

QUALITY OF LIFE WITH HOME ENTERAL NUTRITION

BY

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

MASTER OF SCIENCE

**Department of Community Health Sciences
University of Manitoba
Winnipeg, Manitoba**

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ABSTRACT

A multimethod descriptive, qualitative and quantitative research design was used to study the concept of quality of life of adults living with home enteral nutrition and to determine what life is like living the experience. Emphasis in this study is on the qualitative ethnographically-oriented interviews which are then supported by quantitative data supplied by the SF-36 Health Survey results. Twelve adults, within the Manitoba Home Nutrition Program, were interviewed using a semi-structured interview guide. All interviews were audio-taped, transcribed verbatim and coded using a mnemonic system developed by the investigator. Common themes were determined based on frequencies. Theme-related codes were searched using the edit/find function in MSOffice Word computer software. The SF-36 Health Survey was scored as per Medical Outcomes Trust scoring procedures. The SF-36 scores were compared to U.S. population norms and parallel technologies (home parenteral nutrition, dialysis, ventilator support) using t-tests. The SF-36 Health Status Survey results indicate that the home enteral nutrition group reported lower levels of physical functioning, physical role, general health, vitality, and social function than the average U.S. population. This was confirmed by the qualitative analysis. Common themes identified included: immobility due to the pole; time commitment infringes on activities; impact on normality; and benefits including survival. Managing the tube feed regimen poses many challenges to individuals. Those individuals that are able to adjust and adapt their own treatments to fit their lifestyles report less restraints imposed by this technology.

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I dedicate this thesis to those individuals that shared their lives with me in the pursuit of understanding Quality of Life with Home Enteral Nutrition. This is the first research of its kind and their voices will hopefully reach many and benefit future individuals.

An individual is never an island to themselves and their choices in life impact many others. I would never have achieved this milestone without the constant and dedicated support from my husband Kevin. His patience and hardwork during my preoccupation is appreciated beyond words. I also thank the other four men in my life, my four sons, Nick, Jay, Jeffrey and Zachary for their pleasant distractions. The enthusiasm from my second son Jay, especially during the production phase, definitely kept the momentum going. Other family that cannot go without mention include my sister-in-law Janet and my parents for their child care support.

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I. Introduction

What is it like to live on nutrition support? What is it like to receive eighty to one hundred percent of your food via a tube? Enteral nutrition involves feeding directly into the stomach or small bowel with a feeding tube. Specially formulated liquids are delivered to the stomach or small bowel via either a naso-intestinal tube, a gastrostomy or a jejunostomy. Health professionals prescribe nutrition support on a long term basis but there is very little research on the implications of this regimen on an individual's quality of life.

An extensive bibliographic search produced no publications examining the impact of home enteral nutrition support on quality of life. The majority of the literature discussing quality of life and enteral feeds involves individuals in vegetative states and focuses on the ethical issues of prolonging life. (Ashby and Stoffell 1995, Curran and Hyg 1994, Dunlop et al. 1995, Glover 1990, Goldstein and Fuller 1985, Lo and Dornbrand 1986, Steinbrook and Lo 1986, Steinbrook and Lo 1988).

What life is like for individuals receiving long term tube feeds at home is unknown. Health care professionals can make assumptions based on clinical observations but no systematic data exists on the emic perspective of the patient.

Hence the purpose of this research project is:

To determine what life is like for individuals, within the Manitoba Home Nutrition Program, who are receiving long term tube feeds at home using qualitative and quantitative research methodology. Quality of life data (QOL) will be obtained using ethnographically-oriented semi-structured interviews in conjunction with a standardized survey to assess health status and well being (SF-36 Health Survey: English-Canadian version).

The idea for this multimethod approach emerged from a preliminary unstructured interview that was conducted by the researcher in previous work using the principles of grounded theory. In this preliminary unstructured interview, with an elderly woman receiving home nutrition support, two main themes were identified. The two themes were: 1) the informant's perception that her life was now regimented and restricted by her rigidly timed feedings; and 2) her inability to cope with never eating again. The first theme, in the woman's narrative was raised twenty-seven times and the latter twenty times in a one hour interview (Hotson 1992).

Not all individuals receiving home nutrition support are unable to consume food but all must maintain feeding regimens. The messages revealed in this interview were consistent with Strauss's comments regarding management of regimens: "regimens may even occupy so much time that they are virtually at the centre of a person's life" (Strauss 1984, 37) and that "regimens lead increasingly to social isolation"(Strauss 1984, 40).

At the end of the preliminary unstructured interview when asked “What does this artificial feeding mean to you?” The informant stated:

“Actually I shouldn’t say this, if I didn’t have it I’d probably be dead and sometimes I wonder if there is an easy way out. It’s prolonging a very difficult thing....I’m just prolonging this lingering death, that’s all.”

This theme was only stated once, in this single brief interview, but it should not be overlooked.

This preliminary unstructured interview triggered many questions. Are these consistent themes amongst most individuals receiving home nutrition support? Would people with different ages, different disease states and different tube feed regimens tell different stories? How does home nutrition support impact on an individual’s quality of life?

To answer these questions the researcher chose to utilize a multimethod approach for the research design. Ethnographically-oriented interviews were selected in order to extract general information from the respondents since very little is known about what life is like on home enteral nutrition. Discussing life on home enteral nutrition covers the many domains that are believed to form the construct of quality of life. These domains include: social function, health, psychological and emotional well-being, perceptions of well-being, socio-economic status, and physical function.

The combination and corroboration of both qualitative and quantitative research methodologies strengthens one's results. To support the qualitative data it was decided to quantify quality of life using the SF-36 Health Survey. This measurement tool was selected for the following reasons: 1) it is a well accepted generic tool for measuring quality of life in many disease states (Bowling 1995); 2) the eight health dimensions are consistent with the quality of life construct (Hotson 1993); 3) the questionnaire can be administered in five to ten minutes (Ware 1993); 4) validity and reliability have been well tested (McHorney, Ware, and Raczek 1993, McHorney, Ware and Sherbourne 1994); and 5) data can be compared to population norms or across studies (Ware 1993). Details regarding the methods of the research design can be read in chapter two.

Supporting literature is cited throughout the entire dissertation but the concentrated literature review is found in chapter three. This chapter contains two main sections. The first section of this chapter provides supporting literature for the rationale of selecting ethnographically oriented interviews and the SF-36 Health Survey for the QOL measurement tool. The second section encompasses a brief literature review on quality of life of individuals dependent on other life supporting technologies deemed parallel to home enteral nutrition by the author. These technologies include home parenteral nutrition, dialysis and ventilation.

The study sample is described in chapter four including demographic characteristics, tube feed characteristics, treatment duration, illness states, weight history and whether or not food is consumed orally. Case studies of four selected informant narratives are presented. This enables the researcher to set the stage on what life is like on home tube feeds. These narratives highlight some of the themes that will be covered later in the thesis.

In order to continue setting the stage for the emerging themes, the qualitative data is also introduced, using a different format, in chapter five “Living with Home Enteral Nutrition”. The responses to the first experience question ‘What is it like to live on tube feeds?’ is summarized in this chapter. Themes introduced in this chapter include: the pole; the impact of the tube feed regimen on time; the restrictive nature of the treatment, the difficult nature of adjusting to this technology; the positive aspects of the technology keeping them alive; recall of food preferences; the impact of continuous nocturnal feeds on one’s sleep; and themes emphasizing that one can not isolate tube feeds from the effects of their illness on their life. Subsequent chapters elaborate on these themes. It is important to note that chapter five is only an introduction to these themes. Only a few respondents may have mentioned these themes during their response to the first question while others may have discussed these themes later in the interview. One needs to get a better representation from the group as a whole to determine that these are common themes.

One common theme, as discussed in chapter six, pertained to the equipment associated with the tube feeds. The intravenous pole, in particular, was viewed as restrictive and cumbersome in nature. Individuals felt that the pole significantly impacted on their mobility.

Managing tube feed regimens can pose many challenges to individuals living this experience, as demonstrated in chapter seven. The impact this tube feed regimen has on time and how individuals organize their time and adopt alternate feeding methods to enhance flexibility in their treatment is an example of such challenges. The tube feed regimen impacts their social lives, their favourite activities, sleep and their sense of normality.

Entrenched in most of the responses was the theme that the tube feeds were intertwined with their illness regarding its effects on life. As illustrated in chapter eight, respondents had a difficult time separating themes about life with tube feeds from themes related to illness and health. For many, they were one in the same. It was the combination of everything that impacted on their quality of life.

Despite the challenges, there are positive aspects of home enteral nutrition. The positive themes are not frequently mentioned during the interviews but are definitely strongly conveyed. In chapter nine the reader will see that the concept of survival is a short but strong message.

In the final two chapters, we return to investigating quality of life as perceived by the Manitoba Home Nutrition Program respondents. The tenth chapter examines the qualitative analysis of the interview data. When respondents are asked to describe their own quality of life, they mention domains that impact significantly on their quality of life. The eleventh chapter, on the other hand, examines the quantitative analysis of quality of life as measured by the SF-36 Health Survey. This data is then compared to U.S. norms and across studies to other parallel technologies including: home parenteral nutrition, dialysis and ventilation.

Consistencies between the themes of what life is like on home enteral nutrition, the qualitative themes and the quantitative results of quality of life are summarized in the conclusion.

Before one can go any further some background information on the group and service delivery program under study is required.

The Manitoba Home Nutrition Program:

The Manitoba Home Nutrition Program (MHNP) is a provincial endeavour funded by the Manitoba Health Services Commission to provide home-based nutrition therapy to individuals. Nutrition therapy may consist of either enteral nutrition, parenteral nutrition or hydration therapy. Parenteral nutrition is used for patients who

are unable to absorb adequate nutrients through the digestive system. These patients are fed via an intravenous line placed in a large vein. Hydration therapy is used for patients requiring fluid, but not nutrition. Enteral nutrition involves feeding directly into the stomach or small bowel with a feeding tube. The program is a shared venture between Health Sciences Centre and St. Boniface General Hospital and has been formally in operation since 1991.

The mission of the MHNP is to facilitate the optimal delivery of specialized nutrition support at home, utilizing a team-centred approach. The Nutrition team consists of dietitians, nurses, physicians, a pharmacist, and pharmacist technician. The MHNP is committed to excellence in the provision of comprehensive assessment, education and ongoing evaluation of individuals requiring nutrition support at home. One of the goals of the MHNP is to enhance the quality of life of Manitobans who require specialized nutrition support at home.

Prior to this research project, the program had approximately 5 parenteral nutrition clients, 88 enteral nutrition clients and 0 hydration clients. The home enteral nutrition group is of interest due to the limited information available in the literature regarding this patient population.

II. Research Design and Methods

Study Design

A multimethod descriptive, qualitative and quantitative research design was used to study the concept of quality of life of adults living with home enteral nutrition and to determine what life is like living the experience. Emphasis in this research is on the qualitative ethnographically-oriented interviews which are then supported by quantitative data supplied by the SF-36 Health Survey results. The advantages of adopting a qualitative, narrative approach is clearly stated by Gareth Williams (1987, 98):

“this concern with measurement appears to have led researchers to overlook the significant contribution to understanding that can be derived from qualitative studies which examine patients’ experiences on their own terms and in their own contexts.”

Researchers have studied quality of life using ethnography. (See chapter three for examples in the literature). Ethnography, as stated by Laskiwski and Morse (1993, 144), is:

“based on the presupposition that groups of people share a cultural reality that results in their sharing beliefs and values. These beliefs and values are often implicit so that they are not readily apparent to those not integrated into the culture. Ethnography provides a method for making the implicit explicit, for interpreting the perspective of those within the setting and for communicating this perspective to those outside.”

It is important to note that this research project was not an ethnography but used ethnographically-oriented interviews to obtain qualitative information.

Quantitative assessment of the respondents' quality of life was measured using the SF-36 Health Survey (see Appendix A for letter of permission from Medical Outcomes Trust). The Manitoba Home Nutrition Program patient population is diverse in their medical backgrounds, treatments, demographic characteristics and cultural background. Due to this diversity a generic outcome measurement tool for assessing quality of life is most appropriate. Literature supporting the SF-36 Health Survey is presented in chapter three. The SF-36 Health Survey was selected to assess health-related quality of life because it is a generic index or measurement instrument that can be conducted in approximately 5 to 10 minutes. According to Ware (1993) it has been well tested within a variety of settings, languages and disease states. Conditions and interventions where the SF-36 Health Survey has been used include: end stage renal disease with dialysis, bowel cancer, esophageal cancer, head and neck cancer, home antibiotic therapy, irritable bowel syndrome, nutrition and weight loss to name a few (Ware 1993). Therefore, results can be compared across studies and to population norms. (See chapter eleven for comparisons to U.S. population norms, and to groups supported by home parenteral nutrition, dialysis and ventilators.)

The combination and corroboration of both qualitative and quantitative research methodologies strengthens one's results. According to Brewer and Hunter (1990) the multimethod approach has a number of advantages for theoretically oriented research including the ability to more strongly confirm one's theory when one

employs multiple methods. No one method of research is perfect and each method can benefit from corroboration with findings from other methodologies. Employing “different types of methods helps to guard against and to correct for inherent methodological biases either for or against certain types of theories.” (Brewer and Hunter 1990, 53).

Methodologies were also adapted, during the data collection period, to accommodate specific individual needs and to capture significant groups that were eliminated due to the selection criteria. Examples of this adaptation are explained later in the development of the written interview guide and in the administration of both interview guides.

Interview Guide:

Both the ethnographically-oriented interview and the quantitative SF-36 Health Survey are combined to form the structured interview guide. This interview guide (see Appendix B) is divided into three sections: 1) SF-36 Health Survey; 2) background information including demographic characteristics, weight history, duration on tube feeds, time involvement with feeds, volume and type of feeds; and 3) experience on tube feeds (e.g. How has tube feeds affected your family, work and social life?).

The SF-36 Health Survey was conducted at the beginning of the interview because according to Ware (1993, 4:5) it is important in the administration of this tool

that one “[does] not discuss respondents’ health, health data, or emotions with them before they fill out the questionnaire.”

Sequence of Semi-Structured Questions:

The background information questions were pretested (N=2) to determine appropriate sequencing of questions. During data collection the experience question “Why do you need home tube feeds?” was placed earlier in the interview. It originally was question number nine and was changed to question number two during the first interview. It was determined that this information was needed earlier in the interview to understand further responses.

Reconstructing Existing Instruments:

After the first four interviews, the interview guide was re-evaluated and minor changes were made. Additional questions pertaining to height and hunger were added.

Probes were also added based on data already collected. For example:

Question 6. What do you usually do while you’re feeding? (probe re: mobility with tube feeds)

Question 8. How has home tube feeds affected your working life? (if retired: your activity)

Question 10b. If NO, what is it like to never eat food? (probe re: cravings, compensated activities)

During the interviews, when respondents were asked to describe their quality of life, several respondents used the terms poor, fair, good or very good. In order to

compare these responses. supplementary questions were asked to elicit how respondents would rate their quality of life.

16. I realize that quality of life is difficult to define, but in your own words how would you describe your quality of life currently? (If the answer is poor, good, etc. ask WHY?)

Re-wording to Enhance Understanding:

The last question of the interview guide was written to elicit a comparison between the qualitative questions and the quantitative questions in capturing the respondent's perception of their health and quality of life. Respondents appeared to have a difficult time answering this question. Responses were short and did not involve elaboration. In an attempt to enhance the understanding of this question it was re-worded. The original question was as follows:

“What did you think of the written questionnaire at the beginning of the interview compared to the verbal questions? Did the written questionnaire represent how you feel about your quality of life? Did the questions represent how you feel about your health?”

which was then changed to this question:

“At the beginning of the interview you completed a written questionnaire. Did the written questionnaire represent how you feel about your quality of life? Did the questions represent how you feel about your health? How did the written questionnaire compare to the verbal questions with regards to capturing how you felt about your quality of life? and How you felt about your health?”

Written Questionnaire:

During recruitment the investigator noticed that potential candidates were being eliminated due to the fact that they were unable to communicate verbally. A significant proportion of patients followed by the Manitoba Home Nutrition Program have head and neck cancer and have undergone surgical interventions resulting in impaired oral communication. Limiting the interview to strictly verbal input was excluding an important group. The structured interview guide was redesigned to accommodate written input (see Appendix C). Background information sections were identical. Instructions for completing the questions were provided in the Experience section. The respondent was encouraged to provide as much detail as possible about their thoughts, feelings, and experiences and to provide examples of actual situations. More probes were included in the written questionnaire than were included in the interview guide.

Sampling

Our initial target population included all individuals who receive home enteral nutrition support within the province of Manitoba. A provincial registry of home enteral nutrition patients does not exist though and it is difficult to ascertain the actual numbers of individuals who are receiving this treatment. The Manitoba Home Nutrition Program at the time of the research project followed approximately 88 enteral patients within the provincial health care system and constituted our sampling frame (see Appendix D). This sampling frame is program specific and results may be

only generalized to individuals, in Canada, who receive home enteral nutrition within an organized support program.

Sampling the MHNP patients was purposive and theoretical. Purposive sampling concentrates on an identified appropriate patient population. Theoretical sampling was based on the potential theory that the patient's quality of life may be more impacted by the underlying disease state than the artificial feeding itself as shown in Smith's (1993) study with parenteral nutrition. "TPN is not the problem, the [underlying disease] is." (Smith 1993, 504). It is important that the final sample reflect a broad range of disease states since this is characteristic of the patient population.

The Manitoba Home Nutrition Program's patient population is quite diverse. Disease states include: cancers, various neuromuscular disorders, cerebral vascular accidents (CVA), Crohn's disease, head injury, and motility disorders (see Appendix D). Patient numbers for each specific disease state are very small (n=1-7). The exception is cancer (n=27) and neuromuscular disorders (n=24) which are the largest groups. The age distributions varies. Fifty-two percent of the patient population are over the age of twenty. During the year these statistics were recorded, 70 patients were on the waiting list. Recent changes within the program have presently eliminated this waiting list.

The MHNP population was screened by the MHNP Coordinator using the following inclusion and exclusion criteria:

Inclusion Criteria:

1. Registered with the Manitoba Home Nutrition Program
2. Receiving home enteral nutrition support for a minimum of 1 month.
3. Physically/mentally able to participate in a one and half hour interview as judged by the MHNP professional staff.
4. Age > 18 years.
5. Male or female.
6. Fluent in English
7. Resides in Winnipeg or is willing to be interviewed in Winnipeg.
8. Agreeable to consent.

Exclusion Criteria:

1. Receiving home enteral nutrition support for less than 1 month.
2. Age < 18 years.
3. Non-English speaking.
4. Unable to obtain consent.

A preliminary screening of the MHNP population showed that approximately 19 subjects would be eligible. Most subjects were eliminated because they were less than

18 years of age. The researcher decided at the onset that the research project was only to investigate quality of life in adult patients on home enteral nutrition. The researcher did not want to complicate the project by including children. Issues regarding consent, and interview content and appropriate quality of life measurement tools differ between adult and pediatric populations.

Based on the MHNP 1996 annual report, it was estimated that approximately 50% of the sample may have cancer. Cancer may be a potential confounder regarding its impact on quality of life. Cancer's impact and trajectory may differ from that of chronic or progressive disease states. Therefore, it was originally planned to stratify the sample into two groups: cancer and non-cancer. Out of the potential nineteen candidates though, only four had cancer. Therefore, at the time of research design, stratification was not necessary.

All eligible patients were asked to participate until approximately twelve to nineteen patients were interviewed or when saturation was achieved. Saturation refers to the point in qualitative research when no new information is being obtained through conducting additional interviews. The researcher continued to interview respondents until the themes became repetitive. Predicted sample size was determined based on Kuzel's (1992, 41) experience:

“Although the rules are not hard and fast experience has shown that 6-8 data sources or sampling units will suffice for a homogenous sample, while 12-20 commonly are needed when looking for disconfirming evidence or trying to achieve maximum variation. Selection continues to a point of redundancy.”

The smaller sample size was not selected because the pool of potential respondents was not homogenous.

Ethics:

Ethical approval was obtained from the University of Manitoba Faculty Committee on the Use of Human Subjects in Research on April 2, 1997. (see Appendix E). Prior to ethical approval, the researcher had negotiated permission to conduct the research with members of the Manitoba Home Nutrition Program Team. The Manitoba Home Nutrition Program agreed to support this research project via access to their patient population, distributing information letters, contacting patients initially and forwarding names of consenting individuals to the researcher (see letter of support: Appendix F).

Informed written consent (see Appendix G) was obtained from the informants, just prior to their interviews, by the investigator. During the negotiation of informed consent, the interview process was explained and permission to tape-record the interview was requested. All participants agreed to the audio-taping. Informants were informed that participation was completely voluntary and that they could withdraw from the study at any time. It was also emphasized that their decision would not affect the care that they received from the Manitoba Home Nutrition Program. The consent agreement made it clear that the researcher was not affiliated with the Manitoba Home

Nutrition Program in any way and that this research was not funded or initiated by the Manitoba Home Nutrition Program.

Techniques to maintain confidentiality were used when reporting the data. These techniques included assigning pseudonyms to respondents; and removing any identifiable features such as occupation, illness states, weight, religion, and family members. The researcher acknowledges the fact that the sample is small and that respondents may be identifiable to the members of the Manitoba Home Nutrition Program Team only.

Method of Recruitment:

In January, 1997, a letter was sent to all MHNP clients over the age of 18 who resided in Winnipeg, informing them of the study (see Appendix H). This letter was mailed by the MHNP secretary. One week following the mailing, the MHNP clients were contacted by phone by the MHNP secretary to obtain initial agreement of participation. The MHNP secretary followed standard responses to common questions as previously written by the researcher (see Appendix I). Names and phone numbers of potential informants (i.e. willing to consent) were forwarded to the investigator.

Twenty-one MHNP clients were contacted to participate in the research study. Ten agreed to participate and eight did not meet the inclusion criteria. The eight that

did not meet the inclusion criteria included two who were deceased; one who was no longer on the program; one who was no longer receiving tube feeds, two who were hospitalized and two were unable to communicate verbally. Three clients would not give initial consent to participate. The investigator contacted the ten potential participants by phone to arrange suitable interview time and location. Eight of the potential participants were interviewed and two were never interviewed. One was disoriented during the entire data collection phase of the research project and the other had returned to his native reserve and his immediate family had lost contact with him. Consent was obtained, from individuals who agreed to participate, by the investigator prior to the interview (see Appendix G).

After the structured interview guide was redesigned to accommodate written input individuals who could not communicate verbally and those who had originally denied access were contacted again to see if they would be willing to participate in a written questionnaire. Three out of the five clients agreed to participate and one had died. In July 1997, letters were mailed to two more MHNP clients and both agreed to participate. Only one of these clients was interviewed because the other was moving at the time of data collection and timing was inconvenient. The data was determined at that time to be rich and saturated based on criteria of theme repetition. The interviews became repetitive and interviewing was discontinued.

Data Collection:

Twelve interviews were conducted, by the investigator, from May 17, 1997 to August 12, 1997. All interviews were conducted in respondent's place of residence. Eight of the interviews were verbal. These interviews varied in length from one and a half hours to three hours and ten minutes. The average time per verbal interview was two hours (see Table 1). Two interviews involved written responses. During the written interviews the respondent was visited in their home by the researcher. During this initial visit, consent was obtained and the SF-36 Health Survey was completed. The researcher then explained the written questionnaire and a date for pick up of the completed form was established. The questionnaire was picked up and reviewed by the researcher at a later time. Questions regarding clarification of responses were asked via the telephone. In one of the cases, questions were asked of the spouse since the respondent could not communicate verbally.

