart data to completed questionnaires. More specifically, matching was indicated in order to determine the relationship between the independent variables and the outcome variables and to assess the factors that influence participation in adult diabetes follow-up, specifically health beliefs, transition experience and health status and participation in diabetes health care in the pediatric period.

The pediatric and adult chart audit forms were coded by the researcher using a separate system. The list of matching chart audit codes, instrument codes and names were kept under lock by the researcher in a separate location, and will be destroyed after the analysis is completed. Charts were accessed as per the policy of the facility, and not removed from that facility. A copy of the consent form was placed on each record.

There was no direct benefit to the individual to participate in this research. The benefit to participation was the ability to help future young adults who are transferred to adult care. No mental, emotional or physical harm to the subjects was anticipated with the research study. The risks to the subjects were minimal, and related to the time necessary to complete the instruments. The estimated time for completion of the written instruments was thirty to forty-five minutes.

All raw data will be kept under lock and key for a period of seven years and then destroyed. Only the researcher and thesis chair have access to the original data.

Summary

The HBM serves as a framework in which the diabetes educator can study individuals with diabetes, or make an educational assessment of clients, focusing interventions upon relevant identified attitudes and beliefs (Becker & Janz, 1985). Variables indicated by the literature review were incorporated into the pediatric and adult chart audit

forms, and in the Transition Questionnaire (Appendix D). This research project met many of the diabetes research needs identified at the American Association of Diabetes Educators recent research summit (Glasgow, 1999). This study contained "practice-oriented research" addressing effects of the practices of the health care organization on the health and health care of individuals; examined the "relationships among various outcomes and of the process to outcomes linkages," and was "conducted with representative patients, providers, and settings" (Glasgow, 1999, pp. 74 & 84).

CHAPTER 5: FINDINGS

In this chapter, the findings of the study are reported. A description of the recruitment process, the demographic profile of the sample, and the findings from the pediatric and adult chart audit are provided. Following discussion of the recruitment process and description of the sample, the data from the relevant analysis will be addressed according to each of the research questions.

Recruitment of Sample

Screening of this sample by RA #1 for the inclusion and exclusion criteria indicated that 95 persons met the eligibility criteria. A reason for this difference from the sample projected from DER-CA statistics of 173 may be that the DER-CA statistics represented transfer to adult diabetes medical care only in Winnipeg, rather than both medical and educator care. Letters were sent to those 95 potential subjects.

The maximum number of attempts to contact potential respondents was five. As seen in Chart 1, seventeen persons returned their survey after the first mailing and did not require any further contact. Surveys were re-mailed to 23 persons at their request or due to RA identification of a new address. This second mailing resulted in seven further completed surveys. Research Assistant #2 attempted to contact all those who did not reply after the first mailing. A total of 174 attempts at contact were made to the remaining potential subjects, with a mean of 2.2 contacts per remaining potential subjects (see Table 1). Fourteen individuals were unable to be located, despite efforts to locate a new phone number or address. They were each counted as one contact. Those who were contacted by phone and refused to participate consistently indicated that their only barrier was their busy schedule. Parents who were spoken to in the attempt to locate or speak to the potential

subject also indicated receiving such feedback from their children.

Chart 1

Outcome of recruitment attempts (n = 95)

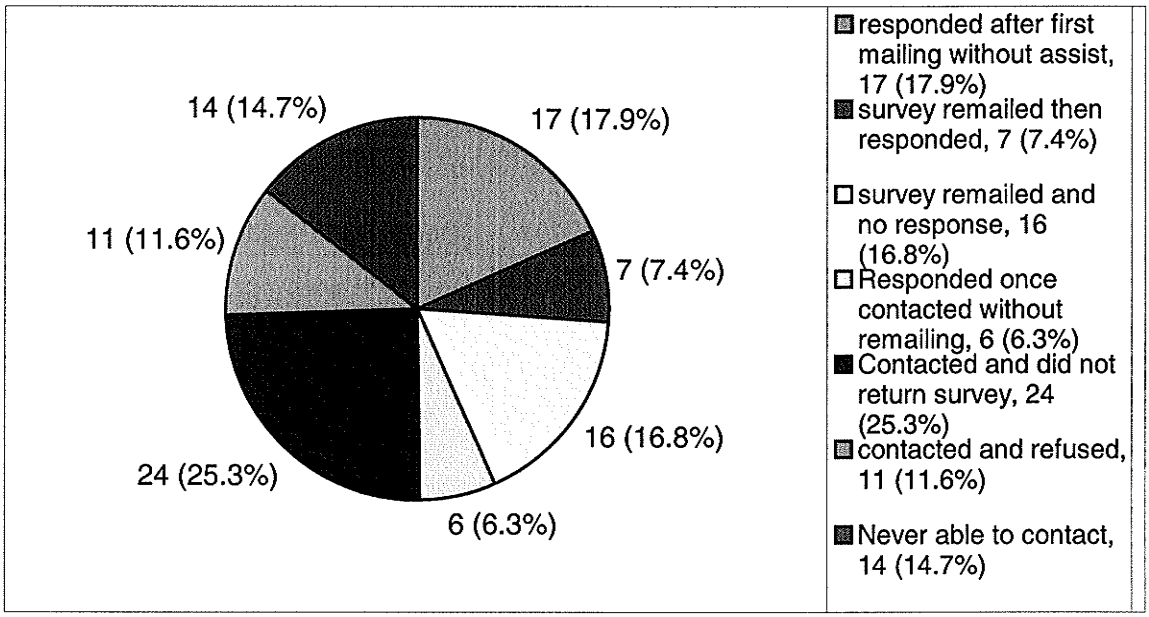

Table 1

Total Number of Attempts to Contact Potential Participants

Number of attempts at contact	Total number of potential subjects (%)
0	17 (17.9)
1	28 (29.5)
2	24 (25.3)
3	13 (13.7)
4	6 (6.3)
5	7 (7.4)
Mean no. of attempts at contact per potential subject excluding first mailing	2.2
Total number of potential subjects	95

Twelve persons (12.6%) who returned the surveys were determined to be ineligible upon audit of their pediatric chart by the researcher, primarily due to care by

diabetes educators outside of Winnipeg during pediatrics or referral to adult diabetes educators outside of Winnipeg. Sixty-four persons did not return the survey, for a final rate of non-participation of 67.4%. The remaining 19 persons (20%) were confirmed as eligible upon audit of the pediatric chart and comprised the final sample. The return rate for the survey was 31/95 or 32.6 %.

Of the 95 persons to whom surveys were mailed, 47.4% (n = 45) were female, and 52.6% (n = 50) were male. A large gender difference was noted in the survey return rate. Proportionately more females who were mailed the survey returned the survey than males (n = 20 or 44.4% of females compared to n = 11 or 22.0% of males; see Table 2 below).

Table 2

Outcome of Recruitment by Gender

			Outcome of Survey			Total
			Returned and eligible	Not returned	Returned but not eligible	
Gender	Female		(14)	(25)	(6)	(45)
		% of all females	31.1%	55.6%	13.3%	100.0%
		% outcome of survey	73.7%	39.1%	50.0%	47.4%
		% of total	14.7%	26.3%	6.3%	47.4%
	Male		(5)	(39)	(6)	(50)
		% of all males	10.0%	78.0%	12.0%	100.0%
		% outcome of survey	26.3%	60.9%	50.0%	52.6%
		% of total	5.3%	41.1%	6.3%	52.6%
Total #			19	64	12	95
%			20.0%	67.4%	12.6%	100.0%

Description of the Sample

The final sample size consisted of 19 participants (see Table 3). Of the 19 subjects, 14 were female (73.7%) and 5 were male (26.3 %).

According to the pediatric chart audit, four subjects lived outside of Winnipeg at the time of transfer, but were still referred to a diabetes health care team in Winnipeg. On the survey, the majority of the subjects (n = 17 or 89.4%) reported that they were single or engaged. Most subjects resided with another person (n = 16 or 84.2%), such as a parent, friend, partner, roommate, or various combinations of those individuals.

Table 3

Characteristics of the Sample - Part One

Characteristic	Number (%)
GENDER	
Female	14 (73.7)
Male	5 (26.3)
LOCATION UPON TRANSFER	
Winnipeg	15 (78.9)
Outside of Winnipeg	4 (21.1)
MARITAL STATUS	
Single/engaged	17 (89.4)
Married	1 (5.3)
No response	1 (5.3)
LIVING ARRANGEMENTS	
Live with others	16 (84.2)
Live on own	3 (15.8)

The most commonly reported highest level of completed education was "currently in university" (47.4%) (see Table 4). The most commonly reported employment status was full-time (n = 9 or 47%). The response options did not distinguish between those

who were unemployed and looking for work, and those who were unemployed and not looking for work. Two respondents were coded as "other." One indicated that he/she was a student, looking for work, with the other reporting working full time but as an unpaid intern.

Table 4

Characteristics of the Sample - Part Two

Characteristic	Number (%)
EDUCATION	
High school completed	6 (31.6)
Currently in university or college	9 (47.4)
Completed university or college	4 (21.1)
CURRENT EMPLOYMENT	
Working full time	9 (47.4)
Working part time	7 (36.8)
Unemployed	1 (5.3)

When comparing the chart data to the self-report, an inconsistency was noted in the age of diagnosis with Type 1 diabetes. The mean age of diagnosis with diabetes by self-report was 8.9 years of age, compared to 9.6 years of age as indicated in the pediatric chart audit (see Table 5). Discrepancies between the age of diagnosis using self-report and chart audit ranged from a time period of 2 months to 2 years in six of the nineteen subjects. The age at diagnosis ranged from two to fifteen years of age in both groups. The length of time since diagnosis with Type 1 diabetes was calculated from information obtained in the pediatric chart: the age at transfer minus the age at diagnosis. The mean number of years that the subjects were diagnosed with diabetes prior to transfer was 7.9 years, ranging from 2 to 15 years.

Table 5

Characteristics of the Sample - Diabetes

Characteristic	Years
MEAN AGE OF DIAGNOSIS WITH DIABETES	
Self-report	8.9
Pediatric chart audit	9.6
LENGTH OF DIAGNOSIS BEFORE TRANSFER	
Mean	7.9
Range	2 to 15

Referral Process

At the time of transfer to adult care, clients from the DER-CA are referred to specialized adult diabetes care, consisting of both an adult diabetes physician and a diabetes education team. The standard process for client referral to adult diabetes care by the DER-CA consists of anticipatory discussion with the client, and referral letters. The pediatric diabetes educators refer to adult diabetes educators, and the pediatric diabetes physician refers to an adult diabetes physician. The young adult is contacted by the adult diabetes agency for an appointment after receipt of the referral letter.

Clients who chose to transfer to diabetes health care teams in Winnipeg would typically be referred to a physician in either of three locations and education teams in either of two sites. The adult physician and education team may practice in the same, or in two different locations. As such, the subject may access adult diabetes health care in two locations and times. This is different from their pediatric experience, which is provided in one clinic.

Data were collected from both the pediatric and adult chart audits to examine the referral process. The referral data collected included the date of the last visit to any member of the pediatric diabetes health care team, the date of the first visit to any of the adult diabetes health care team, the presence of referral letters from the pediatric educators and pediatric diabetes physician in the pediatric and adult charts, the dates of the letters and the referral locations. The data was recorded by the researcher on the audit form, and then transcribed to SPSS.

In this study, the majority of subjects were referred to the same location for adult diabetes care and education (n = 9 or 47.4%). The remaining subjects were referred to two separate locations (n = 10 or 52.6%). As Table 6 indicates, clients were predominantly referred for both diabetes care and education to location A. All locations received referrals from either the physician or educators.

Table 6

Location of Referrals from Pediatric to Adult Diabetes Health Care

Location	Adult diabetes physician care	Adult diabetes educators
A	11 (57.9%)	13 (68.4)
B	2 (10.5%)	
C	5 (26.3%)	
D		5 (26.3)
A and C	1 (5.3%)	
No diabetes educator referral letter on pediatric chart		1 (5.3)
Total	19	19

Based on usual DER-CA practices, each pediatric and adult diabetes chart should contain two diabetes referral letters. The pediatric diabetes educators copy their referral

letter to the adult diabetes physician, and the pediatric diabetes physician referral letter is copied to the adult diabetes educators. However, as Table 7 indicates, only 16 (66.7%) of adult charts audited by the researcher contained letters or copies of letters by both the educators and physician. Ideally, each referral letter is also copied to the client's primary care physician, such as the pediatrician or the family physician. The relationship between the presence and absence of referral letters and the outcome variables was not analyzed due to the variability in the number of potential letters per referral and the small sample size.

Table 7

Types of Diabetes Referral Letters Found on Adult Charts

Location	Pediatric physician referral letter only	Pediatric educator referral letter only	Pediatric physician and educator referral letters	No referral letters
A	1	1	10	
B				1
C	1		4	2
D	1	1	2	
Total	3	2	16	3

Length of the Referral Process

The referral process also depends on such practicalities as producing the referral letters. The mean time from the date of the last visit to a member of the pediatric diabetes health care team to the recorded date on the first referral letter by a pediatric diabetes staff was 6.1 weeks (range of 1 to 31 weeks; see Table 8). The mean time between the last visit in pediatrics and the first in adult diabetes care was 22.5 weeks (5.1 to 59.6). The data do not capture the length of time from the dating and signing of the pediatric referral letter, to the copying, mailing and receipt of the letter by the adult team.

Table 8

Timing of Referral Letters to Last Pediatric and First Adult Visits

	Mean
No. of weeks from last pediatric visit to first referral letter	6.1 (1 to 31 weeks)
No. of weeks from first pediatric referral letter to first adult visit	20.6 (3 to 57 weeks)
No. of weeks between last pediatric visit to first adult visit	22.5 (5.1 to 59.6)

Summary

In summary, the recruitment efforts resulted in a final sample of 19 subjects who consented to, and were eligible for participation. A difference in the return rate by gender resulted in a predominantly female sample, with further demographic characteristics detailed. The majority of the subjects were referred to the one location for adult diabetes medical care and education, however referral letters from both the pediatric physician and educators were found on only 66.7% of all adult diabetes health records. The following sections will address the data from those 19 subjects, according to each research question.

Research Questions

Research Question #1

"What is the nature of client follow-up with specialized adult diabetes medical care and education after referral from specialized pediatric diabetes health care for persons with Type 1 diabetes in Winnipeg?"

The Canadian Diabetes Association Clinical Practice Guidelines (CPG) (Metzer et al., 1998) recommends that client assessment occur a minimum of every two to four months, and more frequently if indicated. To answer question #1, the following data

specific to the either the year prior to transfer (pediatric chart) or year after transfer (adult chart) was collected during the pediatric and adult chart audits: dates of visits to the diabetes health care teams; the diabetes staff seen at that visit; Hemoglobin A1C results and normal values; and diabetes related hospitalizations (diabetic ketoacidosis or serious hypoglycemia).

Visits To Pediatric Diabetes Health Care Providers

The DER-CA encourages a minimum number of visits to the diabetes physician and educators every six months during stable periods of diabetes health care. Visits are encouraged at intervals of three months during periods of lifestyle change, poor glycemic control, or when the client has not completed the usual diabetes education, including concepts traditionally discussed during adolescence such as transition to adult diabetes care.

To evaluate the subjects' visits the year before transfer, the following information was collected from the pediatric diabetes chart in addition to the above data: confirmation of diagnosis with Type 1 diabetes; age at diagnosis; age at final visit to DER-CA; and evidence of and date of referral letters to adult diabetes physicians and educators. The date of transfer from pediatric to adult diabetes care was defined as the date of the first pediatric referral letter. The length of time from the time of transfer to the first visit to adult care was calculated in weeks using a web-based program. Length of diagnosis prior to transfer was calculated using SPSS from values obtained on the pediatric chart.

