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Keeping a Balance: The Process of Food Choice among Renal Transplant Recipients

By

Mary Anne Zupancic



**A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment
of the requirements for the degree of Master of Science**

Centre for Health Promotion Studies

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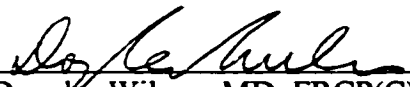
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The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **Keeping a Balance: The Process of Food Choice Among Renal Transplant Recipients** submitted by **Mary Anne Zupancic** in partial fulfillment of the requirements for the degree of Master of Science.



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ABSTRACT

There is a paucity of research exploring how individuals with chronic medical conditions experience food choice in their socio-cultural environment, as well as reported difficulties and negative health impacts associated with dietary prescription non-compliance. Therefore, the objectives of this study were to explore how renal transplant recipients experience food choice; to understand meanings of food and eating; and to make visible the complexity and the inter-related nature of socio-cultural and environmental determinants of food choice. A naturalistic inquiry using direct participant observation and in-depth interviewing were the primary methods of data collection. Constant comparison was used to analyze data thematically. Respondents perceived health promotion/illness prevention and normalcy/quality of life as a dichotomy in the context of food choice. This resulted in a process of selecting food choice strategies that would “keep a balance”. This study makes visible a problematic with respect to respondents’ social context, the existing culture of health care, and effectiveness of health interventions.

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CHAPTER I: INTRODUCTION

1.1 Background and Rationale

Organ transplantation literature has for the most part focused on technical advances and challenges facing medical practice. Long-term success of organ transplantation requires a lifetime dependency on immunosuppressive therapy. Therefore, it is assumed that transplant recipients will comply meticulously with prescribed health regimens to avoid any unnecessary risks that could compromise graft function and to ensure health promotion.

Despite this, there appears to be little research that explores, from the transplant recipient's perspective, the human challenges of living with a transplant. Namely, the ongoing and/or consequent chronic health conditions that prevail following long-term immunosuppressive therapy, and the ongoing demands on time, energy, finances, and relationships of transplant recipients and their families (Merz, 1998). Investigations that explore, describe and explain qualitatively, the nature of living with chronic illness and/or the complex prescribed health regimens associated with transplant, could contribute to better understanding of this phenomenon, particularly in the ongoing search for strategies that improve health outcomes for transplant recipients.

1.1.1 Dietary Modifications and Immunosuppressive Therapy

Transplant recipients require a life long course of immunosuppressive therapy to optimize graft function. Dietary modifications are often required secondary to the development of physical "side effects" resulting from immunosuppressive treatment. For example, excessive weight gain, obesity, cardiovascular disease, hypertension and diabetes are some of the potential health conditions that are both directly and indirectly

attributed to immunosuppressive therapy (Hasse, 1992). These chronic health conditions could successfully be managed with specific dietary, medical and/or other health behaviour modifications (Weseman & McCashland, 1998). A review of the nutrition and transplant literature appears to indicate that diet therapy is an important component in the management and prevention of several immunosuppressive therapy-induced medical complications (Weseman & McCashland, 1998; Mandakini, 1998; Baron & Waymack, 1993; Hasse, 1992).

There is currently an extensive transplant literature primarily concerned with immunosuppressive therapy compliance among transplant recipients. The significance of this extensive literature may reflect the direct and grave impact of medical noncompliance behaviour -namely increased risk of graft rejection episodes and/or graft failure (Greenstein & Siegal, 1998; Rudman, Gonzales & Borgida, 1999). However, compliance with dietary and/or other prescribed health behaviour modifications does not appear to be as extensively studied in this literature. It has been suggested that diets and lifestyle/health behaviour modifications are often prescribed as a method of “control” versus “cure”(Glanz, 1980). Furthermore, it is suggested that noncompliance with immunosuppressive therapy, not dietary prescriptions, will directly impact graft rejection and/or failure (Kiley, Chow, Lam & Pollak, 1993). However, it is also documented in other health and nutrition literature that where diet-related chronic health conditions exist, long term noncompliance with diet will negatively impact health outcomes (Mandakini, 1998; Tonstad, Holdaas, Gorbitz, & Ose, 1995) and will increase health care resource utilization (Glanz, 1980).

It appears, therefore, that compliance with prescribed dietary modifications among renal transplant recipients is a significant issue in need of inquiry despite the relative absence of this issue within the transplant literature.

1.1.2 Compliance and Individual Behaviour

The literature addressing renal transplant recipient compliance behaviour suggests that there is an inadequate understanding of the determinants of noncompliance (Glanz, 1980; Rudman, Gonzales, & Borgida, 1999). However, the majority of this literature, whether medical or dietary, focuses mainly on individual behaviours and fails to address the complex and interrelated nature of the socio-cultural and environmental determinants of health-related behaviours. With respect to dietary compliance, there is currently a paucity of research exploring how individuals experience eating and food choice in their own social and cultural environment (Travers, 1997), particularly among those individuals with chronic medical conditions (Roberson, 1992). Although the medical benefits of dietary compliance are well established, the social, cultural and environmental determinants of eating behaviours are less well understood by health professionals. Despite prescribed dietary recommendations, those living with chronic illness, such as renal transplant, may not associate their food choices and eating behaviour with improved health outcomes (Roberson, 1992). Food and eating may largely be influenced by their social, environmental and cultural circumstances (Roberson, 1992).

1.1.3 Noncompliance: Limits of Individual Behavioural Approach to Health

The population health approach recognizes that there is a need to address cultural, social and environmental determinants of health-related behaviours. Furthermore, these determinants do not exist in isolation of one another, but rather are interrelated, complex,

and have a substantial impact on health outcomes and quality of life (Health Canada, 1999). Renal transplant recipients live with risk of, or chronic health conditions and would benefit from multiple health-related behaviour modifications (Mandakini 1998; Weseman & McCashland, 1998). Therefore, there is a need to better understand and address these multiple and complex determinants of health-related behaviours. This in turn may generate valuable insights with respect to compliance behaviour, health outcomes and quality of life for individuals living with a renal transplant.

1.2 Problem Statement and Research Objectives

In view of the reported difficulties and impact of dietary noncompliance, and the inadequate understanding of the social, cultural and environmental determinants of eating behaviour in chronic health conditions, the objectives of the proposed research are:

- 1. To explore how renal transplant recipients experience food choice within their social and cultural environment.**
- 2. To better understand the meanings of food and eating held by transplant recipients, within the context of diet-related medical conditions and within their social and cultural environment.**
- 3. To make visible the social, cultural and environmental determinants of eating behaviour, and the interrelated nature and complexity of these determinants, by developing a model or framework of these meanings and experiences.**

CHAPTER II: REVIEW OF THE LITERATURE

The following review of the literature will form a foundation that demonstrates the need to better understand health behaviours associated with renal transplant. Furthermore, this review will support the use of naturalistic inquiry as a means of generating this understanding with respect to the social, cultural and environmental influences on individuals living with the chronic health conditions associated with a renal transplant.

2.1 The Impact of Dietary Modification in Renal Transplant

There have been tremendous advances in health care with respect to restoring the quality of life for many individuals by way of a solid organ transplant. The challenge with long-term organ transplants however has been the consequent development of chronic health conditions secondary to immunosuppressive therapy (Weseman & McCashland, 1998). Hyperlipidemia, diabetes mellitus, arterial hypertension, obesity and osteopenia are health conditions that can develop following transplant (Hasse, 1992). These health conditions may also be associated with an increased risk of morbidity, cardiac risk and atherosclerosis (Hasse, 1992; Baron & Waymack, 1993). A mortality rate of up to 50% from transplant-related coronary events is well documented (Mahony, 1989). Obesity is known to be a common health problem resulting from immunosuppressive therapy (Mandakini, 1998), and can exacerbate other chronic health conditions such as coronary artery disease, diabetes, blood pressure, lipids and limit physical functioning (Blumke, Keller, Eble, Nausner & Kirste, 1993).

These chronic health conditions may be controlled with specific or multiple dietary modifications including reductions in dietary fat, carbohydrate, sodium and energy consumption (Mandakini, 1998). Other potential dietary interventions include the need for additional calcium resulting from bone mineral loss secondary to long term immunosuppressive therapy use and lack of physical activity (Hasse, 1992; Mandakini, 1998).

From this review of specific dietary-related chronic health conditions resulting from renal transplantation, it would seem reasonable that nutrition education/interventions designed to prevent and/or control these conditions would likely be considered essential in achieving positive health outcomes. However, health care providers are increasingly frustrated and challenged by non-compliance with prescribed treatment plans among renal transplant recipients. Noncompliance is thought to be one of the major obstacles in achieving positive health outcomes following nutrition education/intervention (Glanz, 1980). Noncompliance behaviour negatively impacts the health outcomes of individuals with chronic health conditions and the health care system as a whole. For example, in Brook's study (as cited in Roberson, 1992) noncompliance behaviour can undermine the success of health practitioner's treatment plans, fail to prevent complications of health conditions, and can result in increased use of health care resources (Roberson, 1992). Therefore, it is not surprising that there is an extensive health literature examining noncompliance behaviour and its determinants.

2.2 Renal Transplant Recipients and Medication Compliance

There is an extensive literature specifically focused on immunosuppressive therapy compliance among renal transplant recipients. It is suggested that noncompliance

with prescribed immunosuppressive therapy is the third leading cause of graft loss following rejection and infection (Greenstein & Siegal, 1998). Of the literature reviewed, the incidence of noncompliance with immunosuppressive therapy ranged from less than 5% (Didlake, Dreyfus, Kerman, Van Buren & Kahan, 1988; Schweizer, Rovelli, Palmeri, Vossler, Hull & Bartus, 1990) to more than 45% (Sketris, Waite, Grobler, West & Gerus, 1994; Kiley et al., 1993). Siegal & Greenstein (1997) reported that 18% of the 519 renal transplant recipients in their study were noncompliant with medications and follow-up care. Of these 18% of noncompliant renal transplant recipients, eventually 91% either lost their grafts or died. These findings are also consistent with other studies (Didlake et al., 1988).

The health impact of this incidence clearly demonstrates the need for further inquiry to better understand noncompliance with immunosuppressive therapy. As well, this literature provides valuable insight into the difficulty and complexity, associated with compliance, in all aspects of the prescribed medical regimen. That is, immunosuppressive therapy may also generate specific health conditions requiring further prescribed health modifications such as diet, exercise, and additional medications. The most prevalent physical side effects of immunosuppressive drugs include obesity, hyperlipidemia (Pirsch, Armbrust, Knechtle, D'Alessandro, Sollinger, Heisey & Belzer, 1995) hypertension and diabetes (Gill, Hodge, Novick, Steinmuller & Garred, 1993). With respect to diet, renal transplant recipients have a strong desire to eat foods previously restricted and may be reluctant to undergo further dietary modifications as well as other lifestyle changes in order to prevent these complications (Mandakini, 1998). Transplant recipients may also adjust or refuse immunosuppressive therapy in response to these

unwanted side effects (Mandakini, 1998; Harwood & Johnson, 1999). Yet immunosuppressive therapy noncompliance and related medical complications could eventually lead to increased risk of graft rejection episodes, graft failure and death preceded by heavy use of medical resources (Blixen & Douglas, 1994).

Furthermore, renal transplant recipients do not exist in isolation of their own social and cultural environments and this further complicates the study of compliance with medical regimens. Rudman et al. (1999) examined some predictors of noncompliance for renal transplant recipients. They concluded that the post-transplant regimen is complex and stressful in that it includes dietary restriction, multiple medical visits for blood work and follow-up, and ongoing dependency on immunosuppressive medications that cause adverse side effects such as weight gain, depression and edema. In addition, predictors of compliance in this group can be expected to be diverse and be influenced by a wide range of psychological, socio-demographic and biomedical variables (Rudman et al., 1999)

The research also suggests that psychological, cultural and socio-environmental factors are often unpredictable and lack consistency between studies with respect to the study of compliance with medications and/or medical regimens. Kiley et al. (1993) found in their study of 105 renal transplant recipients, that males were more likely to be noncompliant with medication and females were found to be noncompliant with diet. Noncompliance was also associated with depression, black race, increased number of medications, unemployment, as well as perceived amount of family and social support, and locus of control attributed to powerful others. Several of these findings were also consistent with those of Schweizer et al. (1990) whereby those of lower socioeconomic

status and different ethnicity tended to be noncompliant with their prescribed medication regimens among the 260 respondents studied.

In contrast however, a large multi-centre study consisting of more than 1400 patients, found that those individuals with a higher socioeconomic status, and in occupations with leadership and decision-making characteristics, were more likely to be noncompliant with their medication regimen. As well, neither sex nor race was found to be a significant predictor of compliance behaviour in this study (Greenstein & Siegal, 1998). Schweizer et al. (1990) also concluded, in their study, that non-compliant behaviour was usually not predictable and was often without an identifiable reason.

A meta-review of renal transplant medication compliance studies was carried out in an attempt to document the often confusing and contradictory findings with respect to compliance research among renal transplant recipients (Greenstein & Siegal, 1998). The authors reported that numerous inconsistencies in methodologies resulted in differences in the findings. As well, they suggested that it is unlikely a single study could adequately examine the entire number of variables previously explored in order to generate a reasonable hypothesis to predict compliance (Greenstein & Siegal, 1998).

Despite these reported limitations, much of the transplant literature reviewed continues to suggest that data from these studies should be used for developing educational behavioural approaches to address non-compliance (Greenstein & Siegal, 1998). It appears that the underlying assumption among this literature is that compliance behaviour can be isolated, quantitatively measured and largely influenced by individual motivation. Interestingly, it is evident from this review that cultural and socio-environmental variables, as well as individual characteristics, do appear to influence

compliance in often unpredictable and complex ways (Prieto, Miller, Gayowski & Marino, 1997).

This extensive quantitative literature, while providing breadth of knowledge, was overall somewhat limited in describing the detailed insight, explanatory power and accounting for variations in context. The concurrent use of naturalistic inquiry could greatly augment these limitations (Achterberg, 1988). For example, there was substantial consistency in the findings of several quantitative studies with respect to younger age and noncompliance with prescribed medical regimens. Schweizer et al. (1990) found that respondents less than 20 years of age were more likely to be noncompliant than those 40 years of age or older. This finding was also consistent with other studies (Siegal & Greenstein, 1997; Sketris et al., 1994).

While this consistency in the findings is important for addressing noncompliance among transplant recipients, none of these studies attempted to explore, describe or explain the incidence of adolescence, youth or young adults (under 20 years of age) as a determinant of noncompliance. However, a qualitative study was located that described the experiences of adolescents between 15 and 18 years of age and living with a renal transplant specifically in regard to medical compliance issues. Although dietary modifications were not addressed, the findings did reveal an over-arching theme of “weighing risks and taking chances”. The significance of this theme was illuminated in the detailed descriptions of study participants, whereby they spoke of multiple physical, cultural and socio-environmental determinants that influenced compliance (or not) with prescribed medical regimens (Harwood & Johnson, 1999).

The value of this study demonstrates the need to utilize naturalistic inquiry as a means to incorporate depth into existing findings with respect to determinants of noncompliance. As well, the need to explore beyond “individual characteristics or behaviour” that is often an implicit assumption in the quantitative transplant literature.

2.3 Meanings of Compliance

Living with one or more chronic illnesses typically involves resigning oneself to certain prescribed medical, physical and/or dietary regimens to control or prevent exacerbation of symptoms (Roberson, 1992; Glanz, 1980). The term “compliance” is associated with desired health behaviours that can bring about alleviation and/or improvement in chronic health conditions (Glanz, 1980). The term “compliance” however, can have multiple meanings in multiple contexts and therefore requires some clarification.

Compliance has been described by Haynes, Taylor & Sackett (as cited in Roberson, 1992) as an allopathic term and has been defined as ‘the extent to which a person’s behaviour (in terms of taking medication, following diets, or executing life style changes) coincides with medical or health advice’. In this context Roberson (1992) adds, the underlying assumption is that medical advice is the “best” advice and that the patient, being a rational human being, will follow this advice precisely as prescribed.

Further to this assumption, there has been some criticism of health professions’ discourse because compliance is thought to imply an inherent dominance over patients/clients by health care practitioners (Glanz, 1980). To alleviate this, some attempt has been made to replace the term with “adherence” or “concordance” suggesting that these terms imply greater participation and/or control on the part of patients/clients in

their health care (Glanz, 1980). However, there has not yet been a discourse-wide consensus that the term compliance implies health provider's "power-over" clients/patients, nor a need to change the term. In fact, most health discourse continues to use the term compliance, or use terms such as compliance, adherence and concordance interchangeably (Glanz, 1980).

Roberson (1992) explored compliance from the patient's perception of their ability to comply with health regimens prescribed to treat chronic health conditions. The findings suggested that practical realities such as socioeconomic issues often prevented compliance with a prescribed regimen. Social concerns such as the desire to eat and drink as others do often influence food choice. Fear or dislike of dependency on the prescribed regimen led to non-compliant behaviours, as did the belief that God would guide and protect these individuals, regardless of the choices made. Roberson (1992) also found that participants became disillusioned with medical advice after compliance with prescribed regimens failed to bring about improved health and conversely, when non-compliance with medical regimens occasionally resulted in improved health. Overall, these findings were consistent with similar literature focusing on patient's perceptions of compliance (Hayes-Bautista, 1976; Stimson, 1974; Chubon, 1989; Chubon, 1988).

In the same study, Roberson (1992) found an overriding theme of "self-management" of chronic health conditions. Participants had their own standard practices for treating these conditions and were influenced by a multitude of factors previously discussed. Ethnicity and/or cultural background did not play a major role in the overriding theme of "self management". This was also consistent with the findings in other literature (Conrad, 1985; Hayes-Bautista, 1976). As well, socioeconomic

background did not appear to influence self-management of chronic health conditions (Roberson, 1992). However, the strategies individuals used to self-manage their health condition(s) would be influenced by cultural/ethnic background and socioeconomic status (Roberson, 1992). The significance of this “self management” theme implies that ultimately patients will decide on what health practices they choose to adopt in managing their chronic health conditions (Roberson, 1992).