Table 1 : Characteristics of the Interviews

ID #	TYPE	PLACE	DATE	DATE #2	START TIME	END TIME	LENGTH (minutes)
#001	Verbal	Home	17-May		3:00 PM	4:30 PM	90
#002	Verbal	Home	21-May		10:05 AM	11:50 AM	105
#003	Verbal	Home	22-May		2:30 PM	4:05 PM	95
#004	Verbal	Home	27-May		1:00 PM	2:30 PM	90
#005	Verbal	Home	16-Jun		10:05 AM	1:15 PM	190
#006	Combo	Home	17-Jun	24-Jun			
#007	Combo	Home	18-Jun	25-Jun			
#008	Written	Home	18-Jun	7-Jul			
#009	Verbal	Home	18-Jun		7:30 PM	9:45 AM	135
#010	Written	Home	19-Jun	24-Jun			
#011	Verbal	Home	8-Jul		10:25 AM	12:25 PM	120
#012	Verbal	Home	12-Aug		11:00 AM	12:25 PM	133
					Total avg. time		120

Two interviews utilized a combination of both written questionnaire and interview. One respondent agreed to participate in the research project but when the researcher arrived at her home, she could only communicate using a writing board. It was decided at that time to accommodate the research design to fit the needs of this respondent. Consent was obtained, the SF-36 Health Survey completed as well as the background section of the interview guide. The experience questions included in the written questionnaire were left with the respondent to complete and a second interview time was set for the following week. In the second combination interview, the respondent initially started out writing responses to the questionnaire but found it difficult to express himself in writing and later requested a verbal interview. The written questionnaire was partially completed and used as the interview guide for supplementation.

All verbal interviews were audio-taped and transcribed verbatim. Written questionnaires were also transcribed including information obtained from follow-up interviews conducted using the telephone. These questions and responses were recorded using notes and then inserted into the transcript at the appropriate section. Two interviews were a combination of both responses from the written questionnaires and transcripts of the interviews. These were transcribed with information organized on a question specific basis. The written response was documented first followed by any additional information obtained through the interview.

Qualitative Data Analysis

A mnemonic indexing and coding system was established by the researcher during transcript reading. Eleven transcripts were read and notes were taken summarizing the interviews. A list of codes was developed from the summarized interview notes (see Appendix J). All transcripts were coded by the investigator. This coding by the investigator as the single rater minimizes inter-coder variation and ensures that there were fewer changes in the coding categories as analysis proceeded. It is also recognized that the approach did not allow assessment of inter-rater reliability.

The following is an example of the coding system that was used. The interviewee is describing the difficult and painful time he has swallowing due to his medical condition and treatment.

2.09; @M; @SWALLOW; @MEDICALCONDITION;
@MEDICAL.THERAPY; @PAIN; @DIFFICULT

Interviewee: "No. I try once in awhile to swallow something and uh my throat just seems to close up, it's very, it seems to be very sensitive to anything going down it. I can swallow saliva but uh, but uhm I for the most part I spit it up and uh and it's very sore and uh when I try to drink something like the first little bit may go down, the second little bit just goes up my nose sort of thing, it's just, it's just uh doesn't work. Something's are just not right there yet. And uh the doctor just says it will take time. So we just wait and see, hoping, trying hard enough but uh, it's difficult with the chemo, doctor says it seems to interfere every time, every few weeks they do something to you that makes it worse. So, just has you start to feel like you're getting better and your throat feels pretty, not too bad, they get to try the treatment and all of a sudden your throat feels terrible again, so.. so, it's difficult."

The number 2.09 refers to the second interview and the ninth page of the transcript. @M means the respondent is male. All codes were preceded with '@' to distinguish codes from text when searching the data with computer software. To protect potential identifications of informants these identifiers were not included in the final text.

Common themes were determined based on frequencies in multiple interviews using summarized interview notes and searching theme-related codes. These theme-related codes were searched using the edit/find function in MSOffice Word computer software. Theme files were compiled on disc. These files were then further analyzed into sub-category themes.

Quantitative Data Analysis

The SF-36 Health Survey was scored following the protocol specified in the Medical Outcomes Trust scoring procedures (Medical Outcomes Trust 1994a and 1994b). Scores were calculated individually and for the total group. Scoring was done manually using a four step process. The first step is item recoding where all responses to the health survey were recoded and assigned final item values. In the second step missing data was identified and a numeric value was calculated to substitute for this missing data. If a respondent answered at least fifty percent of the items in a scale, the scale score would be the average item score across completed items in the same scale using recoded values. (results indicated 0.23% missing data - see chapter eleven). The third step was calculating the raw scale scores for each

dimension. If the respondent answered at least half of the items in the scale, the raw scale score is calculated by summing across the items in the scale. The final step involves transforming each raw scale score to a continuum where 0 is the lowest possible score and 100 is the highest possible score. This transformed scale score can be interpreted as the percentage of the highest possible score. The transformed scale score is computed as follows:

$$\text{Transformed scale score} = \frac{(\text{actual raw scale score} - \text{lowest possible scale score})}{(\text{possible scale score range})} * 100$$

The scale score range is equivalent to the highest minus the lowest possible scale score.

These transformed scales can then be compared to population norms. The transformed scales for each health dimensions were compared to U.S. population norms and to studies of parallel technologies including: home parenteral nutrition, dialysis and ventilation.

Statistical comparison was conducted using t-tests. (See chapter eleven). To compare the sample group to U.S. population norms the following t-test was used:

$$t = \frac{\bar{x} - M_H}{\sqrt{\sum (x - \bar{x})^2 / n(n-1)}}$$

The difference between the sample mean(\bar{x}) and the population mean (M_H) are calculated over the standard error. Standard error is a measure of the variability between means.

When comparing the sample to other parallel technologies the following t-test was used:

$$t = \bar{x}_1 - \bar{x}_2 / s_p \sqrt{1/m_1 + 1/m_2}$$

In this t-test the difference between the means of the two groups are calculated over the standard deviation (s_p). Standard deviation measures variability between individuals.

III. Literature Review

Now that we have selected our research design, what evidence is present in the literature to support this decision. Quality of life is a difficult concept to capture both qualitatively and quantitatively. How does one measure quality of life? What ethnographies have studied quality of life? Is the SF-36 Health Survey an appropriate quality of life measurement tool for this population? The first section of this chapter will provide supporting literature for the methodological design of this research project.

The second section of this chapter will look at parallel technologies. There has been minimal documentation of what it is like to live on home enteral nutrition. As stated previously, an extensive bibliographic search produced no publications examining the impact of home enteral nutrition support on quality of life. Due to this limited literature, one needs to extrapolate information from the literature on other parallel technologies. These technologies include home parenteral nutrition, renal dialysis and ventilator support. In all these situations: the patients are dependent on medical technology for survival; there exists a physical connection to equipment; the method of treatment is invasive; and the frequency of treatment can be on a daily basis. Consequently, these populations may experience similar challenges. This section of the chapter will explain these challenges and provide a better understanding of the quality of life of individuals on home parenteral nutrition, dialysis and ventilator

support. Comparisons can then be made to our sample, the home enteral nutrition group.

Quality of Life:

What exactly is quality of life? Although most of us have some intuitive sense of what quality of life embodies, a precise definition remains elusive. “Quality of life is a vague and ethereal entity, something that many people talk about, but which no one clearly knows what to do about.” (Campbell, Converse and Rodger 1976, 471).

Attempts at establishing boundaries around the quality of life construct have proven difficult. “the idea has become a kind of umbrella under which are placed many different indexes dealing with whatever the user wants to focus on.” (Feinstein 1987, 639). No formal and generally accepted definition of quality of life exists in the literature.

The World Health Organization Quality of Life Group (1995) defines quality of life as an “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL GROUP, 1995, 1405). It is a broad ranging concept, incorporating in a complex way individuals’ physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment. The World Health Organization Quality of Life instrument is currently being developed and tested.

The author has made previous attempts, in a graduate paper entitled 'What is Quality of Life?' (Hotson 1993) to determine what is the construct of 'quality of life' or rather what is the consensus or disagreement on the construct of 'quality of life' as stated in the literature. A variety of terms equate quality of life with such attributes as life satisfaction, well-being, self-worth/self esteem, happiness, satisfaction of needs, achievement of personal goals, perceptions of well-being, health and value of life. (Hotson 1993)

Quality of life is multi-dimensional. What domains constitute the quality of life construct? A preliminary content analysis of twenty-six references, relating to the quality of life construct, was conducted. (See Appendix K). The most commonly cited domains in the literature were grouped into seven categories according to similarities. These categories were social function, health, socio-economic status, psychological/emotional well-being, perceptions of well-being, physical function and intellectual function.

Content analysis of ten qualitative studies looking at quality of life was also conducted (see Appendix L). New dimensions that were revealed in the qualitative studies included: integrated being, institutional life, recognizing a changed life, appreciation for life, being alive, concern for others, privacy, and coping. Integrated being refers to "a sense of wholeness within oneself in relation to the world," (Arruda, Larson and Meleis 1992, 390)

and "having accepted the illness and treatment, and as finding meaning in life as a result of the experience with the illness." (Arruda, Larson and Meleis 1992, 390). These new dimensions were noted by participants who experienced institutionalization, cancer, spinal cord injury, hemodialysis, bone marrow transplant or who were elderly.

Therefore, it is important to combine both qualitative and quantitative research methodologies in order to capture the varied responses that are obtained from both perspectives. It is also important to include health as a dimension when measuring quality of life. Research on valued states of existence have reported that health is the most valued state of quality of life (Bowling 1995).

"In relation to health, health status is increasingly referred to as quality of life...Health-related quality of life, like subjective health status, is patient based, but focuses more on the impact of a perceived health state on the ability to live a fulfilling life...Health-related quality of life is defined as optimum levels of mental, physical, role (e.g. work, parent, career, etc.), and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being." (Bowling 1995, 2-3)

Measuring Quality of Life:

Attempts at measuring quality of life have become more and more popular over time. In a 3 year period, from 1978 to 1980, one would be able to find approximately 200 published articles referring to QOL (Bowling 1991). In 1996, on the other hand, this has increased to over 1500 articles in a one year period. Interest in quality of life has definitely escalated in the past decade. Obviously, more and more researchers are attempting to measure quality of life. The question is are they truly

measuring QOL? In an article published by Schumacher, Olschewski and Schulgen (1991), 127 QOL articles were examined and they discovered that nearly half of the publications (47%) did not assess QOL seriously. Those that did not really assess quality of life, only looked at frequency of hospitalization or re-employment and labeled it QOL. This is a common problem when interpreting quality of life literature.

Quality of life can be measured using different techniques. Self-administered questionnaires represent the most popular method for assessing quality of life. Numerous quality of life measurement tools exist and a critical review of these indexes is beyond the scope of this report.

Most QOL measurement tools can be grouped into two categories - generic measures or disease-specific measures. Disease-specific measures, as the name suggests, are designed for specific disease states. Generic measures are designed for use across a broad range of chronic disease populations. The main advantage of generic measures is that they are “broadly applicable across types and severity’s of disease, across different medical treatments or health intervention, and across demographic and cultural subgroups.” (Patrick and Deyo 1989, S217). Due to their wide applicability, results across studies can be compared. Other advantages usually include rigorous development, validation and revalidation in a variety of research settings. The results are also more generalizeable. One of the most common

disadvantages of generic measurements is usually the length of time required to administer the tool and the complexity of the tool itself.

“The generic measure of choice across many diseases is increasingly the SF-36...the SF-36 is short, well tested and population norms exist” (Bowling 1995, 15). The SF-36 Health Survey is a generic outcome measurement for measuring health-related quality of life. The SF-36 includes one multi-item scale measuring each of eight health concepts: 1) physical functioning, 2) role limitations due to physical health problems, 3) bodily pain, 4) general health, 5) vitality (energy/fatigue), 6) social functioning, 7) role limitations due to emotional problems, and 8) mental health (psychological distress and psychological well-being) (Ware 1993).

The SF-36 Health Survey has been selected to assess health-related quality of life due to the fact that it is a generic measurement that can be conducted in approximately 5 to 10 minutes. It has been well tested within a variety of settings, languages and disease states. Conditions and treatment interventions where quality of life has been measured with the SF-36 include: dialysis, bowel cancer, esophageal cancer, head and neck cancer, home antibiotic therapy, irritable bowel syndrome, nutrition and weight loss to name a few (Ware 1993). Group results can be compared across studies and to population norms (Ware 1993).

Interviews represent the most flexible method of obtaining patient-based quality of life data. What studies have used ethnography to investigate quality of life?

Quality of Life Assessment Using Ethnography

It is difficult to capture ethnographies from the literature relating specifically to quality of life because ethnographers may not necessarily refer to their data as a source of quality of life information. When searching the medical literature for quality of life the following four ethnographies by Starck (1992); Laskiwski and Morse (1993); Doolittle (1992); and Arruda, Larson and Meleis (1992) were found.

Starck (1992) studied the management of suffering in a nursing home using an ethnographic study. It is the philosophy of the nursing home that socialization with one's peers and normalization of activities is essential to maintain a good quality of life. Yet, the losses which occur as persons age and as they give up meaningful symbols of life's achievements, create unavoidable human suffering.

“Without a support system to recognize suffering and to manage its devastating effects, there can be no complete quality of living (Starck 1992, 128).....Quality of life for people in nursing homes is intimately related to the quality of resident-staff relationship..., a basic sense of satisfaction with oneself, the environment, the care received, the accomplishment of desired goals, and control over one's life. It is enhanced by close relationships and meaningful interchange with others, by an environment supporting independence and incorporating personal belongings, and by the opportunity to exercise reasonable control over life decisions.” (Starck 1992, 131)

Choice is an important component to quality of life. Lack of privacy contributes to lack of self-esteem. “Opportunities to engage in religious, political, civic, recreational,

or social activities foster a sense of worth....Quality of life also includes such life circumstances as personal assets, financial security, physical and mental health, personal safety and security of one's possessions.”(Starck 1992, 144).

The impact of home enteral nutrition on these quality of life dimensions such as activities, social functioning, family, relationships, aging, and normalization are further discussed in chapters seven and ten.

In the second ethnography, Laskiwski and Morse (1993) studied patients with spinal cord injuries in a Spinal Cord Unit in Western Canada. Three types of data were collected using participant observations; tape recorded, unstructured interviews; and the use of field diary records of the researchers reflections, feelings and suppositions of ‘what was going on’. The purpose of this study was to determine “What is it like to anticipate living with a permanent disability?” Results indicated that one of the most devastating consequences of spinal cord injury was the loss of the former body. Their inner selves were the same but their outer bodies was now different. This inner self/outer self difference is also expressed by one of the home enteral nutrition respondents.

Patients with spinal cord injury are similar to the home enteral nutrition group with respect to their dependency on equipment. The spinal cord injury group depend on equipment to achieve independence. “Patients were upset to discover that ‘being in

the chair' interfered with their relationships with others" (Laskiwski and Morse 1993, 147). Control is an important aspect of quality of life for this patient group. They disliked being fed because this represented a loss of control. "Maintaining control of the situation demanded assertiveness" (Laskiwski and Morse 1993, 147). and patients achieved this through swearing.. "Swearing appeared to have five different functions in the spinal cord injury unit: to maintain personal space, to maintain the camaraderie of the group, to release emotions, to create personal space and to build facades." (Laskiwski and Morse 1993, 148).

In the third ethnography, Doolittle (1992) describes the experience of recovery following a lacunar stroke. A longitudinal, descriptive ethnography formed the basis of this study in which 120 interviews were conducted with 13 individuals, over a course of six months. Participants were interviewed within 72 hours of the infarct and during acute and rehabilitation phases of recovery. Interviews consisted of structured and unstructured questions about bodily perceptions, responses to disability, and definition and appraisal of recovery.

"Through the first-person descriptions provided by these people, we can better understand the human struggle of stroke. This struggle goes far beyond reaching functional independence. It is the story of becoming acquainted with a new, foreign body and struggling to regain a sense of bodily integrity. The story the patients share is the story of recovery of what matters to them, and their return to a meaningful life." (Doolittle 1992, 125)

Arruda, Larson and Meleis (1992) studied the meaning of comfort from the perspective of immigrant Hispanic cancer patients using ethnographical interviews.

The researcher conducted 30 half hour interviews with 10 Hispanic cancer patients undergoing chemotherapy treatment in a large medical centre in California.

Characteristics of comfort included: “feeling integrated, functioning and normalcy, care and nurturing, security and safety, control and ‘comodo’” (Arruda, Larson and Meleis 1992, 387). ‘Comodo’ is Spanish for “that is related to the concepts of accommodation and alignment and positioning of body parts” (Arruda, Larson and Meleis 1992, 391). Comfort needs evolved into 6 categories: nurturing, familiar environment, safety, quality of life, normalcy, and ‘animo’. ‘Animo is a Spanish word that “describes the need to have a positive mental disposition, drive, or energy to be able to face what one is going through” (Arruda, Larson and Meleis 1992, 392).

In all four ethnographies, a common theme emerges that is important to one’s quality of life. This common theme is ‘control’ or the ‘control’ over one’s own life decisions. The dimension of control is rarely captured in quality of life indexes. As stated previously, other components of quality of life that emerge from qualitative research and not reported in select quantitative studies include: privacy, spirituality, integrated being, familiar environment, appreciation for life, being alive, concern for others, coping and recognizing a changed life. (Hotson 1993).

These four ethnographies illustrate that quality of life can be studied using this methodology. Ethnographically-oriented interviews will enhance quantitative measurements by capturing dimensions of quality of life that are not routinely

investigated. On the other hand, a standardized measurement tool, such as the SF-36 Health Survey will provide a quantitative benchmark where results can be compared to population norms and to other patient groups of different parallel technologies. What does the literature say with regards to quality of life on these parallel technologies: home parenteral nutrition, dialysis and ventilator support?

Quality of Life and Home Nutrition Support

Despite the fact that very few studies have looked at the impact of home **enteral** nutrition support on quality of life, several references have looked at the impact of home **parenteral** nutrition (HPN) on quality of life.

Herfindal et al (1989) surveyed 347 out of 1140 HPN patients in United States using a scale developed by Campbell, Converse and Rodger (1976) to assess QOL. The scale included a multitude of subjective indicators of quality of life such as: Index of Well Being, Psychological Affect, Overall Life Satisfaction, Positive/Negative Affect Scale, and the Affect Balance Scale. When they compared the HPN patients scores to Evans et al.'s (1991) end-stage renal disease (ESRD) population and the United States population scores, these QOL scores demonstrated that the HPN patients perceive that they have a QOL somewhat lower than the ESRD population as well as the American population as a whole.

Herfindal et al. (1989) compared the HPN population to the ESRD population because they felt that these two groups are confronted with similar problems. Both groups are dependent on medical technology for survival. Herfindal et al. (1989) proposed that the reasons why the HPN population perceive their QOL to be somewhat lower than the ESRD population may be due to two reasons. The first reason is that the ESRD population is a cohesive group with similar diagnoses and problems whereas the HPN population is a group with more diverse and complex disease states. The second reason may be that the ESRD patients have regular contact with other patients receiving similar treatments and with health care professionals since they have routine dialysis within a hospital setting. This provides patients with the opportunity to communicate their problems and share similar disease experiences resulting in group identity. Home parenteral nutrition patients, on the other hand, tend to be isolated from other patients and health care providers.

The indicators of quality of life used by Herfindal et al (1989) did not address health related quality of life. Campbell, Converse and Rodger (1976) developed these tools with the intent of assessing the quality of life/standard of living of the average American population. This author believes that when measuring quality of life, especially in a chronically ill population, health is an important component.

In 1986, Detsky et al. interviewed 37 patients receiving HPN in Toronto, Ontario. The purpose of these interviews were to derive QOL scores before and

during HPN. Three techniques were used to assess QOL: category scaling, time trade-off and direct questioning of objectives. The category scaling method anchored presented a continuous rating scale where “dead” was scored a 0.0 and “healthy” a 1.0. In the time trade-off technique, patients were asked to trade a quantity of survival for improvements in quality of life. In the third technique, direct questioning of objectives, the researchers elicited a ‘list of objectives in life’ from each patient and each objective was weighted by the patient as to their ‘importance’. The investigator then used category scaling to measure, on a scale of 0 to 1.0, the patient’s ability to achieve each objective before and during HPN. The QOL scores while on TPN were reasonably good (0.73) for all three techniques. For those individuals who had experienced periods of chronic malnutrition prior to HPN, QOL had improved on HPN.

Recall bias is a significant potential problem with Detsky’s data. All patients were interviewed after they had been on HPN for varying time periods and were asked to recall their lives before HPN. Another problem is that the interview schedule was pretested with nine medical personnel. According to Bach and Campagnolo (1992) medical professionals underestimate quality of life for their patients despite the fact that they are very familiar with the patient group. The validity and reliability of the newly developed portion of this tool (‘direct questioning of objectives’) is also not documented.

Smith (1993) interviewed 116 families and patients to determine the quality of life in long-term TPN patients and their family caregivers. Quality of life was assessed using a battery of tools such as QOL Index, Rosenberg's Self-Esteem Scale, the Center for Epidemiologic Studies Depression Scale, and Cantrill's Self-Anchoring Scale. The QOL Index score was similar to that reported for groups of chronically ill patients requiring hemodialysis or peritoneal dialysis, liver transplant and chemotherapy. The QOL Index score was above the mean score for cancer patients experiencing pain. Psychological, fiscal and social problems included: 1) missing out on activities because of problems with scheduling disruptions and fatigue; 2) worrying about infections; 3) worrying about the disease; and 4) financial problems. Some patients stated "*TPN is not the problem; the [underlying disease] is.*" (Smith 1993, 504). Even with these problems the TPN (Total Parenteral Nutrition) technology was highly valued as life sustaining and therapeutic by these families.

Galandiuk et al.(1990) performed a retrospective analysis of 41 patients with Crohn's disease, whom were placed on home parenteral nutrition, to determine whether HPN had an effect on the course of their disease. Numerical assessment of quality of life was incorporated into the data collection. Quality of life was assessed via three scores: a quality of life score, a social activity score, and a psychological well-being score. In all cases, a score of '1' indicated no change from the pre-illness state, a score of '2' referred to a 50% reduction of well-being, and a score of '3' referred to severe disability. The sum of these three scores was referred to as the

overall quality of life score. Data regarding quality of life was obtained via telephone interviews or via medical charts in the case of deceased patients. The scores were obtained for the pre-HPN period as well as the HPN period. The authors concluded that “HPN appeared to result in a significant improvement in the numerically assessed quality of life.” (Galandiuk et al. 1990, 540).

The QOL score used by Galandiuk is not referenced and therefore one may assume was developed specifically for this study by the researchers. No comment is provided regarding the validation or reliability of this tool. The pre-HPN QOL scores are also subject to recall bias. Determining quality of life data from a medical chart of deceased patients is also subject to bias since it is based on the researchers interpretation.

Ladefoget (1980) assessed the quality of life of 13 patients on permanent home parenteral nutrition. QOL was assessed using the following criteria: 1) no major physical distress, 2) no major psychological symptoms, 3) no substantial restriction of social and leisure activities, 4) ability to accept HPN, and 5) overall satisfaction with conditions of life. Two-thirds of the patients (N=9) fulfilled at least three of these criteria and were assessed to have a ‘fair’ quality of life.

Robb et al. (1983) performed a subjective assessment of patient outcomes of home parenteral nutrition. A written questionnaire administered to 42 patients was

used to describe the demographic, medical, financial, and psychosocial characteristics of their HPN patient population. Most patients believed HPN had a very positive effect on their lives and their HPN program appears to provide them with a reasonable quality of life. The reliability and validity of the tools used to assess quality of life in this study and in Ladefoget's (1980) study have not been documented.

The last two references in the literature that looked at the impact of home parenteral nutrition on quality of life were research studies conducted by Burnes et al. (1992) and by Johnston and Pennington (1993). Both articles did not address the multi-dimensional aspects of quality of life and therefore did not truly measure quality of life per se. Burnes et al. (1992) only looked at physical functioning while Johnston and Pennington (1993) looked at hospitalization and re-employment.