As in Table 9 below, none of the subjects saw any member of the pediatric diabetes health care team four times per year prior to transfer, reflecting three-monthly intervals. Only a minority of subjects (n = 3 to 7, or 15.8% to 36.8%) saw any member of

the diabetes health care team a minimum of two times that same year. The most common number of visits to each pediatric diabetes educator was one time each, with 57.9% (n = 11) of the subjects seeing the nurse (RN) once the year before transfer, 47.4% (n = 9) seeing the social worker (SW) once, and 42.1% (n = 8) only seeing the dietician (RD) once. However, over half of the subjects (52.6%; n = 10) saw the physician three times that year, the minimum of visits recommended by the CPG. In contrast, only one subject met with any of the educators, the RN, with that frequency during the same period of time. The mean number of visits to the educators as a group the year prior to transfer (2.8 per year) was similar to that of the physician alone (2.42). The staff visited most frequently the year before transfer, in order of frequency, was the physician ($\bar{x}$ = 2.4), nurse ($\bar{x}$ = 1.05), social worker ($\bar{x}$ = 1.0) and dietician ($\bar{x}$ = .74).

Table 9

Number of Visits to Each Pediatric Health Care Team Member by Each Subject the Year Prior to Transfer

Number of visits year before transfer	MD	Nurse	Dietician	Social worker	Total # of visits to combined pediatric diabetes educators only (RN + RD + SW)	# of total visits per subject to all diabetes health care team
0	0	4 (21.1)	8 (42.1)	6 (31.6)	2 (10.5)	
1	2 (10.5)	11 (57.9)	8 (42.1)	9 (47.4)	4 (21.1)	
2	7 (36.8)	3 (15.8)	3 (15.8)	3 (15.8)	4 (21.1)	3 (15.8)
3	10 (52.6)	1 (5.3)	0	0	4 (21.1)	1 (5.3)
4				1 (5.3)	0	4 (21.1)
5					3 (15.8)	5 (26.3)
6 to 10					1 (10.6)	6 (31.7)
Range	1 to 3	0 to 3	0 to 2	0 to 4	0 to 8	2 to 10
Mean number visits	2.42	1.05	.74	1.00	2.8	5.2

Note: each visit to each professional is counted once, thus a visit to all members on the same day = 4 visits total

The dates of each visit were also collected to enable calculation of the interval between visits. Due to the low sample size, this data was not analyzed. However, the data did reveal that a large proportion of the visits to the DER-CA in the year prior to transfer occurred as the last visit. In the last year, 40% of the visits to the physician, 40% to the RN, 21% of the RD, and 42% of the SW visits occurred as the last visit prior to transfer, potentially impacting upon the transfer experience.

The mean age of the subjects at their last visit to DER-CA was 17.5 years, ranging

from 17 to 19 years (see Table 10). No correlation was found between the age at the last visit to the DER-CA and either the mean Hgb A1C the year before transfer or the mean Hgb A1C the year following transfer. However, the age at the last visit to the DER-CA was weakly negatively correlated ($r_s = -.464$, $p < .05$) with the total number of diabetes physician visits the year following transfer, but did not correlate with diabetes educator visits. This suggests that the younger the age of the subject at the last visit to the DER-CA, the greater the number of physician visits attended the year after transfer. The length of time between date of diagnosis and transfer was negatively correlated with the number of visits to the pediatric social worker the year prior to transfer ($r_s = -.532$, $p < .01$) suggesting that the longer a subject had been diagnosed the less likely they were to see the social worker the year prior to transfer.

Table 10

Age at Last Visit to Pediatric Diabetes Care

Age	Number (%)
17	11 (57.9)
18	7 (36.8)
19	1 (5.3)
Mean	17.5

On the self-administered questionnaire, subjects were asked for their reasons for visiting, or not visiting, the pediatric diabetes health care team: "If you did attend diabetes appointments with the pediatric diabetes team and physician, what made you decide to go?" Eighteen of the nineteen subjects responded with answers that were categorized into one to two themes for each subject. Subjects reported attending appointments for their general health (n = 12):

"Anything to help me out with my diabetes control sounded like a good thing." (Subject #19)

"Health issues were the deciding factors. After all, diabetes needs checking, and I had questions." (Subject #7)

The other theme that was frequently mentioned was because they "had to" (n = 7 or 36.8%). Of the four persons who specified the source of this influence, three identified their parents as the source of pressure and one, the requirements for the driver's license:

"I wanted to learn more, and I basically thought I had to go." (Subject #8)

"It was just understood that I would go (my mom made me!). And I learned valuable information, like how to adjust my insulin when sick or travelling, diet changes etc." (Subject #3)

One additional person stated that he/she attended in order to obtain specific information on a particular need.

The motivations "had to" and "general health" were further analysed for potential correlation to the outcome variables of metabolic control and number of visits to adult health care using Spearman's rho. Two subjects indicated both "general health" and "had to" as reasons for attending pediatric diabetes health care. These subjects original responses were reviewed to determine the most dominant reason for attendance at pediatric diabetes care. After recoding, eleven persons were found to have identified general health, and six, "had to" as the foremost reason for attendance in pediatric health care. No significant correlation was found between reasons for attendance in pediatric diabetes care and the outcome variables of metabolic control and visits to any member of

adult diabetes health care, the combined education team, nor the total number of visits to diabetes health care.

In contrast to the reasons for attendance to diabetes health care the year before transfer, none of the subjects responded to a question regarding non-attendance: "If you did not attend or book regular appointments with the pediatric team, what made you decide not to go?"

Visits To Adult Health Care Providers

As previously discussed, the youth are referred to an adult diabetes physician and an adult diabetes education team. The recommended frequency of visits to specialized adult diabetes care, as per the CPG, remains unchanged from the year before to the year after transfer, i.e. a minimum of every two to four months, and more frequently if indicated. The adult diabetes health records indicated that the year following transfer, the majority of subjects (57.0%) attended at least two visits with the diabetes physician (see Table 11). Only 10.5% met the recommendation for either quarterly visits or for visits every four months. The number of visits to the diabetes educators was even lower. Most commonly (47.4%) subjects did not attend any visits with the diabetes educators during this same time period, with non- attendance to specific educators ranging from 57.9% to 100%.

Table 11

Visits to Adult Diabetes Health Care Team

	MD	Nurse	Dietician	Social worker or mental health professional	# of subjects total visits combined diabetes educators only	# of subjects and total # of visits
0 visits	1 (5.3)	11 (57.9)	10 (52.6)	0 (100%)	9 (47.4)	1 (5.3)
1 visit	2 (10.5)	6 (31.6)	4 (21.1)	0	2 (10.5)	2 (10.5)
2 visits	11 (57.9)	1 (5.3)	3 (15.8)	0	4 (21.1)	6 (31.6)
3 visits	2 (10.5)	1 (5.3)	1 (5.3)	0	1 (5.3)	0
4 visits	2 (10.5)		1 (5.3)	0	1 (5.3)	4 (21.1)
5 visits	1 (5.3)				1 (5.3)	2 (10.5)
6 to 10 visits					1 (5.3)	4 (21.2)
Range	0 to 5	0 to 3	0 to 4	0	0 to 6	0 to 10
Mean number visits	2.26	.58	.89	0	1.47	3.7

As with the pediatric visits, subjects were asked on the self-administered questionnaire to identify the reasons for their attendance or lack of, in the adult time period: "If you attended diabetes appointments with the adult diabetes team or physician, what made you decide to go?" and "If you did not attend or book all of the recommended appointments with the adult diabetes team, what made you decide not to?"

The most common reasons cited for attendance in the adult period were similar to that of pediatrics, for general health (n = 5 or 26.3%) and "had to" (n = 4 or 21.1%). Two persons indicated the impetus of a driver's license for their attendance, in contrast to one

in the pediatric period, but no one attributed the influence of their parents to their attendance.

Respondents cited from one to two reasons each. Additional reasons for attendance, mentioned one time each were: to address a specific need; being "guilted" by their physician; were reminded to; for reassurance; a habit; upon encouragement from their pediatric team; to meet the adult provider; and feeling comfortable with the adult provider, after the first appointment.

The most common reason for non-attendance in adult diabetes care, described by the twelve persons who responded to that question, was a perception of lack of need (n = 5): "I have only seen the dietician and teaching nurse once or twice in beginning because it didn't seem like I had any concerns or questions for them" (Subject # 3); "I had enough of them before." Two others each indicated that they forgot to attend appointments, or claimed that they were personally responsible for their health, not requiring diabetes health care: "I took responsibility of my health and have educated myself as necessary" (Subject # 2); "Personal independence; [I] felt in some ways [I] had all the information I needed to continue on my own" (Subject # 10). Additionally mentioned one time each were the following other reasons for non-attendance: educator appointments were never recommended; time consuming; would be told what they were doing was not appropriate; felt unwelcome; and guilt over poor self-care. Respondents cited from one to two reasons each.

Using Spearman's rho (r_s), referral either to one location compared to two locations did not significantly correlate with any of the outcome variables related to metabolic control, or visits to adult health care. The Wilcoxon Signed Rank Sum test was also used to

examine for any difference that referral to the same or different location for adult diabetes care site than the pediatric site may have made in the distribution of the mean adult Hgb A1C and in the number of measurements of Hgb A1C the year after transfer. No significant difference was found between these variables, or between the number of referral locations and visits in the adult period, per individual member, the combined education team, and the total number of visits. Neither the presence nor absence of referral letters on the adult chart, nor the number of referral locations related significantly to the outcome variables.

Research Question #2

"What is the reported experience with diabetes health care services of young adults with Type 1 diabetes in Winnipeg who have been referred from specialized pediatric diabetes health care to specialized adult diabetes health care?"

On the self-administered questionnaire, subjects were asked a number of open-ended questions about their experience with transfer to adult care. The first question related to whether they recalled receiving any information regarding their upcoming transfer to the adult team, and if so, to describe the kind of information they were given. In addition, the pediatric chart audit included assessment for documentation of education regarding transfer the year before transfer by each member of the pediatric diabetes health care team.

As in Table 12, sixteen (84.2%) of the subjects recalled receiving information from the pediatric team regarding the adult diabetes team. A comparison of the data from the chart audit with the questionnaire revealed a difference between subject recall and documentation in only one individual. That individual did not recall receiving information in contrast to the physician documentation of transfer. The pediatric chart audit revealed documentation of discussion of transfer information the year before

transfer occurred most often by the physician, followed in order by the nurse, social worker and dietician.

Table 12

Discussion of Transfer the Year Before Transfer

	Self-report of transfer information	Documented discussion of transfer in pediatric chart			
		MD	RN	RD	SW
	Number (%)	Number (%)	Number (%)	Number (%)	Number (%)
No	3 (15.8)	8 (42.1)	12 (63.2)	15 (78.9)	14 (73.7)
Yes	16 (84.2)	11 (57.9)	7 (36.8)	4 (21.1)	5 (26.3)

Subjects who responded that they had received information regarding transfer were then asked what kind of information they received about the upcoming transfer, and how helpful they found that information: "If you did, could you describe the kind of information that you were given?" and "How helpful did you find this information?"

Sixteen out of the 19 respondents stated that they did receive information from the pediatric diabetes team about the adult diabetes program. Of the fifteen who described the kind of information they received, the majority (n = 9 or 47.4%) stated that they received general information on the adult team members such as names and location:

"I was just basically told where I could go to receive further help with my diabetes." (Subject # 8)

"Place I could go for further education and guidance." (Subject #11)

Four of those nine subjects recalled additionally receiving information regarding the

roles or approach of the adult team:

"I was given the location of each adult diabetes clinic and I was given information on how each team approached diabetes education." (Subject # 11)

"They told me that I would be more on my own; that the adult educators would not call to check on things. Which is OK by me." (Subject # 15)

Two individuals recalled discussions in which they were provided with options for adult diabetes care:

"They explained to me how my care would be. I had choices as to who I wanted to see based on their ways of seeing patients." (Subject # 9)

"Names of doctors, locations of the clinics in the city, which would probably best suit me (sex of doctor, where in city, demeanour of doctor)." (Subject # 3)

Six others recalled receiving specific information on certain team members, such as the physician or specific educators. The majority of respondents (n = 10 or 52.6%) found this information helpful (see Table 13).

Table 13

How helpful did you find this information?

Extent of helpfulness	Number (%)
Was helpful	10 (52.6)
Not very helpful	6 (31.6)
Not answered	3 (15.8)

The subject's response was significantly correlated with only one outcome variable related to either pediatric or adult visits, or pediatric or adult Hgb A1C values.

The helpfulness of information was positively correlated with the number of adult MD visits (r_s. 634, $p < .01$ using Spearman's rho), suggesting that those who found the information helpful were more likely to visit the adult diabetes physician.

Difficulty with Transfer

The questionnaire also asked subjects about any difficulties they experienced with their transfer: " Did you experience any problems or difficulties with your transfer?" and "If yes, in what way?" Nine of the subjects (47%) indicated that they did experience some problems or difficulties with transfer. The eight persons who described their difficulties reported a variety of reasons, most commonly related to changes or problems in follow-up (n = 3), and a perception that the adult team was less involved than the pediatric team (n = 3):

> "You go from being known very well by the pediatric staff to becoming another face in the crowd. After the initial visit no immediate follow-up was set. I was encouraged to come as I felt I needed it. My initial visit with the adult team was very disappointing and I have never been back." (Subject # 2)
>
> "I had trouble finding the office and to remember to book appointments every 6 months. I would sometimes end up waiting a few months more." (Subject # 13)
>
> "A little bit of "culture" shock. Adult team not very involved, I don't learn much from them, no new info, not much follow-up." (Subject # 18)

Other reasons that caused problems with transfer and cited one time each related to individual preparedness, personality differences with the adult practitioners, and lack of hope:

> "Just because I was emotionally not prepared for that sort of change in my life."

(Subject # 8)

"Dr. referred to didn't trust/like." (Subject # 16)

"When I left Dr. Pediatrics, there seemed to be less and less hope ahead to come." (Subject # 12)

Spearman's rho was used to identify any correlation between self-report of problems, documentation of discussion of education, self-report of receiving transfer information and the outcome variables. No correlation was found between those variables and either the mean Hgb A1C in the adult period, or visits to any member of the adult health care team. A mean Hgb A1C of 194.7 was reported in the adult time period for those who did report a problem (n = 4 or 21.1%) compared to those who had a mean Hgb A1C result of 146.2 and reported that they did not have a problem (n = 7 or 36.8%). However, there was no significant correlation between self-report of problems and mean adult Hgb A1C using Spearman's rho. The Mann-Whitney U test was also performed to assess for differences in the Hgb A1C in the adult period for those who did vs. did not report a problem with transfer. No significant differences were noted in the distribution of Hgb A1C between those two groups.

Research Question #3

"Is there a change in diabetes health within one year after referral to specialized adult diabetes health care, in particular metabolic control and diabetes-related hospitalizations, of individuals with Type 1 diabetes?"

Measurement of Metabolic Control

Data regarding the subject's Hgb A1C level the year prior to transfer was collected during both chart audits from the lab flow sheets, referral letters, lab print-outs,

and practitioner charting. The dates of tests, test results and normal values for the relevant laboratories were determined. To allow for comparison between different laboratories, the researcher converted each Hgb A1C result to the percent of normal value by the following formula: (actual result divided by the high normal value) x 100. This information was correlated to visit and A1C data, as discussed previously. Evidence of diabetes related hospitalizations, as demonstrated by documentation of diabetic ketoacidosis (DKA) or severe hypoglycemia was searched for during the chart audits by the researcher.