Noncompliance behaviour is complex, multi-dimensional and prevalent among those living with chronic illness. For the patient living with chronic illness, the prescribed medical treatment regimen is but one aspect of a possibly complex daily life. Roberson (1992) concluded by stating that without considering the meaning of compliance held by patients/clients, success in addressing this issue will be difficult. Roberson (1992) also suggested that further in-depth study is required to explore what is involved in living with a chronic health condition, what factors influence an individual’s choice of treatment, and health practitioners’ views of and responses to the issue of compliance/noncompliance for the management of chronic health conditions.

Despite these observations and suggestions, much of the transplant and nutrition literature continues to focus on uni-dimensional and individual behaviour theories to predict and explain compliance (Glanz, 1980; Roberson, 1992).

2.4 Behavioural Approaches to Dietary Compliance

Many of the chronic health conditions associated with renal transplant require changes in eating behaviour and food choice. Further, there is compelling evidence that demonstrates changes in dietary behaviour, associated with many of these chronic health conditions, can impact positively on health outcomes (Glanz & Eriksen, 1993). As a

result, health practitioners and/or nutrition educators have searched for effective strategies to meet this challenge (Glanz & Eriksen, 1993).

In order to better understand what factors influence eating behaviours and food choice, health/nutrition practitioners have historically relied on a number of theories to inform client/patient education and interventions. Theories are valuable for generating understanding and explanation of a certain phenomenon. An excellent theory is judged on the basis of its functionality, parsimony, completeness, simplicity and depth (Achterberg & Clark, 1992). Theory-driven health education has long been regarded as essential in planning patient/client interventions. Many of the theories thought to be useful particularly to increase understanding of eating behaviours, are borrowed from the fields of psychology and others (Achterberg, Novak & Gillespie, 1985). Numerous theories have been cited throughout the health, transplant and nutrition education literature both to explain compliance, and health and eating behaviours. A review of published nutrition education literature found that 71 % use some guiding theory. However, there is no positive correlation between the use of theory for program development and the effectiveness of nutrition education practice (Smith & Lopez, 1991).

There is also speculation that theories derived from the field of psychology may fail to explain and/or predict the complexities of and the multiple influences on eating behaviour (Olsen & Gillespie, 1981). For example, nutrition education strategies frequently incorporate theories that focus on information dissemination. The underlying assumption of these theories is that through the acquisition of knowledge, there will be changes in attitudes and behaviour. However, while knowledge is usually necessary, it is not sufficient to bring about compliance with dietary changes (Glanz, 1980). There have

been weak correlations between nutrition knowledge and/or attitudes and dietary behaviour (Glanz, 1980).

There is however a growing recognition, among health and nutrition practitioners, that dietary behaviour is largely generated by, and maintained through the influence of peers, family, economics and the entire social context (Achterberg & Clark, 1992; Travers, 1997). Food choices and dietary behaviours are often habitual and have developed over many years. Changes in food choice and eating behaviours often require extensive collaboration with significant others and take place over long periods of time (Achterberg & Clark, 1992). Further, the health benefits of changing eating behaviours are likely not immediate, may be abstract, or simply not worth the personal effort to change (Achterberg & Clark, 1992).

The individual lifestyle approach, to health education in general, has had limited success in bringing about improved health outcomes (McLeroy, Bibeau, Steckler, & Glanz, 1988). In response to this, there has been some movement among many health promoting efforts, to explore concepts that incorporate both a sociological and ecological analysis of disease and health (Labonte, 1993), including diet-related aspects (Travers, 1997).

2.5 Alternative Conceptualizations of Health

With the release of two documents, *Achieving Health for All* (Epp, 1986), and the *Ottawa Charter for Health Promotion* (WHO, 1986), many non-biological determinants of health were identified. These determinants are referred to collectively as health risk conditions and include housing, employment, social status, income, environmental factors, social justice and equity. These determinants are considered

equally important in understanding and explaining health and disease. They do not exist in isolation of one another but rather form complex interrelationships and must be addressed from a society (population) wide perspective (Health Canada, 1999).

For individuals living with chronic health conditions, eating behaviours can be greatly influenced by these health determinants in complex and interrelated ways. For example, in an unpublished qualitative study, cardiac patients were interviewed with respect to personal and social barriers influencing dietary compliance of a low fat diet. It was found that the overall influencing theme was culture. Culture was described as “predominantly influencing how and what we eat by determining how we are introduced and socialized to food” (Wright, 1995, p.98). This study found culture to be pervasive throughout a number of themes and present in many themes at the same time. In addition, the participants in this study described, in their narratives, the many social barriers toward maintaining a low fat diet. The conclusions stressed the need for health practitioners to recognize both perceived personal and social barriers when developing education interventions. That is, the ability to comply with dietary recommendations (low fat diets) may not be within the participant’s control when barriers such as affordability of food, availability of food, social environment and food preparation time prohibits long term diet maintenance (Wright, 1995).

In a similar study, Janas, Bisogni & Campbell, (1993) explored the experiences of adults attempting to change their dietary behaviour to control hypercholesterolemia. They found that factors such as money, time, personal and family food preferences were all external influences that would ultimately determine eating behaviour and the strategies used to change eating behaviours.

Alternative conceptualizations of health, such as the socio-environmental approach, have also made visible that most lifestyle improvements tend to occur among those who are financially and academically privileged (Labonte, 1993). Individuals living with multiple socio-environmental risk conditions may have no choice except to place a lower priority on prescribed lifestyle changes such as changes in eating behaviour. For example, Travers (1997) explored the experiences of food acquisition among impoverished women. She found that women who had received “healthy eating” nutrition education were unable to use this knowledge as it did not change the reality of their poverty and the consequent inability to afford “healthy food choices”. Further, Travers (1997) found that nutrition messages such as this had a tendency to foster perceptions of inadequacy and guilt among the participants, for failing to comply with the instruction provided by health care practitioners.

2.6 Summary

This review of the literature has made visible the need for additional inquiry with respect to broadening the understanding of “dietary compliance” and its determinants, and the need to explicate the social and cultural context of renal transplant recipients living with chronic health conditions. The proposed study therefore will be guided by the following research questions. These include:

1. How do transplant recipients experience food choice within their social and cultural environment?
2. What are the meanings associated with food and eating, held by renal transplant recipients, in their social and cultural context, and in the context of their diet-modified medical condition?

3. In what ways do the social, cultural and environmental determinants of eating behaviour work together to influence the experiences and meaning of food choice for transplant recipients?

CHAPTER III: METHODOLOGY

3.1 Rationale for a Naturalistic Approach

This research is concerned with uncovering the experiences and meanings of eating for a particular population (renal transplant recipients) in their socially constructed world. A blend of theoretical perspectives assisted in guiding this inquiry.

Naturalistic inquiry is based on the assumption that reality is shaped and constructed by each individual. As a result, there will be multiple realities because of the variation among individuals. All inquiries therefore will be value-bound and context specific. No objectivity is possible and generalizations can only be made within specific time and context-bound frameworks (Achterberg, 1988). Each individual with a renal transplant will have their own set of beliefs and values about their health and food choices. These will be different from other renal transplant recipients because they are context-bound.

Ethnography is concerned with the culture of a group of people. During long-term interaction with a group of individuals in the context of their everyday lives, one can gain insight into their underlying beliefs, explanations, and meanings that this group hold for certain events in their lives (Spradley, 1979; Patton, 1990). Individuals who live with a renal transplant, their beliefs about their health and health practices, the food choices they make, and the social environment within which they live out their lives, epitomize the essence of naturalistic and ethnographic perspectives and therefore both had application in data collection methods and analysis of this research.

3.2 Sampling Technique

Patton (1990) describes purposeful sampling as a sample selection process whereby one can learn a great deal about the issues of central importance to the research initiative by purposefully selecting information-rich cases.

There are multiple strategies for purposefully selecting participants. Criterion sampling was selected for this study (Patton, 1990). This strategy was selected to explore all cases that met the criterion of “noncompliance” as subjectively defined by health professionals. The purpose is to generate understanding of the lived experiences of those individuals labeled as being “noncompliant” with their diet/health prescriptions.

3.2.1 Criteria for Selection

Participant selection included transplant recipients who have had a renal transplant for at least one to three years. Their renal function at the time of recruitment was greater than 50% with no persistent or major graft rejection. There was no attempt to verify whether a cadaveric or living related donor organ was transplanted as the source of the transplanted organ is not a significant determinant of compliance with the prescribed medical regimen (Kiley et al., 1993). The participants all lived within a two-hour radius of the city of Edmonton. There was an attempt to include multiple cultural contexts in the sample (i.e. ethnicity, occupation/education, socioeconomic status, age, and gender), so that a wide range of experiences could be explored.

In addition, the following “patient characteristics” were used during the patient selection process. These perceived characteristics were identified as being important to explore and understand with respect to addressing overall medical regimen compliance. It

should also be noted that Hathaway et al. (1999) described similar perceived behavioural characteristics, by renal transplant teams, associated with noncompliance.

These characteristics include:

- A difficulty and/or inability to rehabilitate after a reasonable period of recovery time.
- Failure to return for clinic follow-up appointments at scheduled times
- Development of immunosuppressive-related chronic health conditions (such as increasing body weight, hypertension, hypercholesterolemia).
- The inability or unwillingness to modify diet as prescribed by the transplant dietitian.

Finally, purposeful sampling dictates that potential participants will be selected based on their interest in contributing to the theoretical needs of the research and their ability to openly communicate and share their life experiences (Morse & Field, 1995). Therefore, respondents were also recruited based on their willingness to divulge their “own view” of interacting with, and receiving dietary interventions and/or education, from health professionals in the renal transplant program.

Exclusion criteria included: people under the age of 18, multiple transplanted organs, transplant rejection episodes or graft failure, inability to communicate fluently in English, other communication barriers, or severe medical, personality or social situations deemed inappropriate to participate such as concurrent severe psychiatric disorders, unrelated medical complications and/or illness.

3.2.2 Sample Size

Sample size in purposeful sampling is not predetermined. The validity, insights and meaningfulness of qualitative data are associated with the information-rich cases and the observational and analytical skills of the researcher as opposed to the sample size

(Patton, 1990). Furthermore, sample size is determined adequate when no new or relevant data is emerging with respect to categories, category development is dense, and linkages between categories are well established and valid. This process is referred to as “saturation” and is critical for developing conceptually adequate interpretation (Strauss & Corbin, 1990). However, sample size was initially predicted to be between seven and ten participants based on comparable research of Janas et al. (1988), Wright (1995), and Harwood & Johnson. (1999). Sample size prediction was necessary for developing the research proposal (Marshall & Rossman, 1990).

3.2.3 Gaining Entry

The primary data sources for this research was a purposeful sample of patients from the University of Alberta Hospital Renal Transplant Program. The active transplant population of more than 700 cases is multicultural, has significant socioeconomic variability and transplant recipients range in age from children to seniors. Spouses, friends, family or significant others who may be closely associated with the day-to-day lives of respondents and were present during the interview were considered a potential source of additional data. However, in all cases, respondents met with the interviewer alone or secondary sources did not consent to participating.

3.2.4 Ethical Considerations

All ethical concerns were addressed and resolved through the University of Alberta Health Research Ethics Board (HREB) B: Health Research process. Ethics approval to proceed with the research was granted on October 29, 2001. Although the research proposal met all requirements of ethics approval, there were some issues that required reflection.

There are multiple roles of the researcher and not all of these roles were explicated to respondents. The researcher is both a (non-practicing) registered dietitian and a graduate student. It was decided that respondents would not learn of this dual role as it may limit the quality and/or bias the data. Therefore, they would only be informed of the “student role” of the researcher. While the role as dietitian was not withheld if respondents asked, there was a concern that this knowledge may lead respondents to providing preconceived answers that they believe a dietitian would “want” to hear rather than providing spontaneous responses necessary for the integrity of this research. In addition, the status as a student may have helped to eliminate any power differentials that could alter the dynamic of the interview, data, and the level of involvement and depth of responses provided.

As a criterion for participation, respondents would be asked to meet with the researcher in their homes and they would be asked to provide a tour of their eating environment and foods currently available in their homes. These requests were communicated verbally prior to requesting consent to meet with respondents. In addition, these requests were also stipulated in the written consent so respondents were free to refuse consent at any time.

It was anticipated that there might be highly charged emotions and/or attitudes with respect to health care practitioners communicated to the researcher during interviews. The researcher ensured diplomacy and respect for both health care practitioners in the transplant program and respondents at all times. In addition, a contact name/resource was provided during consent procedures, should the respondent feel the need to further discuss and/or seek counselling regarding these expressions.

The research agenda must be in keeping with the mission and vision statement of the organization to prevent conflict of interest. The research initiative was presented to the multidisciplinary team of the Renal Transplant Program and a letter of support was requested and received from the program director.

3.2.5 Respondent Recruitment

The following procedure was established to recruit respondents for the study:

1. The researcher presented the research objectives to the transplant team at a designated transplant rounds.
2. Following ethics approval, the renal transplant dietitian (in association with other transplant team members) facilitated the process of gathering names of potential respondents that fit criteria for the study.
3. The renal transplant dietitian or another member of the renal transplant team approached potential participants to discuss the study. This occurred during the patient's clinic visit or by telephone. Potential respondents were provided with a brief explanation of the study and asked if they would consent to having the researcher contact them for participation in the study. The researcher provided the renal transplant dietitian with a "potential interest" form to record names and telephone numbers. This functioned as consent to be contacted by the researcher for further recruitment in the study.
4. The renal transplant dietitian distributed and collected these forms, as names were collected, following transplant clinics and forwarded them to the researcher.
5. The researcher then started the process of recruiting potential respondents, obtained from the list, by telephone. At this time the research protocol was reviewed including, the initial two-hour approximate time requirement, the possibility of a follow-

up interview on another date, as well as consent for entering the respondent's place of residence.

6. A verbal consent was requested to meet. At that time, a mutually agreed upon date and time, as well as the respondent's place of residence and directions was obtained.

7. At the first (interview) meeting, written consent was obtained prior to initiation of data collection. At this time, consent to observe the eating area and food in the home was also requested.

8. A copy of the information letter and written consent was provided to the respondent. No secondary sources were available and/or consented to participate. The information letter and consent form are located in Appendix A.

3.3 Data Collection

Multiple strategies were employed for collecting data. The strategies included direct observation and in-depth interviewing using ethnographic techniques (Marshall & Rossman, 1990; Achterberg, 1988). Multiple data collection strategies are recommended to strengthen the study design. That is, the strength of one method can offset the weakness of others (Marshall & Rossman, 1990). In this study, direct observation provided data that described the respondent's natural setting and the non-verbal behaviours that occur within this natural setting (Achterberg, 1988).

While ethnographic observations provide rich understandings of the meanings and context of individuals' lives, they are more covert and best employed over long periods of time (Achterberg, 1988). During this study, observation methods were extremely time limited for exploring the "cultural" environment of respondents. Therefore, in-depth interviews, guided by ethnographic principles, served as the primary method of data

collection. The observation methods, albeit limited, did serve to provide a detailed description of the naturalistic setting. They also resulted in a better understanding of context, experiences of respondents not made explicit in the interview, and clarification of issues. Finally, direct observation of the natural setting facilitated reflection and introspection of the researcher's thoughts to better understand and interpret respondents' experiences (Patton, 1990).

3.3.1 Direct Observation

Observation was carried out at the same time as interviews and this occurred in the respondents' home. Observation was largely restricted to the area where the interview was taking place. However, at times the respondent would allow the researcher to observe locations that would otherwise be "hidden" such as other rooms, cupboards, refrigerators and drawers. The researcher noted as many details as possible during and following the interview. These details were recorded in the field notes. The purpose for this direct observation was an attempt to gain additional insight into such issues as diet, eating, food, ethnicity, family, culture and socioeconomic status if possible. It would also assist in verifying interview data. Cookbooks, health books, medical books, any significant pictures, photographs, visible food products, notes/diet sheets attached to wall/fridge, grocery receipts, smells of food or other smells etc. were recorded if observed. In addition, the respondent's body language during the interview process was also noted as this can provide additional data with powerful meaning (Patton, 1990).

3.3.2 In-depth Interviews.

In depth, face-to-face interviews generate a large amount of data in a relatively short period of time. Further, they can permit clarification and allow for collecting a wide

variety of perspectives among various respondents (Marshall & Rossman, 1990).

Interviews can also expand upon and augment observation methods in qualitative inquiry (Patton, 1990). Interviews however can have limitations and weaknesses. For example, if the interviewer does not possess certain skills, expertise and experience it is likely that the quality of the data will be poor. Respondents must also be willing to co-operate and be truthful or data will be compromised (Marshall & Rossman, 1990).

All initial in-depth interviews followed a similar process. Upon entering the respondents' home, introductions and some casual conversation was carried out to put them at ease. The consent procedures followed whereby the researcher read (aloud) the information sheet and the consent form. The respondent was given an opportunity to ask questions, read the consent form again if necessary, and asked to sign two copies of the consent form. The respondents were then given a brief explanation of the nature of qualitative inquiry, the purpose of and conversational nature of the interview, and reminded of the valuable information they would provide to health care providers through this research.

Throughout the interviews, respondents' body language suggested they were relaxed and confident and did not appear to be apprehensive or nervous. Respondents were continuously encouraged to give their perspectives and supported if they chose to discuss in-depth, those areas of interest to them or most comfortable discussing. Patton (1990) suggests that in-depth interviews allow the natural and personal structure of responses to evolve. This will ensure that respondent's perspectives on the social phenomenon interest are obtained.

Although cassette tape recorders were used for recording interviews, and can introduce an extraneous element to the social interaction, respondents did not appear to notice the recorder once the interview was underway. In fact, all individuals were very forthcoming and confident in their responses so these effects were likely minimal.

3.3.2.1 Interview Style/format

A semi-structured interview format was selected for the initial interview in this study. This interviewing strategy involves having a predetermined set of topics that must be addressed during the interview. Wording and sequencing of questions and probes can be modified to best facilitate responses within the unique circumstances of each interview process (Achterberg, 1988). Furthermore, semi-structured interviews have been found to provide the greatest quantity of information, most correct information, and are relatively time-efficient compared to other interview methods (Achterberg, 1988).