Overall, the consensus appears to be that the quality of life of individuals receiving HPN is reasonably good or fair, similar to or slightly below other chronically ill patients and somewhat below the norm for the American population as a whole. Those studies that compared pre-HPN to HPN periods documented an improvement in quality of life among individuals using home parenteral nutrition. Psychological, fiscal and social problems reported included missing out on activities (scheduling disruptions, fatigue), worrying about infections, worrying about the disease, and financial problems. Are similarities found in other technology-dependent situations?

Quality of Life and Hemodialysis

Some studies have compared home parenteral nutrition to hemodialysis due to the fact that patients are dependent on medical technology for survival and it is believed that both populations are faced with similar challenges. (Smith 1993; Robb et al. 1983). What important factors can one extrapolate from this literature since the nutrition literature is limited?

The quantity of information about quality of life among people using hemodialysis is beyond the scope of this report. The majority of literature pertains to the difference in quality of life during various forms of treatment (i.e. hemodialysis versus peritoneal dialysis versus renal transplant versus erythropoietin therapy). Since end-stage renal disease patients illness states are more homogeneous than those with nutrition support, researchers use more disease-specific tools to assess quality of life rather than using generic measurements. Therefore, it is difficult to establish a popular measurement for quality of life from this literature than can be applied to the nutrition support population. The most commonly used broader outcome indicators in the renal population include generic life satisfaction measures, dialysis-specific health-related quality of life scales, functional ability and health status measures (Bowling 1995).

Evans et al. (1985) used a range of indicators of life satisfaction, psychological well-being and also the Karnofsky Performance Index to compare the effectiveness of alternative dialysis methods for 859 patients with end-stage renal disease. The quality

of life scores indicated patients with end-stage renal disease perceive that they have only a slightly lower quality of life than the general population. In treatment-specific comparisons, however, only transplant recipients have a subjective quality of life that did not differ significantly from that of the general population. Conversely, quality of life measured by objective standards (functional impairment and the ability to work at a job for pay) was rated as poor for the dialysis groups. "In short, patients on dialysis are clearly not functioning like people who are well, despite the fact that they are enjoying life." (Evans et al. 1985, 557). These results have been confirmed by others (Simmons and Apress 1990; Bremer et al. 1989; Evans 1991). This strengthens the critical literature which ascribes that one should not place great emphasis on functional ability and work status to determine quality of life. The patients' perspective, not objective data is the important indicator.

Molzahn (1991) reported the quality of life of selected home hemodialysis patients using a descriptive qualitative research design. Ten patients were interviewed using a semi-structured interview guide and asked to complete a series of card sort tasks. The technique is 'pile sorting' where the individual is asked to sort cards into like categories. The theoretical framework for the interview and card sort tasks was the Aristotelian-Thomistic philosophical theory of the good life. According to this theory, seven types of real goods are required to have a good life. These goods include: goods of the body, goods of the mind, goods of character, goods of personal association, social goods, economic goods, and political goods. "The responses of

patients in this study indicated that most of the patients possessed goods of personal association [relationships with people] and economic goods. However, more than half of the subjects indicated that they were lacking health, vigor, pleasurable feelings, freedom of action, and free time, to some extent.” (Molzahn 1991, 179).

According to the Aristotelian-Thomistic philosophical theory, the most important goods are goods of the mind and goods of character. The home hemodialysis patients did not necessarily rank these as having the greatest importance. Goods of personal association and goods of the body were ranked as the most important. This could be explained by the fact that these goods are needed before hemodialysis patients can attain other goods. One of the patients also commented that he would not have ranked goods of the body as high if his health had been normal. (Molzahn 1991). This also strengthens the argument that health is an important component of quality of life when one is chronically ill.

Quality of Life and Ventilator Support

Another patient population that is dependent on technology for survival are those dependent on home ventilator support. To the author’s knowledge home parenteral patients has never been compared to this population. Both groups have diverse illness states necessitating the technology, both require technology on a daily basis for survival, and both implement the technology in their homes and not in a group setting such as dialysis. Illness states or sources of impairment for ventilator

dependent patients may include: spinal cord injury, residual paralysis or late onset effects of poliomyelitis, chronic obstructive pulmonary disease, and neuromuscular disorders. In the literature comparisons of the experience of ventilator users to hemodialysis patients have been made (Moss et al. 1996). What can one extrapolate from this literature that might prove to be similar with those dependent on home enteral nutrition?

Kaufert and Locker (1990) studied ventilator dependent patients using “life historical analysis and ethnographic observation of adaptations in everyday living to examine the shifting relationships between technological systems, the culturally-based ideologies of consumers and professionals and the careers of people with post-respiratory poliomyelitis.” (Kaufert and Locker 1990, 867). These authors used the concept of careers based on the belief that “chronic disabling conditions should be viewed as a series of conceptually distinct but empirically overlapping biophysical, functional, social and psychosocial careers.” (Kaufert and Locker 1990, 868). Data was collected during a follow-up study of survivors of the major Manitoba poliomyelitis epidemic of the 1950’s. Out of 186 individuals who had been placed in a tank respirator during the acute phase, a sub-group of 29 people continued to require mechanical ventilation for more than 12 hours per day. Ten people were selected from this group and interviewed in depth. All had major limb disability in addition to respiratory impairment.

Kaufert and Locker (1990) found that those individuals “who used a ventilator with a mouth tube tended to be less impaired than those with a tracheostomy and were able to breathe independently for up to 12 hrs/day.” (Kaufert and Locker 1990, 873). Those that were told to use the machine for short periods of time but frequently found that too disruptive to their daily living. “Many had developed their own routines that were more compatible to the time and activity patterns of their everyday lives” (Locker, Kaufert and Kirk 1987, 167). Individuals had to find ways of “managing limited reserves of energy” (Kaufert and Locker 1990, 873) and “people had to stick to a fairly strict daily routine involving periods of respiratory support.” (Locker, Kaufert and Kirk 1987, 167). Their “lives became organized around the conservation of energy” and they could not stay away from home for too long due to insufficient energy levels. (Kaufert and Locker 1990, 873).

On the other hand, those who were connected to the ventilator by a tracheostomy, felt they were mobile, less regimented and oxygen and energy levels were not problematic.

“Permanent connection to a ventilator by a tracheostomy freed the individual from these daily routines and the constraints they involved. At the very least, continuous ventilation by a portable machine meant that the person was never forced to stay at home” (Locker, Kaufert and Kirk 1987, 168).”

“Both physical and psychological health improved substantially and combined with a high degree of mobility, transformed the quality of everyday life... The main benefit was an increased supply of energy and a greater zest for living. They not only achieved more during the course of the day, but felt like achieving more.” (Kaufert and Locker 1990, 874-875).

Alcock et al (1984) also documented that many of the patients preferred to use the equipment continuously. "These respirators afford greater mobility because they are attached to an electric wheelchair or walker." (Alcock et al. 1984, 1308).

Bach and Campagnolo (1992) looked at life satisfaction of individuals with post-poliomyelitis who were ventilator dependent. They used Campbell's Scale of Life Domain Satisfaction Measures, Semantic Differential Scale and General Affect scales. These three survey instruments were distributed by mail. Their 'control group' consisted of 273 health care professionals from a trauma centre or two rehabilitation hospitals with ventilator units. The controls were surveyed about their own life satisfaction and were asked to judge how severely disabled ventilator assisted individuals would respond to each questioning.

When the ventilator users with post-polio impairment were compared with members of the control group they

"were significantly less satisfied with their transportation, education, health, social lives, sexual lives, and with life in general. They were significantly more satisfied with their housing. There were no significant differences between the groups when comparing satisfaction with family life and employment, although there was less patient experience with the latter domain. With the exception of health, however, they were generally satisfied in each domain." (Bach and Campagnolo 1992, 935).

Those individuals who used noninvasive methods of ventilator support (e.g. connections through a face mask or mouth piece) reported a higher life satisfaction score than the tracheostomized group. The control group significantly underestimated

the ventilator assisted post-polio individuals' satisfaction with life. Bach and Campagnolo (1992) concluded that:

“many severely disable post-poliomyelitis ventilator users lead productive lives. The vast majority have a positive affect and are satisfied with life. Noninvasive ventilatory support alternatives may lend to greater life satisfaction for these individuals than ventilation delivered via an indwelling tracheostomy. Health care professionals may significantly underestimate their patients' satisfaction with life and this may have a bearing on patient management.” (Bach and Campagnolo 1992, 934).

These finding were supported in other patient populations including traumatic tetraplegia (Bach and Tilton 1994) and neuromuscular disorders (Bach 1992).

What are some of the reasons patients preferred noninvasive methods and some preferred tracheostomies? A mail survey was conducted by Bach (1993) eliciting some of these reasons from 168 ventilator users. Reasons for preferring tracheostomies included: “facility in clearing airway secretions during respiratory tract infections;...greater mobility by comparison with body ventilator use;...[and] better speech than with use of mouth [piece]” (Bach 1993, 1703). Reasons for preferring noninvasive aids included: “greater independence and control of breathing;... facilitation of management in the community;...suctioning no longer needed or absence of secretions;...greater portability or less equipment, supply needs, and upkeep;... greater mobility;...fewer infections;...and more natural” (Bach 1993, 1705).

How do the life satisfaction scores of ventilator dependent individuals with post-poliomyelitis, traumatic tetraplegia and neuromuscular disorders compare to

individuals on home parenteral nutrition? Comparisons can be made because these studies used Campbell's scales when scoring life satisfaction. The life satisfaction scores for the home parenteral nutrition group was 4.4 ± 1.9 (Herfindal et al. 1989). The tracheostomy post-poliomyelitis individuals scored 4.6 ± 1.8 (Bach and Campagnolo 1992). The tracheostomy tetraplegia individuals scored 4.03 ± 1.91 (Bach and Tilton 1994) and the neuromuscular disorder respondents scored 4.94 ± 1.3 (Bach 1992). The home parenteral nutrition group falls within the same life satisfaction score range as these patient populations.

As shown by this literature review similarities do exist between parallel technologies. Very little is known about what it is like to live on home enteral nutrition. Some knowledge can be gained by reviewing other forms of life supporting technology and determining its impact on quality of life and daily existence.

Quality of life of individuals receiving home parenteral nutrition is most often rated as reasonably good or fair and somewhat below the norm for the American population as a whole. Psychological, fiscal and social problems include missing out on activities because of scheduling disruptions and fatigue; worrying about infections; worrying about the disease and financial problems.

Quality of life of individuals receiving hemodialysis are also reported as slightly below the general population. Some hemodialysis patients commented that they were

lacking health, vigor, pleasurable feelings, freedom of action and free time to some extent. Health is considered an important component of quality of life for this patient population.

Quality of life of individuals receiving home ventilator support raised issues regarding mobility, strict daily routines and the issue that portable continuous machinery freed individuals from these strict routines. The vast majority were satisfied with life and health care professionals significantly underestimated their patients' satisfaction with life.

Qualitative research using ethnographically oriented semi-structured interviews will help capture lived experiences. This will not only provide a vehicle for these individuals to tell their story but will also expand the knowledge of the health care professionals who prescribe this treatment. The SF-36 Health Survey will provide a benchmark assessment of quality of life that can be compared to population norms and across different patient groups using parallel technologies. Health care professionals have difficulties estimating their patients' quality of life. Therefore, it is essential for health care providers to understand the implications of home nutrition support regimens in order to help improve or enhance their patients' quality of life.

IV. Who are the People?

Who requires home enteral nutrition support? What are the characteristics of the Manitoba Home Nutrition Program respondents? A profile of the respondents' socio-demographic characteristics, tube feed characteristics, treatment duration, illness states, weight history and whether or not they consume food is presented in this section. Following the general description of the study sample, case studies of four selected informant narratives are then described. These encapsulated narratives enable the researcher to set the stage of what life is like on home enteral nutrition and highlight many of the themes that will be covered in subsequent chapters.

Demographic Characteristics:

Twelve individuals receiving home tube feeds were interviewed for the purposes of this study. All individuals were residents of Winnipeg, living in eleven different areas within the city. Eleven respondents lived in single dwellings and one lived in a senior's home. The mean length of residence was 19 years (median = 21) with only two individuals moving since they had started tube feeds. Only one moved due to health reasons and that was the one residing in the senior's home. This same individual was the only respondent that lived alone. The mean number of people in the households were 3 (median = 3.5). All respondents had relatives living in Winnipeg and talked to them frequently. Only one respondent did not talk to his relatives frequently and that was due to the fact that he was no longer able to speak.

Table 2: Background Information on MHNP Respondents:

Respondent	Sex	Cancer	Age	Duration (Months)	Tube Feed Hours	Perm/Temp Status	Day or Night Feeds	Pump or Gravity	Bolus or Continuous (mls)	Volume	Calories (kcal)
1	M	Yes	42	3	11	Temporary	Night/Evening	Pump	Continuous	2880	3032
2	M	Yes	38	3	17	Temporary	Night/Day	Pump	Continuous	2500	3725
3	F	No	49	18	2.25	Permanent	Day	Gravity	Bolus	940	940
4	M	Yes	76	4	6	Temp/Perm?	Day	Gravity	Bolus	1750	1750
5	F	Yes	72	95	1	Permanent	Day	Syringe	Bolus	1175	1175
6	F	Yes	79	4	14	Permanent	Night/Evening	Pump	Continuous	1175	1763
7	M	No	48	30	7	Permanent	Night/Day	Pump	Continuous	1645	2468
8	M	Yes	65	9	1	Permanent	Day	Gravity	Bolus	1000	1000
9	M	No	25	132	8	Permanent	Night/Day	Pump	Continuous	1250	1250
10	M	Yes	78	20	2.25	Permanent	Day	Gravity	Bolus	940	1645
11	M	No	85	30	2	Permanent	Day	Gravity	Bolus	1422	2147
12	F	No	44	3	8	Temporary	Night	Pump	Continuous	940	1307
RESULTS:											
MEAN			58.42	29.25	6.63					1466.42	1850.17
MEDIAN			57	13.5	6.5					1213	1698

Table 2: Background Information on MHNP Respondents (cont):

Respondent	Assistance	MHNP (months)	Weight	Current Weight (lbs)	Usual Body Weight	% Usual Body Weight	Residence	Residency (years)	Moved since T-F's	Marital Status
1	No	3	Same	185	210	88.1	Split	4	No	Married
2	No	2.75	Gained	161	174	92.5	2 storey	3	No	Married
3	Yes	18	Gained	114	150	76	Bungalow	24	No	Married
4	No	4	Same	184	220	83.6	Bungalow	20	No	Married
5	No	84	Same	117	135	86.7	Bi-level	5	Yes	Widowed
6	No	2	Gained	78	95	82.1	Bungalow	22	No	Married
7	No	30	Lost	130	200	65	Bungalow	27	No	Married
8	No	9	Same	149	150	99.3	Bungalow	21.5	No	Single
9	No	12	Same	132.5	132.5	100	Bungalow	21	No	Single
10	Yes	6	Same	123	123	100	Bungalow	50	No	Married
11	No	30	Lost	155	175	88.6	Senior's Home	30	Yes	Widowed
12	No	3	Gained	94	95	98.9	Bungalow	2	No	Married
RESULTS:										
MEAN		16.979		135.2	155	88.4		19.125		
MEDIAN		7.5		131.3	131.25	88.3		21.25		

Table 2: Background Information on MHNPs Respondents (cont):

Respondent	Number of Children	Household: # people	Relatives in Wpg	Talked to Relatives	Education	Employment	Food	Meals
1	2		4 Yes	Yes	Partial University	Leave	No	No
2	2		4 Yes	Yes	University	Leave	No	No
3	3		4 Yes	Yes	High school	Part time	Some	No
4	3		2 Yes	Yes	High school	Retired	Some	No
5	4		4 Yes	Yes	High school	Retired	No	No
6	2		2 Yes	Yes	High school	Retired	No	No
7	3		3 Yes	Yes	Graduate degree	Leave	Some	No
8	0		2 Yes	Yes	High school	Retired	Yes	Yes
9	0		4 Yes	Yes	Partial University	Student	Yes	Yes
10	2		2 Yes	No	Junior High	Retired	No	No
11	7		1 Yes	Yes	Junior High	Retired	No	No
12	2		4 Yes	Yes	Partial College	Leave	Some	No
RESULTS:								
MEAN	2.5		3					
MEDIAN	2		3.5					

Eight respondents were male and four were female. All respondents were adults, ranging in the ages of 25 to 85 years, with a mean age of 58.4 years (median = 57). Marital status included eight who were married, two who were single, and two who were widowed. The number of children each respondent had varied from zero to seven, with the mean being 2.5 children (median = 2). Educational background varied with the majority completing high school [junior high (n=2), high school (n=5), partial university (n=3), university (n=1) and graduate school (n=1)]. Nine respondents were Protestant, two were Catholic and one was classified as other.

Six of the respondents interviewed were retired, four were on a leave from work due to illness, one was a student, and one worked part-time. Eleven different occupations were represented in this group. Family income were categorized as follows: <\$20,000 (n=2); \$20,000-\$40,000 (n=1); \$40,000-\$60,000 (n=5); and >\$60,000 (n=4). The majority of the group had a family income >\$40,000.

Illness States:

With regards to illness the respondents can be divided into two major groups, that being cancer (n=7) and non-cancer (n=5). Those in the cancer group included six individuals with head and neck cancer and one with cancer in the gastrointestinal tract. The non-cancer group included illnesses such as neuromuscular diseases, pancreatitis, Crohn's, stroke, and motility disorders.

Home Enteral Nutrition Regimen:

How long have these people been on home tube feeds? The length of time ranged from three months to eleven years. The mean number of months was 29 (median = 13.5). The average length of time that these individuals were followed by the Manitoba Home Nutrition Program was 17 months (median = 7.5). How many hours are they tube feed? The number of hours ranged from one to 17, with the mean being 6.6 hours every 24 hours (median = 6.5). Six respondents fed themselves at night and six fed themselves during the day. Subsequently six respondents fed themselves using a continuous infusion while six fed themselves using a bolus method. Continuous infusions were typical of night feeders and bolus infusions were typical of day feeders. Six individuals used a pump to infuse their tube feeds, five used gravity drip and one used a syringe.

Home Enteral Nutrition Characteristics:

Eight different tube feed products were used by the group including Jevity, Nutren 1.0, Nutren 1.5, Nutren 2.0, Isocal HN, Boost, Resource Plus and elemental products. The average volume fed in a 24 hour period was 1466 mls (median = 1213 mls). The number of calories infused ranged from 940 kcals to 3725 kcals, with the mean being 1850 kcals (median = 1698). Six of the respondents had maintained their weight over the past three months, four had gained weight and 2 had lost weight. The average weight of the group was 135.2 pounds which was 88.4% their usual body

weight. Eight of the respondents were on home tube feeds permanently, three were temporary and one individual was just recently told that he may no longer be on tube feeds temporarily and that it might be a permanent situation. Only two of the twelve respondents required assistance with their tube feeds. Family members or nurses assisted these individuals with administering their tube feeds.

Out of the twelve individuals interviewed, six individuals did not consume food at all, four consumed minimal amounts of food with difficulty and two were able to consume moderate amounts of food. Those who consumed moderate amounts of food did consume regular meals. Those who consumed minimal amounts of food did not consume food at regular meal times.

As one can tell by the above information the individuals interviewed were a diverse group. In order to provide a sense of the informant's perspective on home enteral nutrition, four sample interviews will be described. These case studies were selected based on age, sex, bolus or continuous feeds, method of tube feed administration, night or day feeds, illness states, and duration of time receiving enteral nutrition support. These four examples may represent typical individuals receiving home nutrition support.

Barb's Narrative:

Barb is a 44 year old female with a malfunctioning gastrointestinal tract requiring total nutrition support via home tube feeds. Barb has just recently started tube feeds in the past three months. At the beginning of therapy Barb was feeding herself for fourteen hours. She now feeds herself for eight hours starting at 10:00 PM and finishing around 6:00 in the morning. Barb runs her tube feeds continuously at 100 mls/hour using a pump while she sleeps. With this feeding regime Barb consumes approximately 1300 calories per day. During her acute illness her weight had declined significantly and with this nutritional support she has returned to her usual body weight within the past three months. With Barb's medical condition there is the belief by the respondent that the tube feeds are only required for a temporary period.

Barb has taken the liberty of adjusting her own tube feeds by decreasing the volume infused since she is satisfied with her current weight status. This weight goal does conflict with the goal set by the Manitoba Home Nutrition Program and this concerns Barb because one of the differential diagnosis for her disease state was Anorexia Nervosa. Barb is very cognizant of this fact and does not want any misconceptions. The fact that this diagnosis was considered disturbs Barb and she is now afraid to mention goal weights with the MHNP:

Barb: "But I'm also sometimes afraid to mention it because then they, I don't want to be labeled as anorexic cause that's what I put up with for months before I was diagnosed."

Interviewer: "Oh."

Barb: "Are you anorexic? Now if I had been a man, I know I wouldn't have been asked that. But because I was a woman. Uh, huh. So I don't want to be labeled as that either and I don't think it's unrealistic to want to be [x] pounds at my height and I don't think there's anything about wanting to be anorexic or anything to do with being anorexic at wanting to be that weight but I'm afraid to mention it because Dr. Yaffe is always there and he asked me a number of times if I was anorexic, before they started to investigate what the problem was."

Interviewer: "Oh, okay."

Barb: "So, but I don't believe that forty year old people just become anorexic either, which I try to tell them. I mean, we're not runway material anymore or, or teenagers....."

Interviewer: (laughs) "Runway material."

Barb: "You know, it's not like we're strutting around in a, in a what do you call it?"

Interviewer: "It's a runway."

Barb: "Runway. Runway. Yeah, we're not doing that and I don't want to and I'm not wearing a bikini anymore, you know, I'm not..."

Interviewer: "You're not striving for that."

Barb: "No, that's not, I just want to feel good in my clothes that I own. (both laugh) You know, but anyhow. So I've sort of been, I'm not sure how I am going to tell them this."

Before Barb was diagnosed with her medical condition she had gastrointestinal problems for approximately two years, and it progressively got worse until the pain was so great she quit eating. Over the first year she did have some tests but things 'went slow'. Provisional diagnoses varied as they searched for a definite diagnosis. Barb was eventually hospitalized for seven weeks and it was during that hospitalization that she was finally diagnosed and informed that she would require tube

feeds. During her hospitalization a feeding tube was surgically placed. What were her thoughts when they first told her she had to go home on tube feeds?

Barb: "I was, I was very surprised. Uhm, when I first went into the hospital there was a big possibility that I had pancreatic cancer. Cause every time I had a CT scan it showed that I had something on my pancreas.....So when I found out that it wasn't, when I had the MRI done and they discovered that it wasn't anything on my pancreas and that it was a stomach problem I was relieved at first.....And even, even with the talk of tube feedings I was relieved so at that point. But, I don't know. I guess I was shocked. I cried a lot in the hospital, in the beginning when I, when I had to go for the tube feeding, like when I had to go in and have the, when I had to go for surgery to have the tubes put in. I cried a lot before then and I cried a lot after.....But uhm.... and by that point I knew I would have to go home with it. So.... depressed I guess.....Yeah. More, more upsetting then actually depressed. I've never been a depressed person."

Interviewer: "Okay."

Barb: "Like I have moments where I, I cry, I mean I'm a women, I cry as easy (both laugh), I cry very easily. And I get down, I find most evenings I'm down because I hate the tube."

Pain at the Ostomy Site:

Since the operation, Barb finds that she still has a lot of pain from the tube and continues to have gastrointestinal pain from feeding. Barb believes that the pain from the tubing is permanent and the reason for the pain is that the tube is a foreign object in her body.

Interviewer: "Do you think it's uh, it'll be a temporary pain, or something that may always kind of be there?"

Barb: "I think it's something I have to live with, that it'll always be there."

Interviewer: "It'll always be there."

Barb: "Yeah."

Interviewer: "Versus just the surgery type pain then."

Barb: "MmmMmm. I mean it's a foreign object, it's, like with surgery you, you have the pain initially and then it lessens and lessens and goes away."

Interviewer: "Yeah."