As indicated in the Clinical Practice Guidelines (CPG), Hgb A1C reflects glucose control over the preceding two to four months. The CPG recommends measurement every three to four months in all patients taking insulin (Meltzer et al., 1998). Table 14 portrays the total number of HgbA1C results for each subject, both the year before and the year after transfer. Using a time frame of every three months, only one of the subjects met the minimum CPG recommendations of measurement every three months or four times per year, before or after transfer. Using a measure of Hgb A1C every four months or three times per year, reveals that only 31.6% of the subjects (6/19) complied with recommendations prior to transfer.

Table 14

Number of A1C Tests and Mean A1C the Year Before and After Transfer

	Number of persons								
	0 A1C results	1 A1C results	2 A1C results	3 A1C results	4 A1C results	Total # of A1C	Mean % A1C	Range of A1C (% of normal	Mean # per subject
Year prior to transfer	1	0	11	6	1	44	156.6	90 to 230	2.3
Year after transfer	8	2	6	3	0	23	163.8	114 to 322	1.2

Using Spearman's rho, the mean Hgb A1C was then compared to the total number of visits to the MD, RN, RD, education team (RN, SW, RD) and total number of visits to diabetes health care as a whole, both the year before and after transfer, and the length of time between diagnosis with Type 1 diabetes and transfer to adult care. No correlation was found between these variables.

Clients commonly receive Hgb A1C tests either at the time of the visit to pediatric diabetes care, or just prior to a visit to adult diabetes care. Using Spearman's rho, a positive relationship was found between total number of measurements of Hgb A1C the year before transfer and the total number of visits to the pediatric MD, RN, RD, and total number of visits to pediatric diabetes health care as a whole (see Appendix P). This may reflect the practice of the pediatric team directing the subject to attend the laboratory to have the Hgb A1C test completed on the same day as their appointment, and, the reminding and/or accompanying of the youth to the laboratory by their adult care providers who may come with the youth, or subsequently call for the test results.

In contrast to the year before transfer, the year after transfer, no relationship was found between the total number of Hgb A1C measurements and the total number of MD visits. However, as in Appendix Q, a positive relationship was found between the total number of Hgb A1C measurements the year after transfer, and three variables: the total number of visits to the adult RN (r_s .504, p = .05), the total number of visits to the adult education team (RN, SW, RD) (r_s.514, p = .05), and the total number of visits to adult diabetes health care (r_s .486, p = .05). This may reflect the common practice of doing Hgb A1C tests the same day as a visit to a member of the diabetes team, as they can be done in the same facility.

While the number of Hgb A1C measurements varied in their correlation to number of health care visits, no correlation was found between the mean Hgb A1C and the number of visits during the same period of time. No correlation was found between the mean A1C the year prior to transfer compared to the year after transfer. The only correlations found between the mean Hgb A1C and the number of visits to any of the diabetes health team, either before or after transfer (see Appendix Q) was a strong negative correlation between the number of visits to the pediatric diabetes physician and mean Hgb A1C the year after transfer (r_s = -.763, p < .01), suggesting that the greater the number of visits to the pediatric diabetes physician, the lower the Hgb A1C the year after transfer.

The Wilcoxon Signed Rank Sum test was used to compare the distributions between the mean Hgb A1C and number of Hgb A1C measurements, and frequency of Hgb A1C, the year before and the year after transfer. Eleven subjects received measurements of Hgb A1C both the year before and the year after transfer. No difference

was found in the distribution of the values of either of the variables related to metabolic control.

The Wilcoxon Signed Rank Sum test was also used to compare the distributions of total visits to diabetes health care by the sample the year before transfer to visits the year after. The distribution of the total number of visits pre and post transfer were significantly different at $z = -2.025$ and $p = .04$, demonstrating a significant decrease in attendance of individuals following transfer. The change in distribution of visits that was closest to significance of any individual diabetes team member, or of the combined educators pre and post transfer, was the visits to the nurse, at $z = -1.897$ and $p = .058$.

Spearman's rho was used to correlate the total number of visits to diabetes health care the year before transfer to the total number of visits the year after. Of the pediatric visits, only the total number of visits to the nurse the year before transfer correlated to any of the variables related to visits to adult health care. The total number of visits to the pediatric nurse was weakly positively correlated to the number of adult physician visits (r_s .467, $p < .05$), with the total number of visits to combined adult diabetes educators (r_s .475, $p < .05$), and total number of visits to adult diabetes health care ($r_s = .521$, $p < .05$). This suggests that the greater the number of visits to the nurse the year before transfer, the more visits that the subject will make to the adult diabetes physician, the adult diabetes educators as a team, and to the combined members of the adult diabetes health care team.

Diabetes Related Hospitalizations

Only one subject had a documented diabetes-related hospitalization. This subject had one episode of DKA within one week of the last appointment with the DER-CA, initiating both hastened referral letters and joint appointments with the adult and pediatric

educators in the immediate period following the episode of DKA.

Research Question #4

"What factors are associated with attendance at specialized diabetes adult medical care within the first year after referral, in particular, health beliefs, when controlling for other variables?"

Research Question #5

"What factors are associated with attendance at specialized diabetes education within the first year of referral, in particular, health beliefs, when controlling for other variables?"

Research Question #6

"What factors are associated with attendance at specialized diabetes health care (combined medical and educator) within the first year of referral, in particular, health beliefs, when controlling for other variables?"

Subjects returned two completed, self-administered scales along with their consent and questionnaire, one in regards to Health Beliefs and one, in regards to self-efficacy. Responses were transcribed into SPSS for analysis, and correlated with subject demographics and outcome variables related to visits and metabolic control. Research questions 4, 5 and 6 will be addressed together. These research questions were intended to examine attendance and non-attendance as the outcome variables, but due to the small sample size, the outcome variable was modified to the number of visits. Multivariate analysis of the scales and the outcome variables had been intended, including logistic regression, but due to the small sample size, bivariate analysis consisting of Wilcoxon Signed test and Spearman's rho were completed.

Spearman's rho was used to examine the correlation between self-efficacy and health belief, demographic variables (gender, age at diagnosis via chart audit and self-report, length of diagnosis prior to transfer, educational level, living arrangement, and marital status), and variables related to pediatric and adult visits; and Hgb A1C, as collected during the chart audits. Confirmatory Factor Analysis was conducted with both instruments. However, the factors that emerged did not correspond with those developed by the authors of the tools. The small sample size prevented adequate factoring of the items, therefore the sub-scales suggested by the developers of the scale were used. Relevant items in both scales were reverse scored before analysis.

Health Belief scale, demographics and outcome variables.

The final score of the HBM11 is a sum of all questions for a maximum total score of 55. As per Table 15, the scores for this sample ranged from 32 to 43, with a mean total score of 38.8.

Table 15

Health Belief scale mean, total, and sub-scale

	HBM Total Score	HBM seriousness subscore	HBM benefits subscore	HBM barriers subscore
Mean	38.8	12.3	12.7	13.8
Median	39	13	14	14
Range	32 to 43	7 to 17	10 to 15	7 to 20
Maximum possible score	55	20	15	20

None of the demographic variables correlated with either the sub-scales or total score on the Health Belief model. Similarly, no significant correlation was found between the sub-scales or total score and the total number of visits to any member of the

diabetes health care team, total number of visits to educators as a group, or total number of visits to the entire diabetes health care team, both the year before and the year following transfer. Neither was a correlation found in relation to mean Hgb A1C and frequency of A1C, either the year before or the year following transfer.

Self-efficacy scale, demographics and outcome variables.

As per Table 16, the maximum possible total score for the Self-efficacy Scale is 168. The total scores and sub-scores were used for analysis.

Table 16:

Self-Efficacy Mean, Sub-Scores and Total Scores

	SE total score	SE diet total sub-score	SE general total sub-score	SE insulin total sub-score
Mean	133.8	44.95	18.9	53.3
Median	139.4	47	20	55
Range	76 to 161	21 to 60	7 to 24	41 to 60
Maximum possible score	168	60	24	60

The only correlation between the results of the Self-efficacy scale and demographics was a correlation between the self-efficacy insulin subscale and self-report of age at diagnosis. Self-report of age at diagnosis was moderately negatively correlated with the self-efficacy insulin sub-scale (r_s -.511, $p < .05$), suggesting that the younger the subject was when he/she was diagnosed with diabetes, the more capable he/she may feel in handling the decisions related to insulin. The correlation was non-significant when the age of diagnosis from the chart audit was used to calculate the correlation.

The same measures of self-efficacy were analyzed in relation to the total number of visits to any member of the diabetes health care team, total number of visits to

educators as a group, total number of visits to the entire diabetes health care team, both the year before and the year following transfer. No correlations were found. No correlations were found in relation to self-efficacy, and mean hemoglobin A1C and frequency of A1C, either the year before or the year following transfer. Using the Wilcoxon Signed Rank Sum test, no significant difference was found in the distribution of the mean Hgb A1C the year before and after transfer. The differences in the distribution of the frequency of Hgb A1C between the year before and after transfer was significant with $z = -2.676$, $p \leq 007$.

Subject Recommendations

Additional questions in the self-administered questionnaire asked the subjects for their recommendations for the transfer from pediatric to adult diabetes care. In answer to the question, "In your opinion, what factors should determine the time for transfer from pediatric to adult health care?" most respondents identified age as the determining factor (n = 13 or 68%). Six of those who identified age indicated that age alone should be the criteria for transfer, with a further seven identifying age in conjunction with at least one other factor. For example, six respondents stated that both age and personal readiness should determine the time of transfer. Other factors mentioned by respondents included personal or professional life; and a combination of length of diagnosis, age, maturity and personal readiness. The following combination of factors were mentioned once: home and work life; length of diagnosis, maturity and age; age and personal readiness and maturity; and that transfer should not occur directly to adult care but first to a transition clinic.

After providing their recommendations for transfer criteria, subjects were asked to

identify an age that should be used if age was used to determine the time for transfer. "If age was used to determine the time of transfer from pediatric diabetes care to adult diabetes health care, in your opinion, what would be the ideal age?"

Fourteen respondents identified 18 years or an age range that encompassed 18 years of age as the appropriate time for transfer to adult diabetes care. These age ranges varied, with some people indicating 16 to 18 years as the appropriate time, while other ranges consisted of 17 to 19 years, 18 to 19 years, or 18 to 20 years. The lowest age range that was reported was 14 to 16 years. Three respondents identified 19 years or older as the ideal age for transfer. One stated that the age of 18 would be the ideal time and that personal maturity would need to be taken into account. One person stated that the age of transfer should depend on when the diagnosis was made: "If you're under 10, maybe 14 or 15 years of age. But if you were 16 or 17 years of age, maybe wait until you're 18 or 19." Another subject differentiated young adult from adult regarding when to transfer from pediatric care: "To adult - 19 years old; to young adult – 16 or 17 years old."

Subject's responses were grouped into age categories. The largest response was the age of 18 (42.1%). Two or 10.6% indicated that the youth should be transferred at the age of 18 or younger, while 31.8 % indicated that youth should be transferred when older than 18 (21.2 % = 18 to 20 years of age; 10.6% indicated > 20 years). An additional three subjects indicated each that the criteria of age should be related to the youth's maturity at that age, age at diagnosis with diabetes, and the type of diabetes adult clinic the youth was referred to.

Subjects were also asked what they would change about their transfer: "If you could change anything about how you were educated about, or referred to the adult

diabetes care, what would you change?" Sixteen subjects responded with one to three recommendations each. The most common response was "nothing" (n=5 or 26.3%), however one of those persons further added their wish to stay with the pediatric clinic. One other person also mentioned this latter request. The most commonly mentioned suggestion after changing "nothing" was to be provided with a choice of adult practitioners (n = 3 or 15.8%) and to meet the adult practitioners ahead of time (n = 2 or 10.5%). Other recommendations were mentioned one time each: a smaller, more personal adult clinic; delay the age of transfer; the need for a transition (not transfer) to adult care; gradual movement to adult care; to add a specific education component; and to amend the lack of education and follow-up in the adult program.

Subjects were next asked which of three settings they would consider ideal for young adult diabetes care: stay with the pediatric diabetes team, and move to adult care at about age 25; a clinic for people 18 to 25 years of age, then move to adult care; move straight to adult care at the age of 18; or other. Most subjects indicated a specialized clinic for an age range of 18 to 25 years (12 or 63%). Only one person agreed with staying with the pediatric team, with two supporting a direct transfer to adult care. Two respondents recommended that persons be provided with a choice of programs and or time of transfer, at or around the age of 18.

After relating their opinion of the ideal setting for young adult diabetes care, subjects were asked their opinion of who the diabetes health care team for persons 18 to 25 should consist of: the pediatric team; the adult team; or a mix of the two, some familiar pediatric staff and new adult staff. All persons responded. The majority of persons (15 or 73.7%) recommended a mixed team, followed in order of frequency by the

adult team (3 or 15.8%) and one time only, the pediatric team (1 or 5.3%). One of the persons who suggested an adult team added the following additional idea: "The first visit to the adult care would be nice if the pediatric team joined to meet the patient to make them feel more comfortable." One individual indicated that the choice of team should depend on individual preference.

The subjects were lastly asked for any further comments or suggestions. Eight persons responded with one to four suggestions each. Their responses reinforced earlier comments and suggestions. Two persons suggested adding a young adult clinic. One person each responded according to the following single themes: establish a young adult group/network, individualize transfer time; and have a joint first visit with pediatric and adult team. Other persons commented along several themes: adult clinic hours unsatisfactory; adult team understanding of young adult lifestyle poor; were given too much autonomy in the adult program in deciding when to make next appointment and making it; to transfer earlier; that the pediatric team "baby" persons; that there is no perfect transfer time; that a relationship has been built with the pediatric team; and that the combination of being a young adult [and] having new (adult) faces [and] a tough setting are difficult to adapt to:

> "It is really hard to say when the perfect time is because everyone is different. I know some friends that loved their pediatric team, but me on the other hand, I couldn't wait to get out of there. There is just something about being 16 or17 and talking to puppets. They totally baby you to the point that you feel like it is a total waste of time. So if it were up to me I would have been transferred sooner." (Subject #8)

"I do believe in the adult care system, but I think that after forging a relationship with pediatric care members over a number of years and leaving is tough on the patient. The pediatric team is like family where a patient can open up and speak candidly on issues. Throwing a young adult into a "tougher" setting with new faces who know very little about the patient is extremely hard to adapt to in terms of creating relationships. The option of "c" in question 18 (joint pediatric and adult care) would be most advantageous since the pediatric team is "old" and the adult team would be the transition part of the growing phase." (Subject #1)

Summary of the Findings

Several findings are noteworthy. None of the subjects met the CPG recommendations for the frequency of visits in both the pre-transfer and post-transfer period. The number of visits decreased the year following transfer compared to the year before, particularly to the diabetes educators. The mean number of total visits decreased from 5.2 per subject prior to transfer, to 2.26 after transfer. Using Spearman's rho, a few significant correlations were found between the variables, related to visits the year following transfer. From the year before transfer, the total number of visits to the pediatric nurse was weakly correlated to the number of adult physician visits, the total number of visits to combined diabetes educators, and total number of visits to diabetes health care. Using the Wilcoxon Signed Rank Sum test, the difference in the total number of visits pre and post transfer was also significant.

The only demographic variable that was significantly correlated to the subject's visits to health care in either pediatric or adult health care was the subject's age at the last visit to the DER-CA. This was weakly negatively correlated with the total number of

diabetes physician visits the year following transfer. As discussed in the previous chapter, as obtained in the questionnaire, the subject self-report of the helpfulness of transfer information from the pediatric diabetes team was positively correlated with the number of adult MD visits.