Semi-structured interviews were approximately 1 hour in length and guided by ethnographic principles of Spradley (1979) Interview guides are located in Appendix B. The purpose of using ethnographic principles for questionnaire development was to generate cultural data (Marshall & Rossman, 1990). Spradley (1979) suggests that analyzing cultural data brings forward an understanding of the cultural meaning to the phenomenon under study. The value of the ethnographic approach is its focus on culture through the expressions and perspectives of the participants themselves (Marshall & Rossman, 1990). The weakness in this method however is due largely to the limited skill and experience of the researcher, and the possibility that participants will not answer truthfully, resulting in a fundamental flaw in analysis (Marshall & Rossman, 1990).

A second interview was conducted with six participants, via telephone, using respondents' narratives from the initial interview to describe emerging themes, categories, subcategories and the conceptual framework and process. As well, any clarification or elaboration of data from the initial interview was also addressed at this time with each respondent. This was necessary to further develop themes, verify analysis of the first interview responses, and to allow for further clarification and a more accurate description of the respondent's socio-cultural environment.

Thematic saturation appeared to be reached at six interviews. Two remaining interviews were utilized as a means of discriminate sampling, that is, to ensure the major theme, categories, sub-categories were well developed and to verify the conceptual framework and its process (Strauss & Corbin, 1990). These two interviews were carried out following the second round of interviews. Both the second round of interviews and the process of discriminate sampling served as multiple data collection points and provided additional validity checks or "triangulation", to ensure a more accurate depiction of the phenomenon under investigation (Molzahn & Shields, 1997).

3.3.3 Organizing and Recording the Data

Data gathering started by arranging one interview at a time. Various pertinent demographic information including medical/renal history, age, gender, education/occupation, income, number of people living in household, and ethnicity were obtained from respondents, toward the end of the initial interview. A 3-digit code number for each respondent was assigned to ensure confidentiality and was the only written identification on the file folder (on the tab). A two-letter pseudo initial was also assigned for documentation purposes. All fieldnotes, correspondence, information, taped

interviews and subsequent transcriptions were kept in these file folders. A tally of respondents' names and their corresponding code numbers was kept for reference purposes, in a secure and different location than that of the file folders. There was no identification of respondents anywhere except on this tally sheet.

Three audio-taped interviews were transcribed by the researcher and all remaining interviews were transcribed by a clerical assistant due to the researcher's time constraints. However, the researcher carefully listened to and compared all tapes and transcriptions, upon completion of the transcription, to ensure accurate representation. The tapes were then kept in file folders along with other data collected. Following completion of the research project, the tally sheet, tapes and all file folder contents will be held in a secure location for the five-year required time period mandated by the University of Alberta.

3.4 Data Analysis

Transcribed interviews and field notes were coded thematically by searching for and identifying common threads that extended throughout each interview and set of interviews (Morse & Field, 1995). Thematic coding categorizes naturally occurring commonalties and differences in the data using inductive analysis to name and interpret emerging themes (Marshall & Rossman, 1995). Once this initial coding procedure was completed, the constant comparative method of data analysis (Strauss & Corbin, 1990) was performed to compare new data to identified themes using logical analysis to ensure logical "fit". The themes were then developed and confirmed with study respondents and modified as necessary as well as regular debriefing with members of the research team to enhance trustworthiness of the data analysis.

The following process details the steps and rationale used in the analysis:

1. Following completion of six interviews of eight potential recruited respondents, ideas for analysis were starting to emerge very rapidly. It was decided that the need to step away from data collection to pursue these emerging ideas was critical to the analysis process. Furthermore, the raw data was becoming excessive to manage and required some organization at the very least.

2. Each interview was initially viewed as an individual case for in-depth study. All tape-recorded transcriptions and field notes were organized, cleaned up, and numbered by participant code, interview number and sequence in transcript. These were kept in an electronic folder labelled "Transcriptions Interview 1" on a word processor. (Hard copies of transcribed data, emerging themes, tapes, notes and floppy discs were kept in the participant's file folder for safe-keeping.)

3. All transcriptions were filed electronically according to each individual's specific code. A hard copy of the transcription was coded first to generate ideas (concepts). These were then collapsed into categories and sub-categories and entered electronically into a "Themes" folder created on a word processor. Each "category" and/or "sub-category" was labelled on an electronic file within the "Themes" folder and electronic "copying and pasting" of modified transcribed data was entered as appropriate.

4. Once the major theme, categories and sub-categories were largely determined using/encompassing the narratives of the participants themselves, any further questions and/or need for data verification was noted (in the field notes) for follow-up with respondents during the second round of interviews.

5. After comparing and contrasting the six interviews, the emerging main theme, its subsequent categories and sub-categories were then organized into multiple draft

conceptual frameworks. There was an ongoing process of re-reading interview transcripts to check for alternative concepts and/or cases that failed to fit. This was necessary to strengthen the validity of the emerging and final framework. The two outstanding interviews would function to further develop these concepts and bring about theoretical saturation.

6. The six respondents were contacted, by telephone, for a second semi-structured interview (this interview was not audio-taped). Each respondent was provided with a brief explanation of the emerging framework and provided with quotes from his/her initial interview to explain how the final theme, categories and sub-categories emerged. Respondents were then asked to clarify any pre-determined ambiguities found in the initial data collection and to verify whether or not this conceptualization was a true representation of their experiences and if not, to explain what they perceived to be true.

7. Following the second set of interviews, re-reading/re-categorizing individual cases and cross-case categorizing again was carried out. New features and clarification resulted in modifications as required.

8. Face-to-face interviews were carried out with the remaining two respondents. Transcription and analysis of the final two interviews further developed and verified the main theme, its categories and sub-categories. In addition, the first draft of the analysis was submitted to a member of the thesis committee for review and discussion. This “peer debriefing”(Merriam, 1988) increased the reliability and validity of the data analysis.

9. A final draft of the framework was composed and one final review of the transcripts and notes from the second round of interviews was checked against the draft to elicit any information that could influence the components of the framework.

10. All respondents received a written summary of the data interpretation along with a letter of gratitude for their participation. This would ensure that respondents had a final opportunity to review the interpretation of data and respond should they deem necessary. The summary of data interpretation and letter of gratitude is located in Appendix C.

This research occurred at two levels of analysis. The first level of analysis was at the individual level, where meanings and experiences of eating among transplant recipients in their cultural context were revealed. The second level of analysis was the understanding and explanation of the basic social process of the phenomenon, and the development of a model of human behaviour grounded in the data (Morse & Field, 1995). This analysis occurred by comparing and contrasting individual themes in the data and discovering the relationship of these themes to one another. Following this process an interpretation and/or explanation of a social phenomenon is generated, namely, the determinants of eating and diet among this group of renal transplant recipients within their social and cultural environment (Strauss & Corbin, 1990).

3.5 Reflections of Methods

The goal of a credible study is to ensure that the inquiry process was carried out in such a way that it accurately identifies and describes the subject (Marshall & Rossman, 1989). This study was guided by the assumption that the experience of eating and food choice can only be generated by value-bound and context-bound beliefs about food choice and eating behaviour of each transplant recipient. Therefore, the study is credible because it reflects the multiple realities of food choice and eating behaviour of the respondents themselves.

Validity is defined as whether or not a study is measuring what it is supposed to measure (Marshall & Rossman, 1989). Naturalistic inquiry is valid by the very fact that it explores and describes individuals' experiences, provides in-depth description of the complexities, variables and interactions that are completely embedded in and derived from the data (Marshall & Rossman, 1989). Furthermore, several other validity checks were employed in this inquiry.

All interviews were tape-recorded and transcribed verbatim to ensure an accurate depiction of the interview process. All interviews were carried out with the (same interviewer) researcher enhancing consistency of the interview process among all respondents. Although, the interview questions were not pilot-tested, they were reviewed and modified by experienced members of the research committee. The researcher informally tested the questions for any existing ambiguities or problems of coherence with friends and family.

Multiple data collection strategies are recommended to strengthen the study design. That is, the strength of one method can offset the weakness of others (Marshall & Rossman, 1990). The use of direct observation and in-depth interviewing were used in this study enabling a more accurate depiction of the phenomenon under investigation (Molzahn & Shields, 1997). Any data collection or analysis process that was modified was documented and a rationale provided.

As themes were developed, negative instances were explicated and accounted for in the description. All study respondents were contacted for a second interview to verify the findings against their perceptions. Any differences were noted and study results were

again modified to reflect respondents' experiences as necessary. Regular debriefing with members of the research team also enhanced the trustworthiness of the data analysis.

The ability to make generalizations about qualitative study results or transfer results to other settings is not usually a recommended practice. Data collection and analysis in qualitative studies are guided by specific theoretical parameters (Marshall & Rossman, 1989). Furthermore, despite purposefully selecting a range of demographic characteristics among this study's population, the group was fairly homogenous given their ongoing connection to, and experiences with the renal transplant program, and somewhat similar levels of acculturation, i.e. living within the city of Edmonton. Therefore, in order to accommodate generalizations to be made and/or transferring the results of this study to other settings, the researcher ensured that all theoretical assumptions were explicated and the associated methods employed were adequately detailed. This will enable others to assess the degree to which findings are transferable or can be generalized (Marshall & Rossman, 1989).

Data quality is entirely dependent upon the expertise and experience of the researcher (Marshall & Rossman, 1989). This was the researcher's first attempt to carry out a qualitative study independently. However, ongoing discussions with research committee members to clarify and/or resolve ambiguities and assist in the research decision-making process helped to minimize these effects. Furthermore, many years of experience providing patient care as a clinical dietitian, and working within different areas of Nephrology, greatly facilitated the clinical background to this study and the social interaction with respondents.

CHAPTER IV: RESULTS AND DISCUSSION

4.1 Introduction

All eight potential transplant recipients initially identified by the transplant team for recruitment consented to participate in the study. The sample of respondents for this study was comprised of four males and four females ranging in age from 31 to 70 years old. Seven respondents lived in households with at least one other adult; one lived alone; three lived with a spouse, one lived with two elderly parents, and two respondents lived with a spouse and one or more children. Two respondents were employed outside the home; all others were either retired, on long-term disability, or worked inside the home. Family income for the respondents ranged from \$21,000 to >\$50,000 per year. Education level of respondents ranged from high school to university. All respondents stated that they were responsible for, or had an equal role in, food procurement and/or meal preparation within their household. Medical history and associated treatment regimens were limited to those respondents chose to share from his or her perspective during the interview process. Six respondents stated that they had diabetes, seven respondents were visibly overweight, and three respondents had had an acute episode of renal failure that resulted in transplant, with no associated chronic illness prior to or following the transplant.

There was some first generation ethnic representation within the sample. Two individuals were of Chinese origin and one individual migrated from Trinidad. While there is a considerable population of Aboriginal people within the transplant program, none were recruited for this study. This decision was made based on respect for, and sensitivity surrounding, the Aboriginal population. That is, Aboriginal people are a

unique group that must be given additional ethical consideration, adequate time and sensitivity with respect to developing trust in research relationships. Given the limited time lines of this study and special considerations necessary, the Aboriginal population would best be approached as a distinct or separate study to meet ethical requirements, respect, and do justice to their particular circumstances.

Although the original intent of the research was to focus on food choice in the context of renal transplant exclusively, it quickly became evident that respondents expressed their experiences with food choice and eating in the context of any existing and/or previous health conditions including the transplant. In fact, the perceived presence or absence of health conditions became integral to the emerging conceptual framework with respect the phenomenon of food choice. In addition, when respondents described their experiences with prescribed health regimens, they often discussed issues with respect to exercise and medication as well as diet, therefore it was important to incorporate these into the analysis where appropriate.

4.1.1 Results

The data analysis was guided by and addressed the following research questions:

- 1. How do transplant recipients experience food choice within their social and cultural environment?**
- 2. What are the meanings associated with food and eating, held by renal transplant recipients, in their social and cultural context, and in the context of their diet-modified medical condition?**

3. In what ways do the social, cultural and environmental determinants of eating behaviour work together to influence the experiences and meaning of food choice for transplant recipients?

In order to address the initial research question, the description of food choice and eating experiences among study respondents was conceptualized and organized into five salient categories and their sub-categories. These categories and sub-categories represented specific “conditions” and their particular “influences” on food choice and eating behaviour of respondents respectively. Furthermore this organization of respondents’ food and eating experiences built the foundation for addressing the remaining research questions.

This overall theme of “keeping a balance” addresses the second research question whereby the meanings of food choice and eating behaviour among respondents differs in their social and cultural context, and in the context of their prevailing health conditions. That is, the meaning of food choice and eating behaviour was different as respondents’ discussed their health needs and their need for quality and/or normalcy of life. Respondents for the most part did not perceive food choices necessary for their health needs, as congruent with food choices they perceived as giving them pleasure, improving their quality of life and living normally. Therefore, respondents utilized food and eating strategies that attempted to “balance” both their health needs and quality of life/normalcy.

The final research question was addressed by developing a conceptual framework. This framework reflects respondents’ personal beliefs, external conditions (categories), their influences (sub-categories), and the complex inter-relationships among them with respect to food choice and eating behaviour. Furthermore, the framework makes visible

the process of food choice and eating behaviour in a dynamic cycle of change. The main theme and essence of this conceptual framework is most appropriately described as “keeping a balance” and represents the ways in which the social, cultural and environmental determinants of food choice and eating behaviour work together to influence the experiences and meaning of food choice for transplant recipients.

4.2 Food Choice and Eating Experiences among Renal Transplant Recipients

The following section addresses the initial research question by describing the experiences of food choice and eating behaviour among renal transplant recipients. These experiences have been organized into salient categories and subcategories that describe of food choice and eating among study respondents. Figure 1 provides a schematic of these categories and subcategories.

Although the following discussion generalizes these “conditions”(categories) and their corresponding “influences”(sub-categories) among all study respondents, the discussions will also reflect the range and/or dimensions of respondents’ experiences. This is necessary to demonstrate that while these conditions and influences may be common to all respondents, each has a very unique experience to describe.

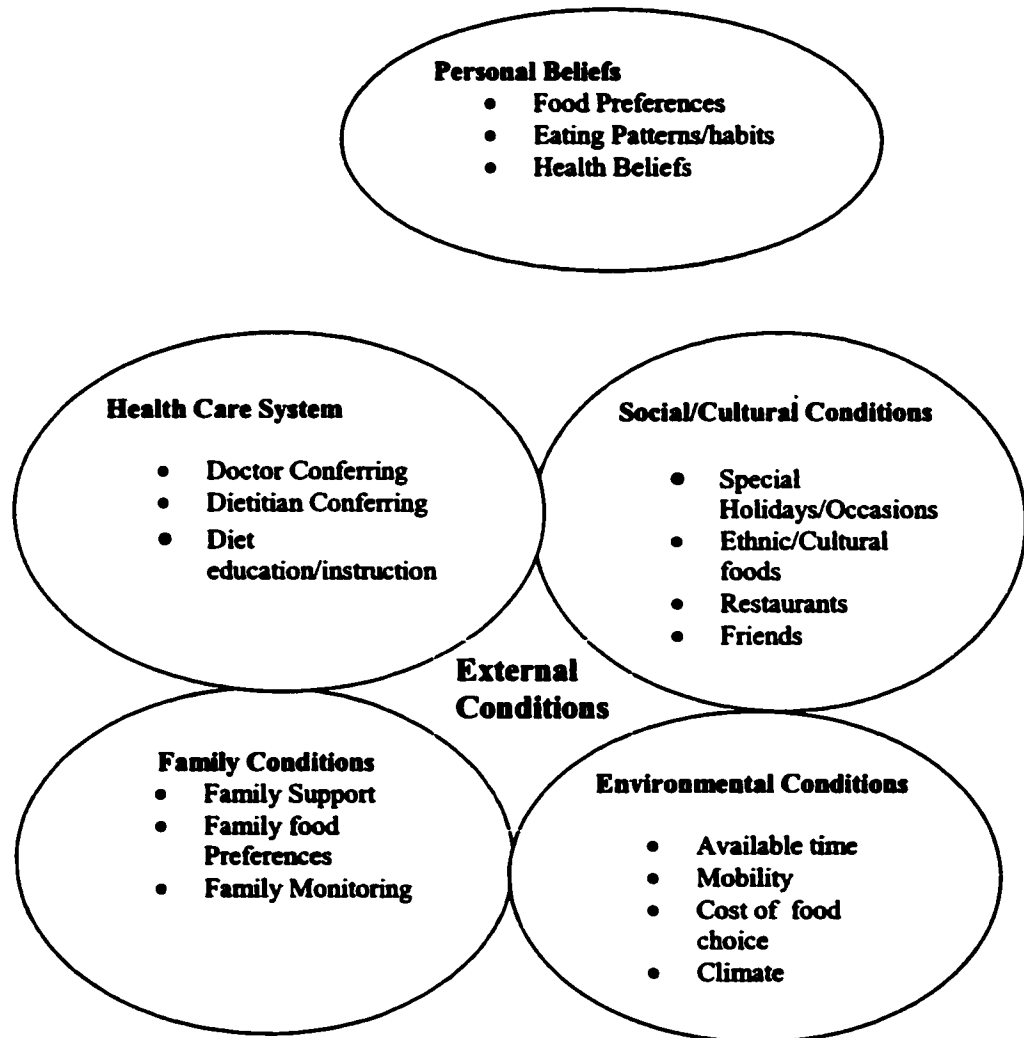


Figure 1 Main Categories (bolded) representing “conditions” and Sub-Categories (non-bolded) representing “influences” describe the experiences of food choice and eating behaviour among study respondents.

4.2.1 Personal Beliefs

“Personal beliefs” was the largest category and was the determinant of food choice strategy assessment by the respondent. This category was also the most complex and difficult to describe as it is continuously in flux, interacting with, and being influenced implicitly by external conditions. The sub-categories within personal beliefs represent those external influences that have been adopted as truths by the respondent at that particular point in time.