Barb: "Where as this is, I think it's always going to be there, it's a foreign object in my body. I can't imagine people not having pain, when they tell me that pain, that people get use to it very quickly and easily and I'm not a suck (both laugh). I don't think I am. I've always had good pain tolerance."

Impact on Sleep:

This pain disturbs her sleep. Her sleep is also disturbed by numerous washroom visits and the fact that she is still not accustomed to sleeping in a different position. Barb has to sleep on her back with a wedge propped behind her head. Barb frequently wakes up tired.

Restrictive Nature of the Tube Feed Regimen:

Barb refers to her tube feeds as restrictive and hates being tied to the pole.

The pole is very difficult to move around the house

Barb: "It's frustrating, cause I've always been a very active person. So I find it restraining."

Interviewer: "Restrained at, at the fact that it takes so long?"

Barb: "Yeah and that I'm tied to this pole and everywhere I got to go I got to take this pole with me and this tube is hanging, you know.....And I find that if I'm tied to it during the day that it really restricts me I mean I'm bumping into anything with this pole. It's huge, you know, it's a big wheel base on it."

Impact on Social Life:

Barb finds that the tube feeding regimen impacts on her social life to some degree. She finds that she never stays out late at night anymore because she needs to return home in time to begin her nightly routine. Her nightly routine consists of a bath and then she hooks herself up to the tube feeds. As a result of this shorter evening, she does feel she misses out on things, such as Rainbow Stage, parties, and family gatherings.

On the other hand, the tube feeds have had little impact on her social life during the day. A couple of times a week she will go out with her friends to shops and restaurants. Her friends will eat lunch and she will consume either tea, water or some small amounts of specific foods that she can tolerate.

Missing Favourite Foods:

In the following narrative Barb explains how food can literally jump out at you and stare holes right through you when you cannot consume foods normally. It begins with the rationale for eating in restaurants:

Barb: "I'd rather be with them, and so they are eating, I rather be with them than not. I'm not, and I find a lot of my friends are very apologetic for eating in front of me and I think that, and I always tell them that's silly. I mean you got to eat to live. I can't eat. So.....uh food jumps out at me. I mean, it stares holes through me. Cause I love food. But uh, and I had tried tasting food when I've been with them. I've taken bites of their food to taste it.....And sometimes, sometimes I uh, sometimes very instantly depending on what it is I have tremendous indigestion and this pain, like food is stopped here and it hurts. Sometimes not, sometimes a little later it'll bother me. Sometimes not."

Interviewer: "Do you uhm, does it bother you when they're, they're eating in front of you at all.... other than what you mentioned about the?"

Barb: "Other than I wish I could eat it no. No."

Interviewer: "Are you satisfied when you have like just a taste of it."

Barb: "Yes."

Interviewer: "And then the...."

Barb: "Yes, especially if I have indigestion pain after, yes, I'm very satisfied with and I think how silly why did I do that."

Interviewer: "Do you miss it then? After you've tasted it and had the pain, does that...."

Barb: "Want me to wish that I had more, yeah. Do I miss it. Yeah."

In the previous quote Barb mentions about missing food. When asked 'What is it about food that one misses the most?' Barb answers this question and gives us some idea on her coping mechanisms:

Barb: ".....Taste of food. It's the taste of food that you miss. I get a lot of discomfort from food but I still love it."

Interviewer: "What is it like to hardly ever eat food?"

Barb: "Horrible. I still crave foods, especially my favourite foods, like a pita, Subway. Oh I just love food.Oh it jumps out at you, it's everywhere, TV, everywhere. I've never noticed it before. It's always on your mind."

Interviewer: "What do you do when you're thinking of food."

Barb: "Go quilt, listen to music."

Self Image:

Missing food is not the only negative aspect of tube feeds. Barb notices that her self image has suffered as a result of the tube protruding from her stomach.

Barb: "Yes, I think my body looks gross with this tube hanging out of it. Not that I ever strutted in a bikini or anything or was runway material or anything but.... Yes, I think it kind of looks gross, my stomach kind of protrudes, it never did before. It does."

Barb: "I remember when it was first put in I hated looking at it. I hated touching the area. Now I clean it regularly. Uh, it's not gross to me to look at. It never was gross looking at anybody else's but when it's your own. (both laugh) Uhm, I, I find I don't like my husband seeing it. Cause I don't, I don't want, you know, I, I think it's, it is gross, to me, that I don't like him to see it. He doesn't care. He, he's got a good attitude. He doesn't care at all that it's there. (tears).... Yeah."

.....

Barb: "And I think that he, he's going to think the same as I think about it, so I just soon he not see me that way. It's silly, I'm sure of it. I, I know that uhm, I know that a lot of men wouldn't tolerate a women this way either, so. And yet he does."

Interviewer: "Okay."

Barb: "And I'm very grateful for it. And yeah, I know a lot of men that this would be no big deal to them either. But, I mean you often hear of uhm, one of the girls I worked with sister was diagnosed with breast cancer and her husband refused to let her have a mastectomy and of course she died, not even a year later, and he of course remarried a week later or two weeks later, yeah that kind of thing, you know a month later or whatever. So....."

Interviewer: "Wow."

Barb: "You know, there's a lot of those men out there that wouldn't tolerate something like this."

Quality of Life:

Despite the changes in Barb's life she still finds her quality of life good and that the tube feeds and her medical condition have only slowed her down.

This narrative introduces themes such as impact on sleep and impact on social life that are discussed in chapter seven: Management of Tube Feed Regimens. This chapter also covers the restrictive nature of the tube feed regimen but specific reference to the intravenous pole is discussed in chapter six. The themes involving the impact on social life and missing favourite foods are found in chapter ten on Quality of Life: Qualitative Analysis.

John's Narrative:

John is a 74 year old male with neck cancer who has undergone radical neck dissection. In one month John had lost approximately forty pounds. Surgery and treatment has now left John with a swallowing disorder. To improve his swallowing he currently attends regular sessions with the speech language therapist and practices alternate swallowing methods. John does his swallowing exercises every day but finds swallowing extremely difficult and opts out of eating food at all.

Interviewer: "Do you eat food at all?"

John: "No.....No I can't, uh, Candace there, who I'm working with uh with the speech path pathology, Candace at the uh St. Boniface, but uh she spent a couple of hours, the first day up there, about two weeks ago and uh, they had some Ensure uh puddings in the can, I had at that point turning my head to the side, swallowing hard, and had it down over here somewhere (points to neck) and that went down not too bad. Water and juice I can't get down, it goes down the windpipe. So, but other than the taste, its too

much work just for the taste. I would take a glass a week. But the taste, it tastes.... To taste food it makes you feel even worse because you can't eat it in a normal manner."

Interviewer: "So why is that, why does it make you feel worse?"

John: "Well because you can't eat it in a normal manner.....It's a real job to tilt your head over to the side and try and get it down. That's hard work."

Interviewer: "Hard work."

John: "Yeah. You know, it's so different from the way you used to eat. I guess you taste the food but it takes a half an hour to get it down. I can't see that it...."

Interviewer: "So since it's hard work to swallow, are you saying that it sort of takes the enjoyment out of eating."

John: "Well, certainly. Makes you feel worse."

John has been feeding himself with tube feeds for approximately four months. He bolus feeds, using gravity drip, four times a day (8:00 AM; 12:00 PM; 4:00 PM and 8:00 PM). His energy intake via his tube feeds is 1750 kcals per day. His feeds are arranged at meal times to reflect some normality. Each feeding session takes approximately 90 minutes, thirty minutes to infuse the formula and then he waits an hour. John finds this time commitment restrictive.

John: "Well, you know, it just seems to me that this tube feeding takes my whole day."

Interviewer: "Takes your whole day."

John: "... for some reason or other. I mean that sitting there, takes my stuff in and I'm sitting there waiting for an hour to go by, so I don't have to be in since February inside..."

John is an elderly male that lives at home with his wife. Both have medical conditions that impair their activities. Both take nutritional supplements. Very little food is actually cooked in their home. Family or neighbors bring meals on occasion for the wife. John is visited daily during the week by Home Care and three times a week by VON. Home Care bathes John every day and cleans the house once a week. The VON changes his ostomy dressing. During the day John putters around the house doing light chores. John requires no assistance with his tube feeds but his wife is the one that has taken on the responsibility of preparing his medications to be infused using a syringe and the responsibility of arranging home care.

Future Dependency on Technology:

John has just recently been informed by the speech language therapist that there is a strong possibility that he will remain on tube feeds permanently.

Interviewer: "What were your thoughts when they first told you that you would have to go home with tube feeds?"

John: "Well, at first I didn't, it didn't really hit me until I got home. Because I was on it in the hospital, I had a tube up my nose and down into my stomach. That was terrible. And uh, when it really hit me was a week ago, a week ago, I guess it's two weeks ago now, when I went up to see Candace and she told me that there wasn't much hope of uh ... of eating again unless the, unless the doctor has something in mind, you know. That really stunned me. Cause up until then I thought it was just a matter of waiting until my jaw got loose. But uh, I don't know what's going to happen now. Have to wait and see."

John seems to be sitting at home waiting to see if things improve. In the meantime he seems to concentrate on the many things he no longer can do due to his tube feeds and

his medical condition. Prior to his illness John was extremely active painting houses, fixing things, doing carpentry work, playing in a band, gardening, and going to the lake.

John: "Yeah, and I can't do that. With everything it just stopped."

John finds that he is just too weak to do the things he would like to do.

Missing Favourite Foods:

It is not only his favourite activities that he misses but food itself. John considers the tube feeds monotonous which eventually can affect one's state of mind.

Interviewer: "Okay. So what is it like to never eat food?"

John: "Oh I miss it immensely. Because I've been used to it all my life."

Interviewer: "Do certain things, things give you a constant reminder of food?"

John: "Well, I guess when you're cooking roast it does. That's a constant reminder.....Yeah, or there's uh, they eat hamburgers, you know, or chicken from the Chicken House, they sit here and eat it. And I've got to sit over there and say nothing. Pretty hard. However."

.....

John: "It's boring to say the least..... after you drink it for months.....Well I can say it's monotonous. Uh, well having to take this every day, in and out on a continual basis and knowing that you're not going to have any change, it's probably plays on your system and your mind, what you're thinking"

Positive Aspects of Tube Feeding:

John does have some positive comments to say about the tube feeds. Positive aspects are further discussed in chapter nine.

Interviewer: "What are the positive aspects of tube feeding yourself?"

John: "Well, if you want to be realistic about it, uh, I suppose it's easier than preparing a meal. Attach a hose to your stomach and sit down and wait, that's all there is to it. No dishes to wash. Just throw the cans in the garbage. That's all it takes. Well you need to wash the equipment and stuff, tubes and everything."

Self Image:

Tube feeds also have not changed the way John thinks about his body. A tube protruding from his stomach does not bother him.

Quality of Life:

John's quality of life has been impacted by this new lifestyle and he believes that the sooner he gets off tube feeds the better. John rates his quality of life as 'not good'.

Interviewer: "Okay. ... Now I realize that quality of life is difficult to define, but in your own words how would you describe your quality of life?"

.....

John: " Well, uh other than the restraints the operation and tube feeding has placed on our lives. I wouldn't say it's changed it that much. It's restrictive and restrained.....Activity."

Interviewer: "Activity."

John: "Yeah. Like I told you, we don't go out to restaurants anyway, dances et cetera that uh Going out for rides and that but uh, ..."

Interviewer: "So, would you say your quality of life is good or"

John: "No, I would say it's not good right now. Very hard on the nerves."

Interviewer: "Hard on the nerves?"

John: "Of course it is. Sure. The sooner I get off it the better I'll like it."

Themes that are mentioned in this narrative include: the restrictive nature of the tube feed regimen (chapter seven); the positive aspects of tube feeding (chapter nine); missing favourite foods and quality of life which is covered in the qualitative analysis of quality of life in chapter ten.

Larry's Narrative:

Larry is a 48 year old male who had a stroke approximately fourteen months ago. The cerebral vascular accident has affected his memory and his ability to communicate. Originally Larry felt he could better complete the interview if he recorded his responses in writing. After several attempts he finally phoned the researcher and asked for a verbal interview since he was having difficulty completing the questionnaire. He found that by the time he wrote his thoughts down on paper he would forget what he wanted to say.

The stroke is not the reason why Larry actually started tube feeds. He has had a gastrointestinal disorder for approximately seventeen years and during those years has had numerous surgeries. Every time Larry would eat he would get sick to the

point where he no longer had a desire to eat. Consequently, his intake was extremely poor. Larry's usual body weight is 200 pounds and he currently weighs 130 pounds which is 65% his usual weight. Larry has been on tube feeds for the past two and a half years. He feeds himself at night for approximately seven hours.

Management of the Tube Feed Regimen:

Larry has adjusted his own rate in order to get the tube feeds in as fast as he can. He is only supposed to run the tube feeds at 250 mls per hour but bumps up the rate so he can complete his feedings faster.

Larry: "... I'm only supposed to take 250, 250 uh the pump, not 300..... but I take 300 because it's faster, you know, if I could get it all in in an hour I'd be happy, you know.....It just takes so much time."

Also to help speed the process Larry has adopted a manual system of infusing the tube feeds which takes a fraction of the time it would take with the pump. Larry finds the feedings very time consuming and often doesn't take all he should.

Mental Health and Acceptance of Life Changes:

Larry's interview overall was very negative. He finds life on tube feeds very difficult. During the interview Larry appeared down and he agreed that he was 'in a rut'. He frequently dwelled on the negative and on his past. Larry does realize that he needs to improve.

Larry: "It's just, I'm just down."

Interviewer: "You're down."

Larry: "Yeah. And uh,.....if I don't get up, you know, I uh, if I start working again or keeping my mind off, off of everything else. It's uh, it's when I'm just sitting there eating or just sitting there, that, it's just terrible. I, I, you know, I think about uh, a lot of things I don't want to think about. Uh, you know, I you know I look around and I see, I see which, you know, which guys are [in executive positions] around here...."

Interviewer: "MmmMmm."

Larry: "And uh, I was a way ahead of them, you know, I, I could be, you know, I, if I wouldn't have been sick I'd uh be [President of——] or anyone of them now cause uh the older [presidents] are gone. I'd be at least a[Vice President] but uh.....then, you know I might have, I might have switched to Real Estate."

Interviewer: "MmmMmm."

Larry: "... you know, because I've got my Brokers license, I've got everything you can get for that and uh, and then I was sick.."

Interviewer: "So you're thinking of what, what you could have been doing..."

Larry: "Yeah, but when I do that I uh, I get down, so I, you know, got to forget about it. Because there 's, there 's not much to look forward to. You know, there isn't uh"

Larry is on a leave from work due to his illness and spends most of the day puttering around the house. The fact that he no longer has his driver's license since his stroke has made him more house bound. Every other day he will walk around the shopping mall. Previous activities that he used to enjoy are either boring now or he can't perform them as well and he finds that frustrating (e.g. computers, golf). He is constantly comparing his current abilities to his functional performance in the past. He comments that he needs to find something new that he didn't do before.

Larry: "But uh, I could do many things very well and I can't do them now, you know, that's uh, if I could find some thing now that I couldn't do then I'd be happy."

Interviewer: "MmmMmm."

Larry: "Or uh, you know, what I couldn't do then but uh...."

Interviewer: "You keep comparing it?"

Larry: "Well yeah sort of, sort of. Uhm I 'm always..... I don't want to live the rest of my life like this. I hope it gets better."

Impact on Sleep:

Larry's sleeping pattern is disturbed and he frequently wakes up in the middle of the night. Since the tube feed pole is not portable, he discontinues his feeds and then manually pumps the rest in the morning. Larry comments that sleeping with the tube feeds has created a separation between him and his wife. He has to sleep in a certain position and is unable to cuddle with his wife.

(written) Question 7. How has home tube feeds affected your family life?

Larry: The tube feeds affect my family badly. During the night when I sleep with my wife the feedings have me in one position so I can't hold my wife and this causes a separation between us.

Social Isolation:

Larry does not only feel a separation from his wife, he also feels isolated from the family during meal times. When asked 'What is it like to never eat food?' Larry writes:

Larry: It makes me isolated from my family. When supper is ready I go into the livingroom and wait or sit at the table and do nothing but drink milk or coffee.

It doesn't bother Larry to see other people eating. He has no interest in food, has no appetite and does not enjoy eating.

Socially the tube feeds have had little impact because he shuts them off and feeds later or not at all. In the past few years him and his wife have been alienated from their friends. Larry feels this is due to his stroke more than the tube feeds themselves

Larry: "No. No. No we've uh, we've, see we've uh, in the last two years, we've uh, over two or three years, we've been alienated from all our friends. Uh, very, you know, it's very seldom, that we'll ever see them again. They're uh, they're from all over the city and sometimes we have a party, they come here and if they have a party we go there and uh, just that I, I can't, you know, it's just different now, I used to be uhm, I used to do all the talking, you know, I used to talk very, very freely and, and uh, I always, you know, I always led in conversations and, and now I just sit back and listen. Uh, cause there's a time between my speaking and, and uh hearing. You see I can understand everything you're saying but when I try, when I try to say something I can't say it right, so I I don't know."

Self Image:

Larry's body image has also changed over the years.

Interviewer: "Has tube feeding changed the way you think of your body?"

Larry: "Oh yes, of course. It's made my body very uh, very slim. You know, when I look around, you know, look around for the muscles, you know, I remember what used to be there and what is there now uh, I'm still uh, surprisingly I'm still strong. Uhm, although my, you know, I'm only 130 and nothing shows up. I would, I would like to get up to 180 pounds again now and maybe I will, I don't know. Uh,.....it's uh, I just gotten to the point of life, that I just take things as they come."

Larry considers his quality of life to be fair and that his 'day is very uneventful.' In order to see improvement Larry feels that he needs to start trying to eat again.

Larry raises numerous themes in his narrative. Modifying treatment such as using alternate methods of administration of tube feeds or faster rates is discussed in chapter seven: Management of the Tube Feed Regimen. Also in this same chapter one can read further on the impact on sleep and the impact on one's social life. Family and the acceptance of these life changes are discussed in the qualitative chapter on quality of life.

Audrey's Narrative:

Audrey is a 72 year old female who had head and neck cancer, radical dissection and multiple reconstructive surgery eight years ago. Audrey was hospitalized during the entire first year of her illness. To this day she is still disfigured. Audrey also has a tracheostomy and uses a nebulizer to administer certain medications twice a day. With her talking tracheostomy Audrey's enunciation of words was sometimes difficult for the researcher to hear so the researcher repeated her comments for confirmation. These repetitive statements were eliminated from the following quotes for the benefit of the reader.

Audrey is unable to swallow and has been feeding herself tube feeds for approximately eight years. She feeds herself four times a day at meal times and gets

approximately 1200 calories per day from her tube feed formulas. Audrey uses a syringe to infuse her feeds, which she finds a lot faster and cleaner than the gravity drip. Each feed can be finished in fifteen minutes versus thirty minutes using the gravity drip method. Syringe feeding was an idea that she picked up during a hospital stay in one of Winnipeg's community hospitals.

Audrey: "So,uh, when I went into[the hospital], this was how they were feeding me, you see, and I thought, well why am I using that thing and it breaks and they leak, and what a mess."

Management of the Tube Feed Regimen:

Audrey has not only altered her feeding method on her own, she adjusts the amount of tube feeds she thinks she needs, she adjusts the timing of her feeds and she has also learned how to change the balloon in her gastrostomy tube when it breaks. As Audrey states "You learn a heck of a lot when you have to."

Audrey: "There's a little balloon at the end and sometimes it breaks and it just comes out."

Interviewer: "So you have an extra tube around in case that happens?"

Audrey: "I have five."

Interviewer: "You have five and you just change it yourself."

Audrey: "Yeah, they showed me, like when.... before that uh, to be removed I had to go to the Hospital and get it changed cause they had to do it within the first half hour or it would start closing....The balloon... and with the new Doctor..... she showed me how you change it yourself....So I was trying and I watched, you know, they have this mirror. Where you can watch what ever she's doing. It was close enough so you could see everything they were doing and she explained as she was going along....At first I thought there was no way I was going to do that, but you get caught at 4 o'clock, 4 o'clock in the morning, who are you going to get."

Interviewer: (laughs) "Who are you going to get.... So, when it breaks you know right away because it wakes you up...."

Audrey: "Oh because you're soaken wet."

Interviewer: "Yeah, because it prevents the juices from coming out."

Audrey: "Well you feel wet, you wake up.....MmmmMmmm. And it goes. And its gone. You got to look for it in your bedding."

Interviewer: "Is it painful at all when you change it?"

Audrey: "Noo. Well actually at first, when he first put that in I thought, oh my God, I'll never be able to live with that. It hurt....So, then you have to get used to the rubber next to your stomach like your skin....And it burns. It's just like a baby's bottom when it gets uh diaper rash and all that. Actually, you get around that."

Impact on Normality:

Audrey supplements her daily intake of five cans of Boost with cream soup, juices, milk, coffee and beer. During the interview Audrey or her son-in-law often refer to her 'drinking liquids'. This created some misunderstanding, on the part of the researcher since it was assumed that that meant she consumed liquids orally. This was in fact not true. When Audrey referred to drinking liquids she meant infusing them into her gastrostomy tube. Audrey has adopted a 'normal' phrase such as drinking to represent tube feed infusion.

Interviewer: "You can drink liquids?"

Family: "Yeah, yeah."

Audrey: "Any liquids."

Family: "Any liquids."

Interviewer: "Okay..... So you're supposed to take them [Boost] five times but you probably get more about four on average because.."

Audrey: "Yeah."

Interviewer: "..... and you eat some liquids as well."

Audrey: "Oh I have soups and juices and"

Family: "The coffee."

Audrey: "... I've got enough I'm telling you."

Family: "Yep."

Interviewer: (laughs) "Okay."

Audrey: "If I drank five of those, I wouldn't get off this chair."

Impact on Activities:

Syringe feeding takes very little time, is portable and gives Audrey the independence to do things she likes to do. Audrey's favourite activities include shopping with her daughters, gambling, traveling, knitting, and baking. She will often go out with her daughter and return home several hours later. Audrey also travels several times a year via plane or bus. In the following narrative a family member emphasizes Audrey's autonomy and ability to do the things she loves in life.

Family: "Yeah, the feeding stuff, what, what's happening is uh, Mom is not anchored at home. She wants to go somewhere, as matter of fact, she's been down to the States a few times. She grabs, she takes enough supplies"

Interviewer: "Okay."

Family: "She went to Vegas, she brought supplies."

Interviewer: "Okay, that's great."

Family: "And this way, uh, the thing is uh, it's reliable, when we need it it's there. Uh, Mother takes it with her all the time. She's not dependent on

staying home, where is my next meal coming from or who is going to give it to me or I came unprepared. There it is. Uh, we can go visit the granddaughters or her daughters, she can go and visit anybody she wants, she packs up and all the stuff is there. She takes it with her, so to that, it gives her the independence and uh, she doesn't have to rely on anybody. Which makes a big difference. Because, first thing, if uh, in all honesty, we're going to say okay, we going to need to look after her, I don't think Mom would be alive today. The bottom line is uh, she has retained the things she cherishes and there is no way I'm going to take that away from her."

Interviewer: "Yeah."

Family: "And, not only that, she doesn't, she doesn't have to rely on anybody to do it. Otherwise you're looking at taking Mom and placing her into a home, which doesn't fit her profile. Forget it. Some people do. But the home feeding has given her the autonomy."

When Audrey travels she makes arrangements ahead of time and transportation is always ready at the airport. She has a suitcase always packed ready to travel in case the opportunity arises.

Interviewer: "So, back to that your social life part, may be you can tell me a little bit about the traveling you've done, like how mobile you have been with the tube feeds, where you've gone?"

Audrey: "Well I've been on the aircraft, I've gone to Vegas.....And certainly the airport, they got a wheelchair for me, waiting at the air terminal, and they take me out to the taxis, wheelchair....hotels got one for me when I get to the hotel....."

Interviewer: "Like a wheelchair."

Audrey: "Uh huh.....Take me straight up to my room so this, after that it's all about going gambling and you see, take my walker with me."