Similarly, a few significant correlations were found between the variables. A strong negative correlation was found between the number of visits to the pediatric diabetes physician and mean Hgb A1C the year after transfer. The difference in the distribution of the frequency of Hgb A1C measurement between the year before and after transfer was significant. Only one of the subjects met the CPG recommendations for the frequency of measurement of Hgb A1C both before and after transfer. A positive relationship was found between the total number of Hgb A1C measurements the year after transfer, and the total number of visits to the adult RN, adult education team, and total number of visits to adult diabetes health care.

The content analysis supported the findings of the chart audits. Close to half of the participants (n = 9 or 47%) reported having some difficulty with their transfer to adult care, however this variable did not significantly correlate to any of the outcome variables. Persons attended both pediatric and adult health care primarily to maintain their general health and because of a perception that they "had to," however these reasons did not significantly relate to any of the outcome variables. The perceived differences by the subjects between the adult health care team and the pediatric health care team, particularly in the areas of follow-up practices and the lack of involvement with the subjects by the adult health providers were clearly evident reasons for reported difficulty with transfer.

Finally, the youth were asked for their recommendations of the optimal setting and staffing for a young adult diabetes program. The predominant recommendations were for a specialized diabetes health care team for those aged 18 to 25, consisting of a mix of both the familiar pediatric diabetes team and the newer, adult team.

CHAPTER 6: DISCUSSION AND IMPLICATIONS

In this chapter, the findings are examined. The findings are compared to findings from other studies and possible explanations for the discrepancies are presented. The use of the HBM as an appropriate conceptual framework is examined. Finally, the limitations of the study, areas for future research, and implications stemming from this research are reviewed.

Sample Demographics

The sample demographics in this and other studies will be compared. All studies reported on the sample demographics of age and gender, however the measurement of other demographics variables varied. Gender was only noted to have an influence in this study, in relationship to response rate. In contrast to other studies discussed in the literature review and potentially due to small sample size and differential response rate by gender in this research, no difference was found by gender in any of the outcome variables. The demographic variable of the subject's age at the last visit to pediatric diabetes care influenced attendance, and will be discussed later.

In this research, and the study by Frank (1996), the majority of subjects were living with someone else, and most, often, with a parent or family member. The majority of Frank's subjects (50% to 68%) were full time students at completion of the research. While in this study the most common educational level was currently in university or college (47.4%), subjects were also most commonly working full time (47.4%). Frank did not capture employment status. Frank further captured the ethnicity of the subjects, reporting that 58% (compliant group) to 90% (non-compliant group) of the subjects were of Canadian origin. No other studies were found that captured ethnicity.

Response Rate

A strength of this study was the attempt to collect data from the entire target population. Unfortunately, the overall response rate for this study was low (32.6%) relative to similar studies, despite additional attempts to enhance recruitment. While Pacaud (1996) had a similar response rate of 36% using two mailings to the last known address, there is no record of the additional methods to increase the response rate, such as determining alternate addresses or phone call follow-up. The highest response rate found was in the study by Eiser et al. (1992). Initial recruitment in that study utilized personal contact in-person during clinic and phone contact by a diabetes specialist nurse, with an overall 74% completion rate.

The response rate by gender was notably different in this study than others. Frank (1996) and Pacaud et al (1996) had a sample consisting of 63% and 54% female respectively, however their response rate per gender was not defined. The response rate in Court's (1993) survey did not differ by gender. The population of clients transferred by the DER-CA in the five-year period of this research was 47.4% female, while women accounted for 73.7% of the subjects. Little research was found on the influence of gender on response rates, however Krosnick (1999) indicated that generally, young adults, males and people with the lowest education levels are underrepresented in survey research. In this research, the subjects had all completed high school, with 13 (68.5%) either currently in or having completed college or university.

In contrast, the proportion of potential subjects who could not be located was lower in this study than in most other studies. Fifteen percent of this population was unable to be contacted. Frank (1996) was unable to contact 26% of her potential sample, Bartsch et al. (1989) were unable to contact 40 % of the graduates, and Pacaud et al. (1996)

received back 17% of her surveys due to unknown address. The lower rate compared to other studies may be due to the varied attempts by this study's RA to locate the subject.

Personalized follow-up of non-respondents typically increases the response to surveys (Wooley, 1984). Thirty percent of the second set of surveys mailed at the request of potential subjects or due to RA identification of a new address were returned completed, similar to the overall response rate. Another approach utilized in this study that encourages response was the use of an introductory letter by a known person of authority and expertise, or trust (Barriball & While, 1999), the medical director of the DER-CA. This letter and instruments were not personalized to each youth, methods that can enhance participation in survey research (Barriball & While, 1999; James & Bolstein, 1992). Personalized contact with potential subjects has a positive impact on return rate and allows for clarification of any possible misunderstandings (Polit and Hungler, 1999). Distribution of questionnaires in a clinical setting typically yields a high response rate (Polit and Hungler, 1999). Other methods of personalization in this study could have included the encouragement of potential subjects who met the inclusion and exclusion criteria by their adult diabetes practitioners or the presence of RA's in the diabetes clinics when potential subjects were scheduled for appointments. An RA could personally introduce the study and if subjects were interested, facilitate completion of the tools and consent, methods unavailable with this study due to time limits and cost. The participation rate in the survey study of Hanna and Guthrie (2001) of type 1 diabetes and health behaviour was 97% with a study introduced and completed during a diabetes appointment.

Diabetes Demographics

The duration of diabetes prior to transfer to adult diabetes care was similar in all studies that reported this information. The mean duration of diabetes in this study was 7.9 years, comparable to that of Eiser et al. (1992) of 8.5 years and Frank (1996) of 8 years. Pacaud et al. (1996) did not specifically calculate the duration of diabetes, but the difference between the mean age at diagnosis and mean age at transfer in her subjects was 8.1 years. Similarly, the mean age of diagnosis with diabetes was comparable to most studies (Court, 1991; Eiser et al., 1993; Frank, 1996), ranging from 8.9 to 9.6 years of age in this study, to 10.9 by Pacaud et al. (1996). These similarities may result from the similar subject ages at transfer and the peak incidence of Type 1 diabetes.

Explanations for Research Findings

The intent of this study was to examine the experience of young adults with Type 1 diabetes in Manitoba as they moved from specialized pediatric diabetes health care to specialized adult diabetes health care. The summary of and explanations for the research findings are presented, and compared to other studies.

Diabetes Health

Diabetes-related Hospitalization

Only one subject in this research identified a diabetes-related hospitalization in either the year before or the year after transfer. This isolated episode was not examined in correlation to any other variable. This finding was in contrast to most other research, which found an increased rate of hospitalizations the year following transfer. Bartsch, Barnes, Jarret and Lindsay (1989) found a high hospitalization rate of 28% the year following transfer from pediatrics. Frank (1996) also found a significant increase in hospitalization (p

< .05) pre and post transfer among those who had fewer follow-ups in the adult period. The lower rate in this study may relate to sampling error due to the small sample size and self-selected sample, inaccuracy of self-report, and errors in documentation. As will be discussed later, it is also possible that non-responders experienced worse diabetes health than responders.

Metabolic Control

Metabolic control - frequency of assessment. The Canadian Diabetes Association Clinical Practice Guidelines (CPG) recommends measurement of Hemoglobin A1C every three to four months (Meltzer et al., 1998). Only one of the subjects met the CPG recommendation of Hgb A1C measurement of every three months. Only 31.6% of the subjects (6/19) followed the minimum CPG recommendations of measurement every four months prior to transfer, and only 3/19 subjects (15.8%) did the same after transfer. While there was a positive relationship between the number of Hgb A1C measurements and number of visits in the pediatric time period, no relationship was found between the number of measurements and the number of visits in the adult time period. Additionally, the mean number of assessments of Hgb A1C decreased after transfer. The year before transfer, the DER-CA was encouraging routine visits every six months, however subjects were able to go to the laboratory and measure their Hgb A1C every three months.

The infrequency of measurements and decline the year after transfer may relate to the greater independence of the young adult during the adult time period and to different policies in the pediatric and the adult diabetes program regarding measurement of Hgb A1C. The adult diabetes physicians prefer the Hgb A1C to be measured at the laboratory several days prior to the diabetes medical appointment. This requirement adds an

additional appointment to be remembered and attended than in the pediatric time period. Furthermore, the informal adult care provider such as a parent, who may remind or encourage the youth's participation in the pediatric time period, may no longer accompany the young adult to the adult diabetes clinic or be aware of the need for this additional visit. Also, the year following transfer the adult care provider would no longer be provided with any information regarding the Hgb A1C results, or lack of testing by the diabetes health care team, another possible source of external reinforcement that is lost after transfer. Lastly, in North America, young adults are expected to accept responsibility for their self, and begin to differentiate from their family (Wright and Leahy, 2000). These potential differences may also explain the significant difference in the distribution of the frequency of Hgb A1C between the year before and after transfer.

Metabolic control – results. The literature on transfer identifies the deterioration in metabolic control upon transfer as a major concern, due to the relationship to potential long-term diabetes. This concern has intensified in the diabetes health care community since the results of the Diabetes Control and Complications Trial (DCCT).

In this study, the mean Hgb A1C % of normal increased from the year before transfer to the year after transfer. The only correlation found between the mean Hgb A1C and any other variable was a strong negative correlation between the numbers of visits to the pediatric diabetes physician and mean Hgb A1C the year after transfer. This could reflect a positive health influence of the pediatric diabetes physician into the year after transfer, with persons that visit the pediatric diabetes physician more often experiencing a lower Hgb A1C the year after. This explanation however would leave unanswered why the pediatric diabetes physician would not have had a similar influence during the time of

care provision. Thus, this result could also be a spurious finding secondary to sample size and self-selected population.

Two exceptions to deterioration in metabolic control upon transfer were found in the research. Orr, Fineberg, & Gray (1996) did not find any deterioration in Hgb A1C in a young adult clinic with an adult health care practitioner in a familiar pediatric setting with pediatric and adolescent/young adult diabetes programs that shared a similar philosophy. Salmi et al. (1986) found a significant decrease in Hgb A1C after transfer, reporting that the treatment methods between the pediatric and adult clinics were similar. As will be discussed later, the subjects' recommendations for changes in the type, setting and staffing of diabetes clinics for young adults, support the concepts in the above models.

The CPG also provides guidelines for evaluating the levels of Hgb A1C. The percent of upper limit of Hgb A1C is related to the risk of developing the chronic complications of diabetes as follows: "inadequate" glucose control (action required) = A1C > 140%; "suboptimal" glucose levels (action may be required) = 116 to 140% of upper limit; "optimal" glucose levels ≤ 115% = target; and "ideal" ≤ 100%. As per these guidelines, all subjects experienced inadequate glucose control both before and after transfer. The DCCT found that subjects aged 13 to 17 years had higher mean Hgb A1C values compared to adults, despite intensive treatment and support (DCCT Research Group, 1994) but did not further analyze the adult sample by age. In the DCCT, intensive therapy, aiming for near normal glycemic control, delayed the onset and progression of long-term complications by 39% to 74% (DCCT Research Group, 1993). Long-term complications are responsible for a substantial portion of the extensive economic, physical and social costs of diabetes, as indicated in chapter one.

The low number of measurements of Hgb A1C and the inadequate metabolic control both the year before transfer and the year after supports the concept that the challenges of the young adult associated with transfer to adult care begin prior to the referral process. This further reinforces the concept of transfer to adult care as a process that bridges the pediatric and adult time periods, rather than an event that begins and ends at the time of referral to adult diabetes care.

Nature of Follow-up

Frequency of Follow-Up

Due to the inability to access all the records of young adults transferred to adult diabetes care during the study period, it was not possible to determine an overall rate of dropout or fallout from diabetes care after transfer to adult care, as calculated by other researchers and discussed in chapter three (Bartsch et al., 1989; Eiser et al., 1992). Similarly, the sample was not large enough to enable an operational definition of lack of follow-up, or as defined by other researchers, "non-attendance," or "non-compliance."

The CPG recommends visits a minimum of every two to four months (Metzer et al., 1998). This time frame was not used to define attendance vs. non-attendance in this study, due primarily to the limited sample size and also to the contrast between those guidelines and DER-CA recommendations to families of visits approximately every six months after the first year of diabetes.

Health Professional Follow-Up

The diabetes physician was seen most frequently of all of the diabetes health care team, both before and after transfer. This may reflect a number of factors. Physicians are historically viewed as the dominant professional in health care. Physicians are the primary

professionals involved in the screening, diagnosis and treatment of diabetes-related complications, in contrast to the primarily education role of the diabetes educators. Physicians are also the only health care professionals who can sign the medical certificate authorizing a driver's license. If needing to prioritize their time, the young adult may choose to attend appointments with a provider whose role is more historically deemed as important, and who can provide services such as lab tests, screening for complications and prescriptions. Court (1993) asked his subjects age 15 to 18, their view on the importance of professional staff in the diabetes clinic, using a five-point rating scale. While this study did not do the same, his findings that the most important staff member identified was the physician (96.2%) is consistent with the above attendance.

Following transfer to adult diabetes care, subject attendance at educator appointments decreased further than those with physicians. Barriers created by program differences could influence this further reduction. In the pediatric period, educator and physician appointments occur in the same location, are booked by the same secretary, and can be coordinated on the same day. While older youth are encouraged to book and attend appointments on their own, their adult care providers often remain involved in this process. In adult health care, all of the above differ, requiring not just adult independence in booking and attending appointments, but doing so in up to two new locations.

The only other study that explored follow-up with diabetes educators was Wysocki et al. (1992), as part of an exploration of transition to adulthood. Via self-report of health care utilization, 67.9% of the participants aged 18 to 23 denied involvement in education the year prior, whereas 89% had kept at least two physician appointments.

The sole correlation between pediatric and adult diabetes visits was the weak, but positive relationship between the pediatric nurse visits, and visits to the adult physician and adult diabetes education team. Of all pediatric educators, the nurse demonstrated the greatest number of visits. This could be indicative of a greater influence on the part of the nurse, or greater priority placed by those subjects who attend health care visits on what may be viewed as issues more traditionally dealt with by the nurse, as compared to a dietician or social worker/mental health counselor. Using the Wilcoxon Signed Rank Sum test, the total number of visits pre and post transfer was also significantly different, but the limited correlations between the pediatric and adult visits do not provide an explanation as to why.

In addition to barriers to attendance related to the health care environment, the impact of sociopsychological and developmental issues of young adulthood on diabetes health should be considered, as discussed in chapter three. These include the normative behaviours such as reduced parental control, strive for independence and numerous transitions or discontinuities in life, home environment, employment or education. These, in addition to increased risk taking behaviours, may compete for time and attention with diabetes health (Wdowik et al., 1997).

Self-report of Reasons for Attendance

The subjects' self-report of reasons for attendance at diabetes clinic were similar to those found in other studies (Court, 1991 & 1993; Eiser et al., 1993; Frank, 1996). Consistent themes included attending because of some external pressure such as by a parent or due to a need for a driver's license. Similarities were also found in subjects' reasons for not attending, primarily cited as due to a perceived lack of need, regardless of actual health status. Such findings suggest that strategies to promote attendance in this age group should

include the importance of external influences. While subjects in Eiser et al. identified the importance of learning about diabetes as a contributing factor in their attendance, this influence was noticeably absent in subjects in this study. This may relate to differences in the pediatric diabetes education programs, however the other diabetes education programs were lacking in description. Adult diabetes educators and physicians within the programs in this study anecdotally relate a perception that youth feel they no longer require education. Other research such as Court (1991) has queried possible social influences on attendance, such as the opportunity to meet other youth, or perceived barriers such as the discomfort in the physical environment of an adult clinic, including being in a waiting room with older persons or those with diabetes related complications. Subjects did not describe such influences in this study. Minor variations in these results could be due to a number of issues beyond sampling, such as culture, variations in health care programming and organization, and variations in the transfer process. Another reason for differences could be the research methodology and questions. For example, Eiser et al. used predefined options in a Likert scale to explore reasons for attendance, while this study utilized open-ended questions to minimize the potential researcher bias in the response options.