4.2.1.1 Personal Food Preference

Personal food preference was identified as having different degrees of influence on food choice strategies among all respondents. Respondents tended to discuss their food choice strategies relative to the compatibility between prescribed diet and/or “healthy” food choices, and their personal food/lifestyle preferences. This variation in the degree of compatibility tended to influence what foods they selected or refused to eat and the duration of using these food choice strategies. The following respondent finds her food preferences are not compatible with her diet prescription and therefore infrequently adheres to her diet: “I’m a very fussy eater...I don’t eat vegetables... I don’t want eggs, you can only eat so much cheese and I don’t eat peanut butter and, you know, who eats beef for breakfast.”(AY, Interview 1). Another respondent discusses a food dislike and her consequent refusal to consume this food despite the recommended health benefits:

When my weight was going pretty low (after the transplant) the dietitian said to combine some milk into my diet for the weight, and the pills I was taking because of our bones. I did it in the hospital but when I came home I stopped. It’s not that

I'm allergic to it or anything I just don't like it and I never did eat it (TP, Interview 1).

Another respondent discusses her attempt to incorporate dietary guidelines with food preferences but ultimately finding little success:

In the beginning I tried that... it was pretty boring...always prepared the same way and I like my sauces and stuff like that, and I'm continuing to eat them whether they want me to or not...I tried the low fat dressings before, I've tried them and they're just horrid to me, like the mayonnaise, or Miracle Whip can't be low fat (KW, Interview 1).

In contrast, respondents who were able to find congruence between food preferences and dietary recommendations could maintain these food choice strategies for longer periods of time. The following respondent tells of her success in satisfying food preferences with dietary guidelines: "I started buying Mrs. Dash and I got to enjoy it, so I use that opposed to salt. And I've never been a big salt person" (KW, Interview 1). This was similar to another respondent's strategy: "...and like some of the vegetable choices, I can have tomato juice which is a vegetable. I like tomato juice" (AY, Interview 1).

Another respondent discusses her dislike for a food that incidentally is not a good choice for her health condition: "Like if it's fried, or deep fried, ...I always, I never eat the skin. You know if there's the least bit of fat on any kind of meat, I cannot eat fat, I cut it right off...so it doesn't bother me (if I must avoid it)" (AY, Interview 1).

Other respondents attempted to compromise their food preferences to follow dietary recommendations. One respondent recalls his preference for preparing foods a certain way in the past but due to his increasing need to control his health condition he

has been able to modify food preparation techniques to satisfy both his food preferences and health needs:

There's something that I used to love but we don't do it anymore...we marinate all our meats here and I trim the fat, and then we take them out (pause) we used to fry them but we don't do that no more because the chicken absorbs so much of that oil...tastes nice...but oh boy too fattening...so we do the chicken we just shake it with shake and bake it's way better we fry very little, broil and bake instead" (NJ, Interview 1).

Participants' beliefs about healthy food choice strategies are not necessarily consistent with those of their health care providers exclusively. Perceived food choice strategies are often the result of multiple external influences. One respondent recalls that he likes to drink alcoholic beverages while watching sporting events on television -a social/cultural influence. While his belief that drinking alcoholic beverages is a not good choice for his chronic health condition, he reveals his strategy to make this choice more acceptable for his health:

Well ah I have a few drinks eh...and wish I didn't have to but I do feel for a drink once in a while...when I watch a hockey or football game I pour myself a nice drink of rum or something like that. But I can't drink beer cause it shoots the sugar up eh...rum it doesn't and if I drink wine its dry wine eh (NJ, Interview 1).

Other respondents identified food choices they believed were compatible with their food preferences and health but due to other more powerful external influences, they chose not to consume these foods or consumed them very infrequently. One respondent explains that she enjoys a food she believes is also very health promoting. However

because her children dislike and refuse to consume this food, and the additional time that would be necessary to prepare an alternate meal, the respondent chooses not to consume this food in her home. Family food preferences and time limitations are a more powerful influence on her beliefs and therefore will ultimately determine her food choice strategy implementation:

Liver is good to keep up my iron and I'm the only one in the house that seems to enjoy liver but I never make it...my husband said yeah well if you want to make it fine but then you have to make another meal and its just not, well, we're very busy (KW, Interview 1).

Another respondent discusses the dynamic state of change with respect to his personal food preferences. During a follow-up interview this respondent revealed that he recently stopped consuming certain food products he had previously enjoyed and thought to be health promoting. This change in strategy occurred following the viewing of a television program where it was revealed that high levels of certain harmful chemicals exist in these food products:

Well since I talked to you last I've changed some of the foods I used to eat...I was watching this show on T.V., it turns out these foods have the same ingredients as anti-freeze so I've cut them out completely even if they have good nutritional value I'm not eating them anymore (LM, Interview 2).

This comment reveals two important observations with respect to food choice strategies. First, it reflects the power of external conditions to influence, in this case the media, and how quickly one can change their beliefs and therefore food choice strategies. Further,

personal beliefs about food choice and its relationship to health are not exclusively an influence of the health care system.

Food preferences represent more than food likes and dislikes. They are a complex blend of personal beliefs and associated food choice strategies used in the ongoing effort to control the balance between quality of life/normalcy and health promotion/illness prevention. Food preferences also carry implicit values that reflect the embedded cultural norms and therefore exist in a dynamic state of change and always context bound. Furthermore, by explicating personal food preferences, one can better understand the rationale and consequent food choice strategies employed.

4.2.1.2 Eating Patterns

This sub-category is closely related to food preferences. Respondents described the degree of congruence between their preferred or “normal” eating patterns and “prescribed” meal plans from health care providers and ultimately how this impacted the strategies they executed.

One respondent discusses a life-long eating habit he referred to as “grazing”. He describes grazing as eating small amounts of food throughout the day that he believed was best for his lifestyle, as opposed to designated meals at designated times of the day recommended by health care practitioners. He then described the lack of congruence between his normal eating habits and controlling his medical condition. This led to compromising his “normal life” to control his health resulting in increased tension in the balance between his quality of life/normalcy and his health condition. However, over time he found a strategy, via his physician, to accommodate his former way of eating:

I'm a grazer. I like to graze. Something like cattle. That's been all my life. Its not so much a preference its just that my body seems to be able to go that way. It's just that growing up in a family that, um, where I played, and I played in a band from the age of 14, and it was, you know, late night practices, all night sessions, and ah... lets eat now... so it was very much spontaneous from my early years on...but initially with the insulin, you had one shot in the morning and you knew you had to eat. Right away you had to eat lunch, and then 5:00 rolls in and you are going to be taking another shot...to carry you into the night...ah and so I found that very constraining and very limiting. Then I got in to a doctor that taught me how to reaction shoot and ah, I find that I've got a lot more control. Now I just eat and say ok that's good for so many units of insulin and then I shoot (LM, Interview 1).

In contrast, one respondent describes the need to train himself to avoid his normal eating habits in view of increasing the risk of a worsening health condition. He perceived that changing his eating habits to "skipping meals", whenever his appetite would allow, will eventually lead to improved control of his illness. The need to balance his health condition at the expense of his normal eating habits was the strategy he currently employed at this point in time:

I'll tell you what, the way I've conditioned myself now I don't restrict myself to breakfast at such and such a time or lunch at such and such...I eat so when I'm hungry and I do this to keep my food intake down...ah well, some days I get up and I feel like having breakfast so your not going to skip you have breakfast but

you might be able to skip lunch, so that's how I'm going to do it, control your intake then you control your insulin better (NJ, Interview 1).

This strategy is not necessarily consistent with those his health care providers had recommended, however it indicates that personal beliefs will ultimately assess and dictate what strategies will be implemented. This finding was consistent with those of Roberson (1995) and Harwood & Johnson (1999) whereby personal strategies are often the result of multiple influences from multiple external conditions not exclusively allopathic health care.

Another respondent struggles with years of having no regular eating pattern due to the day-to-day variations in her appetite coupled with recommended meal plans provided by dietitians to maintain control of her chronic illness. For this respondent meal plans/eating patterns are perceived as unrealistic and exhausting work to plan and implement and she occasionally needs to escape by eating spontaneously to balance her quality of life/normalcy:

Well sometimes I couldn't care less, I look at it and you, you know, and yet I know I've got to eat...I know pretty well what my portions are supposed to be and that type of thing...its always in the back of your mind what's the next meal going to be sort of thing, you know...yeah sometimes its you know, it gets to, I don't know, I just can't be bothered, I'd like to just forget about this sort of thing. I stray once and a while (AY, Interview1).

Another respondent described a strategy that he referred to as "staying on track" with his health condition. The strategy was to occasionally "break away" from his diet. That is, temporary noncompliance with prescribed foods and/or

meal plans was key to ongoing health maintenance and keeping a balance: “Well sometimes you know you have break free from the diet in order to get back on track...I feel good about it because I know it will get me back” (EC, Interview 1).

Another respondent described her need to keep a balance between quality of life and health needs:

Sometimes I break the rules, like I’ll eat bacon for my protein choice at breakfast, and it tastes wonderful, but I’m not supposed to eat it, you know, the foods that taste wonderful but I have to do it, I need to have variety in my life, like you said before, it’s a balance (TV, Interview 1).

Prescriptive meal plans and “normal” eating habits are perceived as polar opposites at worst and somewhat congruent at best. The food choice strategies executed becomes a means to keep a “balance” between health recommendations with normalcy/quality of life.

4.2.1.3 Health Beliefs

All respondents had very specific health beliefs as to whether or not they had a chronic illness or current health problem following the kidney transplant. Respondents also varied in their beliefs about the risks to their health from food choice and this led to the consequent strategies they employed. Furthermore, all respondents discussed some aspect of their current health condition that they believed was not in their control however, they differed in their food choice strategy rationale with respect to this perceived lack of control.

4.2.1.3.1 Perceived Risk to Health.

Respondents that had a long history of diet-related chronic illness, or perceived they could be at risk of increasing illness from food choice, identified the need to focus strategies on maintaining good health via appropriate food choice. In contrast, respondents that did not perceive food choice as impacting their health, employed strategies, such as eating whatever foods they preferred, to satisfy their quality of life and/or normal food preferences.

One respondent epitomizes his need to be continuously vigilant with healthy food choice in order to have a normal/good quality of life and how this discovery had evolved over time:

I'm exercising extreme caution so that um um I can have the full benefit of of the health that I have now. By the way, I don't want to go for it and then say damn it I should have done this and should have done that...its not that I led a bad life before I lived a good life...ate good drank good...but its just the problem...I think when I look back all the suffering that I've experienced, the pain, the anxiety when I had to go for procedures of an invasive nature, that is enough to drive the FEAR into me that I don't want to go back there...no (NJ, Interview1).

In contrast, another respondent with no previous or existing illness felt that it was his responsibility to protect "the gift" of a new kidney. He would utilize whatever eating strategy was necessary to protect this kidney even at the expense of consuming foods, recommended by health care practitioners, that he had had difficulty tolerating:

I have to watch the food and amount I eat so I don't gain more weight this is because I don't want to make the kidney work so hard...they told me I need to

drink more milk for my bones but I have diarrhea when I drink it... I can only take it when I have my day off but I try to drink more whenever I can (EL, Interview 1).

One respondent, with no previous chronic illness and who did not perceive current risk of illness from food choice, tended to focus her food choice strategies on quality of life and normal eating habits:

I think that's why everything was God's will for me because of my age, and no other health problems or anything, that's all it was, was the kidneys were damaged, that's it, nothing else is wrong with me...I made the decision not to follow that as strictly as they wanted...the diet information is useful but it depends on the overall health after the transplant like if your diabetic, most definitely follow, you know. But I didn't have to worry about that (KW, Interview1).

These two quotes similarly represent how health beliefs ultimately influence food choice strategies but the consequent "balancing" between quality of life/normalcy and health promotion/illness prevention for each respondent is different. That is, one respondent, fearing potential risk of illness, is focused on improving the health side of the balance, while the other respondent, believing she is not at risk of illness, is focused on maintaining her quality/normalcy of life.

4.2.1.3.2 Health Strategies.

Some respondents with a long history of diet-related illness found health strategies, other than restricting food choice and/or changing eating behaviours, to improve the balance between quality/normalcy of life and managing chronic illness.

These health strategies were adopted as personal beliefs and resulted from influences of the health care system and/or other external conditions.

Respondents that believed their health condition could be negatively affected by food choice found strategies for balancing foods they desired to eat with diet-appropriate foods. One respondent talked about using his insulin and blood sugar monitors to accommodate flexible food choices. This would enable him to have food choices that would increase normalcy and quality of life while keeping his health in balance. The respondent labeled the strategy “reaction shooting” which he believed allowed him “normal physiological functioning” to bring about normalcy/quality of life:

Ah I do what I call reaction shooting ah if I eat, I say ah okay that’s good for so many units of insulin and then I shoot...I react manually, as the, in many respects as the pancreas reacts automatically...I use a meter I use it about 4 or 5, 3 or 4 times a day. But then I can tell by the degree of dryness in my mouth...its 25 years of experience...and I know I need to shoot some more juice. See before I could only eat so many calories and you could only eat so much fat and you had to do all those exchanges...Now I just look at a meal and say okay its worth 10, 12, 14 units. Its practice... and then the next couple of hours I check my blood sugar and see ah 6.4 ...or if 7.2 I should, I ease off the next hour... and won’t have a snack (LM, Interview1).

Another respondent similarly used exercise as a strategy to consume what she “normally” would eat. That is, she didn’t follow a prescribed diet nor restrict her consumption of any foods. “As long as I exercise three times a week I have no problem I

eat whatever I want...with no exercise its much harder (to control diabetes), I would have to restrict what I eat”(TP, Interview 1).

Another respondent had a similar strategy but insisted that appropriate food choices in appropriate quantities, coupled with blood sugar monitoring was the essential combination in his attempt to bring about control of chronic illness/good health:

Sticky rice is something that I love but if I eat too much of that sticky rice WOW ...so I have to know if I'm eating sticky rice compared to parboiled rice I need to eat half as much, just little tricks...you have to eat whatever is not going to drive your sugar up so much that your not going to have to put an extra big shot of insulin...what you have to do is stay really close to your daily intake of insulin, its going to vary its not going to be the same every day but you don't want it going too far out ...checking the blood sugar that's the key take it from me if you check your blood sugar you can monitor a lot of other things around it (NJ, Interview 1).

All respondents discussed strategies that they have adopted as personal beliefs to weigh the balance toward normalcy/quality of life or controlling the chronic illness aspect. Those strategies perceived to simultaneously control illness and enable some degree of normalcy/quality in their lives would be executed indefinitely because the “balancing process” would be less challenging. However, no respondent stated that they restricted food choice and eating behaviour to control their health condition exclusively and indefinitely. This reflects that food choices associated with quality of life/normalcy are never perceived as completely congruent with prescribed and/or health-related food choices.

4.2.1.3.3 Control Over Illness.

Respondents had different perceptions with respect to the degree of control they possessed over their past and/or present health situation or chronic illness. Interestingly all respondents cited experiences in which they perceived they had no control of worsening health but differed in the degree to which they would attempt to overcome or gain some control particularly with food choice strategies. One respondent describes his struggle to control his weight but is unable to restrict his food intake due to the need to use food as pain relief for intense stomach pain resulting from prescribed medications:

All transplant patients have a problem with weight...my stomach wouldn't allow me to be without food it was always upset...always hurting, it was always gaseous and um it was painful to be hungry and you always had to put something in your stomach...it was just the medication was pretty harsh on your stomach...but now my stomach has been strengthened and I can do with less food now (NJ, Interview 1).

Two respondents describe a similar situation whereby their eating habits and/or food choices have changed in ways not congruent with strategies to maintain good health and/or control illness. However, they insist they have little control over these "side effects"(resulting from their prescribed medications and/or health condition) and therefore must compromise their health at times. "Well I've got more of an appetite it seems. Some of the medications I think do that, the anti-rejection drugs give you more of an appetite...now I want to eat more than my diet says" (AY, Interview 1). The second respondent:

I have a weakness for snacking. Chocolate. Now I didn't get that bad of a, since my transplant the need for chocolate has been very great, and sweets...previous years I wanted nothing to do with dessert or anything and it just escalated and they (my family) even commented to me. They said we've noticed that you've been shoveling in the sweets, after the transplant (KW, Interview 1).

In contrast, another respondent recalls that his recent LDL levels are not acceptable for optimal health and that this is likely the result of prescribed medication. Nevertheless, he attempts to alter his food choice to do what he can to regain some control of the situation:

The doctors had found my LDL cholesterol was 3.2, normally its 2.7, 2.8...but normally for a person in my situation it's a problem keeping that down with the medication and such. So I got a booklet to describe what to watch out for, and the one thing being the, I thought canola oil, would be a good fat, but its not, its hydrogenated, so now I got the one that's non-hydrogenated (EC, Interview 1).

Some respondents that perceived they had no control over their worsening health condition used this as a rationale to justify consuming their preferred food choices indicating that at that particular time they were likely concentrating on strategies that improved their quality of life/normalcy. In contrast, other respondents who, despite acknowledging lack of their control over their worsening health condition focused their food choice strategies on health maintenance more so than quality of life, i.e. consuming their favourite foods.

4.2.2 External Conditions

It was evident in this study that respondents followed a similar process when adopting external influences as personal beliefs. It is also apparent that multiple external influences were often tacit, tightly woven into the narratives of respondents' experiences, often influencing simultaneously, and not easily isolated from one another. This was consistent with the findings of Stimson (1974) and Chubon (1989) who discovered that patients evaluate prescribed treatments and health care practitioners' actions based on their own ideas, experiences and knowledge in addition to numerous other external factors such as family and friends.

With further discussion of each identified external condition (categories) and the influencing factors (sub-categories) within each condition, it became evident as to how these identified external conditions influenced personal beliefs in complex and interrelated ways. It should be noted that the number and type of external conditions are not all-inclusive, rather are those identified by this particular group of respondents' narratives throughout the interview process.

Personal beliefs are continuously interacting with and being influenced by external conditions, therefore discussing them as separate entities is difficult, and at times overlap with other external conditions and influences is evident. Furthermore, it was also difficult to determine the influence of the researcher on respondents because of the associated "health focus" of the research itself. The health care system has a tremendous cultural influence over society in general and this may have resulted in some degree of unintentional bias among responses.

4.2.2.1 Health Care System Conditions

Perhaps one of the most influential external conditions weaving its way into personal beliefs in this particular research context was that of the health care system. Within this category there were several sub-categories that reflected a potential for influence on personal beliefs. The following potential influences (sub-categories) were identified and described by the respondents.