Interviewer: "So you travel with your walker?"

Audrey: "Yeah."

Interviewer: "And you travel with your ventilator?"

Audrey: "Yeah."

Interviewer: "Yeah, you bring, you pack everything up. All your equipment."

Audrey: "I got the whole shimalahoo. I got a suitcase ready for it."

Mental Health and Acceptance of Life Changes:

Life was not always like this for Audrey. It took a long time, more than a year at home, before she would even go out in public. It took time to build up her confidence and come to the realization that there is nothing she could do about it and one had to get on with their life.

Interviewer: "How long did it take before you felt that confident to go out?"

Audrey: "Oh, about a year."

Interviewer: "So you were in the hospital for a year and then you were home for about a year before you then felt you were ready to start taking it out."

Audrey: "Yeah. It takes time....Uh, huh, you have no self confidence. You gotta say 'Well the heck with it I'm going to go and I don't care what anybody says....The thing that hurt me, I think was when, we went shopping around Christmas time and this little girl looks at me and she went to her mother and she said 'What's the matter with that lady?' And she looked scared, that hurt....But my granddaughters, uh, they come in to the... 'Hi Gran' nothing."

Interviewer: "Yeah."

Audrey: "And here's this little strange child which uh, and I just, you know, trying to set her up there. Even that doesn't bother me now."

Interviewer: "Yeah, kids are curious."

Audrey: "At one, in fact one little girl, she kept pulling away and hiding behind her mom and I said to her 'You come here' and when she, and she came kind of, she wasn't quite sureAnd I says 'You don't have to be afraid of me.' And she says 'No?' And I said 'No'. I said 'I wouldn't hurt you.' And

then she touched my face and she was fine. She went with her mother quite happy but the child before that, well that was before I was really going anywhere, other than the hospital for the treatment or some darn thing. In fact, it was at the hospital, that this little girl said that to her mother and I felt that's great right in the hospital, there's others worse than me but after I said 'Uh the heck with it I'm going to go, I don't care.'"

Interviewer: "So after about a year, you figured that's about the time when you able to get out."

Audrey: "Yeah, just gradually I went out. It took time. I felt funny when I walked by anyone, they kind of glanced at you. It kills you. But what are you going to do, if I had to stay in the house all the time I'd go nuts. I'd be ready for Selkirk."

Interviewer: "Yeah. So that first year must have been very rough?"

Audrey: "Oh yeah..... Well, I had a lot happening to me when I was in that hospital though. Things I saw, I was nervous, they saw the wound, but you kind of shut away in a vacuum, I didn't think uh what's the use in going on about it. It's gone."

Interviewer: "Yeah."

Audrey: "Half is not gone, but it's very bad. Then you make the best of it. There's nothing else you can do."

Quality of Life:

Overall, Audrey's interview is positive and she is definitely experienced with this new way of life. Audrey considers her quality of life good and she can do whatever she pleases. Audrey does not feel that tube feeds has changed her quality of life. When she compares it to the beginning, life is a lot better.

Interviewer: "How about when you look at your quality of life or now compared to that first year when you came home?"

Audrey: "It's got a lot better."

Interviewer: "It's got a lot better."

Audrey: "Oh yeah. And getting back my self confidence again. I lost it for a long time, I didn't care if I came out of the hospital or not. When I think back now, it just goes through my mind about what I was thinking then, my God are you stupid."

Audrey's narrative continues to support themes such as management of tube feed regimens, impact on activities, mental health and acceptance of life changes and quality of life. Another theme that was covered included impact on normality which is further discussed in chapter seven.

Summary

These four individuals represent the variety of situations one can encounter when working with people who are tube feeding themselves at home. This group is diverse with many different scenarios. Respondents will vary with regards to their illness, age, background, method of feeding, duration of feeds, time of feedings, and the number of months or years they have received tube feeds. Despite these many differences there are common themes that many respondents mention during their interviews.

These four narratives were presented to provide a total picture of individual lives on home enteral nutrition and to introduce common themes that are presented in subsequent chapters. Themes that were highlighted in these four narratives include: 1) management of tube feed regimens; 2) the restrictive nature of the tube feeds and the intravenous pole; 3) altering treatment to lessen the impact on time; 4) the impact on

social lives leading to social isolation for some; 5) the impact on activities; 6) missing favourite foods; 7) the impact on normality; 8) mental health and acceptance of life changes; 9) the impact on sleep; 10) the positive aspects of tube feeds; and 11) quality of life.

V. Life with Home Enteral Nutrition

What is it like to live on home tube feeds? Health professionals, that work with this patient population, wonder what is the patients' perspective. Unfortunately, they never have the opportunity to invest the amount of time that listening to a person's narrative, relating treatment experience to lifestyle, requires. The literature, regarding parallel technologies, tends to deal with the person's interface with this technology. Very little is known with regards to the person's interface with enteral nutrition technology.

Therefore, the opening question in the experience section of the interview guide was, 'Can you describe to me what it is like to live on tube feeds?' This question gave the individuals an opportunity to describe their perspective of life with home tube feeds without any prior leading questions, topics or influences. This opening question seemed to set the stage for the rest of the interview. For instance if the interviewee had many negative things to say with regards to life with tube feeds, generally the entire interview carried a negative tone and vice versa, if the individual had no problem with tube feeds at all, the remainder of the interview was fairly positive.

The responses to this question were numerous among the twelve subjects interviewed. Several themes, that will be discussed later, originate in this opening

response. The difference between this section and further discussion, is that in the opening responses one individual may have discussed a particular theme but later on in the interviews several respondents may have raised these issues. Therefore, further chapters justify the commonality of these themes. It is important to analyze the qualitative data in this manner to capture what first comes to mind when respondents are questioned 'What is life like on home tube feeds?'

Themes that will be covered include: technology; impact on time; the restrictive nature of the tube feed regimen; acceptance of life changes; positive aspects of tube feeding; the concept that tube feeds are intertwined with their illness; the impact of life with no food; and impact on sleep.

Technology:

Five out of the twelve subjects made some reference to the pole or machine being annoying, restrictive or cumbersome. The restrictive nature of technology was also experienced by other individuals living with parallel technology as mentioned in chapter three.

Jim feeds himself for approximately sixteen to eighteen hours every day and has done so for three months.

Jim: "Well it's a bit cumbersome, you have to drag this pole around the house (laughs, both laugh).

Interviewer: "You got a walking partner."

Jim: "Yeah, you got a walking partner uhm, you know, from that point of view.... you can sit and watch TV or or you know sit and talk to people with it going, it's not an inconvenience in that regard but it's very slow. so you have to drag the pole around for a lot of hours and have it attached to you while your sleeping and uh, you know, when you have to go to the washroom in the middle of the night you have this pole to contend with and you got to make sure that the hose doesn't come undone, you know, while your sleeping and roll over....." ".....It uh, you know, so sleeping is, you know, it's good you can get a lot of feeding done while you're sleeping but you can't sleep all the time. (both laugh) The rest of the time you're dragging the pole around."

The next individual comments that 'the machine is going all the time' despite his positive attitude and the fact that he feeds himself mostly while he is sleeping and juggles four hours of feeding in the evening. The individual attributes his positive attitude to the fact that life with tube feeds for him is short term and he anticipates discontinuation in the next few weeks.

Paul: "It's very annoying to have to keep plugging into your machine every once in a while. The machine is going all the time."

Some people stated that they felt nailed down or tied to the pole. Larry has lived with home tube feeds for three years and was only supposed to be a night feeder. Larry finds that he can't sleep at night, not necessarily due to the tube feeds, but stops his feeds, in order to get up. He resumes his feeds for approximately thirty minutes during the day. Even though Larry feeds himself for a short period during the day, he still feels nailed down to the tube feeds.

Interviewer: "Is it uncomfortable at all?"

Larry: "MmmMmm, when I'm awake."

Interviewer: "When you're awake."

Larry: "Yeah, just to sit there and let the stuff flow, it's just uh like, like being nailed down, sitting there waiting for this stuff to pump in, you know."

Barb has recently just begun tube feeds in the past two months. She currently feeds herself for ten hours from 10:00 PM to 6:00 AM. She also comments how difficult it would have been in her previous bi-level home.

Barb: "I hate it. Uhm,.....why?.... Uhm..... It's a strange feeling clinging to a little tube. Uhm... I don't like it. I hate being tied to my pole. I feel restricted.....And I find that if I'm tied to it during the day that it really restricts me I mean I'm bumping into anything with this pole. It's huge, you know, it's a big wheel base on it."..... "So it's, I'm bumping into everything, I can't get around."

Interviewer: "Is this, is your house uhm, one level...?"

Barb: "Yes."

Interviewer: "It's a bungalow."

Barb: "Yeah. Which we lived in a bi-level before, so I mean this is a godsend, this house, that I was in this house when it all happened because I don't know how I'd manage in a bi-level. You know, cause our bedrooms were all on the lower level there."..... "The living area was up the stairs. You know, I would have been restricted to the, to the basement, to the lower level the whole time."

Interviewer: "Yeah. Is it hard to wheel.....?"

Barb: "Oh, I would have gone crazy. I couldn't have dragged it up the stairs."

As individuals interface with this technology they find they feel a sense of being physically tied down to their equipment. Further discussion pertaining specifically to this 'pole' is found in chapter six.

Impact on Time:

A second theme that originates in the opening question relates to perceived time versus real time. Individuals perceive that the tube feeds are time consuming regardless of the actual amount of time that is required to administer the tube feeds. Their perceptions is that no matter how fast they run their tube feeds, it's just not fast enough. Some individuals alter rates or alter the method of delivery in order to shorten the time spent during feeding.

As mentioned in the previous chapter, Larry was originally only going to feed himself at nights with his tube feeds but finds that he cannot get all the volume in during that period because he wakes up during the night and the pole is not portable to move to another area in the home. Therefore he discontinues his tube feeds and finishes them in the morning or in the evening. Larry has adapted a method of manually pumping his tube feeds during the day in order to do it faster.

Larry: (written response) It takes many hours that conflict with my daily routine.

Interviewer: "It, what do you mean by uhm, this last part that it conflicts with your daily routine? Does your feeding at, you are feeding at night, do you find that you have to feed during the day too?"

Larry: "Yeah, I do sometimes, because at night, I uh, I uh, I wake up and I uh, and at 3:00 in the morning wake up and shut off the feeding.....And uh, and I go to sleep and I, and I feed during the daytime."

Interviewer: "Okay. So why do you shut them off in the middle of the evening, night?"

Larry: "Well because, because it, it's located at my bed, and you know, I don't want uh, stay in bed all, all night. You know I get,...."

Interviewer: "Oh, okay... you want to get up."

Larry: "It's, it's not portable. It's not portable.....If it was portable, I would, you know, I could carry it around more. I could carry it around all the time."

.....

Larry: "I get up and I, I go downstairs and I fall asleep and I wake up and I go back and get uh, and I, I often do my, you know, I do it away from the machine, just squeeze that thing there.....I can, see I can squeeze it like this. (squeezing noise) See. It's sucking through and the tube comes in there."

.....

Interviewer: "You just do it manually instead of being hooked up to the pump.....How long does a can take that way?"

Larry: "Oh, uh it is about, about a fifth of the time. I can do it way faster than an hour."

Larry had adopted a manual feeding system that can deliver approximately 625 to 750 mls in half an hour. But he finds that he if administers any amount greater than 375 mls he will get diarrhea.

Larry: "But then I can't take the, it doesn't uh agree with my stomach then I'll get diarrhea from it."

.....

Interviewer: "Okay. And you do it manually?"

Larry: "MmmMmm.....Cause it's faster."

Interviewer: "But then you'll get diarrhea."

Larry: "Yeah, well sometimes."

Interviewer: "Sometimes not all the time."

Interviewee: "No, no, if I do, if I do one, one and half or two cans it's all right but if I do more than that...."

Larry not only pumps manually to get the tube feeds in faster he also adjusts the rate.

Larry: "I'm only supposed to take 250, 250 uh the pump, not 300.... but I take 300 because it's faster, you know, if I could get it all in in an hour I'd be happy, you know."

Interviewer: "Yeah." (both laugh)

Interviewee: "It just takes so much time."

Other comments with regards to time and rate were as follows:

Paul: The machine is going all the time..... I don't like being hooked up to the machine for the length of time

Jim: "...but it's very slow. Uhm, you know at the 300 mls per hour it takes four hours, four hours for that bag. Uhm, so it's, you know, to get the appropriate amount of nutrition it takes a lot of hours so you have to drag the pole around for a lot of hours and have it attached to you while your sleeping and uh, you know.."

Jim: "Uhm, you're restricted, if you feel like going outside you obviously, would you go outside to do things, uhm you're sacrificing, you know, feeding time, so last night I went to my son's soccer game and uh, you know, that's two hours of no feeding, so, you know, an hour here and hour there and you start running short of hours of feeding, so you cutting into your feeding time. There's no way you can speed it up, it's just, it's, there's only so many hours in a day."

Interviewer: "And you're running it at a ..."

Jim: "I'm running it"

Interviewer: "... at a high rate."

Jim: "300 is the fastest rate it goes."

Wife: "But your stomach can't take it."

Jim: "Yeah"

Regardless of the amount of time an individual actually tube feeds themselves, it is perceived as very time consuming. This theme is consistent whether the respondent feeds themselves for ten hours during the day, like Jim, or in Larry's case for thirty minutes.

Restrictive Nature of the Tube Feed Regimen:

Time impacts on ones ability to do things. Consequently the third common theme, which is related to time, is that individuals feel the tube feeding regimens are restrictive. As illustrated by the following quotes tube feeds are perceived as cutting into individuals time to do other things.

Mike: "Oh it's, it cuts into time to do things.....Like going out with my friends in the, in the evening, if I have to be on tube feed I can't go anywhere."

Barb: "...Uhm... I don't like it. I hate being tied to my pole. I feel restricted."

Interviewer: "Okay. Uhm, you mentioned that you find it restricted.....Do you find that there are things that you are missing out on or...."

Barb: "Yes, cause I find, you know, uh we never stay out late anywhere, I mean we always have to be home around 8, 8:30 cause I have to have my bath before, it's something I have to do before I get hooked up and everything.....So it's, yeah.... uhm Rainbow Stage is out of the question."

It is also interesting to note that with Larry, although he only feeds himself approximately thirty minutes during the day he still comments that he finds that it

conflicts with his daily routine. During further discussion he mentions that it conflicts more with traveling and vacation.

Larry: (written response) It takes many hours that conflict with my daily routine.

.....

Interviewer: "Okay..... So can you give me an example how then it uhm conflicts with your daily routine? Just so I understand that part a little bit."

Larry: "Well, I'm not really doing anything so it doesn't conflict very much....You know, uh, when it does, like if I have to go out, I go out, I just, I uh, don't, I don't let that conflict with it, with anything.... I just stop it and leave it and"

Interviewer: "Do it later."

Larry: ".... do it later, yeah.....Uh the reason it uh, it really conflict, it doesn't conflict me at all when I'm home, it's when I want, when I want to go, we're, we're going on holidays this summer.....And now that's going to be a, it's going to be, you know, I'm uh, you know it's going to be difficult."

Interviewer: "Yeah, have you..... where are you going to go on holidays?"

Larry: "Oh we're going to go to Clear Lake this year and Saskatchewan and..."

Larry has traveled in the past, but has never required as much tube feed as he does now. He mentions about his trip to Florida and his inability to consume foods which resulted in a ten pound weight loss in one week.

Interviewer: "Okay, so have you traveled"

Larry: "Yeah."

Interviewer: "..... with the tube feeds before?"

Larry: "and I haven't taken this much, you know, I uh....."

Interviewer: "Okay. So you were eating food more before."

Larry: "Yeah, or nothing and I would lose the weight uh,In fact what I would do, when we went to uh Florida, I couldn't, I took some of the stuff but uh, I lost ten pounds in a week. You know, I, I ate what, you know, what I felt like and I didn't feel like eating very much.....So I'm uh, that's why I'm down on weight and not getting up."

The restrictive nature of the tube feed regimen impacts on respondents' ability to participate in favourite activities including social functions and traveling. Refer to chapter seven for further discussions pertaining to these themes.

Acceptance of Life Changes:

Larry alludes to the fact that he finds the tube feeding difficult when he wants to travel. The fact that life with tube feeds and adjusting to these life changes are considered difficult in general, is the fourth theme identified by five individuals in the first question.

Larry: (written) It is very difficult. Before feeding I was a very independent individual and now I am a dependent. Tube feedings are hard to live with.

Lucy: (written) Living on tube feeds is difficult in certain ways, such as never tasting the food that smells and looks so good and wanting so badly a glass of orange juice or cup of tea or coffee and knowing you probably won't ever taste them again. It also means you give up normal activities (such as going out for dinner) that you had always taken for granted.

John, whose experience is described in the case studies in chapter three, is a head and neck cancer patient who recently found out that his tube feeds are probably a permanent situation. He had been under the impression that he would be able to eat

again. The initial portion of John's interview was not tape-recorded (due to error) and therefore his response to the first question 'Can you describe to me what it is like to live on tube feeds?' is not recorded in its entirety. Brief notes were taken following the interview and during. John's response to this question was:

John: "You don't really want to know."

Based on this statement and the rest of the interview it is clear to the interviewer that John finds tube feeding extremely difficult.

Allan tube feeds himself three times a day, at breakfast, lunch and at supper and has been doing so for approximately two years. Allan describes the difference from when he first started tube feeds to now and the time period that was needed to make that adjustment.

Allan: "Well, when I first had to, I thought that it would be the end of the world.....But, but now..... it really doesn't bother me, if I go visiting I bring it, I bring, not the pole, but I bring the bags and a few boxes and people are sitting at a table and they're eating a steak and uh, it's mostly my relatives that I go to, they all have hooks close to, to the table where they eat, where I can hook the, you know. And I prepare my stuff and uh, they eat and I eat and I can talk and they can't. (both laugh)."

Interviewer: (laughs) "You never talk with your mouth full."

Allan: "But uh, at first I found it, well it was quite different thing, but now it gets on okay. You know."

Interviewer: "So at, at the beginning"

Allan: "At the beginning I, I uh found it a little tough, you know...."

Interviewer: "It was tougher."

Allan: "Yeah, uh...."

Interviewer: "Okay. How long did it take before you were okay with it?"

Allan: "Oh, I still got, oh I would say maybe..... six months or so."

Audrey has been tube feeding herself for seven years. She has made adjustments in her care as to the amount of tube feedings, the types of foods infused into her gastrostomy, and the method of infusion. Audrey syringe feeds herself at breakfast, lunch and supper. She has basically discontinued gravity drip feeds on her own initiative. Overall her interview is very positive. But when asked at the beginning of the interview 'Can you describe to me what it is like to live on home tube feeds?' her response is one word:

Audrey: "Terrible."

Social Isolation:

Audrey further elaborates by explaining that she feels isolated to some extent when her family eats in the other room and she's alone. (Audrey has a tracheostomy and to make sure the researcher understood what she was saying, the interviewer repeated her comments for confirmation. These repetitive statements were eliminated from the following quotes for the benefit of the reader.)

Audrey: "MmmMmm. When you see everybody using a knife and a fork you feel kind of left out.....So, I don't know if that answers your question."

Interviewer: "Yeah. So it's actually, uhm, the fact that you can't sit down and eat some solid food like a regular"

Audrey: "MmmmMmmm. If I had my choice, I would choose not to have it."

Interviewer: "If you had the choice you would rather not have the"

Audrey: "That's right. I just have to have that.....Yeah. Feel like you got dinosaurs or contagious disease or something. You know, the way, you know, don't want to be a bothered and ..."

Interviewer: "You feel like you have some kind of contagious disease that people try to stay away."

Audrey: "Yeah. Makes you feel like almost like your abandoned..... Oh I guess you don't know what I'm talking about."

Interviewer: "Well, can you give me an example of feeling abandoned."

Audrey: "Well I eat here, having what I have and they're in there. It's like I'm not here at all."

Audrey misses eating with her family and preparing meals.

Interviewer: "And you miss that kind of eating"

Audrey: "Yeah."

Interviewer: "with other people."

Audrey: "Yeah, and used to preparing the dinner and sitting down with the rest.... that's what nearly kills me at first. Now I'm carrying on, I don't care anymore.....So, I guess I, I don't it's hard uh, and I think anyone will tell you that. But, you get so, there's nothing I can do about it, until I die and I don't have to worry about it."

Not everyone claimed that it was actually difficult but some individuals definitely stated that they either hated it or didn't like it or as in Audrey's case thought it was terrible.

Barb: "I hate it. Uhm,.....why?.... Uhm..... It's a strange feeling clinging to a little tube. Uhm... I don't like it. I hate being tied to my pole. I feel restricted."

Paul: "Oh I don't like the smell, I don't like the machine, I don't like being hooked up to the machine for the length of time."

Tom is no longer able to speak because of surgical head and neck resections. Written responses were obtained and questions were asked of the spouse during telephone follow up. Tom also comments on disliking tube feeds. His wife further supports how difficult it must be, from her perception, when she comments that it is a sad situation.

Tom: (written)
I don't like it. I miss my favorite foods - dinner etc. with my family.

.....

Interviewer: "Does he feed while you're eating?"

Wife: "No, I feed him before."

Interviewer: "What does he do while you're eating?"

Wife: "Nothing, except sitting downstairs watching TV or reading. Sits down in rec room. There's no point in bringing mine downstairs or bringing him upstairs. He can't eat what I'm eating. Kind of a sad situation but that's the way it has to be."

Accepting these life changes is difficult. Over time, some are able to adjust but these individuals still perceive life with enteral nutrition not to be an easy road.

Alive: The Positive Aspects of Tube Feeding:

Despite the fact that many felt that this way of life is difficult they did not forget the positive aspects that it keeps them alive, healthy and that it provides them with energy to do the things they want to do.

Lucy: (written response) But the plus side is knowing you would probably not be alive today if there wasn't some way to substitute for not being able to eat

and drink normally and the tube feeds seem to be the best way to accomplish this.

Barb: "I hate it. Uhm,.....why?.... Uhm..... It's a strange feeling clinging to a little tube. Uhm... I don't like it. I hate being tied to my pole. I feel restricted. Uhm, but I know that I'm healthier than I've probably ever been in my entire life. (laughs) Uhm, I don't know. That's all I can say."

Mike: "So, it also makes me more tired and I have bad heart burn problem with it afterwards. But on the upside, I have energy, managed to develop into a normal man."

When an individual interfaces with life-sustaining technology, no matter what themes may be important to an individual, the bottom line is that it keeps them alive. This survival theme is a definite benefit to those on home enteral nutrition as discussed in chapter nine.

Central Concept of Food in Life Narratives:

Another theme that is mentioned frequently in the opening question has to do with food as the focal point. Out of the twelve individuals interviewed, six individuals did not consume food at all; four consumed minimal amounts of food with difficulty; and two were able to consume moderate amounts of food. Several references were made with regards to missing favourite foods, preferring eating, or never tasting food again by those respondents who did not consume food or consumed minimal amounts of food.

Interviewer: "Can you describe to me, in your own words, what it is like to live on home tube feeds?"

Paul: "Umm, well I prefer eating... I'll tell you that?.....I prefer eating, It's very annoying to have to keep plugging into your machine every once in a while."

Lucy: (written response)Living on tube feeds is difficult in certain ways, such as never tasting the food that smells and looks so good and wanting so badly a glass of orange juice or cup of tea or coffee and knowing you probably won't ever taste them again. It also means you give up normal activities (such as going out for dinner) that you had always taken for granted.

Tom: (written response)I don't like it. I miss my favorite foods - dinner etc. with my family.

Some individuals missed food but not the physical act of eating due to swallowing difficulties. For example, Wendy mentions that she does not miss eating per se but later in the interview when discussing favourite foods she becomes very emotional. To cope with this gap in her life Wendy uses her humour to pretend.

Wendy: "Uhm, well can't go out for dinner. Uhm, just something that has to be done. Well it's a lot better than eating. Uhm...."