Demographic Variables and Diabetes Health Care

As in chapter five, the only demographic variable in this research that was significantly correlated to the subject's diabetes health care either the year before or the year after transfer was the subject's age at the last visit to the DER-CA. The subject's age was weakly negatively correlated with the total number of diabetes physician visits the year following transfer, inferring that the younger adults may perceive a greater need for health care follow-up. Only one other research study was found that identified a significant

influence of demographic variables to diabetes health care during the transfer period. As discussed earlier, Frank differentiated between compliant and non-compliant youth. She found that non-compliant youth were significantly less likely to have gone beyond high school education.

Referral Process

The only other research found that examined the role of the referral process was that of Frank (1996), who examined the presence or absence of referral letters in the pediatric chart. Frank found that the group defined as non-compliant with follow-up after transfer was significantly less likely to have a note of referral documented on the medical record (40% vs. 80%, $p < .01$). As clients of the DER-CA await contact from the adult agency to make their first appointment, the lack of a referral letter to adult diabetes care could provide another barrier to effective transfer. The variety of locations of referrals by both educators and physicians within the small sample size prohibited analysis of the influence of referral letters to attendance in this research. However, the site of referrals to adult care in the same location as pediatric diabetes care had the lowest number of missing referral letters.

A further administrative influence on effective transfer is that of the time from the last visit in pediatrics to the date of receipt of the referral letter to the new adult diabetes care providers, a mean of 22.5 weeks. The only component of that length of time that could be quantified was the time from the last visit to a member of the pediatric diabetes health care team to the recorded date on the first referral letter by a member of the pediatric diabetes team, a mean of 6.1 weeks. While the length of time between visits is slightly longer than the frequency of recommended visits by the CPG, it is not inconsistent with the frequency of visits before or after transfer.

Discussion of Transfer the Year Before Transfer

A question raised extensively in the diabetes literature is the youth's preparedness for transfer (Betz, 1998; Blum, 1995; Magrab & Millar, 1989). The issues related to preparation includes young adult issues such as sexuality, use of drugs and alcohol, and readiness for independence; and issues directly related to transfer or referral to adult diabetes care such as knowledge of the upcoming transfer, and names and locations of new adult diabetes care providers. This study addressed only the latter issue. Sixteen (84.2%) youth in this study recalled receiving education regarding the upcoming transfer. Although those who found the information helpful were more likely to visit the adult diabetes physician, this study could not determine if those subjects were initially more interested in education and follow-up care, and thus more likely to recall education and attend appointments, or if the nature of the education influenced their actions.

Subject Experience with Transfer

Forty-seven percent of subjects in this study reported that they had a problem with transfer. This is greater than the 32.8% of subjects surveyed by Pacaud et al. (1996) who reported that they had a problem with transition. Pacaud et al. found only two variables that were significantly linked ($p < .01$) with either a self-perceived problem with transfer or a delay in follow-up of over six months after referral: i) the difference between ideal age at transition suggested by the subject and the age transferred, and ii) the number of physicians seen by the patient before establishing regular follow-up, variables not identified in this research. Using a five-point Likert scale, subjects in Eiser et al. (1993) recalled little difficulty in transferring clinics. The mean age of their transfer was lower than in this and most other studies, at 15.9 years of age.

Criteria for Referral

Age at Referral

The mean age at transfer for the subjects in this study was similar to the majority of other research (Frank, 1996: Pacaud et al., 1996). As with most other studies, age was the dominant factor in the decision as to when to refer patients to adult diabetes care.

Subject Recommendations for Referral

Age. The recommendations by subjects regarding the ideal age for transfer were different than in most other studies. Similar to other studies, subjects supported an individualized time for transfer. However, if a specific age was to be used as the criteria for transfer to adult care, subjects in this research recommended that transfer occur at a younger age, or the same age, as currently practiced. This is particularly in contrast to Pacaud et al. (1996), who found that young adults who perceived a problem with transfer were more likely to be transferred at a younger age than they would recommend as ideal, and where the majority of subjects (65%) felt that they should have been transferred after 18 years of age. While subjects in this study continued to recommend that age remain a factor in the decision of when to transfer, most often, age was to be used in conjunction with other factors, such as personal readiness. Subjects in Court (1991, 1993) identified the clients' readiness to transfer as the most important criteria in the decision to transfer, prioritising readiness as criteria for transfer over age. More subjects in Court recommended an older age for transfer, with 35% to 45% of subjects suggesting that transfer occur up to the age of 25, in contrast to the 10.6% in this research who suggested an age greater than 20 years.

Additional youth recommendations for change in the transfer process. The subjects in this study had many recommendations for the transfer process, in addition to the role of

age in referral to adult diabetes care. In contrast to their determination of the age for transfer, the remaining recommendations were very similar to other research. Interestingly, despite the marked reduction in follow-up into adult diabetes care, when asked specifically for their recommendation of how to change the referral process, the subjects most common recommendation was "nothing." However, the subjects added further comments regarding this process at a final open-ended question at the end of the survey.

Subjects expressed an interest in meeting the adult diabetes staff prior to transfer and to be provided with a choice of adult diabetes practitioners. While the pediatric diabetes staff would state that subjects were provided with a choice, this may not have been perceived. The lack of coordination in care and philosophies between the adult and pediatric program was also noted, but no specific recommendations made, as in other studies, of increased coordination. The challenges noted with booking appointments in the adult program was one of the differences noted, and may have been the basis for subject recommendations to change the follow-up system in the adult program and reduce the autonomy of the youth in booking appointments. While much had been speculated anecdotally as to the youth's experience and recommendations for transfer, a limiting factor in this study remains the response rates.

Ideal setting and health care team. Consistent with other research was the subject's recommendations for a specialized diabetes clinic for an age range of 18 to 25 years when provided with a choice of settings based on the models in the literature, as in chapter three.

The ideal health care team suggested by youth within this setting was a mix of familiar pediatric staff and new adult staff. Other literature expressed the views of youth on the differences between the pediatric and adult care practitioners (Bronheim et al., 1988;

Ferguson, 1988; Komp, 1991; Nasr, Campbell, & Howatt, 1992). Within this research, although not specifically asked, subjects identified similar diverse views on practitioners, occasionally relating preferences either for or against the pediatric and adult team.

Some challenges to a combined health care team have been noted in the literature. Recruitment of a skilled adult specialist with an interest in young adults has been identified as difficult. According to Schidlow and Fiel (1990), many an effort in establishing a transition program has been aborted at this stage because of frustration, lack of interest, or dearth of individuals in the adult setting. Adolescent and young adult specialists are evolving as a recognized medical specialty (American Academy of Pediatrics, 1982; Council on Child and Adolescent Health, 1988), but remain limited in medicine and nursing in Manitoba. Anecdotally, additional questions regarding potential changes in the health care system that may be required for the implementation of a combined health care team have been raised locally and will further require clarification. These issues include the specific medical and educator staffing of the combined team, whose facilities and support staff to use, and concerns regarding medical billing.

Use of the Health Belief Model as a Conceptual Framework

Some aspects of the HBM seem pertinent for this study. The HBM enabled the organization of the many variables in the study and provides a comprehensive framework to tailor assessments and interventions that may influence transfer to adult care. The implications of the two tools that measured the components of the Health Belief Model will be reviewed.

Health Beliefs

The final score of the HBM measures psychological readiness to take action. Neither the total score, nor any subscores of the HBM correlated significantly with any of the outcome variables. Hurley (1990a) did not describe the scores of her sample within scale development, nor was any research found using young adults with diabetes and the HBM11. Thus it is not possible to compare the total and sub-scale scores in this sample to other research. The scores in this research were the highest for the benefits subscale. According to the HBM, this would suggest that compared to the other dimensions of barrier and seriousness, the participants are most motivated to take action if they feel that the perceived effectiveness of their actions would reduce the threat or severity of a problem, such as poor diabetes health (Janz & Becker, 1984; Rosenstock, 1974). Regardless, the low combined internal consistency among all items in the HBM11 questions the validity of this scale in the measurement of the Health Belief Model with young adults with Type 1 diabetes.

As in chapter three, the HBM has been extended beyond its initial purpose in explaining preventive health behaviour to explaining sick role behaviour in chronic illness, including diabetes. While the HBM11 had been used to measure health beliefs in persons using insulin, no research was found that used or evaluated the scale specifically on young adults. Although the HBM11 demonstrated concurrent, criterion-related and predictive validity when tested with adults, the beliefs and perceptions of young adults, and the influence on health behaviour may not be similar to that of the adults tested by Hurley (1990a). Hurley further described the samples she used in the modification and testing of the HBM11 and the self-efficacy scale, the IMDSES, as highly motivated, who

had selected treatment at a tertiary care centre that specializes in tight control. As discussed in the literature review, young adults are generally not similarly highly involved in their diabetes health or self care. The HBM11 was not pre-tested among potential subjects, nor was it checked for current content validity among current diabetes health care team members. A measurement tool using open-ended questions may have better evaluated the influence of the components of the HBM on this sample.

The content validity of the scale was also likely affected by the changes in diabetes management and diabetes education methods, goals and philosophies since the HBM11 was last modified in 1990 (Hurley 1990a and 1990b). For example, does the statement " I believe I will always need my diabetes meal plan and insulin," reflect a perception of the seriousness of diabetes, as suggested by Hurley, or a belief in the extensive diabetes research for a cure or improved management strategies? A higher score on the following reverse scored item, such as strongly disagreeing, would reflect readiness for care, according to Hurley: "I believe that my meal plan and insulin will prevent diseases (complications) related to diabetes." According to Mikhail (1981), such potential fear may be counterproductive, a contradictory explanation to the HBM. Mikhail (1981) explained a possible counterproductive reaction to the perception of threat in that "fear messages may motivate avoidance behaviour or denial rather than control if the person lacks the knowledge of feasible ways of coping with the threat or believes that coping may incur a high cost" (p. 74).

Although the Health Belief Model provides a comprehensive framework for the organization and identification of variables, the HBM11 does not appear to measure how those variables influence the young adults perception of the perceived barriers,

susceptibility and severity to health, and subsequent diabetes behaviour. Overall, the validity of the HBM with young adults was questionable, and it did not add to an understanding of young adult diabetes behaviour.

Self-efficacy

The only aspect of self-efficacy that correlated to any of the outcome variables was the negative correlation between self-report of age at diagnosis and with the self-efficacy insulin subscale. The strong inter-item correlations on the total scale and diet subscales, and the acceptable correlations for the general (.75) and for insulin (.67) subscales confirm that the items in this scale and the sub-scales were consistent in measuring the same concept. The insulin subscale had the lowest alpha coefficient in the original use of the scale (Hurley, 1990b) and in this research (.67).

The threats to the validity of the IMDSES are similar to those of the HBM11, such as the changes in diabetes care and philosophy since the development of the scale; the testing of the IMDSES on highly motivated adults who had selected treatment at a tertiary care centre that specializes in tight control; and the influence of the developmental status of young adults. The high inter-item correlations in the scale suggest that the items in the IMDSES measure a similar concept, such as self-efficacy, the conviction that one is capable of carrying out a health recommendation. However, the lack of correlation of the scale with any of the outcome variables challenges whether those convictions relate transfer or the diabetes health and health care of young adults. Contrary to the premise of Rosenstock (1985) when he added self-efficacy to the HBM, the IMDSES did not provide a more powerful approach to understanding and influencing health-related behaviour, in this case, in the young adults with type 1 diabetes.

Methodological Limitations

The limitations of research must be made explicit in order to understand the validity and reliability of the research findings (Polit and Hungler, 1995). The study had both strengths and limitations. Several limitations will be highlighted.

The major and most obvious limitations of this study relate to sample size and selection bias. Further, it was not possible to evaluate bias related to self-selection due to the demand by one facility for consent prior to chart review. Thus, the results are not generalizable to any population.

The requirement for consented chart review prevents any estimation as to whether the sample was representative of the population, and is therefore a threat to external validity. According to Polit and Hungler (1999), a response rate greater than 60% is sufficient to assume that the sample is representative of the target population. As nonresponse is not a random process, low response rates may introduce serious bias. The representativeness of a sample can be evaluated by comparing the demographics of the sample to the target population. Studies such as those by Eiser et al. (1992) and Brownlee-Duffeck et al. (1987) have found that non-responders were on more insulin/kg, had worse glycemic control, and had more emergency hospitalizations. The challenges related to the difficulties in gaining consensus on access and methodology from multiple sites after many months is also a significant finding in this study, due to the impact on the duration of this research, eventual changes in data collection and recruitment, and the potential impact on similar research in the future.

The Canadian Diabetes Association Clinical Practice Guidelines (Meltzer et. al., 1998) recommend follow-up for persons with Type 1 diabetes occur with a diabetes

expert. Due to this position, and practical limitations related to an exhaustive search of health records, this study did not capture data related to young adults who may have sought or obtained some diabetes health care or monitoring through their generalist. A review of the diabetes charts would not capture follow-up with non-specialist health care personnel such as family physicians, walk-in clinics and hospital emergency care, unless this information is disclosed by the subject to their diabetes educators or physician, and recorded by that health care provider.

It was not within the range of this study to address the evidence of long-term complications in the sample. In this self-selected sample, the mean Hgb A1C remained in the unacceptable range as defined by the CDA throughout the transition period. One population left unstudied is the health care delivery and education in the rural population of youth with Type 1 diabetes. The emerging crisis of Type 2 diabetes among the pediatric and adolescent population in Manitoba has also raised the question of transfer among youth with Type 2 diabetes, also not addressed in this research.

This research did not examine the developmental processes of the young adult. As in the literature review, research is lacking in the developmental processes of the young adult, particularly with chronic illness, with the developmental norms of late adolescence or early adulthood often attributed to the young adult. As Rosen (1995) suggests, the natural history of young adults may be associated with or exacerbated by self-destructive behaviour or failure to participate in care. Further, the young adult may not be developmentally ready to assume the greater responsibility for health care that is expected of an adult (Betz, 1998). In diabetes, as in this study, a relative deterioration in self-care, and in participation with health care, begins in late adolescence (Hanna and Guthrie,

2001), prior to the transfer to adult care, and may be exacerbated by the transfer. If the young adult does attend adult diabetes care, strategies that could enhance their diabetes health and self-care were also not addressed.

Much of the data from medical records is reliant upon the client's cooperation, with the validity lessened if the client does not provide that information (Aaronson & Burman, 1994). Similarly, history taking and recording, which requires accurate client recall, clinician interviewing skills, and accurate recording are subject to more discrepancies than physical assessment findings and laboratory findings (Aaronson & Burman, 1994).

Failing to locate information from records would result in a threat to validity and reliability (Aaronson & Burman, 1994). Only one site in Winnipeg is available for specialized pediatric diabetes care, emergency care and hospitalization. Both the DER-CA physician and educators record on the same health record. Thus, the risk of loss of information was low in the pediatric time period. In contrast, adult diabetes chart information may be found on one hospital chart, or on a combination of private facility charts and hospital charts, with different forms and methods of data recording. Further, a chart review may not capture diabetes-related hospitalizations where care was not received in the facility where the adult diabetes health care providers practice or where neither the client nor the health care centre report that hospitalization. A chart audit as a method of accounting for diabetes-related hospitalizations the year after transfer is more dependent on the subjects reporting such episodes to adult diabetes health care providers. The loss of hospitalization and health data could be greater in the time period of adult health than in pediatrics, but is not possible to be accurately determined.