4.2.2.1.1 Physician Conferring.

All respondents perceived traditional medicine to be their best and/or only source of health information and care. Some respondents described experimenting with non-traditional health practices in the past, had considered and/or were using alternative remedies to complement traditional health care. Others described maintaining some degree of skepticism in the dominant health care system but overall felt confident in the care they were currently receiving. At the time of the interview all respondents denied subscribing to any other health practices unknown to their physicians. This was somewhat consistent with Roberson (1992) who found that respondents were generally satisfied with the care they received from their physicians. However many of her respondents had far less trust in allopathic medicine, regularly used other sources for health advice, and were more critical and suspicious of the care they were receiving from physicians. This may be reflective of differences in the culture of Canadian and American health care systems.

All respondents in this study expressed some degree of dedication and commitment to their physicians and subscribed to the implicit ideals of the traditional medical system. The following respondent echoes this statement: “the hospital is my

primary source of information as far as my medical stuff and my food and stuff and they work together in conjunction with my family doctor if they need to talk about anything” (NJ, Interview 1).

Respondents appeared to trust and be highly influenced by their physician’s recommendations despite recalling events about disappointment and perceived failure of medical care in the past. Some respondents rationalized these events, accepted the consequences and/or just moved on to new physicians granting the same degree of trust and confidence in their new physician:

...and ah my former family doctor he didn’t have a clue what he was doing...and every time I said this, this and this he said that he, well, I’m giving you my best, so what am I going to do I’m not a doctor... so looking back now I should have got a second opinion and I wouldn’t be in this position today but its after the fact....but I must admit that even at the hospital they had trouble controlling my blood pressure it took quite a bit of effort to get things right...that’s good now though (NJ, Interview 1).

This same respondent also perceives his initial diabetes education as the reason for his kidney failure yet this experience has not appeared to influence his personal beliefs about trusting in the medical system:

Well when I first became diabetic I went to the school at the hospital and uh they showed me how to take insulin and stuff but I don’t think they were showing you right that’s my perception cause the way they were showing...well I think that was the primary cause of my kidneys going down I didn’t have very good control of my sugar that way...I’ve learned the hard way (NJ, Interview 1).

When speaking of strategies to control her chronic illness, the following respondent demonstrates the degree of influence she has adopted from her physician, into her personal health beliefs:

It (immunosuppressive medication) has to be carefully controlled. I'm going for blood tests in the morning and, ah, they might drop that, depending on what the blood test shows...I do my own blood sugars twice a day at least. And I have a diabetic doctor...I write down my readings and take it to him and he'll say so oh that looks pretty good...so he says keep it up and then he sees me in three months...when my blood sugars were up I didn't like it so I went to see him and he said oh yeah it's the medication, he'd change it... and if the blood sugars would go up high, I'd give him a call and he'd say well try this or try that and he'd help me adjust it (AY, Interview 1).

Another respondent had similar comments with respect to adopting her physician's recommendations into her own personal health beliefs. However, there were limits to the type of recommendations she would adopt based on her preconceived health risk beliefs from other external influences. When asked about the importance of complying with prescribed health recommendations she believed that compliance with medication was essential. However, food choice and exercise were not considered essential largely because they were perceived as having very little potential to threaten her health at the present time: "Food is not, but medication is very important. It's a number one priority, I do take it, it's just like clockwork. I know when I'm supposed to take it, and then just sit down and do it" (KW, Interview 1).

As for recommended activity by her physician, the respondent states:

I'm very out of shape. I'm the first to admit it and it takes a lot...I just noticed a few months ago that I'd have chest pains...the doctor, like he was concerned about that ...he gave me a stress test and checking my heart, and just nothing is wrong, it's just lack of exercise... he told me you're just out of shape, that's it...get with the program, he made suggestions for me what to do, you know (KW, Interview 1).

When asked if she took his advice she responded:

I'm the type I can't exercise, I'm not that kind of person. My job that I had for twenty years was my exercise...I don't do that job anymore, I just can't, I'm slowly getting up the, you know, I'm the type of person if I go to exercise, I need somebody to come with me, I can't do it myself, I need the motivation from somebody else (KW, Interview 1).

Although the term "compliance/noncompliance" was never articulated in the discussions with respondents, at times it was certainly implied as respondents perceived they would be held responsible for not achieving certain health outcomes due to lack of carrying out prescribed health regimens. One respondent discusses his feelings about his current health status and the fear of his upcoming interaction with his healthcare providers. "I'm gaining all this weight and I don't know why, I try to do what they say but I gain anyway now I'm so afraid to face the doctor because I know she'll think I'm not watching for my kidney"(EL, Interview 1).

The experiences respondents described and meanings associated with those experiences reflect the embedded culture of health care. That is, the respondent is a passive recipient of care and more problematic is the perceived need to "please" their

physicians and/or “fear” physician disapproval if they fail to achieve certain health outcomes. This was clearly evident in the following statement:

Well since the last time I talked to you I lost 5 lbs. When I told my doctor, well he wasn't really happy about it, you know, not enthusiastic at all and I thought it was really good, but you know he just thinks that's not good enough and that I should lose more weight...it's really discouraging to me that he wasn't that pleased (KW, Interview 2).

Despite the value respondents placed on their physicians and the provision of health care they received, what was most striking in the narratives was the implicit paternalistic value respondents placed on their physicians. The physician was described as having “power over” their care and they were “passive recipients” of care. This reflects that the “ideology” of traditional medical and behavioural concepts of health is still embedded in these individuals' beliefs.

4.2.2.1.2 Dietitian Conferring.

In contrast to physician influence, respondents overall had mixed perceptions as to the degree of influence dietitians would have on their personal health beliefs and consequent food choice strategies. Some respondents felt that dietitians' functioned as ongoing “reminders” to get back on track with prescribed diet and/or healthy food choices, and that this was essential to influencing their strategies for improving health: I just saw the dietitian about three, four weeks ago...and she just sort of put me back on speed about the diet and more conscious about the types of fat. I reviewed that now and actually lost maybe about two pounds since the last three weeks so I'm getting back on

the right track...you sort of get back after so many months, or years, of getting away from the full balance (EC, Interview1).

A similar response was provided whereby this individual felt a counselling session with the dietitian would catapult her into changing current food choice strategies that focused on her health needs:

Well they say things like hey don't be stupid or you'll lose both your feet kinda stuff, it's like a kick in the butt, they say go back to your diet again, go back to your exercise, it's just the right kind of a push and it really gets me going, its nothing I don't already know but it's that I wasn't doing it and I will go back quicker so it works for me (TP, Interview 1).

Respondents were often more reflective of and sensitive to the approaches dietitians used to communicate food choice and diet recommendations. The meaning of these approaches had a much greater impact on whether or not respondents would consider adopting the actual information/education as a personal belief. However, overall there was no guarantee that the information provided would exclusively influence food choice strategies. The previous respondent explained that she could recognize the difference between "supportive approaches" and "criticizing approaches" to counselling and is sensitive to "victim blaming". "It doesn't have to be pointing the finger at you, I don't want to feel really small, it's like falling of the bench and you want some help getting back on it" (TP, Interview 1).

Another respondent described a similar experience and the consequent impact on her beliefs about the value of nutrition counseling:

At the diabetes clinic I guess the diet information was helpful but I felt like a school kid and getting my fingers slapped so now I just avoid them (dietitians) whenever I can, I duck and hide (laughs). And really I know what works for me and more talking to them about it isn't going to change things that much...I try my best and if my blood sugars are pretty good then I've achieved what I set out to do (TV, Interview 1).

Similarly another respondent was asked what might make patients feel cheated and angry about their need to restrict their food choice and change their eating behaviour to control illness/improve health, he responded: "Well maybe they'd feel that way because they're going by the book, the dietitians book, for me I use my foods in conjunction with the book" (NJ, Interview 1). A similar response echoed the same sentiment:

Well some dietitians have the enlightenment that you could, that there's flexibility that can be garnered from the way food is prepared and the combinations of food one puts together. Others go by rote and if it didn't jive with the book, it didn't. So you just parted company and that was that...the thing is, an enlightened dietitian would say you have options then you're both on the same wavelength but some of them, this is the one that goes by rote, and there's no options (LM, Interview 1).

When asked what approaches to counselling would be more effective, the following respondent suggested dietitians utilize a more egalitarian approach as opposed to using a dictating approach and support the expansion of food choice options as opposed to limiting them:

The thing is, the trick is in, is the psychology, positive psychology...it's try this, try that and see what happens if, as opposed to don't do this, don't do that and slap your hand, you know, in other words be more of a coach with a positive attitude than a disciplinarian with a negative attitude...they should ask and say but never tell (LM, Interview 1).

The same respondent had another thought when asked if he thought that dietary information from a dietitian was valuable. Interestingly, he did not think the information was valuable for him, yet suggested a specific group of individuals who he perceived were most in need of a dietitian's advice, but acknowledged that they would be a group less likely to accept it (diet advice):

The only time, really the only time I listen to the dietitians is in the hospital, if I have to listen to them. And then okay fine let them say their thing but I'm going to enjoy the way I die. I'm not going to die a depraved mind...No not really it (diet information) isn't (valuable) because unless it was life-threatening or it was life saving um the thing is the most, the person in most need of a dietitian, and the ones that will listen to them the least, are the poor people who are into a life of junk food (LM, Interview1).

This respondent believed that his food choices at this time are appropriate for satisfying his quality of life and health needs. He also believed a dietitian could not offer food choice alternatives that could influence his existing beliefs and bring about change in behaviour. However, in suggesting where dietitians might be more useful in influencing individuals, he implicitly acknowledges how the social and cultural environment continues to encourage unhealthy eating practices and food choices among

those most vulnerable. He also perceives that dietitians are not adequately focusing on preventing these influences by being proactive and using effective approaches that foster healthy eating habits especially among those at risk, versus being reactive and counselling those already living with chronic illness. However, when asked to elaborate on the food choices of poor people, the respondent implicitly believed that poor people are to blame for their “unhealthy” eating habits and require a health professional to “teach” them “healthy” food choices. While beyond the scope of this paper, his comments reflect the potentially “false beliefs” of society that food choice is simply a voluntary behaviour that can be changed:

When I see a person buying with their welfare money 25 bags of potato chips and pop, and other junk food and I'm buying for the same amount of money ...I can go buy some cheap hamburger, salad vegetables and keep maintaining a fairly well maintained, balanced diet...they say this is the food I like and therefore I'm going to eat it and its totally wrong food and I see them feeding it to their children (LM, Interview 1).

The experiences and meanings respondents expressed with respect to dietary counselling approaches is consistent with Roberson (1992) who suggested, based on her study, that health care professionals need to learn more about clients' perspectives on their health problems and their treatment and then respond to these perspectives appropriately.

There was also consistency with comments from respondents in this study and with the conclusions of Roberson (1992) that there should be less emphasis on health care

professionals' identifying noncompliance rates and ways to alter them and more emphasis on enhancing client's efforts to live well with chronic illness.

Furthermore, respondents appeared to be much more sensitive with respect to counselling approaches utilized by dietitians and were cognizant of "victim-blaming" more so than with their physicians. Although respondents valued technical information from dietitians, they were frustrated by the lack of context appreciation and the consequent difficulty with implementing nutrition recommendations. As one respondent clearly stated:

I really don't want to see another dietitian they just don't understand, when they give you the diet in the hospital everything is prepared for you and carefully measured and they say is so easy, well, when you're out in the real world it's not that easy. I try to make the right choices and in a restaurant I try to eat what I think will be ok for me but...there has to be a balance and with her (the dietitian), there was no balance it was just cut and dry this is the way it is and why aren't you doing it that way, so I says I'm human and all humans err...her approach ran me over like a truck (TV, Interview 1).

This is consistent with Travers (1997) who found that patronizing nutrition messages did little to change the social reality for her study participants and their ability to make healthy food choices. Furthermore, Travers (1997) suggests that these "messages" tend to foster feelings of guilt and inadequacy for failing to live up to the standards set out by health care practitioners.

4.2.2.1.3 Diet Instruction/Education.

There was some overlap in this sub-category with personal health beliefs and food preferences indicating the ongoing and interactive nature of the process between them. As previously described, there were different degrees of success depending on congruence with balancing food preferences and personal health beliefs. Some respondents had no success while others found a realistic compromise. No respondent perceived that they were able to implement a dietary prescription completely for an extended period of time. Some respondents' perceived dietary prescriptions as non-life threatening therefore the need to implement the prescribed strategies was not urgent or even necessary. As one respondent described:

I don't see that you have to be strict and to follow that, I think you can go over the line more to the other side as it were. For those who have no problems, other than just the one problem (post transplant), like I don't think they have anything to worry about, who knows, I might be wrong. Who knows I could be doing (KW, Interview1)?

When another respondent was asked about the usefulness of dietary information, on two separate occasions, she believed it was useful yet contradicted herself moments later as she confessed to being unable to use it in her present context. The first comment: "Oh sure I use the sheets. I used to plan my meals like that but I can't do that anymore. I haven't got the energy to do it."(AY, Interview 1), and the second comment, " Well you'd tell them, actually you could you do tell them your food preferences like things that you eat and they'll make up a diet from that. Yeah, so many calories and so forth. Well it

still, but sometimes there's just things that, you know, are just not quite right."(AY, Interview 1).

4.2.2.2 Family Conditions

With one exception, all respondents in the study lived with at least one or more family members at the time of the interview. Respondents described family conditions as having an influence on personal health beliefs but in varying degrees. There were a number of influencing factors (sub-categories) identified within family conditions that reflected the similarities and differences between respondents.

4.2.2.2.1 Family Support.

All respondents living with family members reported some type and degree of support with respect to food consumption, and how this ultimately influenced personal food choice strategies, whether these strategies were focused on personal food preferences or health related food choices. Respondents identified family support ranging from lifesaving to imposing with different relationship dynamics resulting from this support.

One respondent describes the support with meal preparation when her health was very poor. While she greatly appreciated her husband's efforts, she felt guilty that she was not able to show gratitude by consuming all of the foods he prepared:

Yeah my husband is good about, he's good about making meals. Like he'll make meals right after the transplant, he did everything. But I was very hard to please then, I just didn't want to eat. I'd take two bites of meat or something and I'd had it, I didn't want it anymore (AY, Interview 1).

A similar comment was expressed by another respondent: "I don't enjoy cooking except what I learned from my husband. He's the majority cook...I wouldn't say he catered to me (when I first had the transplant), but he was there and would go along with what I would say (about diet) 150 percent" (KW, Interview1).

Respondents also expressed support with meal preparation frustrating at times particularly when family members' beliefs were incongruent with the respondent's beliefs. One respondent discusses his mother's preoccupation with meal preparation and ongoing fears that her son (the respondent) was not getting adequate nourishment. The respondent however, was making an effort to control his food intake and food choice due to his perceived need to control his weight:

I have my own way of eating but my mother always preparing a meal for me, they eat all the time. Here is some noodles that she prepared this morning (it sits on the stove all day) and I'm not going to eat it because I have to watch when I eat and I'm not going to eat until six o'clock (EL, Interview 1).

In contrast, one respondent explained how her mother (also living in the same home and with the same chronic condition) prepared special cultural foods for the respondent. The respondent explained that these foods were provided to promote health, and the mother was an additional source of health knowledge as she often had a greater knowledge about the health impact of cultural foods than did dietitians:

Mom has diabetes too...she makes ginko, that's like chestnuts, into a soup and I have that and she buys some Chinese roots, I don't know what they are but she makes into a soup for me too...the dietitians can tell me how much salt is in bacon but mom knows how much salt is used in the preserved Chinese vegetables,

she knows how they process so I learn what Chinese foods are high in salt from her (TP, Interview 1).

4.2.2.2.2 Family Food Preferences.

Respondents identified family food preferences as an influence when they made decisions about their own food choices. However, the type and degree of influence varied among respondents. For some respondents, influence was framed in not wanting to impose dietary restrictions on family members therefore the respondent would prepare an alternative for him/herself. As one respondent recalls: "I cook a fair bit too...I have enough fish and chicken in the freezer always available so if they want to eat lasagna or chili and that sort of stuff...I cannot restrict them because of me eh" (NJ, Interview1).

At other times, influence of family food preferences was the result of temptation for a strong personal food preference regardless of the health impact. The same respondent describes his assessment process and, with this particular food preference, his decision to consume the food regardless of the health consequences:

If I feel to eat ah ah what they have prepared I might not eat because of just not liking it or just by it not being best for me so I just don't want it, but if I really like it for instance pizza, every once and awhile I like a nice piece of pizza but pizza is one of those things if you trying to loose weight its horrible (NJ, Interview1).

One respondent talks about accommodating fussy child eaters and financial limitations for extra food preparation in the home. The priority is to prepare/serve foods that they will eat to avoid excessive meal preparation and financial burdens. Incidentally, at the time of this interview this participant also believed she did not have to modify her

food choice because she is not at any health risk. Therefore the strategy to ensure balance is to maintain normal eating habits:

The focus of meals is on what the family likes to eat...like Friday we had pizza...my husband wasn't home, the kids like pizza and its just as easy to order in than make a meal for me and a meal for the kids...I have a very fussy son and me and my husband aren't fussy so my food choices have to be what he'll eat otherwise I'm making three or four different meals and it's the financial thing again eh (KW, Interview1).

In contrast, one respondent who is in charge of meal preparation in the home insists that the family will eat what she prepares because she is taking on the work of feeding the family. Further, she believes their health needs are similar to hers with respect to food choice. Therefore she will prepare those foods appropriate for controlling her diabetes and/or prepare foods that she herself prefers to eat:

I'm the cook in this house and I decide what we'll eat, my philosophy is take it or leave it, and besides, they (family) don't question it because most of them are watching their weight anyway so their not tempted by rich food... mom always was a plain cook, I didn't grow up on all those fancy sauces and things so now that I'm a diabetic, I make the same food that I always used to eat and like to eat and it fits with my diet too (TV, Interview 1).

This respondent has also revealed that her childhood eating habits have had a life long influence on her food preferences and cooking strategies today. She also makes an implicit assumption that the food she prepares for the family is acceptable to them because they have similar dietary needs.