Interviewer: "You find the tube feeds better than eating?"

Wendy: "Yeah, well I know, if I eat, well I have tried a few things but I really have to work at it. So it's, I guess it's better, better than nothing ... but uh my husband 'Oh I have to find something for supper.' That's one thing I don't have to do anymore. Try to put things together but I was asking my husband what do you tell me. I pretend a lot, there's one nurse who comes here she asks me what I'm having for lunch and I usually say..... I pretend a lot."

Interviewer: "You pretend that you are going to have lunch."

Wendy: "Yeah, like on TV that's a show called Being the Pretender, well they pretend what occupations or whatever, well I pretend what I'm going to eat, like usually it's uhm like it's teenburger and onion rings or uhm, corned beef sandwich with a dill pickle, stuff like that... and anything else and I'll say that's enough"

Interviewer: "Okay... so the nurse will ask you what you'd like for lunch today and you tell her teenburger with onion rings."

Wendy: "Yeah, I've had plenty of those."

Interviewer: "And then she'd hook up the Carnation stuff."

Wendy: "Yeah, tell me good appetite and all that. And just give it to me. And after I finish she'll ask me 'How did you enjoy that now.' And I'll tell her I was just thinking about those things."

Food and eating have many different meanings including pleasure or oral satisfaction through taste; connection to individual's role or function as the one who prepares and organizes meals, and social aspects such as restaurant eating, holidays, special occasions, family and friends. Only three individuals routinely sat with their family while the family was eating.

Along with discussing food, it became evident to the interviewer that these individuals sometimes used their own terminology regarding the tube feeds that made communication and understanding the respondents statements difficult. Respondents sometimes referred to their tube feeds as food, milk, or milkshakes and as detected later on in the interview, the act of infusing the tube feeds as drinking and eating.

Paul: "And uh it gets so that you don't like the smell of the food, you can smell it anywhere. I, I can smell it on myself, you know. I feel like I smell like the food. My wife says she doesn't notice it, nobody else notices it, but I can tell."

Interviewer: "You're senses are more aware of the food around you?' (thinks he is talking about all food not tube feed at this point).

Paul: "I can smell that stuff a mile away." (nods head in agreement)

There is no separate theme pertaining to food itself in this report. The reason for that is that food seemed to play an integral part of many aspects of the respondent's lives. Consequently one will find 'food' embedded in a variety of other themes.

Tube Feeds Intertwined with Illness:

Food is not the only concept that is entrenched throughout the narratives. The impacts of tube feeds on life are intertwined with the impacts of illness. The respondents find it difficult to separate tube feeds from their medical condition and health. It seems to be a combination of everything. One individual raises this theme in the opening question.

Jim: ".....uhm because of , I guess, you, you know, you know, I not saying it's the tube feeding but because of uh what's going on in my body I have to sleep, you know, in an upright position. And uh, you know it takes some adjustment. I guess part of that is the tube feeding to keep it down. When I was lying down and I tube feed it seems to want to come up all the time."..... "Yeah, the 300 while I'm awake it, it seems to be able to take most of the time. The odd time my stomach gets, the saliva.... , I'm sort of backing it up a bit, I swallow saliva, well I think I swallow saliva, I swallow something or I go through the motion of swallowing but that seems to make my stomach upset because the saliva is all funny because of the radiotherapy, it's all foamy. Uhm, the salivary glands have been disrupted and uh, uh it's all foamy saliva so when the air gets into your stomach it makes you sort of nauseous and burp, uncomfortable, so uh sometimes it difficult to tell what the actual uh problem is, if it's the tube feed, you know, just not agreeing with me at that present time or if it's uh something to do with the, the uh saliva and the treatment or just uh the process that going on in my body."

Refer to chapter eight for further discussion.

Impact on Sleep:

Another theme that will be revisited later (chapter seven), has to do with the impact of the tube feeding regimen on an individual's sleep. All night feeders commented that they had to get up in the middle of the night to go to the washroom. Whether this affected their sleep depended on the individual. Three individuals raised the issue of sleep during the opening question.

Interviewer: "You mentioned that you feed yourself a lot while you're sleeping. Does it interrupt your sleep at all?"

Jim: "Fortunately, I still sleep through the night."..... "I'm a pretty good sleeper."

Interviewer: "Well that's good."

Jim: "Uh, you know, there are times when I sit up at night and can't sleep because you're uncomfortable but uh for the most part I would say no it doesn't interrupt my sleep. I'm able to, to lie back and go to sleep."

Interviewer: "You don't have to get up to go to the washroom or..?"

Jim: "Yeah, you do have to get up to go to the washroom. What I find, (chuckles) I don't know if this is this or just getting old or something to do with what's going on in my body...."

Interviewer: (laughs) "Old!!!"

Jim: "You feel like, you know, when you suddenly feel like you have to go to the washroom, you have to go now, it's uh, you have no delay, like its I'm not sure...."

Out of the three that mentioned sleep, only one commented that their sleep was negatively affected by tube feeds. Those individuals with gastrointestinal illnesses seemed to be most affected during their sleep by the tube feeds than those with other

illnesses. The following example is from an individual's narrative who has a gastrointestinal disorder

Family: "We also have to be careful if he's going out first thing in the morning, then if he's on tube feeds he doesn't sleep as well and because of his brain surgery, when he's tired his brain doesn't work as well, so if he's got a lot to do on a certain day, he'll not have tube feed that night so that he can"

Interviewer: "Sleep better."

Family: "Yeah, so he can sleep more. But we play that by ear."

.....

Interviewer: "MmmMmm. So when you're tube feeding at night and and it interrupts your sleep that's because of the soilage or do you have to wake up and replenish your tube feeds as well?"

Mike: "No I have to go to the washroom."

Family: "He has to pee."

Interviewer: "Okay, you have to get up, go to the washroom...."

Mike: "Yeah, sometimes an upset stomach too, lying in one, just from being, from lying down."

Interviewer: "Okay. Is it comfortable, uncomfortable while you're feeding."

Mike: "I get heartburn from it."

Interviewer: "You get heartburn."

Mike: "Yeah, very bad heartburn from it."

Interviewer: "Okay, do you get any bloating or, or cramps?"

Mike: "Yeah, I get gas from it too."

One individual made comments with regards to a disturbed sleeping pattern but could not verbalize the cause.

Interviewer: "Does that interrupt your sleep, feeding at night?"

Larry: "Yeah, it does I wake up twice during that, that uh...."

Interviewer: "Is that uh, to go to the washroom or ...?"

Larry: "Yeah, go to the washroom or, or just whatever?"

Interviewer: "Okay. So you mentioned that you may shut it off in the middle of the night."

Larry: "MmmMmm and I, I finish it up in the morning."

.....

Interviewer: "Okay but not in the, like which did you say about three in the morning you might just shut it off."

Larry: "Yeah, around three I might just shut it off. Yeah."

Interviewer: "And is that cause it's just bothering you or...."

Larry: "It's just uh, I just don't want to be in bed any longer."

For individuals who tube feed themselves at night, sleep may or may not be disturbed. Those with gastrointestinal disorders tend to report greater disturbance in sleep. See chapter seven for further details.

Summary:

What is it like to live on home tube feeds? Responses to this question by individuals living the experience cover a wide variety of issues. Various themes including the impact of technology; the infringement on time; the restrictive nature of

the therapy; the individual's perception on the difficulties of this life style on one hand and the positive aspect of providing life, health and energy on the other hand; the impact of not eating; the affects on one's sleeping patterns and the inability to distinguish between the negative effects of illness and tube feeds on sleep, are highlighted in the responses to the introductory question of the interview guide. Are these themes common among others that were interviewed? Subsequent chapters will help answer this question.

VI. Technology: The Pole

Individuals living on home tube feeds are dependent on technology for survival. This technology consists of various supplies including tubing sets, enteral feeding bags, formula, syringes, and gauze dressings. Equipment includes intravenous poles, infusion pumps or gravity drip valves. It is the equipment or more commonly, 'the pole', that was mentioned by all participants to be a problem. Eleven respondents currently used the pole to infuse their enteral feeds. From those eleven respondents twenty-five citations are related to the pole.

Mobility Within Their Homes:

Some individuals find that the pole is so cumbersome that they have a difficult time moving it around their own home. The wheel base is large, they bump into furniture, they have a difficult time moving it up and down stairs and rolling it on carpet is a challenge. One has to remember that the intravenous pole was originally designed for hospital use where linoleum flooring is common place and patients seldom carry the pole up or down flights of stairs. Some respondents find that the immobility of the pole restricts them to a specific area in their home.

Interviewer: "Okay. How was that when you fed yourself during the day?"

Mike: "The day, uh, it interfered with everything cause I had to stay upstairs, also dragging the pole around, ..."

Interviewer: "Okay, you had to stay upstairs..."

Mike: "Yeah."

Interviewer: "Up here?"

Mike: "Yeah, then eventually we were able to bring it downstairs, so I was able to watch TV downstairs, use the computer."

Family: "So if you did it during the day, you didn't like it as much because, you really were attached to something, and you had to push your pole around."

Mike: "And because I was tired, I was already tired having to drag the pole around on a carpeted floor didn't help."

Family: "It was a pain."

Mike: "Yeah."

.....

Interviewer: "So you couldn't go downstairs cause you couldn't....."

Mike: "Draggin the pole down."

Interviewer: "...take the pole down."

Family: "And we have a low ceiling in one area, so the pole would hit the ceiling, so anyway, we, we adjusted things and he learned, that he could take the pole down, he took it apart....And he'd rehook and then when he was in the low area of the ceiling he would just tip and lift, and well you adjust and so after a while it wasn't so bad, but it's a nuisance to have to carry all this stuff with you....."

The type of residence, in relation to the amount of stairs, impacts on the respondents mobility within their homes. Barb mentions how she is glad that she no longer lives in a bi-level because she would not be able to move the pole up and down the stairs.

Barb: "And I find that if I'm tied to it during the day that it really restricts me I mean I'm bumping into anything with this pole. It's huge, you know, it's a big wheel base on it."

Interviewer: "Yeah."

Barb: "So it's, I'm bumping into everything, I can't get around."

Interviewer: "Is this, is your house uhm, one level...?"

Barb: "Yes."

Interviewer: "It's a bungalow."

Barb: "Yeah. Which we lived in a bi-level before, so I mean this is a godsend, this house, that I was in this house when it all happened because I don't how I'd manage in a bi-level. You know, cause our bedrooms were all on the lower level there.....The living area was up the stairs. You know, I would have been restricted to the, to the basement, to the lower level the whole time."

Interviewer: "Yeah. Is it hard to wheel.....?"

Barb: "Oh, I would have gone crazy. I couldn't have dragged it up the stairs."

One respondent mentioned that he preferred sitting while he was feeding during waking hours because he was tired of pushing the intravenous pole around in the hospital and also because he was concerned that his dog would play with the tubing.

Interviewer: "So while you're tube feeding yourself, you'll read magazines or books, you'll watch some television. Do you ever move around the house..like uh bake or cook... while you're even feeding yourself?"

Paul: "No, no. You see with that dog up there, he'd like to grab my tube and go for a run (chuckles) ... no I don't do that."

Interviewer: (chuckles) "Do you stay away from him while you're feeding yourself?"

Paul: "No, no, no ...he's got the idea like if I'm sitting here with the machine going to stay away... but if uh I was walking around the kitchen and concentrating on what I'm doing, not concentrating on what the tube is doing he would, he would come and...."

Interviewer: "Play with it."

Paul: "Play with it, yeah.... so you know this way uh...I had enough walking around the hospital and dragging this pole.....around cause I had 4 pumps on it at one time, for a while there...so I had enough of that at the hospital...so I'll just sit for now."

Although only three respondents out of the twelve mentioned that they were unable or unwilling to move around the house while their tube feeds were running, only one respondent actually moved around on a regular basis while he was feeding during the day. This individual fed himself for 18 hours every 24 hours..

Interviewer: "....so what do you usually do while you're feeding?"

Jim: "Uhm, play with the kids or , or uh, lately we've been cleaning the house, because our house is sort of flood torn apart now for flood stuff so that, you know open through boxes an sorting through old junk and throwing things out. Just any, you know, you can do a lot of things. You can tote the pole around and that and carry it with you, so you can carry on ... do quite, inside you can carry on quite normal activities uhm, you know yesterday I did a little cooking and uh, did dishes or whatever you can. You can carry on pretty normally dragging the pole along and having it stand beside you. '

Mobility Outside the Home:

Not only were some people restricted to a certain area in their homes while they were feeding, some respondents could not see themselves taking the equipment outside of their homes. Respondents who were on tube feeds for less than a year seemed to perceive feeding themselves away from home more of an impossibility than those who were on the tube feeds longer.

Question 9. How has home tube feeds affected your social life? (Include times when you have fed yourself outside of the home if this has happened.)

Lucy: (written) Occasionally some relatives will come over in the evening, even on the machine I am able to enjoy this, but I never can go out

unless I was to change the time of starting the feeding until later which would mean running the pump later in the morning. With having the pole and pump it wouldn't be convenient to feed other than at home.

Jim: "Uhm, you're restricted, if you feel like going outside you obviously, would you go outside to do things, uhm you're sacrificing, you know, feeding time, so last night I went to my son's soccer game and uh, you know, that's two hours of no feeding, so, you know, an hour here and hour there and you start running short of hours of feeding, so you cutting into your feeding time. There's no way you can speed it up, it's just, it's, there's only so many hours in a day."

Travel:

Some individuals believed that they were unable to travel and that the pole was a contributing factor.

Question 13. What are the negative aspects of feeding yourself?

Lucy (written): There isn't any way I can get off the tube feeding so that is a downer that I face all the time as it is impossible to do some of the things you would otherwise do (example - my husband would like us to do some traveling.)

Interviewer: "You mention for the negative that uhm, it's impossible to do some of the things that you'd like, you'd do otherwise such as your husband likes to go traveling. Is that because there's just so much stuff to pick up and"

Lucy: (nods yes)

Interviewer: "Do you think that after you've been on it for a while, may be you'll get a little more used to it or do you see any difference in the future?"

Lucy: "With using a pole it isn't something I would expect to change."

Seven individuals did mention that one could hang their tube feed bag on a nail, hook or coat hanger in someone else's home or at their cottage but only five respondents

actually followed this practice. Those individuals that had used these alternate methods had been on tube feeds for a mean length of time of 37 months (median = 25 months).

Interviewer: "So how has the tube feeds affected your social life then?"

Audrey: "It hasn't bothered me none."

Interviewer: "Doesn't bother you none."

Family: "No, we take her to parties and we've taken that with us."

Interviewer: "Okay."

Audrey: "I have straightened a coat hanger and hung it on a nail."

Interviewer: "Straighten a coat hanger, hang it on nail"

Audrey: "Pretty soon your good with a hammer."

Some individuals had still never traveled far from home despite being on tube feed for several years. Wendy has been on tube feeds for eighteen months. In that time period she has left the house once. She discusses what they need to do to get her out but in actuality this has never been done to date.

Wendy: "I like fishing a lot."

Interviewer: "You like fishing."

Wendy: "So we may have to do things a little differently, here at home we have the pole, but the motor home isn't tall enough to have the pole, the guys are going to have to make up uh a hook or something."

Interviewer: "Oh, okay. So you travel in the motor home?"

Wendy: "Yeah."

Interviewer: "But the pole's too tall."

Wendy: "Right."

Feeding at Work:

When respondents tried to foresee how they could incorporate their feedings into their workplace, the pole was viewed as a hindrance.

Interviewer: "So how would say tube feeds has affected your working life?"

Jim: "Well uh, it's limited as well my working life is limited because of uh, you know, the situation but, it would limit my working life because I wouldn't be able to drag, you know, drag it around and carry on my regular duties and uh, you know, I could sit in the office and do something but uh, I wouldn't be able to go on job sites and stuff, you know, carry a pole around and that, so, you know, if a person were to try and do that it wouldn't work. But uh, you know, you could sit in an office and have a pole, there would be no problem with that I don't think. It really, it really, I sort of mentioned before, you know, my working life isn't just limited by tube feeding, it's the whole situation and the way I feel and my health and everything. So, uhm, you know, it's hard to decide if it would have any impact at all."

Quality of Life:

The pole is cumbersome and the tube feed regimen is restrictive. This impacts significantly on mobility. Kaufert and Locker (1990) identified that improvements in mobility impacted positively on the quality of life of persons with post poliomyelitis dependent on ventilator support. .

*"Both physical and psychological health improved substantially and combined with a high degree of mobility, transformed the quality of everyday life."
(Kaufert and Locker 1990, 874)*

A portable machine meant that the person was never forced to stay at home. Since these respirators were attached to electric wheelchairs or walkers one could achieve greater mobility (Alcock et al. 1984). Alcock and co-workers (1984) also noted that

many of the patients preferred to use the equipment continuously. Continuous use of equipment that is mobile was viewed as easier to manage than scheduling treatment into your daily routine. When the home enteral nutrition respondents were asked about their quality of life one respondent made reference to the pole:

Question 17. Did home tube feeds change your quality of life?

Larry (written) Yes.

Interviewer: "And you said yes. In what way did it change it?"

Larry: "Well, I've always got a pole next to my bed, uhm, I've got to sleep, you know, on my back, you know, facing up to the, and uh, I don't know."

Interviewer: "Has it made it better, has it made it worse?"

Larry: "Oh it's made it worse. But then again it's keeping me alive, so it's better"

Sense of Normality:

For some respondents, the pole symbolizes illness. It is a constant reminder that life is not normal. There is a degree of comfort with this new way of eating and a fear of trying to eat normally again.

Interviewer: "Okay, what about the negative aspects?"

Jim: "..... it makes you, it reminds you that you're sick. It's uh, it's uh a constant reminder of what you're going through. I guess that's the other thing."

Interviewer: "Because you have that presence with you... a lot."

Jim: "Yeah, most of the time. Yeah, it's a big part of my life, me and my pole."

Interviewer: "You and your pole." (laughs)

Jim: "My pole. So it's yeah it's a constant reminder of what you're going through.... And it sort of, I guess getting off it sort of presents some fear that uh, it introduces sort of some fear that uh, trying to do it or how ever you would do it or what's it going to be like to try to feed again.... sort of that whole scenario. You know, to, to just reintroduce solid foods and stuff,... you know, sort of a fear in uhm, how that's going to feel... when I get off it and get back to normal or when I'm trying to get back to normal. I'm not sure, so it introduces a bit of fear and it reminds you that that's going to be coming"

Respondents perceive they are tied or nailed to this pole because of its continual presence.

Barb: "It's frustrating, cause I've always been a very active person. So I find it restraining."

Interviewer: "Restrained at, at the fact that it takes so long?"

Barb: "Yeah and that I'm tied to this pole and everywhere I got to go I got to take this pole with me and this tube is hanging, you know."

Summary:

The pole was frequently mentioned as being restrictive or cumbersome. Individuals felt that it not only restricted them to their homes but to a specific area within their home. The type of dwelling, the presence of stairs, pets, and carpet all influenced ones mobility. This mobility also impacted on travel. Travel was seen difficult for some because of the pole. Others used alternate hanging methods. The pole symbolized illness and was a constant reminder of their situation. Some respondents commented that they were nailed or tied to the pole. This constant attachment infringed on how they saw themselves in the future work force.

A more portable system of tube feeds on a regular daily basis warrants further investigation. One example may be the tube feed travel pack which consists of a knapsack that holds the enteral pump, bag and tube feed product. This method may provide an alternate choice for individuals to increase their mobility within their homes as well as outside of their homes.

VII. Management of Tube Feed Regimens

Management of the tube feed regimen can pose many challenges to individuals living this experience. According to the literature, psychological and social problems of persons living with parenteral nutrition included missing out on activities because of problems with scheduling treatments (Smith 1993). One common theme when describing what life is like on home tube feeds is the fact that the tube feed regimen is time consuming. The amount of time, in hours, that it takes an individual to feed themselves impacts on many aspects of their lives including their ability to continue favourite activities such as hobbies, sports, and social activities.

The tube feed regimen is also considered restrictive. The organization of this time and one's ability to be flexible with this regimen seems to enable the individual to better cope with this new lifestyle.

Impact on Time:

Nine out of the twelve respondents commented on the impact on time or the number of hours that it actually took them to conduct their tube feed regimens. In these nine interviews, time was mentioned on twenty-seven separate occasions.

Comments such as:

Paul: "The machine is going all the time.", "I don't like being hooked up to the machine for the length of time."

Barb: "Being tied to it for so long."

John: "It just seems to me that this tube feeding takes my whole day."

Jim: "...it's very slow."

Larry: "It takes many hours that conflict with my daily routine.".....
"I find the feedings very time consuming and I often do not take all I should."

Mike: "It cuts into time to do everything."

According to Strauss, "To be hooked into the frequent use of machinery can be profoundly disturbing, if only because one feels a slave to the machinery." (Strauss 1984, 36). Larry's comments help validate this point.

Larry: "..... And uh, it uh, it really has, it really has kept me sort of, like an inmate, not just a patient, you know, uh....."

Sleep was considered a good use of time in which one could infuse a large volume of tube feeds. Six respondents fed themselves continuously (i.e. a specific volume per hour for 'x' number of hours during a twenty-four hour period). The majority of these continuous feedings were done during their sleep.

Jim: "It uh, you know, so sleeping is, you know, it's good you can get a lot of feeding done while you're sleeping but you can't sleep all the time. (both laugh). The rest of the time you're dragging the pole around. There's no way you can speed it up, it's just, it's, there's only so many hours in a day."

If they needed to continue feeding during the day, it was these hours that impacted on their life. The number of hours spent feeding during waking hours was believed to have a negative impact on one's activities.

Barb: "I remember some mornings sitting there till eleven, 11:30, and my cans would finally finish and I hated being tied to it that long."

Interviewer: “Do you think that tube feeds have changed your quality of life?”

Paul: “..... If I was on it permanently yeah I would find it a hindrance. I would find it uh eventually it would become a problem I would think because being I would become more active then I'd have to end up with more cans and I'd have to have it on for a longer time, so.... it wouldn't uh it would become a burden, you know.”

Interviewer: “Start to infringe on the other things that you want to do.”

Paul: “Yeah, the other things I'd want to do uh, if I want to play baseball or something, I can't I got to plug in, you know or uh, you can't play football, you can't get tackled anymore, you know, rugby's out. (laughs), soccer...”

Conversely, if there were only a few hours to feed during the day, less impact on life was perceived.. It was easier to organize daily activities around lesser hours of tube feeds.

Paul: “It isn't that bad cause you can always juggle ten or eleven hours around the day, you know.... because you can sleep for seven, six or seven, so huh, the other four you can figure out what your going to do.”

Acceptance of the amount of time is related to one's expectations. One person commented that they were pleased to learn that they would not have to feed themselves for twenty-four hours every day as per their hospital routine.

Question 3. What were your thoughts when they first told you that you would need to go home on tube feeds?

Lucy (written): It particularly pleased me to learn I wouldn't be attached to the machine twenty-four hours a day at home as I was in the hospital. They started in the hospital increasing the rate the food would flow through the pump and thus cut back on the time I was attached so I was perfectly ready to carry on at home and felt quite all right about it.

.....
Interviewer: "Yeah. And the amount of time on the tube feed made a big difference on how you felt as well..... Yeah..... Why is that?"

Lucy: "I couldn't be free during the day as I can now."

Interviewer: "To do things you want to do?"

Lucy: (nods yes)

Interviewer: "Are you able to go out during the day, do you go out and?"

Lucy: (nods yes)

Acceptance of the amount of time is also related to one's past experiences. One individual commented that they would have had less time if they had to be hospitalized to receive their tube feeds like in the past.

Interviewer: "MmmMmm. So over all the years do you feel that uhm you've been able to uhm, do things that you like to do"

Mike: "Yeah."

Interviewer: "....uh, socially, with friends and it hasn't uhm...."

Mike: "Well it has cut in but I would have been a lot worse had I not had the tube feeds. Could have been in the hospital."