Practical limitations similarly excluded examination of DER-CA client follow-up with specialized diabetes health care practitioners if the subject moved from Winnipeg or sought specialist diabetes health care in another location in Manitoba. These numbers were unable to be determined.

The date of the referral letter from the DER-CA may not match the exact date that the letter was sent to the adult health care provider. Human resource issues within the DER-CA could have caused an indeterminable delay between the typing, signing, photocopying and mailing of the referral letters.

The lack of standardized instruments and lack of replicated research are common problems in this and other studies of transfer. Although the measurement tools chosen for this study had proven psychometric properties, they did not add any insight into the subjects' actions or beliefs around the transfer period. The questionnaire was modeled after that of Pacaud et al. (1996), however remained subject to the same recall bias. Limitations common to HBM studies were common in all of the studies found: a retrospective study of small, non-random samples, without a control group, limiting generalization. Finally, the mailed package was not pre-tested for recipient reactions, such as interest, completion time, instrument clarity, or reaction to layout or format.

Recommendations for Future Research

Implementing a variety of methods for subject recruitment and for collection of self-report data may better meet the diverse interests and needs of this heterogeneous age group. Alternative methods to the self-administered questionnaire could include a structured telephone survey or in person interview. Subjects who were contacted on the phone by RA#2 may have consented to answer questions at that time (Barriball & While,

1999), particularly as time was the biggest reason for refusal mentioned by those contacted and refused. The use of different methods to recruit subjects and collect data would increase the cost of the research, and could adversely influence the quality and quantity of data collected (Polit and Hungler, 1999). Thus, the use of multiple approaches must be weighed against the potential variances in the data that different methods may introduce. However, maximizing the response rate to gain a more representative sample may be particularly important given the relatively limited population of young adults with Type 1 diabetes. Pre-testing of the mailed package, and the telephone script of the RA may have identified any barriers to recruitment within those methods.

Incentives have been found effective in sustaining participation in some Canadian research with adolescents with Type 1 diabetes (personal communication, Dr. M. Lawson, October, 2001). In diabetes clinical trials, support with free diabetes supplies is the norm. In low risk research where there is no personal benefit to participation, small incentives may increase recruitment without evoking ethical issues related to threat of perceived coercion or bribes. The literature regarding the use of incentives suggests that low-cost prepaid incentives such as a cheque or cash, are more likely to produce a higher response rate than no incentives or rewards contingent on survey return (Church, 1993; James & Bolstein, 1992). Incentives require some financial sponsorship, but can be minor in cost, such as movie certificates or compact discs. A review of the research that identified issues of recruitment and incentives in young adults looked at vulnerable populations, such as young adults with sexually transmitted diseases or prostitutes.

This research demonstrated that metabolic control was sub-optimal prior to transfer to specialized adult diabetes health care. Similarly, the frequency of visits was

lower than recommended by the Clinical Practice Guidelines both before and after transfer, but further deteriorated after transfer. Research with a longer time frame could examine factors that contribute to return to specialized diabetes care, correlations with diabetes health, motivations for return to diabetes health care, and the experiences of those who returned to health care. Research exploring issues of transfer for the smaller populations of youth with Type 2 diabetes and of youth with Type 1 diabetes from a rural area would provide a more comprehensive understanding of transfer issues relating to Manitoba youth with diabetes.

Implications for Nursing

An essential member of the team identified in many studies was the nurse co-coordinator, serving as an interim liaison, client advocate; and facilitator of communication among team members, patient-management plans, joint planning and the transfer itself (Russell et al., 1996; Schidlow & Fiel, 1990). The nurse is in an ideal position to implement research findings; advocate for youth recommendations, such as for a jointly staffed young adult clinic; evaluate health and resource outcomes of new initiatives; assess the client's health beliefs, understanding and readiness for transition; and then intervene with identified barriers. As Betz (1996) states in her editorial regarding transition "This is an opportune time for nursing to take a leadership role in enhancing the capacity of existing community-based transition models for in facilitating interagency collaboration efforts to develop new models," and to co-ordinate long-term program efforts with the emerging transition models being developed (p. 271). As stated by Michael and Sabo (1996), a major role of the diabetes nurse is in providing research-based evidence on which care can be based:

> Because the current healthcare environment is focused on clinical outcomes, those involved in diabetes care and education must base their activities on scientific- and research- based literature. Implementing care or educational programs based on past practice, position statements, or subjective patient data is no longer appropriate (p.23).

The visits to the pediatric diabetes nurse were the only visits that correlated positively to the visits to adult diabetes health care. Furthermore, the nurse was the most frequently visited pediatric diabetes educator the year before transfer, and the second most frequently visited the year after. Staffing levels confirm that the nurse was not more available for visits than the other diabetes educators. Possible reasons for the greater influence of the pediatric nurse educator were not explored, but could be related to the self-selected sample, perceived greater importance of the nurse or the nursing role, or a positive influence by the nurse.

Implications for Future Research

The results of this project will be useful in advocacy for future plans for a diabetes education and medical program for young adults in transition. The newly diagnosed client requires a relationship, and communication, with a consistent health care team. Future research should be designed to explore the appropriate model for the newly diagnosed young adult. Future research should also explore the norms for young adult behaviour, and the influence of the family on this age group and the transfer to adult care.

In many chronic illnesses in pediatrics, the population is restrictive in size, with specialized health care available in a limited number of sites, usually one site (Grey & Sullivan-Bolyai, 1999). Grey suggests two alternative approaches to this issue. The first, the

use of multiple sites, has the potential disadvantage of increased variance due to differences in the health care setting, treatment, management, differing philosophies about the intensity of management desired, demographic composition, and available data. Additional practicalities of multi-site research including finances, time, ethical and access approval to pediatric diabetes sites outside of the province were barriers to this approach in this research. A second possible approach to a limited sample size is the use of a noncategorical disease variable, including subjects from more than one type of disorder. This second approach assumes that the experience of a chronic illness is more important to the young adults transfer than the specific disease. While the sample size would be increased if the target population included those from more than one disease model, the challenge would be to identify and control the many further potentially extraneous variables.

Conclusion

The results of this study suggest that problems related to the transfer of young adult with Type 1 diabetes to adult care are part of a process beginning before the date of referral, in the pediatric time period. The youth in this study had both similar and divergent experiences and recommendations, compared to other research. Youth in this study clearly indicated a desire for a young adult clinic staffed jointly by pediatric and diabetes practitioners, with the time for transfer to be individualized, but not later than the current age of 18. For the diabetes health care community to fully meet the needs of the young adult, they must also move beyond self- imposed organizational barriers to cooperate in multi-site and multi-program research and development. The health care system must also work to better understand, accept and integrate the often confusing and conflicting wishes of the young adult for independence who at the same time, express difficulty booking and

attending appointments. Those youth who did not attend felt as if there was no need, despite evidence that their diabetes health was unacceptable. The rationalization for that opinion remains unclear. The young adult is not well understood, and they have showed that before trying to meet their needs, attempts must be made to hear and understand them. Nursing has the opportunity to be at the forefront of advocating for the young adult by facilitating research and program development, based on the outcome of that research, and cooperation among staff, programs and research committees.

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Appendix A

DER-CA statistics

	1994	1995	1996	1997	1998	1999	Total 1994 to 1998	Mean 1994 to 1998
Graduates - total	40	34	53	65	60	51	252	50.4
Moved out of Manitoba	10	3	10	14	4	n/a	41	8.2
Other (referred outside of Winnipeg)	7	10	15	19	15	n/a	66	13.2
To adult service Winnipeg- total	28	29	43	32	41	n/a	173	34.6
Death	2	2	0	0	0	n/a	4	

N/a = not available

Appendix B

Options for Adult Diabetes Medical Care and Education in Manitoba

Diabetes education for adults is available from education programs at:

1) A community based diabetes education program in Winnipeg, located within a community health clinic, consisting of three EFT (equivalent full-time) nurse educators and two EFT dieticians. Practitioners document on the community clinic chart.

2) Hospital A, one of two tertiary care hospitals in Winnipeg. The diabetes education program consists of a diabetes education team with two EFT each of Nurse Educators and Dieticians. The diabetes team provides service to clients who receive medical care from a physician affiliated with Hospital A. Educators document on the facility charts.

3) One of nine rural provincial government diabetes education programs. Each team consists of a nurse and dietician. Equivalent full time varies with each location. Documentation occurs on private diabetes charts.

4) Hospital B, one of two tertiary care hospitals in Winnipeg. The diabetes education team consists of 2 EFT each of Nurse Educators and dieticians. Documentation occurs on the facility chart.

Clients of the DER-CA with type 1 diabetes are provided with a number of options for adult diabetes medical care (endocrinologists or internists) who are located at:

1). Hospital A: five M.D.'s who document on the hospital's chart;

2). Private practice: two MD's who practice at Hospital A. also practice at community institutions. At the private practice, physicians document in their private chart.

3). Hospital B., Winnipeg, one M.D. who documents on the hospital's chart.;

In addition to the above referrals, unknown to the DER-CA, the client may choose to seek medical care solely from their Family Physician, a walk-in clinic, or internists referred to by other practitioners. In addition to the above referrals, unknown to the DER-CA, the client may make the choice to seek medical care solely from their Family Physician, a walk-in clinic, or internists referred to by other practitioners.

Appendix C

Letter of Support

Appendix D

Questionnaire on Transfer from Pediatric to Adult Services for People with Type I Diabetes

Code no._____

You have been sent these questionnaires because you previously were referred from pediatric diabetes health care (Diabetes Education Resource for Children and Adolescents) to an adult diabetes team (physician, nurse dietician etc.). This questionnaire aims to get at your experiences and opinions about the process of the transfer, and recommendations you may have for the future. There are no right or wrong answers. This information is confidential. Your personal information or your answers will not be shared with anyone from either diabetes team.

Please feel free to add any comments or leave blank any questions that you may not wish to answer. Please circle the answer that fits you the best, or fill in the blank.

In the first part of the questionnaire I would like to ask you a bit about some basic information about yourself.

1. Your date of birth: _____/_____/_____
   day month year

2. Gender: a) Male b) Female

3. Marital status:
   a) Single b) Live with partner c) Married d) Separated/Divorced
   e) Other: (please specify)_____

4. When were you diagnosed with diabetes?:
   4.1 Year: _____
   4.2 Your age at the time was: _____

5. What is the highest level of schooling that you have completed:
   a) Did not complete high school
   b) Currently in high school
   c) High school completed
   d) Currently in university or college
   e) Completed university or college
   f) other: _____

6. What is your employment status:
   a) currently working full time
   b) currently working part time

c) unemployed
d) other: _____

7. Who do you live with:
   a) live on your own
   b) live with parents
   c) live with spouse
   d) live with friends
   e) other:_____

Thank you. That background information is very helpful. Now I would like to ask you some questions about your experiences with the pediatric diabetes team, before you met with your adult diabetes health care team.

1. To begin with, did you receive any information from your pediatric diabetes team about the adult diabetes clinic or adult diabetes education team?

   Yes No

   If yes, please answer questions a) and b). If no, please go to question #2.

   a) If you did, could you describe the kind of information that you were given?

_____

_____

_____

   b) How helpful did you find this information? *(Please circle one response)*
   To a great extent
   Somewhat
   Very Little
   Not at All

2. If you did attend diabetes appointments with the pediatric diabetes team and physician, what made you decide to go?

_____

_____

_____

3. If you did not attend or book regular appointments, why didn't you?

_____

_____

_____

The next three questions refer to your experiences with your transfer to adult diabetes health care.

1. Did you experience any problems or difficulties with your transfer?

Yes No

If yes, in what way?

_____

_____

_____

2. In your opinion, what factors should determine the time for transfer from pediatric to adult health care? Some examples may be your age, when you think you are ready, when you leave home etc.

_____

_____

_____

_____

3. If age was used to determine the time of transfer from pediatric diabetes care to adult diabetes health care, in your opinion, what would be the ideal age be?

_____

The next questions refer to the year following your transfer to adult diabetes health care.

1. If you attended diabetes appointments with the adult diabetes team or physician, what made you decide to go?

_____

_____

_____

2. If you did not attend or book all of the recommended appointments, why didn't you?

_____

_____

_____

3. "If you could change anything about how you were educated about, or referred to the adult diabetes care, what would you change?"

_____

_____

_____

_____

Some studies have suggested that a "transition or transfer" program for young adults with Type 1 diabetes could be developed in a number of different ways. The final two questions ask your opinion on what you feel would be the ideal program for the diabetes care and education of young adults (18 to 25 years):

1. What do you feel would be ideal setting?
   a). Stay with the pediatric diabetes team, and move to adult care at about age 25
   b). There would be a clinic for people 18 to 25 years of age, then move to adult care
   c). Move straight to adult care at the age of 18
   d). Other _____

2. Who do you feel would be the ideal health care members of a diabetes health care

team for people between the ages of 18 and 25?

a). The pediatric team

b). The adult team

c). A mix of the two, some familiar pediatric staff and new adult staff

d). Other _____

Please use the space below to add any further comments or recommendations.

Now, please answer the next questionnaire called Diabetes Health Beliefs.

Appendix E

Diabetes Health Belief Scale

Thank you for your continuing participation in this study. The following statements describe what some people believe about diabetes and its treatment. After reading each statement, please circle one of the letters on the right hand side that best expresses your beliefs. There are 11 statements. **There are no right or wrong answers.**

The choices are:

sa = strongly agree
a = slightly agree
n = neutral
sd = slightly disagree
d = strongly disagree

1.	I believe that my meal plan and insulin will prevent diseases (complications) related to diabetes.	sa	a	n	d	sd
2.	My diabetes is no problem to me as long as I feel all right.	sa	a	n	d	sd
3.	My diabetes will have a bad effect on my future health.	sa	a	n	d	sd
4.	My diabetes will cause me to be sick a lot.	sa	a	n	d	sd
5.	I believe I will always need my diabetes meal plan and insulin.	sa	a	n	d	sd
6.	I believe I can control my diabetes.	sa	a	n	d	sd
7.	I believe that my meal plan and insulin will control my diabetes.	sa	a	n	d	sd
8.	I would have to change too many habits to follow my meal plan.	sa	a	n	d	sd
9.	It has been difficult following the meal plan prescribed for me.	sa	a	n	d	sd
10.	I cannot understand everything I've been told about my meal plan.	sa	a	n	d	sd
11.	Taking my insulin interferes with my normal daily activities.	sa	a	n	d	sd

Thank you. There is one more questionnaire left. It contains questions on how you manage your diabetes care.

From: Hurley, A. C. (1990). The Health Belief Model: Evaluation of a diabetes scale. The Diabetes Educator, 16(1), 44-48.

Appendix F

Insulin Management Diabetes Self-Efficacy Scale

This next survey includes statements that describe what some people believe about their ability to take care of their diabetes. Please take the next few minutes to indicate what *you* believe about your ability to manage *your* diabetes. After reading each statement, circle the number that best expresses your beliefs. There are 28 statements, please answer each one. There are no right or wrong answers.

Circle:

1	If you strongly agree with the statement,
2	If you moderately agree with the statement,
3	If you slightly agree with the statement,
4	If you slightly disagree with the statement,
5	If you moderately disagree with the statement,
6	If you strongly disagree with the statement.
NA	If the statement does not apply to you.