4.2.2.2.3 Family Monitoring.

Respondents cited different emotions about family members that monitored their eating habits and food choices with respect to their health condition and these emotions would likely have some degree of influence in the process of assessing food choice strategies. Some respondents were grateful and perceived the comments from family members about appropriate food choices in terms of endearment: “She’ll keep me in mind when she’s cooking eh she’ll say you know this isn’t very good for you so I’ll make another dish for you” (NJ, Interview 1).

Others were neutral about the comments expressed by family members, and proceeded to control their own food choices despite comments: “I’m in charge of myself as far as what I eat and sometime my sister will tell me I don’t think you should have that much but I’ll say no I think I CAN have that much” (TP, Interview 1).

Another respondent recalled the comments his wife makes, regarding food choice, from time to time but suggested that didn’t influence his food choice strategies as much as her own food preferences that ultimately influenced his food choices:

She wouldn’t be doing the watch the fat stuff...well yes she does now and then...but she loves salads, she’s like a rabbit and she’ll say I feel like a Waldorf or a Caesar salad and I make a great salad so you know, well I can say I end up eating a lot of greens because of that (LM, Interview 1).

Some respondents perceived comments about food choice and quantity consumed as policing and/or unnecessary bantering:

He’s telling me if I’m eating too much, or the wrong thing. Oh yeah, like I had what was it was like Turtles and they have cashews in them. I usually eat a

couple...he'll say how many are left and he'll count how many are left and ask how many did you eat? Not that my husband matters, you know, cares about, he should be following a diet too, so (AY, Interview 1).

Family dynamics are another powerful influence with respect to personal beliefs and food choice strategies at many different levels. Families are also influenced by external conditions and therefore contribute to the complexity of food choice and eating behaviour in the home environment.

4.2.2.3 Social and Cultural Conditions

Social and cultural conditions have a tremendous influence on personal beliefs, although usually implicit. Social and cultural conditions also overlap with all other external conditions in varying degrees. Within this category are several influencing factors (sub-categories) that reflect the similarities and/or differences within each respondent's particular context.

4.2.2.3.1 Special Occasions/Holidays.

All respondents were influenced by and had specific strategies for food choice on special occasions and holidays. However the degree of influence and consequent food choice strategies varied among respondents.

Some respondents described food choice, on these occasions, to be based largely on their personal food preferences and to a lesser extent, the perceived health impact from consuming these foods, regardless of whether or not they had a chronic health condition. The following respondent describes her strategy when selecting food at these events: " I pick and choose. Oh yeah, like if I'm going to have birthday cake, well I don't

eat the icing so I scrape the icing off and eat the, the cake part of it...now if it was real cream I might think about it but icing doesn't turn my crank"(AY, Interview1).

Other respondents were more concerned about the impact on their health from their food choices. For one respondent, the influence on food choice was largely generated from past illness experience and not wanting to repeat similar events. The strategy would be to select foods that would fit with perceived dietary guidelines:

I reached a point in my life where lets say...20 years ago I went to the same party...all that food on the table I'd say WOW lets dig in...because everything looked so good now I don't do that no more...I just take a little bit of this and a little bit of that, you know, to taste...because I don't want to deal with it down the line...I don't want to blow my diet (NJ, Interview1).

Other respondents had very different beliefs about food choice with respect to special occasions. One respondent describes her current experience of consuming favourite foods in unlimited amounts, during special occasions, to enhance her quality of life. This is in contrast to her past experiences whereby she would select foods recommended for her health needs: "Oh I just go for it whatever I feel like (eating)...like that, I used to, with the salads and you know, but no, not anymore"(KW, Interview 1). This quote suggests that at this point in time the respondent is focused on foods that give her pleasure and increase the quality of her life especially during special occasions.

4.2.2.3.2 Restaurants.

All respondents had consumed foods in restaurants at some point in time. However, the influence on food choice in restaurants differed between respondents, and as previously described, food choice was also influenced by other external conditions at

the same time. One respondent described the process of eating in a restaurant stating that restaurant selection was based primarily on mutual agreement of food preferences with those accompanying him. Following this, he would determine whether or not the restaurant selected by the group would offer those foods that are congruent with his diet requirements. If he had been “straying” from his diet and the restaurant selected is perceived to further threaten his health, he declines to attend with the group:

We try, when I go out with friends in this building, we try to get a mutual ground of agreement on what’s the best restaurant for us. So we go from there, so and so might not want Chinese, maybe not Italian. So we go down to the restaurant down the street here, which is a little bit Chinese, a little bit some other things, so they can have say an English type meal, beef or something, its kind of a compromise... If they go for pizza, I’ll say no, I had it last week and I don’t want to get over, too much of that. Because its not really good for the diet, too much fat in it (EC, Interview 1).

When asked about what might influence food choices in restaurants, other respondents only cited food quality and satisfying their food preferences when eating in restaurants due to the financial output: “The quality of food yeah, like when I go, especially if we go out. I mean were paying, you know, you’re paying for it, you want to enjoy it and have what you want the way you want” (KW, Interview 1).

Another respondent cited food preferences as the major influence of her food choice in restaurants. However, she added that by ordering food from the “Senior’s Menu,” which provided smaller portions, she would consequently be controlling or limiting foods that might be inappropriate for her diet:

I have certain things off the senior's menu that I like to eat... the veal cutlets I like... "Yeah yeah, I always eat off the seniors menu if I can in a restaurant.

There's not an enormous portion that they give you .So actually it's both. It's not a bad meal and its a smaller portion that they give you" (AY, Interview1).

The same respondent also stated that she kept some prescribed dietary modifications in mind when eating in restaurants. Coincidentally these "diet modifications" were those that were also congruent with her food preferences -a dislike for salty foods. Interestingly, she implicitly acknowledges consuming some other foods (hamburgers and french fries) that would be reflective of her personal food preferences and likely incongruent with her dietary prescription. However, having incorporated a prescribed healthy food choice (no salt) "balanced" consuming foods she preferred:

...and when I go to, say Wendy's, I get their junior deluxe and always ask for it without salt. I'm used to that. And same with McDonalds, if I'm going to have a hamburger there, I always ask for it without salt, the same with the fries, without salt, so still salt-conscious (AY, Interview1).

Respondents cited many examples of this strategy elsewhere in their narratives whereby they would "balance" a health-promoting food choice with a "bad" but preferred food choice.

4.2.2.3.3 Ethnic/Cultural Foods.

All respondents cited some experience with cultural/ethnic foods with respect to food choice. Some respondents felt that their choice of specific ethnic/cultural foods had health benefits as well as satisfying food preferences and would eat them routinely:

We're a good half culture half Canadian here...so um a great percentage of our food would be rice and um...in our culture we eat a lot of peas and beans...their not fattening and they have a lot of vitamins and we get our protein from beans eh, ah yah, fits good when you eat beans you don't have to eat much meat...you see in this culture here you eat a 12 oz steak but when you eat beans and peas you only need 4 or 5oz is plenty (NJ, Interview 1).

Some respondents felt their cultural/ethnic foods were potentially unhealthy, however their availability for consumption was usually limited to special occasions: "Ukranian foods, and you know how wonderful their food is, nice and fattening, and cream, and dill. We don't cook a lot of em... we have them like every holiday" (KW, Interview1). Similarly, another respondent recalled: "Oh yeah, at Christmas, well if somebody makes one, what they call a tourtiere, which is a meat and pork pie. Oh I just have a little chunk"(AY, Interview1).

One respondent reported a dislike for the western cultural foods yet felt frustrated because these were the only foods most often available in his particular social circumstances (i.e. restaurant at work) and also dominated his diet prescription:

I don't understand how people eat those Subway sandwich, the bread is so dry and that pieces of meat is so awful...when I get a diet I can't use the sandwich because I just can't eat that...my Chinese food is mixed together we don't put it separately and weigh it like a sandwich. So I can't follow the diet. I try but I just can't... I don't know if my foods are bad for my diet because I have no information about my Chinese food (EL, Interview 1).

4.2.2.3.4 Friends.

All respondents denied that friends could influence their food choice, specifically with respect their health condition. At times however some respondents felt pressured by friends to consume foods they perceived as being inappropriate for their health and used strategies to stop this pressure:

I think some of my friends um when I was taking dialysis some of my friends couldn't quite understand why I would shy away from this and shy away from that...but um what I did there to is to I would know which place wasn't comfortable or willing to challenge the situation I'd say you stay away from that...then you don't have to deal with that you know what I mean? If I'm going to a place where people are going to question why this and why that and I'm going to be uncomfortable well then...don't go there (NJ, Interview 1).

However, the same respondent felt that friends would not try to pressure his food choices if he communicated his health condition to them: "But people are very understanding that way if you tell them you have this or you have that they'll accommodate you"(NJ, Interview 1).

In contrast, one respondent recalled that her friends were too sensitive with respect to her health condition. By accommodating the respondent with food choices to fulfill her health needs was perceived, by the respondent, as socially unacceptable:

My friends are very good to me, when I go for dinner they say let me make something special for you for your diet, but I say don't fuss over me, I don't want to draw attention to myself. I say just put out what you normally make and I will

pick and choose around it for my diet and I just try to balance it the best I can (TV, Interview 1).

Some respondents also recalled their experiences with friends who had similar health conditions. While there was little discussion with respect to food choice, these interactions were very powerful means of information sharing and support for respondents. Furthermore, they expressed gaining more knowledge from these lay individuals than their health care practitioners:

When I had my transplant I got one kidney and my (hospital room) partner got the other, since then we have kept in touch we talk about... how we're doing and any things strange going on with the transplant. We can tell each other about information that we hear but mostly it's just nice to have someone to talk to who has the same problems (TP, Interview 1).

Similarly another respondent recalled:

I have a good friend, she is on a (insulin) pump and she keeps her blood sugars real tight and she's smart, had diabetes for about 50 years and knows more than the doctors I'd say...well she has really helped me controlling mine... and well sometimes she gets a little too low and I look over and see her nodding off and I get some food into her...so I guess we help each other (TV, Interview 1).

In contrast, another respondent described how she perceived pressure from her friends to lose weight in a very indirect and implicit way:

You know I have friends and I always talk to them about my weight, and they say, no, we don't care, we're just so happy that you're healthy now. You know you

should you know don't worry about your weight, and there THEY are ALL TOOTHPICKS (KW, Interview 1).

The social interactions between friends can be a very powerful means of support or alienation. Most respondents felt that their friendships were positive in that they contributed to both their quality of life and their wellness. However social pressure from friends, particularly those perceived to be implicitly judgmental, can be damaging to both quality of life and health.

4.2.2.4 Environmental Conditions

Respondents identified a number of influences within their perceived environment that had an impact on their strategy implementation toward their quality of life/normalcy or their health promotion/illness prevention goals. These influences are not all-inclusive but were those most salient during the interview process.

4.2.2.4.1 Time Availability.

Respondents differed in the degree to which time influenced their food choices. Some respondents felt that prescribed health regimens, especially diet, were extremely time consuming and/or incongruent with lifestyle habits. Other respondents had difficulty with meals because of time constraints in general.

One respondent recalls that he finds it difficult to take time out of his daily routine to prepare foods appropriate for his diet, or this activity may not be his daily "habit":

The only thing is doing other things...and when I would like to get around to doing some muffins so at lunch and dinner I can have these dietary type of muffins rather than the ones with too much sugar or whatever. So just

trying to get around a time to, ah to do these things, maybe time, maybe habit (EC, Interview 1).

Excessive time was also implied in the need to be constantly thinking about food procurement, preparation and consumption whether one is feeding a family and/or following a special diet. One respondent recalls her frustration with the lack of time to prepare “good” meals for her family and her perception that the dietitian has no appreciation of her frustration by suggesting how easy “home-made” diet modified foods are to prepare:

We’re very busy with the boys you know. I just find it rushed, and I would rather not be rushed. Yeah, I like to make time and take my time and make sure its right (meals)...but if it’s (activities) three nights a week ...that’s a lot. And your driving, you know, across the city or wherever you have to go, so you know, I’m not cooking like I would like to for them (family)...well and this dietitian, she was saying how easy it was and stuff...and you know what, I can’t see myself making this stuff then letting it sit in the fridge (KW, Interview 1).

When asked what would make this respondent happy about eating her comment was:

If somebody fixed it all for me and measured it and everything. It would be good.... Well you always have to think about I, you know, like what vegetable am I going to have, you know, and how much of this can I have and what kind of meat and am I allowed this or that...and when your shopping I would think do I have to buy this or that or that, I have to have that, so it was always you’ve got to think of it (AY, Interview 1).

One respondent cited the energy demands of his job and finding little available time to recover from his fatigue in order to implement a prescribed activity regimen within the same day. Interestingly this respondent also questions why his physically demanding job is not sufficient to qualify for exercise to control his weight:

I know I need to exercise but I come home so tired...all day I'm running and loading the plane with food and unloading...sometimes many planes in one day. But they (healthcare practitioners) tell me this is not right kind of exercise you need so I buy step machine I try to use it but I'm too tired to use it (EL, Interview 1).

Similarly, another respondent recalls her ability to incorporate exercise into her daily routine in the past but now that her daily routine has changed, fitting in exercise is very difficult:

When I worked, I would walk over a mile to get to work everyday, now that I no longer work, I don't get that exercise and it's really difficult to find the extra time now to go for a walk... we used to live in a huge house and just trying to keep it clean was exhausting, boy did I get a workout so I didn't need to find time to go out and do exercise (TV, Interview 1)

What is significant in this quote, and similar to others, is that in order for this respondent to implement health-enhancing strategies such as exercise, this is most effectively carried out when the activity is coincidentally health enhancing and a necessity within the context of her daily life.

Another respondent had a similar experience whereby the recommended meal pattern for her diabetes is not congruent with her current work schedule. Furthermore,

despite having reasonably well controlled blood sugar levels, she believes ultimately, that not following the recommended meal pattern is problematic:

My meal pattern is very bad, bad for my health and bad for me, like in the mornings sometime I go without breakfast...sometimes I only have my lunch and supper since I started working again...my work is very irregular its always been this way. In the hospital I had three balanced meals according to the diabetic diet...now I sometimes have to skip meals or have at different times, and according to the dietitian that's not balanced for me. I do try to balance my work with my food and I do check my blood sugars and they are usually good but this is not in keeping with the rules of the diet and sometimes my sugar gets low (TP, Interview 1).

This response reflects multiple influences on eating behaviour at various times. That is, the respondent has adopted personal beliefs about the purpose of dietary meal plans. She also identifies the conflict between her work and time demands (social environment) and maintaining prescriptive meal plans, and the influence of health care practitioners on her beliefs about meal plans. This is another example whereby all influences come together in complex ways and ultimately influence food choice strategies that vary over time.

While time is the major influence on whether or not certain health promoting food choice and exercise strategies are implemented, what is striking is the need to find some degree of compatibility within respondents' social context for health promoting strategies to be adopted and implemented. That is, the social context appears to dictate if and when respondents will adopt and implement health-promoting strategies.

4.2.2.4.2 Mobility.

Respondents overall did not cite any difficulty with respect to food procurement, whether to satisfy food preferences or maintain good health. However, one respondent did provide an example of how immobility has not only limited her ability to improve her health condition but also has profoundly limited her quality of life/normalcy. This respondent recalls her dislike of exercising despite knowing it could improve her health and now she has trouble walking which has further exacerbated her ability to carry out an exercise regimen. Furthermore, this respondent's immobility has also restricted her independence. For example, she must be chauffeured to the grocery store followed by excessive periods of time needed to do what previously was perceived as a simple task of getting groceries. This reflects that her immobility has had a much greater negative impact on her quality of life/normalcy than her need to carry out exercise for improved health:

Well I'm not an exercise person, I don't exercise. I have a problem, I can't walk long distances. So I try to, I've got a treadmill downstairs, I try to go on it a couple of times a day for a minute or two at a time. I don't know if it helps build my legs or not, but now... my oldest drives when I go shopping and I have a little cart that I push, and I do one aisle and sit, and I do one aisle and sit. I can't walk very far at a time so this is much more trouble for me now than knowing I'm not being able to get the exercise that I should be (AY, Interview2).

4.2.2.4.3 "Cost of Food Choice".

All respondents stated that they had adequate financial resources to nourish themselves. Some respondents identified the "cost" of implementing health-related food

choice strategies suggested by the dietitian. One respondent recalls the expense of a meal replacement that met her health needs but she was unable to continue to use this strategy due to the overwhelming financial expense:

Well she (the dietitian) is the one that recommended, like she gave me some I don't know the name...she gave me a sample of it. And it was these tiny bottles. Well I bought a case of the, ah, but oh, prohibitive, \$57 for 27 of the little suckers (AY, Interview 1).

Similarly, a respondent discusses the "promoted" health recommendation of eating five to ten servings of fruits and vegetables every day. Although she appreciates the health value of fruits and vegetables, she cites financial constraints as well as other external influences at this point in time, that ultimately prevent her from implementing the strategy of eating five to ten servings of fruits and vegetables each day:

Well my husband and I see those ads on T.V. telling us to eat five to ten servings of vegetables a day and well, you know, we say how do they expect us to do that when our kids hate most of them and well I'm not going to buy broccoli at \$7.00 a bunch in the winter and have it rot in the fridge cause I'm the only one who eats it...we have a garden in the summer and there's nothing like fresh vegetables from the garden they're so healthy and delicious too, but in the winter we just can't eat vegetables they taste horrible, like the tomatoes...taste like wood and the cost well, and who wants to drink tomato juice all the time (KW, Interview 2).

Another respondent identified a financial barrier to carrying out his prescribed exercise needs: "I used to do it (work out) eh but it became too expensive...it was at the Y there but I just dropped it but um a but I have to get back there" (NJ, Interview1).

4.2.2.4.4 Climate.

The same respondent also identified climate extremes as another barrier to carrying out his prescribed exercise regimen in addition to the financial barrier. The respondent felt that following his transplant he had become highly sensitive to cold weather and as a result has failed to go out and exercise and that his decision to avoid the cold is not a good for his health:

I don't like the cold weather anymore since the transplant I have to wear another shirt to keep warm so the cold weather isn't best for me...consequently you won't find me going out and exercising out there and I know that's not best for me I don't know if you count that as pushing my limits (NJ, Interview, 1).