Family: "It would have cut in more...."

Mike: "Yeah, that's what I'm saying."

Family: "...because he would have been hospitalized."

This was not the case for everyone. Each individual seemed to have a different perception of the extent to which their time commitment to feeding regimens was an

'inconvenience'. Larry made the above comment *"It takes many hours that conflict with my daily routine."* , *"I find the feedings very time consuming and I often do not take all I should"* despite the fact that he feeds mostly during his sleep and only feeds himself for approximately one half hour during the day. Larry wishes he could feed every other day to free up some time.

Larry: "Oh, everything I guess but uh, you know, being dependent on the tube feeding is, is uh, makes me feel helpless. Uh..... you know, I could uh, you know, I just like, you know, I, I wish, I wish I could be every other day. You know, then I could, you know, do what I want, but uh. This is all right I guess. I, I'm going to start eating but uh, I can't, I don't feel like it."

Intermittent Tube Feed Administration:

Is there a difference between bolus intermittent feeds and continuous feeds?

Six respondents fed themselves intermittently. Their bolus feeds were planned around meal times. Only one of these six respondents commented that they felt that the tube feeds took up their entire day. The other five included: one individual who already led an extremely regimented lifestyle due to her illness; one individual who was elderly and was content with following a daily routine; one individual who provided no comments pertaining to time; and two individuals who adapted their regimen to fit around their activities. One of the latter individuals also had adapted methods to shorten the time to implement the tube feed regimen. This respondent made no comments with regards to the impact of time.

Impact on Social Functioning:

Seven respondents made reference that the tube feeding regimen impacted on their social lives. Respondents found that they went out less with friends, some favourite social activities were eliminated, the tube feed regimen and illness impacted on their ability to eat in restaurants and impacted on their families. The next three respondents share aspects of their social lives.

Mike: "Oh it's, it cuts into time to do things."..... "Like going out with my friends in the, in the evening, if I have to be on tube feed I can't go anywhere."

Jim: "Well there's social activities, we don't do anything really other than uh maybe go visit the families, you know, one of the siblings or something like that but uh or the odd friend, but uh, other than mostly people come here or, or uhm, we have no social life really at all any longer. And I'm not suggesting that that's necessarily the tube feeding but it's just a result of everything."

Larry: "I really think that's uh, that's uh the only thing that uh, that is bad about this. Is uh, I don't, I don't have my, I have no freedom to go, to go places and uh to do things, so I just, I don't and I think that's bad, you know, I could uh, like I could easily be going to [work], you know and meeting up with, you know, with the guys and the girls andI don't, you know, I spend much too much time at home. But uh, hopefully it'll change."

Some individuals missed participating in activities or hobbies that involved social contact. John used to play the organ in a musical band but due to his illness and tube feeding regimen he is no longer able to play..

Interviewer: "MmmMmm How has the tube feeds affected your social life?"

John: "It's not very good..... We were never the type of people who went to dances and all that sort of thing. Because I used to get out uh quite a bit playing, you know, I go to these homes for an hour or two playing for the patrons. I enjoyed it. Except other than that so. I doubt I'll get back to it."

Social Meaning of Food:

Food has many social meanings to individuals. One example is restaurant eating. Four of the respondents mentioned that they missed eating in restaurants.

Elimination of these social activities can lead to social isolation.

Lucy (written): Living on tube feeds is difficult in certain ways, It also means you give up normal activities (such as going out for dinner) that you had always taken for granted.

Tom (written): I used to enjoy going to the shopping centre, having coffee and meeting old friends. Now because I am not able to speak coherently I have withdrawn from these activities.

Adapting to Restaurant Eating:

One respondent continued to go out with friends to restaurants but ordered minimal amounts of food. Barb explains some tricks of the trade for restaurant eating and what it's like to see the food people are eating.

Barb: "..... Uhm, and I have a fair amount of friends, so then different friends will stop by during the day and take me out for a ride or we'll go out to a tea room or a craft place to whatever, uhm, probably about twice a week I'd say..... Well maybe even more often sometimes."

Interviewer: "So you mentioned that you'd go out to like a tea room or a craft room...So do you go and have tea or?"

Barb: "I try, I always take my salt with me, to lower the acid cause tea is very high....And I find the acid, acidic things nauseate me tremendously so I ...I usually don't get very far then a couple sips of tea. But I usually put salt in it and it tastes horrible, absolutely horrible. (both laugh) It just tastes awful or often I'll just have water, glass of water."

Interviewer: "Oh, okay. And your friend will have something."

Barb: "Yeah. She'll have tea or something to eat or whatever."

.....

Interviewer: "But you still get to go and enjoy the social...."

Barb: "MmmMmm. I'd rather be then not.....I'd rather be with them, and so they are eating, I rather be with them than not. I'm not, and I find a lot of my friends are very apologetic for eating in front of me and I think that, and I always tell them that's silly. I mean you got to eat to live. I can't eat. So.....uh food jumps out at me. I mean, it stares holes through me. Cause I love food. But uh, and I had tried tasting food when I've been with them. I've taken bites of their food to taste it."

Interviewer: "Okay."

Barb: "And sometimes, sometimes I uh, sometimes very instantly depending on what it is I have tremendous indigestion and this pain, like food is stopped here and it hurts. Sometimes not, sometimes a little later it'll bother me. Sometimes not."

Impact on Evening Activities:

Some respondents found that the tube feed regimen had a greater impact on their social lives during the evenings especially if this is when they began their tube feed regimen.

Interviewer: "Do you find that there are things that you are missing out on or...."

Barb: "Yes, cause I find, you know, uh we never stay out late anywhere, I mean we always have to be home around 8, 8:30 cause I have to have my bath before, it's something I have to do before I get hooked up and everything.....So it's, yeah.... uhm Rainbow Stage is out of the question."

(notes on Barb's interview)

Family - visits but for shorter times. Her sister in Morden had a family reunion. They came early but left early and missed mostly everyone because had to get back to tube feed.

Impact on Family:

In the above quotes, family has already been mentioned by three respondents. Four respondents in total discuss family when identifying activities that they miss.

Wendy spoke at length with regards to missing her family fishing trips. Her immobility due to her illness and tube feeding equipment as mentioned in chapter six impacts on these fishing trips. The feeding schedule and equipment make it difficult to accommodate unscheduled family activities.

Interviewer: “How has the home tube feeds affected your family life?”

Wendy: “Can’t be the same.”..... “Uh, everything was unorganized for.... it really changed things. Uh, guess all the feeds changed that, I’ve gained weight, a little plumper, but other than the....., my activities been... Oh I haven’t tried fishing yet, pretty hard, ... too cold to go fishing right now but shouldn’t make any, any trouble.”

Interviewer: “So you haven’t tried fishing... is that what you said... fishing?”

Wendy: “Right.”

Interviewer: “Did you guys used to go fishing a fair bit?”

Wendy: “Oh yeah, yeah.”..... “I like fishing a lot.”..... “So we may have to do things a little differently, here at home we have the pole, but the motor home isn’t tall enough to have the pole, the guys are going to have to make up uh a hook or something.”

.....
Interviewer: “Do you get out uh in the motor homeat all?”

Wendy: “Uh, well not last year, or pardon me, there was once we went out, they caught cat fish last fall but we usually go for jack or walleye, pickerel or bass whatever. One time, — saw a sturgeon, I don’t remember coming across any before. So we’ll try again. He keeps on saying we’ll try again. I’d like to catch a big muskie, we’ve caught a small one but...”

Interviewer: “So you have gone fishing once.”

.....
Wendy: “Yeah uh things just have not worked out.”.

During the interview the narrative revealed that Wendy rarely gets out of the house.

Interviewer: “Okay. Do you go out uh, out of the house?”

Wendy: "Uh, no."

Interviewer: "No."

Wendy: "I'd like to but..... things just haven't worked out that way."

Tube Feed Regimen Restricts Travel :

Not everyone was confined to their homes like Wendy. Three respondents, including Wendy, mentioned that they did not go out and/or did not travel despite the fact that they would like to. The tube feed schedule restricted the flexibility in their day for travel.

Interviewer: "The way you schedule your tube feeds during the day, if you had more energy do you feel that it would be, uhm, a burden that it takes an hour and half to around the feed?"

John: "Oh, well yeah. It's restricting your movement because I can't jump in the car and go to my son's place or go up to the lake. See we have a cottage up there at Hecla Island. I'd just love to go up there but I can't go."

As mentioned in the previous chapter, Lucy considers traveling impossible. The intravenous pole poses as a barrier for her when envisioning how she could feed herself away from home. Later in the interview, Lucy started to wonder if she would be able to travel with the tube feeds.

Lucy: "I wonder if they'll allow a pole on the plane."

Adapting Technology Regimens for Travel:

Some respondents were able to travel. Five out of the twelve respondents mentioned that they did travel or saw themselves traveling in the future. Only three had actually traveled. Each respondent adapted their technology regimen to allow

traveling. Mike did not even take his tube feeds on the trip and continued to consume small amounts of food orally.

Interviewer: "Have you ever, uh, over the years taken it out, like gone to somebody's house or fed yourself somewhere else other than the house?"

Mike: "No."

Family: "Like if we would go on a trip...."

Interviewer: "MmmMmm."

Family: "....and we would be away for two weeks and he was at that time on quite a lot, like every night..... I would try and feed him for quite a few weeks a little bit during the day, like, before, like from 4:00 on and bring his weight up to a higher level, so when we left for two weeks and he would be losing weight he would have an extra five pounds to lose, cause within two weeks he could lose 15 to 20 pounds.....So if we built up enough extra, so even if he lost he wouldn't get below a certain level and that's how we did it."

Interviewer: "Okay, so you just bumped him up a bit in his weight...."

Mike: "Right."

Interviewer: "... form a little buffer there, went on a trip."

Family: "And came back emaciated but"

Mike: 'Started again.'

As stated in chapter five, Larry actually took his tube feeds with him to Florida but found it very difficult to follow his tube feed regimen. Consequently he lost ten pounds in one week. Both Larry and Milk lost weight traveling.

Audrey has traveled several times via airplane or bus with her tube feeds. She finds that she is able to maintain her tube feed regimen during her travels and is able to

maintain her weight. Audrey has adopted the syringe method of administering tube feeds. Audrey considers this method of feeding more time efficient, less messy and gives her the flexibility to go out more and to travel. Audrey spoke extensively about her traveling experiences (see chapter four). She always keeps a suitcase packed and ready for travel in case her relatives call and then she could leave at any minute.

Audrey also feeds herself on the plane while she is traveling.

Interviewer: “*Oh, okay. Do you ever feed yourself in public ... like do you take it with you and, and then?*”

Audrey: “*On the aircraft I have.*”

Interviewer: “*On the aircraft you have.*”

Audrey: “*But that's not really public.*”

The previous narratives were based on actual experience. Two respondents, who had never traveled before, did not anticipate any problems as they reflected on future plans.

Interviewer: “*In the survey you mention that ‘As of now I haven't had to feed myself away from home.’ ... do you plan on traveling in the future?*”

George: “*Well I might be going to the lake.*”

Interviewer: “*Do you have your own cottage or is it somebody else's?*”

George: “*We got our own cottage in Gimli, well just by Gimli - Arnest.*”

Interviewer: “*When you go are you going to take all your tube feeding stuff are you going to take the pole?*”

George: “*I'll leave the pole at home. I'll find something else to hang it on.*”

Interviewer: “*Do you anticipate any problems?*”

George: "No, it's just like being at home."

Impact on other Activities:

Other activities that the tube feed regimen had an impact on included hobbies. John mentions several times during his interview how tube feeds and his illness have negatively impacted on the numerous hobbies he used to enjoy prior to this new lifestyle.

Interviewer: "So how did your thoughts change now that your actually living with the tube feeds?"

John: "Oh, well I'm restrained. I'm a guy that, you know paints the houses, and fixes it up, does carpentry work, and get around, have a house rented out. I was pretty active since I retired, so this is pretty yeah I played in bands,.... matter of fact I played at Old Folks homes, to the old people I called them, the old people. (both laugh) You know West Park Manor or Tuxedo Villa, places like that. There was two or three of us, we go out and we did a lot of that. Entertained. Every Thursday, we were the act for the Legion, the army and navy and so on. I had to cut all that out."

George, on the other hand is able to continue with his favourite sports such as golf, curling and bowling. The only negative thing he has to say regarding the tube feed regimen is that he his unable to do heavy yard work. Later in the narrative he realized that this is due more to his health and energy levels. Contact sports was only mentioned by one respondent.

Paul: "Yeah, the other things I'd want to do uh, if I want to play baseball or something, I can't I got to plug in, you know or uh, you can't play football, you can't get tackled anymore, you know, ruby's out. (laughs), soccer..."

Water activities such as swimming and hot tubbing could no longer be done due to the gastrostomy.

Paul: "..... And uh, I guess uh..... this has kept me out of my hot tub. Hot tubs and saunas are out. You know, so I'm glad I'm getting rid of this."

Social Isolation:

Home enteral nutrition impacts on one's ability to schedule favourite activities.

A time consuming regimen can increasingly lead to social isolation (Strauss 1984).

Larry describes how his tube feeding regimen has isolated him from his family.

Larry: "You know it's so time consuming. Uh,..... just uh, you know, it wraps you up into one person, you just, you're not part of anybody else.....You're just here and the feeding coming in."

Larry feels separated from his wife while they are sleeping and isolated from his family

while they are eating. Isolation from their family is also illustrated by this respondent.

Audrey: "Feel like you got dinosaurs or contagious disease or something..... Makes you feel like almost like your abandoned.....Oh I guess you don't know what I'm talking about."

Interviewer: "Well, can you give me an example of feeling abandoned."

Audrey: "Well I eat here, having what I have and they're in there. It's like I'm not here at all."

Restrictive Nature of the Tube Feed Regimen:

When individuals start to miss certain activities in their lives, whether it be social functions, friends, family, travel, sports or hobbies and when time restraints become an issue, individuals start to get a sense that their lives are restricted. The

following narratives illustrate respondents perceptions that the tube feeds were restrictive and restraining:

Jim: "....Uhm, you're restricted, if you feel like going outside you obviously, would you go outside to do things, uhm you're sacrificing, you know, feeding time,...."

John: "Oh, well I'm restrained..... . I had to cut all that out."

John: ".....it restricts your movement immensely..... It's restrictive and restrained.....activity."

Allan: "My quality, my quality of life. Like I say, okay,the fact I had to have these at meal times, kinds of restricts me, uh restricts my activity some, in a way, you know, but uh I don't go, I don't go out to strangers too much. I go to my relatives, my children and my relatives, I go to their homes and they all know my case and so I'm satisfied that they would, they would sympathize with me rather than 'Oh look, look guys, look at him', you know."

Barb: "It's frustrating, cause I've always been a very active person. So I find it restraining."

The restrictive nature of the tube feeds is also be related to the pole as mentioned in the previous chapter on technology.

Barb: ".... I hate being tied to my pole. I feel restricted."

The restrictive nature of the tube feeds is also related to whether the respondent adjusts their tube feeds schedule around their life or schedules their life around their tube feeds.

Flexible versus Rigid Tube Feed Regimens:

One theme that emerged from the interviews was that it appears that respondents who adjusted their tube feeds around their activities commented less on the restrictive nature of the tube feeds. Seven of the respondents adjusted their care somewhat to fit their lifestyles. Only two of them mentioned that the tube feeds were restrictive in some way.

On the other hand, those respondents that were more rigid with their regimen found the tube feeds more restrictive. Five respondents followed a rigid care plan for their tube feeds. Four of these respondents mentioned that they found the tube feeding regimen restrictive. The fifth respondent led an extremely restrictive lifestyle due to her illness and never mentioned the restrictive nature as a separate point. It was more entrenched in her total way of living.

Here is an example of two individuals who discuss how tube feeds impact on their evening. Paul is flexible with his tube feed regimen:

Interviewer: "What if you need to go out in the evening?"

Paul: "Well, then if I know I'm going out I'll feed in the afternoon, lunch time or something till about 4 o'clock or 5 o'clock. Go out for the evening and plug in when I get home. It isn't that bad cause you can always juggle ten or eleven hours around the day, you know.... because you can sleep for seven, six or seven, so huh, the other four you can figure out what your going to do."

whereas Barb follows a more rigid schedule:

Interviewer: "Do you find that there are things that you are missing out on or...."

Barb: "Yes, cause I find, you know, uh we never stay out late anywhere, I mean we always have to be home around 8, 8:30 cause I have to have my bath before, it's something I have to do before I get hooked up and everything."

Interviewer: "Have you ever tube fed at different times in the day, like if you know you want to go somewhere and got in some feeding at a different time?"

Barb: "No I haven't. No I always do it at the same time."

Interviewer: "Okay."

Barb: "Simply because, I think because I dislike it so much, I make it, it's part of my night routine and that's just how it is."

Interviewer: "Okay."

Barb: "I guess I'm kind of rigid."

A less rigid treatment schedule decreases the restrictive nature of the tube feed regimen. One family member gives this advice to people managing home tube feeding regimens.

Family: "Yeah and we had sort of figured out how to work it. Uh, and I guess, if people are uhm, given the information and told that they don't have to be so rigid about stuff, I guess they would probably find quite simple, like once you get into the routine of doing stuff. It's like anything else, you just do it. It, it tends to be a nuisance when you think back on it, but when you're doing it, it's just like, you just do it."

Adjusting Treatment to Fit Lifestyle:

Adjusting care may include rearranging the timing of the feeds, altering the method of feeding and changing the number of tins of nutritional supplements that are fed in a twenty-four hour period.

Timing of Feeding Schedule:

Some respondents feed themselves at different times during the day depending on what activities they have scheduled. George illustrates how he arranges his feedings around his active lifestyle.

George: if I'm doing anything like working outside or playing any sport I'll judge accordingly when to eat.

.....

George: Tube feeding hasn't affected my social life at all. Before I bowl - I have something to eat (pureed) then after when I get home have tube feeding. I do the same when I golf or curl as of now I haven't had to feed (tube) myself away from home.

If something comes up Larry will just shut off the tube feed and continue it later. This same technique has been previously mentioned by Jim.

Interviewer: "So how has the home tube feeding affected your social life?"

Larry: "Oh uh in the same way, I figure, it, it doesn't affect my social life because I'll do anything I want to do and stop eating....."

Interviewer: "Okay."

Larry: "..... but then I'll lose weight....."

Tom mentions that one also has to schedule their feedings around appointments.

Tom (written): Sometimes feeding times have to be rearranged for Doctor's appointments etc. My wife has to arrange her schedule also but all in all we are managing quite well.

Altering Method of Tube Feed Administration:

Altering the method of tube feed administration is another technique of increasing flexibility. For example, Audrey prefers using a syringe to feed herself due to the fact the it's faster, cleaner and easier to operate than the gravity drip method (see case study in chapter four). Larry also changes his method of infusion from a battery operated pump to his own manual system of pumping.

Interviewer: "Okay. And you do it manually?"

Larry: "MmmMmm.....Cause it's faster."

Altering Volume of Tube Feed Received:

Changing the amount of tube feed one receives in a twenty-four period is another form of altering treatment. Mike's narrative illustrates his individual nutrition strategy for treatment. Depending on his circumstances the volume of tube feed was adjusted accordingly. Mike adjusted his tube feed volumes depending on the amount of food he was able to consume, his weight and whether or not he needed more sleep.

Mike: "But then uh, my weight, we noticed my weight going down so we've started doing it every other night or every, every night to boost you back up. Then it goes down to every other night. Then intermittently as needed once I, uh my nutrition's back to where it should be."

.....

Family: "And so from then on we just did our own thing. And I just guess at stuff and what works we did and what didn't work we didn't do. And we really use it more as a, sort of an aid so that we didn't have to drive [Mike] crazy about eating. So it was a lovely thing to have, so if he didn't eat

he would just get more tube feed. And at the beginning he just always had to have tube feeds and when he was really bad he would just increase the amount."

.....

Family: "And it took almost three months to get him into a real good weight. And then we cut back to every night, he would get about 1200 calories plus eating.....And then we cut back to like to every other night. And that's what we've sort of kept up, unless he now gets much better, like if he, if he's eating much better then, he may not get tube fed for a few weeks. When he tells me his watch is floating around on his hand, we start tube feeding. So we don't weigh him and obsessed about stuff like that."

A conscience effort was made by his family to not have the tube feeds or his weight a focal point in their lives.

Family: "Cause we use little, because you can, you can get quite obsessed and then that's a waste. And so, when his watch starts to float we may bump up what we're, we're doing. If we're doing nothing, we do a little bit more, if we're doing a lot we do a little bit more. And that's how we've been doing it."

.....

Family: "And but it's also we've never sort of been uh monitored all that much when it comes to tube feed. We've sort of done our own thing. And we just use common sense versus rules and uhm, ...And so his tube feeding has gone really well because we have done it by gosh and by golly. And quite frankly a lot of medical personnel do everything by gosh and by golly also."

Three other respondents also fed themselves a different volume of tube feeds than that which was recommended by the Manitoba Home Nutrition Program. In all cases it was a reduced amount.

Audrey: "I'm supposed to have five cans, but that's a heck of a lot..."

Family: "She's supposed to have five cans of Boost but she'll take four. Yeah, yeah, she'll take four but then she takes her soup"

One respondent was leery about telling the nutrition team that she had reduced the amount of tube feeds because there was a disagreement in goal weight and she did not want to get labeled with anorexia nervosa again.

Interviewer: "That's why you haven't mentioned about the three cans yet cause you..."

Barb: "No, no and I thought maybe I could, by then it would be fall and I could get myself back up to four cans, but I really don't want to put myself back up on four cans because I really don't want to gain a whole lot more.....And I find three cans maintains me or causes me to gain like one pound every couple of weeks kind of sort of... You know, that's what it seems to be doing. But that's, I feel fine weight wise the way I am.....But I hope they don't scream at me. (laughs) Like [the dietitian] won't, but.... [the dietitian] also thinks that I should get up to [x] pounds and I don't agree with her. I told her no I don't want to be that heavy again. So.....But I'm also sometimes afraid to mention it because then they, I don't want to be labeled as anorexic cause that's what I put up with for months before I was diagnosed."

The respondent's ability to be flexible with their tube feed regimen was not related to the intermittent or continuous scheduling of the tube feeds. In the adjusted care group three were fed with bolus feeds and four were fed continuously. In the rigid care group three were fed with bolus feeds and two were fed continuously. Therefore there are differences between ventilator dependent patients and those on home enteral nutrition. Alcock et al. (1984) documented that patients dependent on ventilator support preferred continuous treatment. The difference is the mobility of the two technologies.

Impact on Sleep

One common belief is that if one feeds themselves during their sleep, the tube feeding will disturb their sleep to the point that it would be considered a hindrance. Is this perception shared by those who live the experience? Respondents who fed themselves during waking hours did not make any comments regarding sleep. All six respondents who fed themselves during sleeping hours did comment regarding the impact on their sleep since they were directly asked by the interviewer. Four of these individuals stated that the tube feeds did interrupt their sleep but it really didn't bother them. Two respondents made several comments that the tube feeding impacted significantly on their sleep.

Paul: "Go to sleep and the machine does the rest."

Interviewer: "Does it beep when it's over and wake you up?"

Paul: "Yeah and I just turn it off."

Interviewer: "Do you feel that it uh interrupts your sleep at all?"

Paul: "No, no it's not a big deal. Just turn it off and that's it."

One respondent stated that the tube feeds did not affect his sleep but contradictory to his statement, he commonly woke up around 3:00 in the morning and could not fall back to sleep again. The reason for this disturbed sleeping pattern was undetermined.

Interviewer: "It, what do you mean by uhm, this last part that it conflicts with your daily routine? Does your feeding at, you are feeding at night, do you find that you have to feed during the day too?"

Larry: "Yeah, I do sometimes, because at night, I uh, I uh, I wake up and I uh, and at 3:00 in the morning wake up and shut off the feeding...And uh, and I go to sleep and I, and I feed during the daytime."