1.I can carry out practically all of the self-care activities in my daily diabetes routine.	1	2	3	4	5	6	NA
2. I am confident in my ability to manage my diabetes.	1	2	3	4	5	6	NA
3. I feel unsure about having to use what I know about diabetes self-treatment every day.	1	2	3	4	5	6	NA
4. I don't think I can follow my diabetes routines every single day.	1	2	3	4	5	6	NA
5. I can eat my meals at the same time every day.	1	2	3	4	5	6	NA
6. I can stay on my meal plan when I eat in familiar places away from home (such as at a friend's house).	1	2	3	4	5	6	NA
7. I can stay on my meal plan when I eat in unfamiliar places.	1	2	3	4	5	6	NA
8. I'm not sure I'll be able to stay on my meal plan when the people around me don't know that I have diabetes.	1	2	3	4	5	6	NA
9. I'm not sure I'll be able to follow my meal plan every day.	1	2	3	4	5	6	NA
10. I can correctly exchange one food for another in the same food group.	1	2	3	4	5	6	NA
11. When I go to parties, I can follow my meal plan.	1	2	3	4	5	6	NA
12. I can exercise several times a week.	1	2	3	4	5	6	NA
13. I can't exercise unless I feel like exercising.	1	2	3	4	5	6	NA
14. I can figure out when to call my doctor about problems with my feet.	1	2	3	4	5	6	NA

15. I can routinely apply the recommended lotion to my feet	1	2	3	4	5	6	NA
16. I cannot test my blood or urine when I am away from home.	1	2	3	4	5	6	NA
17. I can recognize when my blood sugar is too high.	1	2	3	4	5	6	NA
18. When I feel sick, I can test my blood or urine more than I routinely do.	1	2	3	4	5	6	NA
19. I can take my insulin using the recommended procedure.	1	2	3	4	5	6	NA
20. I may have difficulty taking my insulin when away from home.	1	2	3	4	5	6	NA
21. I can adjust my insulin dose based on the results of my urine or blood tests.	1	2	3	4	5	6	NA
22. I'm not sure I can figure out what to do about my insulin dose when changes occur in my usual routine.	1	2	3	4	5	6	NA
23. I can do what was recommended to prevent low blood sugar reactions when I exercise.	1	2	3	4	5	6	NA
24. I can figure out what self-treatment to administer when my blood sugar gets higher than it should be.	1	2	3	4	5	6	NA
25. I'm not sure I can recognize when my blood sugar is low.	1	2	3	4	5	6	NA
26. I'm not sure I can adjust my diabetes self-treatments if I get a cold or the flu.	1	2	3	4	5	6	NA
27. I can fit my diabetes self-treatment routine into my usual life style.	1	2	3	4	5	6	NA
28. I think I'll be able to follow my diabetes plan even when my daily routine	1	2	3	4	5	6	NA

changes.

Do you have any comments you wish to add about confidence in your ability to self-manage your diabetes?

Please send the yellow consent form and completed questionnaires in the stamped, self-addressed envelope. Please keep the green information package for your information.

Thank You

Christina B. Whittaker

© 1988 by Ann C. Hurley.

Cover letter

Health Sciences Centre

Hôpital général St~Boniface General Hospital

ALTH SCIENCES CENTRE
r. A. Angel
r. H.J. Dean
r. B.J. Kaufman
r. J.A. Moorhouse
r. L.J. Murphy
r. B.L.G. Nyomba
r. C.J. Richardson
r. S.P. Taback
r. V.C. Woo

BONIFACE HOSPITAL
r. S.M. Ludwig
r. E.A. Salamon

SECTION OF ENDOCRINOLOGY & METABOLISM

June 1, 2000

Dear

I am working with a graduate student researcher from the Faculty of Nursing, University of Manitoba interested in understanding the experiences and opinions of young adults with Type 1 diabetes about their transfer from pediatric diabetes care to adult diabetes care. This study has been approved by the University of Manitoba Nursing Ethical Review Board. This study is separate from the study you have been notified about one month ago from researchers at the University of Calgary. We are eager to participate in studies regarding the needs of young adults with Type 1 diabetes.

I have identified your name from the database of the Diabetes Education Resource for Children and Adolescents as being a person with Type 1 diabetes between 19 to 24 years. I would like to invite you to participate in this study. This would involve 30 to 45 minutes of your time, at home, to complete written questionnaires.

All information collected on these questionnaires and in the interview will be confidential and kept in a secure place.

This research may help us better understand the needs of individuals in your age group and to adjust delivery of care to meet these needs. Your participation would therefore be greatly appreciated. If you are interested, please read the attached information and consent package. If you agree to participate in the study, please then fill out and sign the consent form and return it in the enclosed envelope.

I would be most happy to answer any questions you might have. You can also call the student Christina Whittaker, or her thesis advisor, Dr. Pamela Hawranik .

Sincerely yours,

Heather J. Dean, MD, FRCPC
Professor, Department of Pediatrics
Head, Section of Endocrinology and Metabolism

Enclosure

ALTH SCIENCES CENTRE
n GG449, 820 Sherbrook Street
nipeg, Manitoba
1R9

(204) 787-3433 (Clinic 787-2870)

ST. BONIFACE HOSPITAL
Room C5111, 409 Taché Avenue
Winnipeg, Manitoba
R2H 2A5

Ph. (204) 237-2908

* CHILDREN'S HOSPITAL
Pediatric Endocrinology
Room FE325 - 685 William Avenue
Winnipeg, Manitoba R3E 0Z2

Ph. (204) 787-7435

Appendix H

Telephone Script to be used by Research Assistant

Hello. May I speak to _____?
(respondent name)

If the potential subject no longer resides at this phone number:

Would you know where _____ could be located?
(respondent name)

If the potential subject is available:

My name is _____. I am a research assistant for the study, Transfer of young adults with Type 1 diabetes from pediatric to adult diabetes care. I am calling to follow up on information and questionnaires sent to you regarding this study from Dr. Heather Dean, and the student, Christina Whittaker. I am phoning all those who have not responded to see if they indeed received the package. If you have misplaced your package of information, with consent form and questionnaires, we would be pleased to send you another. If you have received the package, and do wish to participate, we would appreciate if you could complete and return the consent form and questionnaires as soon as possible. If you have any questions, please do not hesitate to contact either the student, Christina Whittaker, or her thesis chair, Dr. Pamela Hawranik

If you have decided not to participate, we thank you for your time and consideration.

Appendix I

Operationalization of Variables.

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
Age at final visit/transfer to the DER-CA	- ratio unit of measurement - continuous variable - calculated via syntax formula			Pediatric chart	Pediatric chart audit form
Age at diagnosis with Type 1 diabetes (self-report)	- ratio unit of measurement - continuous variable			Transition questionnaire	Self-administered questionnaire
Age at diagnosis with Type 1 diabetes (chart audit)	- ratio unit of measurement - continuous variable			Pediatric chart	Pediatric chart audit form
Changes recommended in transfer process (per subject)	open-ended question		X	Transition questionnaire	Self-administered questionnaire
Date (year) of diagnosis with Type 1 diabetes (per subject)	nominal	yyyy		Transition questionnaire	Self-administered questionnaire
Date (year) of diagnosis with Type 1 diabetes (chart audit)	nominal	yyyy		Pediatric chart	Pediatric chart audit form
Date of birth	nominal	dd-mmm-yr		Pediatric chart	Pediatric chart audit form
Date of birth – self report	nominal	dd-mmm-yr		Transition questionnaire	Self-administered questionnaire
Date of diagnosis with Type 1 diabetes	nominal	dd-mmm-yr		Pediatric chart	Pediatric chart audit form
Date of final visit to the DER-CA	nominal	dd-mmm-yr		Pediatric chart	Pediatric chart audit form
Date of referral letter to adult diabetes educators	nominal	dd-mmm-yr		Pediatric chart	Pediatric chart audit form

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
Date of referral letter to adult diabetes medical care	nominal	dd-mmm-yr		Pediatric chart	Pediatric chart audit form
Discussion of transfer by educators, year prior to last visit with pediatric diabetes educators	dichotomous choice	yes = 1, no = 2.		Pediatric chart	Pediatric chart audit form
Discussion of transfer by physician, year prior to last visit with pediatric diabetes physician	dichotomous choice	yes = 1, no = 2.		Pediatric chart	Pediatric chart audit form
Educational status	Ordinal	Did not complete high school = 1 High school completed = 2 Currently in university or college = 3 Completed university or college = 4 Other = 5 No response = 99		Transition questionnaire	Self-administered questionnaire
Employment status	nominal	Currently working full time = 1 Currently working part time = 2 Unemployed = 3 Other = 4 No response = 99		Transition questionnaire	Self-administered questionnaire
Experience problems or difficulties with transfer (per subject)	dichotomous choice	1 = yes 2 = no No response = 99		Transition questionnaire	Self-administered questionnaire

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
Experience problems or difficulties with transfer (per subject)	open-ended question		X	Transition questionnaire	Self-administered questionnaire
Factors the subjects feel should determine the time for transfer	open-ended question		X	Transition questionnaire	Self-administered questionnaire
Frequency of diabetes related hospitalization pre-transfer	Ratio unit of measurement			Pediatric chart	Pediatric chart audit form
Type of diabetes related hospitalization pre-transfer	Nominal	1 = DKA 2 = severe hypoglycemia 99= unknown type		Pediatric chart	Pediatric chart audit form
Frequency of diabetes-related hospitalization during the first year of specialized adult diabetes care	Interval			Adult chart	Adult chart audit form
Type of diabetes related hospitalization post-transfer	Nominal	1 = DKA 2 = severe hypoglycemia 99 = unknown type		Adult chart	Adult chart audit form
Gender	nominal	1 = M; 2 = F		Pediatric chart	Adult chart audit form
Gender of non-respondents	nominal	1 = M; 2 = F		DER-CA database	Dr. Heather Dean
Health Beliefs	- continuous variable	- Total score ranging from 11 to 55 - Mean of total and sub scores - Scoring of separate dimensions: - Benefits 3 to 15		Diabetes Health Belief Scale (HBM11)	Self-administered questionnaire

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
		- Barriers 4 to 20 - Seriousness 4 to 20 99 = missing data			
Ideal age for transfer (per subject)	- ratio - continuous variable			Transition questionnaire	Self-administered questionnaire
Ideal health care team (per subject)	nominal and descriptive	1 = The pediatric team 2 = The adult team 3 = A mix of the two, some familiar pediatric staff and new adult staff 4 = other _____ 99 = No response	X	Transition questionnaire	Self-administered questionnaire

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
Ideal setting for young adult health care (per subject)	nominal and descriptive	1 = Stay with pediatric diabetes team, and move to adult care at about age 25 2 = A clinic for people 18 to 25 year old only, then move to adult care 3 = Move straight to adult care at the age of 18 4 = other ____ 99 = No response	X	Transition questionnaire	Self-administered questionnaire
Information regarding transfer to adult care	Nominal -dichotomous	yes = 1, no = 2.		Transition questionnaire	Self-administered questionnaire
Information regarding transfer to adult care (subject description)	open-ended question		X	Transition questionnaire	Self-administered questionnaire
Information regarding transfer to adult care (how helpful)	Ordinal	1 = To a Great Extent 2 = Somewhat 3 = Very Little 4 = Not at All helpful 99 = No response.		Transition questionnaire	Self-administered questionnaire
Length of diagnosis with Type I diabetes prior to referral to adult diabetes health care	Ratio unit of measurement -calculated via syntax				

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
	syntax				
Living arrangements	Nominal	1 = Lives on their own 2 = Lives with parents 3 = Lives with spouse 4 = Lives with friends 5 = Other 99 = No response		Transition questionnaire	Self-administered questionnaire
Location of adult diabetes educators referred	nominal	1 = St. Boniface Hospital 2 = Health Sciences Centre 3 = Rural DER 4 = Youville DER 5 = Outside of Manitoba 6 = Other 99 = not found		Pediatric chart	Pediatric chart audit

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
Location of adult diabetes physician referred to	nominal	1 = Winnipeg Clinic 2 = St. Boniface Hospital 3 = Health Sciences Centre 4 = Diabetes specialist outside of Wpg 5 = Diabetes specialist outside of Manitoba 6 = Other 99 = Not found		Pediatric chart	Adult chart audit
Marital status	Nominal	1 = Single 2 = Living with partner 3 = Married 4 = Separated/ Divorced 99 = No response		Transition questionnaire	Self-administered questionnaire
Metabolic control during the first year of specialized adult diabetes care	Interval - A1C - pre transfer - A1C value/assay upper limit x 100			Adult chart	Adult chart audit form

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
Metabolic control during the year prior to transfer to specialized adult diabetes care	Interval -A1C post transfer -A1C value/assay upper limit x 100			Pediatric chart	Pediatric chart audit form
Metabolic control of non-responders the year prior to transfer	Interval -A1C post transfer -A1C value/assay upper limit x 100			DER-CA database	Dr. Heather Dean
Number of visits to specialized pediatric diabetes education during the last year of pediatric diabetes health care.					
Number of visits to specialized pediatric diabetes medical care during the last year of pediatric diabetes health care.	- nominal - dichotomous	yes = 1, no = 2.			
Number of visits to specialized adult diabetes education the first year after referral to adult diabetes health care.	open-ended question		X	Transition questionnaire	Self-administered questionnaire
Number of visits to specialized adult diabetes medical care the first year after referral to adult diabetes health care.	open-ended question		X	Transition questionnaire	Self-administered questionnaire
Number of visits of non-responders at specialized pediatric diabetes care the year prior to referral to adult diabetes health care.	open-ended question		X	Transition questionnaire	Self-administered questionnaire

Variable	Measurement	Value labels in SPSS	Content analysis	Source	Questionnaire or chart
Reasons for not attending adult diabetes care	open-ended question		X	Transition questionnaire	Self-administered questionnaire
Reasons for not attending pediatric diabetes care	open-ended question		X	Transition questionnaire	Self-administered questionnaire
Self-efficacy	- continuous variable	Total score ranging from 28 to 168 -99 = "not applicable" or missing data. - Mean of total and sub scores Scoring of separate dimensions: Insulin 10 to 60 Diet 10 to 60 General 4 to 24		The Insulin management diabetes self-efficacy scale (IMDSES)	

Appendix J

Code no: _____

Pediatric Chart Audit

Date of audit: _____

Confirmation of diagnosis with Type 1 diabetes: Yes No

Gender: _____

Date of birth: _____(dd-mmm-yr)

Date of diagnosis with Type I diabetes: _____ (dd-mmm-yr)

Age at diagnosis with Type I diabetes: _____

Town of residence: _____

Date(s) of visits to DER-CA the last year prior to transfer: (dd-mmm-yr)

	Visit (dd-mmm-yr)	**Visit** (dd-mmm-yr)	**Visit** (dd-mmm-yr)	**Visit** (dd-mmm-yr)
Physician				
Nurse				
Dietician				
Social Worker				

Age at final visit to DER-CA: _____

A1C results recorded while at DER-CA (within 1 year prior to transfer):

Date (dd-mmm-yr)	**Result**	**Normal values for lab**	**Calculated % of normal** (result/high nl x 100)

Diabetes related hospitalization(s) the year prior to referral: (dd/mmm/yr) (DKA or severe hypoglycemia)

_____

Date(s) of recorded discussion of transition within 1 years prior to last visit (specify):

	Visit (dd-mmm-yr)	**Visit** (dd-mmm-yr)	**Visit** (dd-mmm-yr)	**Visit** (dd-mmm-yr)
Physician				
Nurse				
Dietician				
Social Worker				

Date of last visit to DER-CA: _____(dd-mmm-yr)

Date of referral letter to adult diabetes health care:

Physician: _____ (dd-mmm-yr) no letter on chart _____

Educators: _____ (dd-mmm-yr) no letter on chart _____

Adult health care agencies referred to:

Diabetes physician		Educators	
Winnipeg Clinic	☐	St. Boniface Hospital	☐
St. Boniface Hospital	☐	Health Sciences Centre	☐
Health Sciences Centre	☐	Rural DER	☐
Diabetes specialist outside of Winnipeg	☐	Youville DER	☐
Diabetes specialist outside of Manitoba	☐	Outside of Manitoba	☐
Other: _____	☐	Other: _____	☐

Appendix K

Adult Chart Audit

Code no: _____

Date of audit: _____ Location of audit: _____

Chart type:

Diabetes physician ☐
Diabetes educator ☐

Gender: _____

Date of birth: _____(dd-mmm-yr)

Town of residence: _____

Date of diagnosis with Type I diabetes: _____ (dd-mmm-yr)

Age at diagnosis with Type I diabetes: _____

Date of referral letter:

From pediatric diabetes physician: _____ (dd-mmm-yr)

From pediatric diabetes educators: _____ (dd-mmm-yr)

Date of visits to adult diabetes health care within 1 year of date of pediatric referral letter:

	First visit (dd-mmm-yr)	**Other visits** (dd-mmm-yr)	**Other visits** (dd-mmm-yr)	**Other visits** (dd-mmm-yr)
Physician				
Nurse				
Dietician				
Social Worker				
Other				

A1C the year following referral:

Date (dd-mmm-yr)	**Result**	**Normal values for lab**	**Calculated % of normal** (result/high normal x 100)

Diabetes related hospitalization(s)the year post-transfer: (dd-mmm-yr) (DKA or severe hypoglycemia)

_____

Appendix L

Ethics Approval

HE UNIVERSITY OF MANITOBA

FACULTY OF NURSING

Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-7452
Fax: (204) 474-7682

Christina B. Whittaker, RN, BN, NPCC, CDE

Winnipeg, Manitoba
R3N 1B9

June 20, 2000

Dear Christina:

Re: Proposal #00/18: The Transfer of Young Adults with Type 1 Diabetes from Pediatric to Adult Diabetes Care

The above proposal has been reviewed by select members of the Faculty of Nursing Ethical Review Committee.