Again, even though the respondent speaks of climate as influencing his health there are multiple external influences at play with his personal beliefs in this statement. This respondent has a "health belief" of having no control over the cold sensitivity caused by the transplant. He also has a "personal preference" that he doesn't like going out in the cold, and yet he knows he should go out and exercise, an influence on his "health beliefs", likely from his health care providers. Furthermore this particular belief changed over time to varying degrees as the respondent continually assessed and reassessed ongoing multiple influences on his personal beliefs. This was in response to his quality of life/normalcy (staying out of the cold) and health maintenance (deteriorating health) becoming increasingly "unbalanced". During a second interview several weeks later, this respondent had increased his activity. He believed he had consumed too much

food over Christmas holidays, had gained weight, and the climate coincidentally had become more forgiving to his cold intolerance. This respondent's change in personal beliefs resulted in a change of strategy. That is, he would start to exercise out doors:

Well since I was talking to you last time oh boy well I, I ate lots over Christmas, too much now my weight's shooting up and so I started exercising more now, since the weather is warmer I've been getting out (NJ, Interview 2).

In summary, it is evident throughout this description of respondents' food and eating experiences, that their personal beliefs, the specific external conditions (categories), and their influences (sub-categories) are not discrete. Rather, they link together in complex ways and ultimately exist in a dynamic cycle of change. The overall theme "keeping a balance" reflects that food choice and eating behaviour hold different meanings for respondents in terms of their cultural and social context, and in the context of their health condition, thereby addressing the second research question. The following section will attempt to organize food choice and eating experiences of respondents and interpret the meanings associated with these experiences.

4.3 Meanings of Food Choice and Eating Behaviour

This section addresses the second research question by describing the meanings associated with respondents' food choice and eating experiences within their social and cultural context, and within the context of their health conditions.

When discussing their food choice and eating behaviour, with respect to health status, respondents acknowledged the importance of adopting dietary recommendations

and making healthy food choices. Respondents also acknowledged the importance of consuming foods and maintaining eating behaviours that were congruent with the quality and normalcy of their daily lives.

However, respondents did not perceive healthy food choices and eating behaviours to be similar to those foods and eating behaviours associated with pleasure and quality of life. In fact, health promoting foods and foods that provide pleasure were largely incongruent. That is, foods that provided pleasure were perceived to impact negatively on health status, and foods that were health promoting were perceived to take away eating pleasure and decrease quality of life. Therefore, respondents adapted by finding “a balance” between consuming foods that were health promoting and foods that provided pleasure and improved quality of life.

In addition, external conditions such as family, friends, social situations or the health care system further contributed to influencing these food choices in complex and inter-related ways. Therefore, respondents needed to continuously assess all of these influences on their food choices and eating behaviours. Eventually they would execute specific food choice and/or eating strategies unique to their perceived needs at that particular point in time. For example, at one point in time respondents might describe a need to focus food choices and eating habits on their health. In contrast, respondents described how, at another point in time, they may feel the need to consume foods that give them pleasure knowing that these foods are not necessarily congruent with foods recommended for their health needs, but will choose to consume these foods anyway.

What remained consistent however, was respondents' need to strike a balance between their health needs and their quality/ normalcy of life as they continuously made food choices and adopted certain eating behaviours.

In addition, to the need to balance food choices, respondents cited "self-control" as the key determinant of food choice strategy implementation in the effort to achieve this perceived balance. As one respondent clearly explained:

What the best I can say about it is every morning I get up and I know in the back of my mind... I have diabetes, I have heart disease, I have a kidney transplant and I say to myself ok you got to control that within your everyday life...yes, exactly, I'd say keeping some kind of balance so you don't go crazy (NJ, Interview 2).

Roberson (1992) suggested that a less developed perspective of patient compliance, existing in only a few studies, was patients' need for autonomy, self-management and/or control. In this study all respondents referred to "self-controlling" food choice strategy implementation to ultimately keep a balance between quality of life/normalcy and health promotion/illness prevention. Depending on their perceived "state of balance" at the time of the interview, food choice strategies could be focused on their quality of their life and/or normalcy of life, or their food choices and eating behaviours were focused on improving their existing health and/or illness conditions.

4.4 The Conceptual Framework and Process

This section addresses the final research question by making visible the social, cultural and environmental determinants of food choice, and the interrelated nature and complexity of these determinants, by developing a conceptual framework of experiences and meanings of food choice.

Respondents described their personal beliefs about food choice as the only influence leading to the process of self-control and described through their experiences, how this process occurred. Respondents adopted various personal beliefs about food and eating from one or more external influences and these beliefs would change over time.

Furthermore, changes in food choice and eating behaviour strategies to achieve perceived balance tended to be more or less frequent depending on the degree to which strategies were congruent with both normalcy/quality of life and health promotion/illness prevention. For example, those respondents who found congruence between specific personal food preferences and recommended healthy food choices, tended to maintain these strategies for longer periods of time as these food choices did not disrupt the perceived balance dynamic.

In contrast however, when respondents' personal food preferences and/or normal eating patterns were incongruent with suggested healthy food choice strategies, they tended to utilize these strategies for shorter periods of time or abandon them altogether. Respondents expressed this by describing feelings of confinement and/or conflict within their personal context (from prescribed food choice/meal plans) that ultimately led to a perceived imbalance. This was also consistent with Janas (1993) who found that respondents' dietary change game plans needed to mesh with important lifestyle factors and food preferences if they were to be maintained.

The food choice process was never static but in a dynamic cycle of change and influenced in complex and inter-related ways with external conditions. Personal beliefs actually represent external influences that have been adopted as truths for the respondent at that particular point in time. For example, respondents described increasing

unhappiness and/or perceived poor quality of life resulting from periods of “staying on track” or “following the book” (rigid meal plans) and/or constantly “depriving” themselves of favourite/familiar foods. This eventually led to increased feelings of “deprivation” in their quality of life/normalcy and an increasing imbalance between their quality of life/normalcy and health status. This perceived imbalance resulted in a reassessment of personal beliefs coupled with influences from external conditions. For example, respondents had an increased desire to consume food preferences that they considered “bad” foods. As well, respondents might have a simultaneous self-perception that their health is reasonably controlled at present given their compliance with diet recommendations. The food choice strategy becomes a “breaking away” from the diet prescription, such as eating chocolates or consuming extra quantities of favourite foods, in order to regain the perceived balance of normalcy/quality of life.

Eventually however, continuing to execute these strategies would bring about a new personal belief of decreasing health and/or a worsening health condition such as weight gain and/or high blood sugars. In addition, the respondent will be continuously influenced by external conditions such as conferring with their physician, comments from family, or timely exposure to health information/education, and this may bring about a new or renewed personal belief of failing health.

The influences within these external conditions, coupled with personal beliefs, come together once again in the process of reassessing existing food choice strategies. Eventually however, the need to implement alternative and/or previous healthy behaviours and food choice strategies occurs. Respondents discussed, for example, “getting back on track with diet”, monitoring blood sugar levels more aggressively,

and/or increasing activity in an attempt to “re-balance” health needs with normalcy/quality of life.

This process occurs in a circular dynamic with variation in the frequency and extent of change that occurs each time and over time. Respondents who lived with chronic illness over many years differed in the rate and frequency of change in food choice strategies compared to respondents who denied having a chronic illness prior to, and following renal transplant.

Because of context specificity, many possible combinations and types of food choice and eating behaviour strategies are available to be executed by the respondent at any point in time. Therefore, this process can never be duplicated identically. What appears to remain consistent however is the process whereby meanings and experiences associated with food choice and eating, belonging to the respondent, are generated through ongoing interactions between their personal beliefs and the influences of external conditions. These come together in complex ways to bring about specific food choice and eating strategies that achieve some degree of perceived balance at a particular point in time. A heuristic depicting the process can be found in figure 2. The bolded broken arrows, representing currently employed food and eating strategies are never completely balanced, rather they represent an ongoing state of “tension” to achieve balance by oscillating up or down (like a seesaw). Self-control is the pivot point that commands this perceived balance.

The unidirectional arrow leading up from personal beliefs reflects that despite the interaction between multiple external conditions and the varying degree of influence (as represented by the bi-directional arrows) with personal beliefs, it is ultimately adopted

personal beliefs that control the balance when executing specific food and eating strategies. That is, respondents always adopted influences from external conditions as personal “truths” prior to implementing strategies for balancing quality of life/normalcy and health promotion/illness prevention. This thought was captured in statements from several respondents: “Everybody needs to find their own way” (NJ, Interview 1), “ I’m going to enjoy the way I die and I’m not going to die a depraved mind”(LM, Interview 1), and “they’re not going to tell me to eat this, this and this...and I don’t like that well I’m not going to eat it” (AY, Interview 1).

This overall finding was also consistent with Roberson (1992) who found that individuals living with chronic health conditions develop systems of self-management that are suited to their lifestyles, beliefs patterns, and personal priorities. Furthermore, Roberson (1992) also found that ultimately patients’ choices about complying with recommended health regimens are theirs to make.

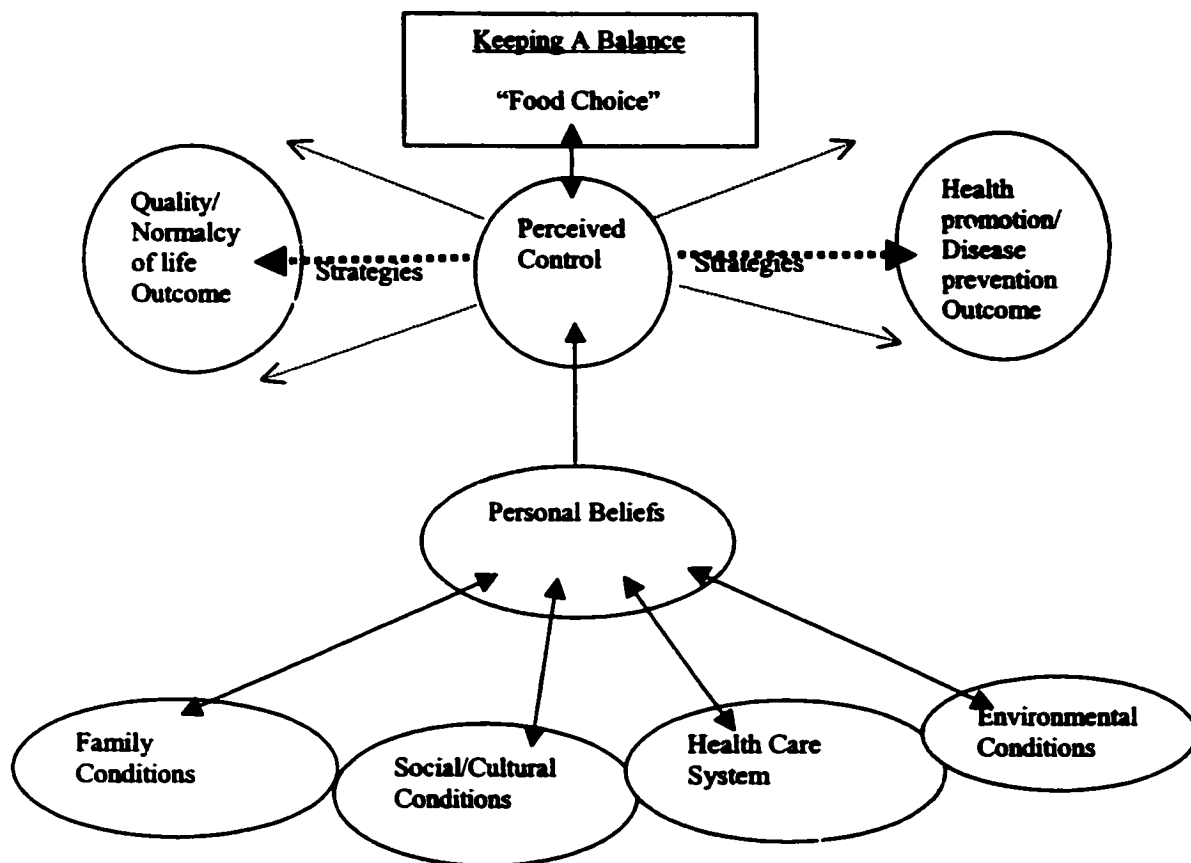


Figure 2 Conceptual Framework

4.5 Discussion

The concept of multiple influences to self-manage health and quality of life was apparent in this study and was seen in other studies as well. Roberson (1992) conceptualized from her findings, that a multitude of factors influenced self-management of chronic illness and this was a means to meet personal life goals and situations. Conrad (1985) in contrast, concluded that a multitude of factors influenced self-management of chronic illness to exert control over health problems. The results of this study suggest that a multitude of factors influence both self-management of chronic illness/health maintenance, and personal life goals focused on maintaining a degree of normalcy and/or quality of life.

Janas et al. (1993) found that dietary change was not an outcome but rather a complex process that involves changes, sometimes simultaneously, in five key areas. Within these five areas are different degrees of change that are influenced by internal and external forces resulting in different strategies and practices for each individual in different contexts. These five areas; knowing and finding out, making and using a game plan, eating foods, checking up, and managing food settings; were in a constant state of mutually shaping dietary change. These results from Janas et al. (1993) could be applied to the data in this study, however, Janas et al. (1993) examined dietary change process exclusively. She did not explicate respondents' rationale behind the process, therefore this would not account for all instances found in this study such as the need to "break away" completely from prescribed diets, or abandon the diet all together at some specific point in time.

Furthermore, there is an implicit assumption by Janas et al. (1993) that beliefs of their study participants are not the “truth”. That is, “accuracy of respondents’ beliefs” was consistently judged against “the truth” of the dominant health care system. This study did not attempt to measure accuracy of respondent’s beliefs against the “truth” or accuracy of the dominant health care system because respondents’ beliefs are the truth in the context of their experience.

Harwood & Johnson (1999) found that adolescent renal transplant recipients weighed the risks and took chances with respect to their prescribed health regimens. This was perceived to be a necessary strategy to balance their normal life while sustaining the life of their graft. The underlying theme is somewhat consistent with the concept of “balancing” quality of life/normalcy and health care found in this study.

Wright (1995) found that individuals have internal and external barriers with respect to maintaining their prescribed diet. There are similarities to this study whereby respondents’ food choice did not occur in isolation of influencing external conditions. However, in contrast to this study Wright (1995) focused exclusively on the barriers to maintaining a prescribed low fat diet. She did not address the meanings and experiences associated with both prescribed diet to improve health status and food choices and eating behaviours that are congruent with normalcy/quality of life.

Although several alternative and previously described conceptualizations appear to be consistent with some of the findings in this study, overall the original concept of “keeping a balance” appears to be most promising for this particular research context. Therefore, final confirmation of the process, main theme, categories, and subcategories was presented to each respondent during the research process. Respondents

acknowledged that food choice is indeed an ongoing balancing process, between quality of life/normalcy and health promotion/illness prevention. They also related to implementing food choice and eating behaviour strategies to maintain some degree of control over this balancing process. Respondents also acknowledged that food choice strategies are in a state of ongoing change and changes would occur over time.

CHAPTER V: SUMMARY AND CONCLUSIONS

5.1 Summary

5.1.1 Summary of the Research Questions

1. How do transplant recipients experience food choice within their social and cultural environment?

The initial research question was addressed by organizing the description of food choice and eating experiences among study respondents into five salient categories and their sub-categories. These categories and sub-categories represented specific “conditions” and their respective “influences” encompassing the social, cultural and environmental determinants of food choices and eating behaviour of respondents. Furthermore this organization of conditions and their respective influences on respondents’ food and eating experiences built the foundation for addressing the remaining research questions.

2. What are the meanings associated with food and eating, held by renal transplant recipients, in their social and cultural context, and in the context of their diet-modified medical condition?

This overall theme of “keeping a balance” addressed the second research question whereby the meanings of food choice and eating behaviour among respondents differed in their social and cultural context, and in the context of their prevailing health conditions. That is, the meaning of food choice and eating behaviour was different as respondents’ discussed their health needs and their need for quality and/or normalcy of life. Respondents for the most part did not perceive “healthy” food choices to be the same

foods that gave them pleasure, improved their quality of life, or were part of their normal life. Therefore, respondents utilized food and eating strategies that attempted to “balance” their food choices to meet both their health needs and their quality of life/normalcy.

3. In what ways do the social, cultural and environmental determinants of eating behaviour work together to influence the experiences and meaning of food choice for transplant recipients?

The final research question was addressed by developing a conceptual framework. This framework reflects respondents’ personal beliefs, external conditions (categories), their influences (sub-categories), and the complex inter-relationships among them with respect to food choice and eating behaviour. Furthermore, the framework makes visible the process of food choice and eating behaviour in a dynamic cycle of change. The main theme and essence of this conceptual framework is most appropriately described as “keeping a balance” and represents the ways in which the social, cultural and environmental determinants of food choice and eating behaviour work together to influence the experiences and meaning of food choice for transplant recipients.

5.1.2 Summary of the Findings

This research expands upon the limitations of previous quantitative studies and supports the findings of several previous qualitative studies. Specifically several quantitative studies reviewed, acknowledged difficulty in attempts to generalize and/or determine discrete characteristics of compliance behaviour in order to predict compliance with recommended health regimens. The findings of this research suggest that food choice and eating behaviour are complex, inter-related with multiple internal/external

influences and change over time. Therefore, it stands to reason why compliance with dietary prescriptions is so difficult to measure discretely and quantitatively.

The findings of this research also build on the findings of several related qualitative studies. Similar findings included the context specificity of food choice and eating behaviour, the dynamic state of food choice and eating behaviour change, the need to self-control food choice strategy implementation, and the influence of multiple internal and external determinants on food choice/eating behaviour.

Most importantly, this study has made visible a problematic with respect to respondents' social context, the existing culture of health care and the effectiveness of information dissemination interventions. Prescribed food choice/diets are consistently perceived to be in conflict with quality of life and normalcy rather than a means to control illness and promote health leading to improved quality of life and normalcy. Therefore, food choice strategy implementation often contradicts health recommendations to some degree and varies over time.

This overall finding is not consistent with the guiding values and beliefs of current health discourse. That is, Achieving Health for All (Epp, 1986), and the Ottawa Charter for Health Promotion (WHO, 1986) adopted by Health Canada, clearly reflect that health is more than the absence of disease. Health is a capacity and resource for everyday living and should be reciprocal and mutually reinforcing with quality of life and well being (Health Canada, 1999). The findings of this research suggest that renal transplant recipients fail to conceptualize their health in these terms. Furthermore, their implicit beliefs are still well entrenched in biological and behavioural conceptualizations of health. However, respondents' frustrations with nutrition and other health

information/education approaches were implicitly revealed and consistent with the current population health and health promotion perspectives. That is, a need to recognize that non-medical determinants of health are complex, inter-relate with individuals and each other, and are equally important in understanding and explaining health and disease (Health Canada, 1999). For study respondents, whether or not they lived with chronic health conditions, food choice and eating behaviour was greatly influenced by non-medical health determinants in complex and interrelated ways. These determinants are referred to collectively as health risk conditions and include housing, employment, social status, income, environmental factors, social justice and equity (Health Canada, 1999).

This research makes visible the need to revisit traditional medical/behavioural approaches to education and practice. There is a need to recognize and address the complex socio-cultural and environmental impact on food choice and eating behaviour. The Population Health (Health Canada, 1999) and the Ottawa Charter of Health Promotion (WHO, 1986) perspectives are vehicles in which to initiate a reorientation of traditional health care ideology. Namely, an ideology that assumes information dissemination will lead to behaviour change, and individuals' food choice exists in isolation of their social context.

5.2 Implications for Practice

A socio-environmental approach to health (also referred to as the new health promotion) will expose new insights, sensitivities to, and opportunities for nutrition education and practice (Labonte, 1993). For example, most lifestyle improvements tend to occur among those who are financially and academically privileged (Labonte, 1993). Individuals living with multiple socio-environmental risk conditions may have no choice

except to place a lower priority on prescribed lifestyle changes such as changes in eating behaviour. Furthermore, as Travers (1997) pointed out, and consistent with findings in this study, patronizing nutrition messages have a tendency to foster perceptions of inadequacy and guilt among participants, for failing to comply with the instruction provided by health care practitioners. As one study respondent eloquently stated: “Well the information was good I guess, but I felt like a school kid getting her hand slapped for not following the rules” (TV, Interview 1).

Nutrition and health educators, knowing the limits of information dissemination, have an opportunity to change their education practice from an individual orientation to a social orientation. That is, by adopting a social orientation, nutrition and health educators must firstly understand and make explicit the ways in which food and eating are socially constructed and organized and how this impacts on the health of all individuals. Secondly, health and nutrition educators can become more active listeners and sensitive to transplant recipients’ issues and needs with respect to food choice and eating behaviours. Finally, health and nutrition educators need to recognize that renal transplant recipients have the capacity to provide creative and effective strategies for promoting health. However, nutrition and health educators need to work collaboratively with transplant recipients, both in the provision of health care, and perhaps more importantly, in the development of health strategies that will ultimately affect everyone’s health. For example, a collaborative effort, between nutrition/health educators and renal transplant recipients, could focus on policy change with respect to accessible and affordable healthy food choices. Education programs could focus on revealing the ways in which food

commerce can work to influence food choices, the potential for negative effects on health, and collective strategies to overcome these effects.

5.3 Implications for Research

The implications for research based on the results of this study are two-fold. First, naturalistic inquiry provides an in-depth exploration into complex issues that can be expanded upon with further inquiry. For example, the main theme, categories, sub-categories, conceptual framework and process could be further tested either qualitatively or quantitatively with other health provision programs and/or other “chronic illness” contexts where food choice and eating behaviour impact health outcomes.

The second implication and perhaps most important given the problematic nature of the findings, is to consider further qualitative inquiry of this research grounded in a critical perspective.

Critical social science assumes that all individuals exist in social relationships and these relationships ultimately organize the social world thus revealing the political nature of human knowledge (Eakin, Robertson, Poland, Coburn & Edwards, 1996). With respect to food choice, application of a critical perspective could assist in making visible the problematic of why healthy food choices are perceived to be incongruent with normalcy and quality of life.

Another feature of critical theory is the exposure of socially conceived individual beliefs, especially those that are false beliefs, created and re-created through the power of dominant ideology to maintain the status quo (Eakin et al. 1996). False beliefs are problematic because they are covert. That is, alternatives to problematic issues are never considered because false beliefs prevent these problems from explication. For example,

Travers (1997) and her study respondents made visible the false belief that impoverished women are to blame for their social circumstances and associated problems. By applying critical concepts, these women were able to, collectively, uncover the root causes of their nutrition problems and expose their false beliefs that they were solely responsible for their situation.

From this research it was evident that many problematic beliefs were false beliefs, both in respondents' everyday social world and in their relationship with the health care system. For example, respondents implicitly believed that they were passive recipients of care, reflecting the "ideology" of traditional medical/behavioural concept of health. By applying a critical approach, this belief could be made visible through a series of collective consciousness-raising sessions.

5.4 Final Conclusions and Call to Action

The ability of renal transplant recipients to implement healthy food choice strategies was highly influenced by, and dependent on ways in which their social world was organized. Once the social organization of food commerce and culture is made visible, transplant recipients are better positioned to discover ways in which they could collectively take control over and ultimately improve their health -a vision shared with the new health promotion (Labonte, 1993).

This research has uncovered multiple important findings with respect to the ways in which food choice and eating behaviour are perceived in both the context of health needs and the context of everyday lives among this group of renal transplant recipients. However, what appears most striking in the findings and in need of action, is the revelation that current nutrition/health discourse is far from reflecting the underlying

values of population health and health promotion approaches. That is, acknowledging the impact of non-biological determinants of health and developing strategies that will address these determinants as integral in health education and care. Continuing to practice with an individualistic approach to nutrition/health education and blaming the victim may have minimal to no effectiveness in bringing about improved health outcomes, and may only worsen health outcomes in the long term. Respondents consistently reported both implicitly and explicitly, their experiences as passive recipients of care, being blamed for poor health outcomes, and the limited and/or ineffectiveness of health/nutrition information dissemination respectively. This is not a criticism of nutrition/health education practice per se, rather it is meant as an invitation to action. This action firstly requires serious reflection, critical examination and questioning of all assumptions currently shaping health/nutrition education practice. Secondly and perhaps most difficult for health educators, will be the realization that change can only occur by accepting the limits of current practice and exploring new and possibly unconventional methods of providing health education and care.

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APPENDIX A

Information Sheet

Title: Exploring the Social, Cultural and Environmental Determinants of Dietary Behaviour among Renal Transplant Recipients: A Qualitative Study

Introduction:

My name is MaryAnne Zupancic and I am a student at the University of Alberta studying health promotion. I am requesting that you participate in a study that will explore the experience of eating when you have a kidney transplant. I'm also interested in speaking with the people that live with you or spend time eating meals with you. Taking part in this study is completely voluntary. You may withdraw at any time, even after signing the consent form.

Purpose of the Research:

The purpose of this research is to find out about your food choices. It is also to find out about how the world around you affects the way you eat. The results of this study will be used to help health care workers understand more about food choices and eating. The answers also will help health care workers to plan better nutrition education for people with kidney transplants.

Procedures:

What will be required of you:

You will agree to meet with me (the interviewer) for one tape-recorded interview. This will take about 1 hour to complete. I would also ask that the interview be held in your home. We will pick a date and time that is good for you.

- I will also ask to see your kitchen, the food that you have and any diet or cooking books or other things about food that you might have at home.
- You will agree to meet again at a later date. The second time may be in person or by telephone for about ½ to 1 hour.
- You will agree to contact the interviewer by phone if you are not able or unwilling to keep the appointment.
- You will be provided with a summary of the results if you wish to receive one.

Possible Benefits:

You will not personally benefit from this study, however, your input will be very valuable to the kidney transplant program. The results of this study may help to improve the care for people with kidney transplants.

Risks or Inconveniences:

There are no risks if you participate in this study. The only inconvenience is the time requirement. This will be about 2 hours in total, and on two different dates. It is possible that you may find talking about your experiences stressful or frustrating. If you do, you may call the transplant nurse practitioner at 407-8099 for assistance.

Confidentiality:

All information will be held in private except when professional codes of ethics or the law require reporting. You can refuse to answer specific questions at any time. You can ask to have the tape recorder turned off at any time. One other person will listen to the tape in order to type the interview. At no time will either of us share your name. We will not share any interview information or other personal information with anyone including your doctor. Your name will be removed from everything and given a code initial in the typed notes.

The tapes and typed notes of your interview will be saved for study use only. They will be kept for 5 years after the study is done. The information will be kept in a secure area (i.e. locked filing cabinet). Your name or any other identification will not be attached to the information you gave. Your name will never be used for any presentations or publications of the study results. The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

Further Information:

If you have any questions about this study, please feel free to contact me, Mary Anne Zupancic, please call: 492-9415 and leave a message.

If you have any other questions about this research and would like an alternate number you can contact the Capital Health Authority Patient Relations Dept. at phone # 407-1040.

Contact Information:

Mary Anne Zupancic, Graduate Student-Centre for Health Promotion Studies, University of Alberta phone # 492-9415(leave message)

Kim Raine, PhD, Project Supervisor-Centre for Health Promotion Studies, University of Alberta #492-9415

Patricia Campbell, MBChB, FRCP (C) Assistant Professor, Division of Nephrology & Immunology, University of Alberta #492-7579

Douglas Wilson, M.D.,FRCP (C) Professor Emeritus, Public Health Sciences, University of Alberta #492-7385

APPENDIX B

Guiding Questions for Interview 1

Participant Code # _____

I'm going to turn the tape recorder on now is this ok with you? Thank you.

Ok...As we go through the questions I want you to think about teaching me what it is like to have a kidney transplant and especially how this has affected things like the way you eat, your food choices, cooking and any special diet that you follow. I'm only interested in knowing about what YOU eat and all the things that influence this, there are no right or wrong answers and no one is going to look at this information and say it is good or bad. But your answers will be very valuable for health care workers that want to better understand how to help other people with transplants. Do you have any questions?

As I mentioned before, I would like to know all kinds of things about eating since you received your kidney transplant. So how long has it been since you had your kidney transplant?

Part I. Exploring Eating Experiences

1. Can you tell me about what it's like to eat since you had your kidney transplant?

Potential probes:

Maybe it would be easier if you tell me about your eating habits as they are right now, how about tell me what you ate yesterday?

Do you avoid any foods?

What kind of meal pattern do you follow (3 meals each day, snacks in between...?)

How have these eating patterns changed over time since your kidney transplant?

2. So how did you think you came to eating this way?

At this point I was wondering if I could take a tour of your kitchen or where meals are prepared and eaten/ I would also like to look at the foods that you would eat.

Potential probes:

food preferences, special diets, food avoidances, dietitian/doctor instruction?

Spouse/family instruction?

Other medical books/articles, other health sources? Ethnic/cultural reasons?

3. Tell me about the way other people might influence the foods that you choose to eat. Who are these people?

Probes:

family, friends, relatives, significant others, health care people

4. What is eating like on social occasions like vacations, birthdays, weddings, thanksgiving?

Probe

let's pretend you're at a restaurant (one that you go to on special occasions) how do you decide what you are going to eat?

Part 2. Exploring the Meaning of Eating

5. So how do YOU feel about the way you eat now?

Probes

indifferent, angry, enjoyment....depends on situation?

6. What do you think the reason is for feeling this way?

Probes

food for pleasure, nourishment, protect health...

7. Tell me about the challenges of eating since you had the transplant?

Probes

financial pressure, social pressure, pressure from health care professionals, availability of food, access to food, cooking etc.

8. Can you tell me about anything that has helped or supported you in the way you eat?

Probes

social support, resources....

Part 3. Implications for Practice

9. If you were advising the transplant program staff how to assist patients with their eating what would you recommend?

Well I think that's great and I have learnt so much from you. Do you have anything else that you think is really important for me to know about the way you eat that I didn't ask or talk about? Thank you. Now just before I finish could I ask a few simple questions:

Part 4. Demographic questions:

of people in household: _____ adults ___ children _____

Ethnic background:

Occupation:

Education :

Age range: 20-30 ____, 31-50 ____, 51-70 ____, 71+ _____

Income\$: <20,000 ____, 21,000-40,000 ____, 41,000-50,000 ____ >51,000 _____

Gender: M ____, F _____

Again thank you so much for your valuable input and I look forward to meeting with you again for the second interview ok?

Field notes

1. Observations of the environment:
2. Methodological issues/problems:
3. Categories arising that need further clarification:

APPENDIX B

Follow up Telephone Interview Guide

Code# _____

Date _____

Hi _____:

As I mentioned before, I would like to share with you my thoughts on the main ideas of the first interview. I will give you an overview of all of the interviews with some specific examples from your interview. It is most important that you tell me anything that is not representing your experiences that you shared with me during our first meeting or if anything has changed since our last meeting.

What I discovered from all of the interviews was that:

1. Quality or normalcy of life is important and good health is important. But often these two goals are in conflict. For example, sometimes the foods you like to eat are not good for your health condition and sometimes the things you must do for your health take away from your quality of life or your normal way of living, like having to follow rigid diets or exercise everyday. Because these two are often in conflict you constantly need to BALANCE them, like a seesaw, in which you "control" how this balance will happen. But there is more, the second thing is:

2. No one else has control over the strategies you choose to use to balance your health and quality of life...these strategies come from your own beliefs about what you need. However, there are always external conditions that provide options and might influence you in various ways, to change your beliefs. For example, your doctors might tell you about ways you can better manage your health and if you believe in what they say you'll take their advice. But at other times you will not accept advice because you may be influenced from some other external condition. For example, when you were first diagnosed with diabetes and didn't believe you needed to watch your diet and such. But no matter how you are influenced and what you choose to adopt in your beliefs, you ultimately want to make the process of balancing the two as easy as possible.

The last thing I think is happening is:

3. The balance between your health and quality of life is always changing and you are always looking for ways to keep that balance easy. So if the foods you like to eat are also recommended for your health then you can live with that food choice for a longer period of time and, you'll eat these foods regularly-they will become routine. But some things like rigid meal plans or really restricted diets may be good for your health but are very unappealing and take away from your quality of life so you tend to "break away" sometime or even quit the diet especially if you think your health is not really being affected. On the other hand, chocolates are good and give you pleasure but too many eaten everyday eventually will cause your health to deteriorate-weight gain, high blood sugars etc So you need to stop eating them after awhile and get the balance back.

Is there anything that I've said that you don't agree with? If yes, Could you tell me what you think is happening?

Last time we talked you mentioned and I thought we could expand a little on these.

1. _____
2. _____
3. _____
4. _____

Is there anything else that I've not mentioned or you think is really important to this study?

Thank you again for your great responses. I will send you a summary of the final report in the early spring. Could you give me your full address:

APPENDIX C**Summary of Data Interpretation and Letter to Respondents**

April 16, 2002

Dear Participant:

On behalf of the entire research team I wish to thank you for your generosity in a somewhat time-consuming request as well as your valuable input into this research initiative.

Through your participation, we as health researchers and health care providers can better understand the complexity of day-to-day food choices and eating behaviour. As well, your comments will be helpful in our continuous search for improving approaches to dietary counselling. I am attaching a very brief summary of the research project for your information as promised.

Thank you again and it was a pleasure to have the opportunity to meet each and every one of you and share your experiences.

Sincerely,

**Mary Anne Zupancic
Graduate Student
Centre for Health Promotion Studies
University of Alberta**

Summary of Research:**Keeping a Balance: The Process of Food Choice Among Renal Transplant Recipients****Problem Statement and Research Objectives:**

In view of the reported difficulties and impact of the inability to make dietary changes, and the inadequate understanding of the social, cultural and environmental factors that influence the way individuals make food choices especially when they have chronic health conditions, the objectives of the proposed research are:

1. To explore how a group of renal transplant recipients experience food choice within their social and cultural environment.
2. To better understand the meanings of food and eating held by these transplant recipients, within the context of their diet-related medical conditions and within their social and cultural environment.
3. To make visible the social, cultural and environmental factors of food choice and eating behaviour, and how these complex factors interrelate with one another. A model or framework of the experiences and meanings of food and eating will be developed to reflect these findings.

Findings:

The following findings reflect the three major points that interviews with respondents revealed:

1. Quality or normalcy of life is important and good health is important to all respondents. But often these two goals are in conflict. For example, sometimes the foods that respondents' liked to eat were not always good for their health condition. As well, sometimes activities respondents must carry out for their health take away from their quality of life or their normal way of living, for example, having to follow rigid diets or exercising everyday. Because these two are often in conflict there is constantly a need to "balance" them like a seesaw in which they "control" how this balance will happen.

2. No one else has control over the food choice and health strategies respondents chose to use to balance their health and quality of life. These strategies came from their own beliefs about what they need. However, there are always external conditions such as family, friends and the health care system, that provide options and might influence respondents' food choices in various ways, to change their beliefs. For example, respondents' doctors might tell them about ways in which they could better manage their health. If respondents' believe what their doctors' say then they will likely take their advice. But at other times respondents may not accept advice because they may be influenced more powerfully by some other external source at another point in time. For example, some respondents talked about when they were first diagnosed with diabetes and didn't believe they needed to watch their diet as closely as they were told. Others however, followed their diets very carefully as they believed harm could come to their kidneys if they did not follow the diet recommendations. Overall however, respondents appeared to make food choices based on the process of balancing health and quality of life.

3. The balance between their health and quality of life is always changing and respondents are always looking for ways to keep that balance easy. If the foods they like to eat are also recommended for their health they can live with that food choice for longer periods of time. For example, they'll eat these foods regularly-they will become part of their eating routine. However, rigid meal plans or restricted diets may be recommended as being good for their health, but this way of eating is very unappealing and can decrease their quality of life. Therefore, respondents would "break away" on occasion or even stop the diet especially if they believed their health is not really affected in a negative way or improving with these rigid meal plans. In contrast, respondents also realized that they couldn't eat what ever they wanted all of the time. For example, chocolates are good tasting and gave respondents pleasure but too many eaten everyday eventually would cause their health to deteriorate, for example, weight gain, high blood sugars etc. Respondents would eventually stop eating chocolates and get the balance back between the quality of life and their health.