I am pleased to inform you that your study has been approved.

I would like to take this opportunity to wish you every success with your research project.

Sincerely,

Susan McClement, RN PhD(c)
Associate Chair
Ethical Review Committee
Faculty of Nursing

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number #00/18

Proposal Title: "The Transfer of Young Adults With Type 1 Diabetes From Pediatric to Adult Diabetes Care"

Name and Title of Researcher(s): Christina Whittaker

Date of Review: June 15, 2000

APPROVED BY THE COMMITTEE: June 20, 2000

Comments:

Date: June 20, 2000

Susan McClement, Associate Chair

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Health
Sciences
Centre
THE UNIVERSITY OF MANITOBA
Faculty of Medicine

St-Boniface
General Hospital

Appendix M

Access and Impact

August 22, 2000

ILTH SCIENCES CENTRE
ıritis Centre
149-800 Sherbrook Street
nipeg, MB, Canada
, 1M4

) 787-2208 (HSC Office)
) 787-1920 (Fax)
) 787-2392 (Appointments)

artment of Medicine
I El-Gabalawy, Director
M Chalmers
MG Canvin
Peschken

artment of Pediatrics
Child Health
Oen
) 787-2020

Christina B. Whittaker

WINNIPEG, MB
R3N 1B9

Dear Christina Whittaker:

Re: RI00:075 " The transfer of young adults with Type 1 Diabetes from Pediatric to Adult Diabetes Care."

The above study was reviewed by the Pediatric Research Coordinating Committee on August 14, 2000, and has been given final approval.

Please inform the Pediatric Research Coordinating Committee of the dates data collection is started and completed (at time of completion).

Thank you.

Yours truly,

Kiem G. Oen, MD, FRCPC
Chairperson
Pediatric Research Coordinating Committee

KGO:jc

c.c. File
Dr. L. Oppenheimer

MEMORANDUM

DATE: July 5, 2000

TO: Christina Whittaker, Principal Investigator,

FROM: Karen Shaw, Research Department, MS748B

SUBJECT: **RESEARCH PROTOCOL: THE TRANSFER OF YOUNG ADULTS WITH TYPE 1 DIABETES FROM PEDIATRIC TO ADULT DIABETES CARE.**
Research Impact #: RI00:075

After reviewing this study with the HSC Research Impact Committee Members, impact on the Medical Information Department has been identified.

In the event retrieval of the HSC medical record is required by the investigator, co-investigator, other study team members, study sponsor or agents of regulatory bodies, **a charge of $3 per record will be levied. Please let me know if the study budget can support this charge, should it become necessary**. Once I have your assurance approval for Medical Information will be forwarded to Dr. Luis Oppenheimer, Director of Research.

Please contact Nadine Mann, retrospective Audit Technician, directly , or ask for her at the main reception desk in the Medical Information Department when charts are required. Please provide her with the Research Impact and HSC account numbers for your study and she will coordinate your request. If you have any questions with regard to the above please call me . Thank you for your assistance.

cc: Ms Gail Grimsen, Manager, Health Information

Winnipeg Clinic
425 St. Mary Ave.
Winnipeg, Manitoba
Canada R3C 0N2
Tel: (204) 957-1900
Fax: (204) 943-2164

September 7, 2000

Christina B. Whittaker

Winnipeg, Manitoba
R3N 1B9

Dear Ms. Whittaker:

Re: The Transfer of Young Adults with Type 1 Diabetes from Paediatric to Adult Health Care

Your correspondence of August 8th, 2000 has satisfied our concerns re the requirements for confidentiality of Winnipeg Clinic records, responsibilities for file access, and storage of information.

To expedite the start of the project you have agreed to the changes on the consent form (copy enclosed) as per our telephone conversation of September 7th, 2000.

The Ethics Committee, therefore, has given approval to your study.

Good Luck!

Yours truly,

June M. James, M.D., FRCPC
Chairperson
Ethics Committee

JMJ/pr

enclosure

Telephone/téléphone :
(204) 255-4840

Fax/télécopieur :
(204) 255-4903

July 11, 2000

Christina B. Whittaker

Winnipeg, MB
R3N 1B9

Re: Access Request for "The Transfer of Young Adults with Type I Diabetes from Pediatric to Adult Diabetes Care

Dear Christina.

I am pleased to inform you that your request to access client charts at Youville Centre, Diabetes Education Resource has been approved.

Please contact Liz Loewen, Clinical Nurse Specialist prior to beginning data collection to arrange to sign a confidentiality agreement. Liz will also arrange space for you to work during this time. As she has discussed with you, it may be necessary to rotate your working location due to a shortage of workspace at the Centre.

Prior to obtaining access to individual charts, we will require a copy of each client's signed consent form, which will then be included in the client's chart. Our reception staff will pull the charts for you.

Best wishes as you progress with your study. If you have any questions or require further assistance during your time at Youville, please don't hesitate to contact myself or Liz Loewen.

Sincerely,

Sylvia Oosterveen
Executive Director

Cc: Liz Loewen

Local: 3266 Fax: 231-0891

TO: Ms. C. B. Whittaker

Winnipeg, MB R3N 1B9

FROM: Dr. J. Foerster
Chairperson, Research Review Committee

DATE: September 7, 2000

SUBJECT: **Experimental Protocol Submission**

This is to inform you that the Research Review committee, at its meeting held on September 6, 2000 reviewed the nursing study titled "The Transfer of Young Adults with Type 1 Diabetes from Pediatric to Adult Diabetes Care", Ref # RRC/2000/0133.

The Committee approved the study and Patient Consent Form and it may now be implemented.

Please be advised that copies of the studies which have been approved **must be retained by the person** doing the protocol for **at least two years** after the study is completed. The study must be kept for a longer term if it is anticipated that there will be a long-term effect.

Thank you for your cooperation.

JF/clr

cc: Dr. P. Hawranik, - Supervisor - Faculty of Nursing, UofM
Dr. S. Ludwig, SBGH Physician
Ms. A. Lemieux, Research & Evaluation Consultant
Ms. B. Petrowski, Program Director - Medicine Program
Ms. K. Neufeld, Director, Quality & Professional Services and CNO
Dr. S. Lucash, President of the Medical Staff
Ms. H. Milan, Pharmacy Department
Ms. D. Halhead, Finance Department
Ms. D. French, Health Records

Appendix N

The Transfer of Young Adults with Type 1 Diabetes from Pediatric to Adult Diabetes Care

Information for Study Participants

I am a Registered Nurse, Certified Diabetes Educator, and a master's student in the Faculty of Nursing, at the University of Manitoba. You are invited to participate in a study examining the experience of young adults with Type 1 diabetes as they moved from specialized pediatric diabetes care to specialized adult diabetes care. Your name was selected from the database of the Diabetes Education Resource for Children and Adolescents from a list of previous clients with Type 1 diabetes who would now be between the ages of 19 and 25.

CONFIDENTIALITY:

This study has been approved by the Ethical Review Committee of the Faculty of Nursing at the University of Manitoba. This study will be conducted in compliance with the Personal Health Information Act of Manitoba. All information will be kept in a locked drawer for seven years, and then destroyed. The findings may be published and presented to health care workers, however your name will not be used on any reports about the study or future publications. **At no time, will it be possible to identify individuals in written or oral report, from this study. Any details that might identify you will be excluded. Only the student (Christina Whittaker), her thesis advisor (Dr. Pam Hawranik) and a statistician will have access to the completed anonymous and coded questionnaires.**

PROCEDURES:

Your signature on the attached consent form is needed in order for the study to proceed. Your written consent indicates:

i) That you agree to complete the attached questionnaire about your experiences and recommendations for the transfer to adult care from pediatric care. It should only take about 30 to 45 minutes of your time. Your name is not needed on the questionnaire.

ii) That you agree for certain information to be obtained from your pediatric and adult diabetes medical charts for the year before and after your transfer to adult diabetes care: Hemoglobin A1C, dates of diabetes related hospitalizations, dates of visits to the diabetes educators and physician; dates of discussion of your upcoming transfer with the pediatric team; the dates of the referral letter from the pediatric diabetes team to the adult diabetes team; and the location of the adult diabetes team that you were referred to.

There are no benefits for you to participate in the study, but the findings will be used to help develop programs for young adults with diabetes who are transferred to adult care. You are under no obligation to participate. If you decide not to participate, this will not affect the diabetes services that your currently receive, or will receive in the future.

CONTACT PERSONS: Should you have any questions about the study, please feel free to contact the student, Christina Whittaker or her thesis advisor, Dr. Pamela Hawranik, Faculty of Nursing at the University of Manitoba . If you have questions about your rights as a research participant, you may contact Lorraine Bisson, Patient Relations Officer, at St. Boniface Hospital , or staff in the Patient Representative office at Health Sciences Centre,

I thank you for your time and cooperation. If you are interested in participating in this study, please complete and return the yellow consent form, along with the

questionnaires in the enclosed envelope, as soon as possible. You may keep this green coloured "Information for study participants." Your opinions and experiences are very important to us to gain an accurate picture of the needs of young adults with diabetes during this time.

Sincerely,

Christina B. Whittaker, RN, BN, CDE, MN student.

Appendix O

The Transfer of Young Adults with Type 1 Diabetes from Pediatric to Adult Diabetes Care

Voluntary Consent

In signing this consent form, I am giving my consent to take part in a study exploring the transfer of young adults with Type 1 diabetes from pediatric to adult diabetes care.

I have received a written explanation about the study, and I understand what is involved. I understand that my decision to participate is voluntary, and that I can decide to withdraw at any time. I can refuse to answer any of the questions on the questionnaires. I understand that if I decide not to participate, this will not affect the diabetes services that I currently receive, or will receive in the future. I understand that my answers to questions and chart information will not be given to anyone other than the student, her thesis committee, and the statistician. No reports of this study will ever identify me in any way. All information will be grouped to avoid identification of anyone who participates.

I understand by my signature, I am consenting:

1. To complete the attached questionnaire, and
2. For the following information to be obtained from my pediatric and adult charts: Hemoglobin A1C, dates of diabetes related hospitalizations, dates of visits to the diabetes educators and physician; dates of discussion of your upcoming transfer with the pediatric team; the dates of the referral letter from the pediatric diabetes team to the adult diabetes team; and the location of the

adult diabetes team that you were referred to.

All information will be stored in a locked cabinet for seven years, and then destroyed.

If I have any questions about the study or my participation I can contact the student, Christina Whittaker , or her thesis advisor, Dr. Pamela Hawranik, Faculty of Nursing at the University of Manitoba . If I have questions about my rights as a research participant, I may contact Lorraine Bisson, Patient Relations Officer, at St. Boniface Hospital.

My signature below indicates that I am informed about the study and I am volunteering to participate.

Date: _____

Name: _____ Signature: _____

My correct address, if different than on the front of envelope mailed to me is:

_____

_____

_____

Please return in the enclosed stamped self-addressed envelope

Thank you

The Transfer of Young Adults with Type 1 Diabetes from Pediatric to Adult Health Care

Please send me a copy of the summary of the research report.

Send to: _____ (name)

_____ (address)

_____

Please return in the enclosed stamped self-addressed envelope

Thank you

Appendix P

Correlation of A1C (Adult and Pediatric) with Diabetes Visits the Year Before Transfer

	Ped A1C mean	Total number A1C ped chart	Adult A1C mean	Total number of A1C in adult charts	Total no ped MD visits	Total no R.N. ped visits	Total no ped R.D. visits	Total no of ped S.W. visits	Total no diabetes educ visits pediatric
Ped A1C mean		-.150	.091	-.200	.043	-.117	.377	-.109	.076
Total number A1C ped chart	-.150		-.387	-.088	.582**	.528*	.467*	.214	.454
Adult A1C mean	.091	-.387		.226	-.714*	-.544	-.171	.010	-.212
Total number of A1C in adult charts	-.200	-.088	.226		-.377	.383	-.122	.005	.115
Total no ped MD visits	.043	.582**	-.714*	-.377		.223	.321	.016	.200
Total no RN ped visits	-.117	.528*	-.544	.383	.223		.677**	.536*	.850**
Total no ped RD visits	.377	.467*	-.171	-.122	.321	.677		.621	.894**
Total no of ped sw visits	-.109	.214	.010	.005	.016	.536	.621		.815**
Total no diabetes educ visits pediatric	.076	.454	-.212	.115	.200	.850**	.894**	.815**	
Total no of ped hc team visits	.136	.608**	-.354	.002	.464*	.813**	.927**	.708**	.949**

* Correlation is significant at the .05 level (2-tailed). ** Correlation is significant at the .01 level (2-tailed).

Appendix Q

Correlation of A1C (adult and pediatric) with Diabetes Visits the Year After Transfer

	Adult A1C mean	Total number of A1C in adult charts	Ped A1C mean	Total number A1C ped chart	Total no adult MD visits	Total no adult RN visits	Total no adult RD visits	Total no of adult SW visits	Total no diabetes educ visits adult
Adult A1C mean		.226	.091	.387	-.326	.097	-.043	.	.091
Total number of A1C in adult charts	.226		-.200	-.088	.386	.504*	.449	.	.514*
Ped A1C mean	.091	-.200		-.150	-.355	-.060	.096	.	.017
Total number of A1C ped chart	-.387	-.088	-.150		.271	-.025	.144	.	.089
Total no adult MD visits	-.326	.386	-.355	.271		.548*	.477*	.	.574*
Total no adult RN visits	.091	.504*	-.060	-.025	.548*		.713**	.	.875**
Total no adult RD visits	-.043	.449	.096	.144	.477*	.713**		.	.956**
Total no of adult SW visits	.	.	.	.	.	.	.	.	.
Total no diabetes educ visits adult	-.019	.514*	.017	.089	.574*	.875**	.956**	.	
Total no diabetes team visits adult	-.166	.486*	-.169	.196	.831**	.851**	.833**	.	.918**

* Correlation is significant at the .05 level (2-tailed). ** Correlation is significant at the .01 level (2-tailed).