Interviewer: "Okay. So why do you shut them off in the middle of the evening, night?"

Larry: "Well because, because it, it's located at my bed, and you know, I don't want uh, stay in bed all, all night. You know I get,...."

Factors That Contribute to Sleep Disturbance:

Frequent Washroom Visits:

So what is it about the tube feeds that can potentially disturb one's sleep? The majority commented with regards to that fact that they had to get up during the night to go to the washroom. Five of the six respondents made references to this.

Interviewer: ".... Do you find that you need to get up in the middle of the night to go to the washroom and....?"

Barb: "Lots."

Lucy (written):During the night I have to get up quite a few times, I am being fed all night.

Interviewer: "You mentioned while you are sleeping and the you're feeding during the night that you have to get up a few times, is that to ..."

Lucy: "Go to the bathroom."

Positioning:

While one is tube feeding at night it is recommended to sleep on their back with their head elevated using pillows or a wedge. This change in positioning may interrupt one's sleep.

Barb: "Well if I run the cans, the amount of cans I'm supposed to it would take me about ten hours, but I haven't been running full, four cans because it's summer and I'm not sleeping well...."

.....

Interviewer: "Okay, so that's eight, eight hours. And you ment, you mentioned that it's, your, your not sleeping as well."

Barb: "No. No. Cause I sleep on a wedge. They, I'm supposed to sleep elevated and I find I have to because if I don't I've terrible indigestion....Pain, so uhm, I sleep on a wedge and I'm not used to sleeping on my back. I've always slept on my stomach..... before. So I don't sleep well. I'm very uncomfortable and I wake a lot.....That's why I decreased them to three. So the time is shorter so that after six I can sleep properly cause I don't use the wedge, then sleep on pillows."

Larry and Jim's narratives reveal that their sleeping positions limit their ability to cuddle with their spouses.

Larry: The tube feeds affect my family badly. During the night when I sleep with my wife the feedings have me in one position so I can't hold my wife and this causes a separation between us.

Jim: ".....Uhm, you know, that uh sleeping, you're sleeping sitting upright, you know, it's pretty uncomfortable position so, you know, it's not for your spouses..... it's not, you know, you're not the most uh you know you really can't snuggle up and then you go to sleep sitting up." (both laugh)

Interviewer: "Curl up beside each other."

Jim: "No, well actually I have a hospital bed now so it's uh, so I'm sleeping upright, sitting there staring at the walls, you know whatever and uh it's uh..."

Interviewer: "And you have that bed specifically so you can feed yourself at night?"

Jim: "Uhm, well I got it because I couldn't lie down, uhm my head was all congested and the VON had suggested doing this. Uhm, it certainly aids tube feeding, it uh, the feeding lying down wasn't working, I, you know, in a horizontal position it wasn't working at all so I was propping myself up

with pillows and stuff so she suggested doing this. That was something that pretty well goes hand in hand with the tube feeding as well."

Gastrointestinal Complications:

In the total sample there were three respondents with gastrointestinal illnesses which contributed to the reasons why they needed home enteral nutrition. These three respondents made the most comments regarding their sleep than any other respondents. Twelve out of the eighteen comments on sleep were mentioned by these respondents with gastrointestinal illnesses.

Family: "... and so it's easier, he has quite an interrupted sleep and stuff when he's on it."

Mike: "MmmmMmm. Yeah. And I'm also not sleeping well because of my [illness] and treatment.....So the tube feeds make it worse."

.....

Gastrointestinal complications during tube feeding may include diarrhea.

Family: "Okay.... But uh, he hasn't been tube fed all month because the last time he tube fed him, he was just leaking so badly, cause his colon's so bad..... and so I asked why, they didn't have a clue, told me to ask the doctor, you know, no one knows these things, they make it up as they go along. So I just, because he's being eating and he hasn't really lost so much weight, so I've been sort of holding back. He's has so much trouble in his uhm, like perianal area, so I just didn't but we're going to have to start again so I thought we might tube feed instead of at night so when he soils himself it's not, it's more contained and so...."

Mike: "And I get as good night sleep as I get."

Family: "Right, so I figured if we tube feed him in the morning for like three, four hours and then when he gets home, when he's awake instead of when he's asleep he can change pads and stuff as he would leak badly."

Other gastrointestinal complications may include indigestion and regurgitation.

Barb: "Yeah, but the wedge starts at my uh smaller back, if I don't slide off of it. But I wake very quickly if I slide off of it, cause I have tremendous, tremendous indigestion pain, you know, it's just a heavy, heavy, ugly feeling if I slide off of it."

Those without gastrointestinal illnesses also noticed some regurgitation that required getting accustomed to.

Jim: "You know again though, that was at the beginning of the treatment or beginning of the, you know, the start of tube feeds so now it might be a little bit different, but even lying on the couch I have to prop myself up because it just feels uncomfortable, you feel like the tube feed, it doesn't seem to stay down. It's, you know, it's all liquid I guess. Just seems to want to come up."

Interviewer: "It would be like eating lying down."

Jim: "Yeah, yeah..."

Interviewer: "It feels weird."

Jim: "It doesn't, it's not natural. It's not the way it's done."

Methods Used to Remedy Disturbed Sleep:

To combat this disturbed sleeping pattern one individual took sleeping pills.

Interviewer: "You might get a couple of nights of good sleep in."

Barb: "MmmMmm. If I've taken a sleeping pill. But I'm running out of them.....And they don't want to give me anymore. And I don't take them every night. I take them maybe once, twice a week. So that I can get a good sleep, once or twice a night, I mean once or twice a week."

Fatigue:

When one's sleeping pattern is disturbed, the possible outcome, one can assume, is feeling tired during the day. Four out of the six respondents who

commented on the impact of tube feeds on their sleep also commented that they felt tired during the day.

Barb: "MmmMmm or just because I'm uncomfortable. I'm uncomfortable sleeping on my back. I just wake."

Interviewer: "So when you wake up in the morning are you tired?"

Barb: "Yes. MmmMmm."

Interviewer: "Are you tired during the day?"

Barb: "Uh yes, yeah, but I won't lie down."

Interviewer: "No."

Barb: "Cause I'm afraid I won't sleep at night."

This sense of feeling tired seemed to be related to either an interrupted sleep and/or their illness and physical health. John is a day feeder and comments that he feels weak due to both his tube feeds and his medical condition.

John: "Well I've been too weak to do anything."
.....

Interviewer: "Has tube feeding changed the way you think of yourself?"

John: "Well, I don't know. I'm a pretty compassionate person, it hasn't really bothered me that much. I guess the main thing is the movement, you can't, you can't find the energy to do the things you used to be able to do."
.....

John: "Yeah. Oh, I could get the energy if I can get active."

Interviewer: "Do you think you'll get energy if you get active?"

John: "Yeah. If I can get active, it's quite easy."

Interviewer: "So one of the reasons you feel you don't have that much energy is because of the tube feeds?"

John: "Yeah..... and my condition."

Interviewer: "Why would you think that you don't have that much energy because of the tube feeds?"

John: "Well it's just the way I feel. I have no energy."

Interviewer: "Do you feel like you"

John: "I should be out planting the garden now, cutting the grass, which I did quite willingly before. I always have my garden in before May the 21st. Now it's, I don't feel like it, I can't"

Despite the fact that Jim does not think his sleep is really interrupted he does comment on being tired during the day.

Jim: "....., but uh, physically I'm weak and tired, and just sapped out and I have a lot of appointments that I seem to go to and it seems to be there's something all the time happening...."

Impact on Normality:

According to Strauss, "the chief business of chronically ill persons is not just to stay alive or keep their symptoms under control, but to live as normally as possible despite the symptoms and the disease.....when regimen, symptom, or knowledge of the disease turns out to be intrusive, then sick persons have to work very hard at creating some semblance of normal life for themselves." (Strauss 1984, 79) During the interviews, seven respondents used the word 'normal'.

When asked the question ‘Has tube feeding changed the way you think of yourself?’ two respondents commented:

*Wendy: “I’m not normal.....No, not really. No.... it’s that, can’t eat the hamburger and fries and onion rings (tears, crying)
.....(40 seconds)...”*

Allan: “I’m not, I’m not normal.....And uh, as far as, as far as uh people come and visit me and they come and we talk and uh, uh, and, I uh think of myself the way I used to be, and uh, and people, people know that I don’t, I don’t think they, they can’t, they can’t resent the way that I am because it’s not their, it’s not their problem, you know. Uh most of them would, would said that I would, you know, oh too bad you gotta eat like this and that, but uh, you know, everybody has something.”

Related to Eating:

Six of the seven respondents who used the word ‘normal’ in their responses mentioned eating when talking about normal behavior.

Interviewer: “Do you eat food at all?”

John: “No I can’t, uh, Candace there, who I’m working with uh with the speech path pathology, Candace at the uh St. Boniface, but uh she spent a couple of hours, the first day up there, about two weeks ago and uh, they had some Ensure uh puddings in the can, I had at that point turning my head to the side, swallowing hard, and had it down over here somewhere (points to neck) and that went down not too bad. Water and juice I can’t get down, it goes down the windpipe. So, but other than the taste, its too much work just for the taste. I would take a glass a week. But the taste, it tastes.... To taste food it makes you feel even worse because you can’t eat it in a normal manner.”

Interviewer: “So why is that, why does it make you feel worse?”

John: “Well because you can’t eat it in a normal manner.....It’s a real job to tilt your head over to the side and try and get it down. That’s hard work.”

Interviewer: “Hard work.”

John: "Yeah. You know, it's so different from the way you used to eat. I guess you taste the food but it takes a half an hour to get it down. I can't see that it

Interviewer: "So since it's hard work to swallow, are you saying that it sort of takes the enjoyment out of eating."

John: "Well, certainly. Makes you feel worse.....You can't sit down and eat it."

Audrey's interview is very positive with regards to her overall outlook on tube feeding but when asked at the beginning of the interview 'Can you describe to me what it is like to live on home tube feeds?' she responds "Terrible" and makes reference to not being able to eat normally.

Audrey: "Terrible.....MmmMmm. When you see everybody using a knife and a fork you feel kind of left out."

.....

Interviewer: "Yeah. So it's actually, uhm, the fact that you can't sit down and eat some solid food like a regular"

Audrey: "MmmmMmmm. If I had my choice, I would choose not to have it."

One individual actually expressed that they have wishes for a normal way of consuming food.

Lucy (written): I do not consume food as well as the tube feed. Although I find I can feel okay about not being able to eat regular food I still think about the was foods had tasted. I don't have any cravings but have wishes for a normal way of consuming favorite foods and sampling different types of foods as in other days. I don't do anything special in the way of activities instead of eating, I just carry on with what has become my way of life the last few months.

One respondent commented that they have a desire to eat because it is symbolic of getting off the tube feeds and getting things back to normal.

Interviewer: “.....So, what is it like to never eat food?”

Jim: “It’s uh, it’s getting difficult, you know, it’s it’s more, it’s getting increasingly difficult to watch people eat. You know, that’s that’s a desire to get off it and and I think this is more an emotional thing because you don’t really feel, I don’t feel hungry. It satisfies your, it satisfies your hunger, you don’t feel hungry, hungry the way you would normally feel. Uhm, you may feel dehydrated I guess, you know your mouth dries up and stuff when your not on it for and I’m not drinking either, but uh, so, so you don’t feel hungry, so it’s not the same but I think a lot of the food business is my desire to want to get off it and I look at it and I crave, just wanting to eat it just because it’s symbolic of getting off the tube feeds and getting things back to normal. That’s I think more closer to what’s happening..... It’s just the desire to get off and the sight of food symbolizes getting off it so you want to eat, smells good and uh, you know, I’m scared now I don’t even know what I’m going to taste once I’m finished this anyway. You know, eating, I’m not sure if eating is going to be as pleasurable that I might imagine but uh, it still symbolizes sort of some sense of normality but uh that’s what I’m sort of looking for.”

The tube feed regimen can become a crutch for some and there is a fear that eating again will not be the same.

Jim: “My pole. So it’s yeah it’s a constant reminder of what you’re going through.... And it sort of, I guess getting off it sort of presents some fear that uh, it introduces sort of some fear that uh, trying to do it or how ever you would do it or what’s it going to be like to try to feed again.... sort of that whole scenario. You know, to, to just reintroduce solid foods and stuff.... you know, sort of a fear in uhm, how that’s going to feel... when I get off it and get back to normal or when I’m trying to get back to normal. I’m not sure, so it introduces a bit of fear and it reminds you that that’s going to be coming and hopefully it will be.....”

Interviewer: “So if it introduces that kind of fear of what’s up and coming does that mean you’re kind of secure with”

Jim: “Yeah, I know, that’s what I’m getting, I’m getting scared of.... I sort of saw that one was coming.” (both laugh) (interviewee stops to cough)

up phlegm) "Uhm, yeah, that's been in the back of my mind and that I've become, become very sort of complacent with it and uh, that uh, this whole not eating is a bit psychological and I'm sure it is. I, you know, I'm not too proud to admit that uh, you know, I don't have things going on in my head too and that the feeding and the drinking, could try a little harder, even would be possible but uh..... I'm going to stick with what uh, what I feel strongest and that's that uh, that is hard to so when I do try it, it hurts too much and it just doesn't feel right, you need to come to someit's not time to do it so... so uh, yeah it does, it could become a bit of, sort of a crutch."

Acceptance of Life Changes:

Two respondents commented that they had to accept this new way of eating to get on with life.

Lucy (written): My thoughts remain the same, after not having been able to eat normally for some time, I feel I have no choice so accept it as my way of life.....Tube feeding has made me realize your body can accept other than the normal way of eating, and I am thankful for that.

Interviewer: "So when you were first getting out of the hospital and you had to take this stuff with you, how did that feel?"

Allan: ".....No, it didn't feel very good.....But uh, you get used to it.....You know, and now, now it comes, it comes, like uh natural, you know, see like dinner time, supper time or whatever, you know, it isn't, it isn't, to me that's my way of doing things, to you, you, your have another way of doing things, so.....As long, as long as there's a hook somewhere, that I can, I can hook these things uh, so that I can put the, a couple of boxes in there and hook them in here, I'm satisfied."

Interviewer: "Okay. So it's like normal now."

Allan: "Yeah. Yeah."

Self Image

When respondents comment on the desire for normality some include the impact on self image.

Jim: "So I'm sure I'll be on it till the end of treatment which it is obvious at this point, my end of treatment is June 2. Uhm, and uh, hopefully not much beyond that. I'd like to try and get back to sort of a normal life. You know, these hoses taken off me and everything.....But it, so at least I could look normal, I don't feel normal, and just get better. I felt good before they started this, you know, before they told me I was sick I felt great." (both laugh)

Mike's Family: "And the family also isn't always looking over his back making sure that he's eating because he's going to get sick. So you just leave him alone and he's just like a normal person, you know, except for, he's got a hole in his stomach, so."

Only three respondents out of the twelve made reference to the negative impact the tube or the hole in their stomach had on their self image. Two of these respondents were male and one was female. All three were on tube feeds for three months and were less than 50 years old. When asked 'Has tube feeding changed the way you think of your body or the way you think about yourself' these informants responded:

Barb: "Yes, I think my body looks gross with this tube hanging out of it. Not that I ever strutted in a bikini or anything or was runway material or anything but.... Yes, I think it kind of looks gross, my stomach kind of protrudes, it never did before. It does."

Paul: "Your self image, I would say it's been a slight change in your self image. You know when uh you're in the shower and stuff and uh you got a tube hanging out, bag hanging on, things like that it's not uh you don't feel as good as you did, like you used to anymore. I guess it's sort of a handicap but uh when you go out and you walking through the mall and things like that, I can see if you had to tow the bag along with you would be different from uh myself where I can just unplug and go and it's not a problem. So..."

Interviewer: "And it's hidden."

Paul: "It's hidden. So it's this self image thing, you see how do you look with this tube hanging out and uh having to clean it uh. Other than that it's not uh a big problem."

Interviewer: "Other than in public and your self image, has that affected like with your family at all, your self image?"

Paul: "Uhm, no, they're used to it. They saw a lot more tubes in me at the hospital than they do here so that's not really a problem. It doesn't bother my wife she's a RN.....So, you know it uh, it bothers me more than it bothers them, you know. Like I uh don't run around with my shirt off or anything. I always have a shirt on, always have my tube tucked away."

Barb comment's that she does not want her husband to see her new body image. Her narrative further reveals that not all men are like her husband and she relays a story about a women with breast cancer whose husband reaction was very different (see case study in chapter four).

Interviewer: "Have your thoughts changed now that you're actually living with it?"

Barb: "Yeah it's not as frightening.....I remember when it was first put in I hated looking at it. I hated touching the area. Now I clean it regularly. Uh, it's not gross to me to look at. It never was gross looking at anybody else's but when it's your own. (both laugh) Uhm, I, I find I don't like my husband seeing it. Cause I don't, I don't want, you know, I, I think it's, it is gross, to me, that I don't like him to see it. He doesn't care. He, he's got a good attitude. He doesn't care at all that it's there. (tears).... Yeah."

One individual when asked whether the tube feeds affected his self image, he commented that he tried not to think about it.

Interviewer: ".....How about to your self image?"

Jim: "Well, I try not to, I try not to think, yeah I , I'm sure some people have raised, it's shocked a few people probably when they see all pumps and stuff like that, you know, sure that uh, it made them feel uncomfortable a little bit, but uhm, I'd have probably would have done the same for me too if someone else was doing it but uh, you know, you do what you have to do, but uh that's part of it. So I'm not too proud to, to uh walk around with the tube or hook it up or anything but if I have to do it, I have to."

Acceptance of Life Changes:

Other respondents that fell within this age category of less than 50 years, had been tube feeding themselves for eighteen to 132 months and commented that the tube did not bother them because they had become accustomed to the tube.

Interviewer: "Has tube feeding changed the way you think of your body?"

Wendy: "No ... not really.....I just know what, uh, the tube is in and it can be used, I can't think,.... well it's another thing to look after."

Interviewer: "What about the tube in your stomach?..... Does that bother you?"

Larry: "Yeah. But not, not so much now. I'm used to it."

Interviewer: "Has it changed the way you think of your body?"

Mike: "No, it's just another part of me, like uh, it's just there."

Interviewer: "Having that button there is...."

Mike: "Yeah, not a problem."

Inner Self versus Outer Self:

During the interviews, two respondents made reference to the fact that ‘that’s not me’ when discussing things that they do now compared to their past.

Barb: “Uh, or, or, rarely the shopping centre, I find I can’t walk the shopping centre very well cause I’m, I’m really sore and that’s not me. I’ve never been a sickly person in my life. Never.”

One of the respondents who has been tube feeding herself for several years and was disfigured due to surgery tries to explain in length that there is a separation between her inner self and her outer self. Her outer self is not her.

Interviewer: “Has tube feeding changed the way you think of yourself?”

Audrey: “Oh yes, I’m not me.....Not the way I used to be. Uh, I’m a different person all together... than I was before all this.....Yeah. I was thinking that but uh, it’s a different style of life. Like, my old life is nothing like this one, it’s not working out. There’s a lot of different things that you have to get used to.....And there’s nothing you can do about it.....You just throw your hands in the air and say well, you just make the best of what you have.”

Interviewer: “Yeah. So is there a sense that there’s a separation from”

Audrey: “Yep.”

Interviewer: “.... your old, old you”

Audrey: “Ooooooh, yeah.”

Interviewer: “.... and now there’s this, a new, you’re a different person....”

Audrey: “Yep.”

Interviewer: “... Things have happened to you and you’re different now.”

Audrey: “MmmMmm. Yeah.”

.....

Interviewer: “What about your self, like your personality, like is it your body that’s different but your personality is still the same.”

Audrey: "Oh, I'm still me.....I had to choose my way, if I don't like something you're going to know it."

Interviewer: "So your personality is the same"

Audrey: "Oh, yeah."

Interviewer: ".... it's your body that now is different. So in that way you view yourself as a different person."

Audrey: "Uh huh."

Interviewer: "Your body is different."

Audrey: "Yeah."

Interviewer: "But your personality and the things you still enjoy to do are the same."

Audrey: "Oh, yeah that hasn't changed. Other than the fixtures. It's just"

Interviewer: "So is it when like when you look in the mirror you just see somebody different?"

Audrey: "Oh, yeah.....That's not me.....That was me." (points to wall with picture)

This concept of inner self and outer self is supported by Strauss's comments "In a genuine sense, any chronically ill person who phases drastically down, or up for that matter becomes a new person in the house..... The same person is likely to become a new person to himself, too, in the sense that his body is no longer what it was and so to some extent 'I am no longer what I was.'" (Strauss 1984, 72)

Summary:

Managing tube feed regimens impacts on many aspects of an individual's life. The time commitment required to implement this technology infringes on social and family activities, travel, hobbies and sports. The restrictive nature of this treatment leads to social isolation for some. One's ability to cope with this new lifestyle is dependent on one's ability to be flexible with time and creative in modifying the technology. Those who possess these attributes notice less impact on their lives.

Impact on sleep is minimal for most. Reasons for waking during feeding include: the need to go to the washroom and being unaccustomed to a new sleeping position. Individuals with gastrointestinal problems had the most difficulty with sleeping and feeding at the same time.

Impact on normality is a common issue with chronically ill persons. The behavior most identified with normal was eating for this group. Respondents commented on missing the normal act of consuming foods and that this needed to be accepted in order to carry on with their new life. Self image was another component of normality for this group. Some felt that they no longer looked normal with a tube hanging from their stomach. These comments were limited to respondents under the age of 50 who had only been receiving tube feeds for a short time period. Those individuals who were older or who had been on tube feeds for longer periods had accepted their tubes..

As stated by Strauss, “Social relationships are disrupted or falter and disintegrate under the impact of lessened energy, impairment of mobility or speech, hearing impairment, bodily disfigurement, time spent on regimens and symptom control and efforts made to keep secret so much about the disease and its management. It is no wonder that chronic sufferers themselves begin to pull or feel out of activity and communication.” (Strauss 1984, 75).

VIII. Tube Feeds Intertwined With Illness

When answering questions during the interviews, respondents had a difficult time separating descriptions of life with home enteral nutrition from their experience of illness and health. The tube feeds were intertwined with their illness in terms of its impact on life. In some narratives the tube feeds and the illness were one in the same. Other narratives revealed a combination of everything impacting on their lives. Only one respondent was able to distinguish between the two and identified that some impacts were due to his cancer and not the tube feeds. Eleven out of the twelve respondents made comments illustrating this meshing of both the tube feeds and their illness.

Tom had head and neck cancer which was removed with radical dissection. He no longer is able to communicate verbally and finds this has impacted significantly on his social life. During the telephone interview with his wife, for clarification on written responses, she comments as to the fact that he does not socialize 'due to his mouth which is part of the tube feeds.'

Interviewer: "For the question, Did home tube feeds change your quality of life? he answered 'Yes, very definitely'... in what way has it affected his quality of life? Has it improved it or decreased it I know it has affected it but in what way?"

Wife: "It has withdrawn him from staying home. He hears about people he's worked with. He will not go out and talk to people. He's just withdrawn himself."

Interviewer: "Is that due to the tube feeds or ..."

Wife: "Due to his mouth which is part of the tube feeds. He would not visit and have to have a tube feed there."

Larry has gastrointestinal problems that affect his weight but when asked how the tube feeding has changed the way he thinks about his body he responds:

Larry: "Oh yes, of course. It's made my body very uh, very slim. You know, when I look around, you know, look around for the muscles, you know, I remember what used to be there and what is there now uh, I'm still uh, surprisingly I'm still strong. Uhm, although my, you know, I'm only 130 and nothing shows up. I would, I would like to get up to 180 pounds again now and maybe I will, I don't know. Uh,.....it's uh, I just gotten to the point of life, that I just take things as they come."

Larry contributes his weight loss to the tube feeds not to the fact that he has had multiple surgeries and an extensive gastrointestinal illness. Being dependent on the tube feeds also makes Larry feel useless.

Question 14. Has tube feeding changed the way you think of yourself?

Larry: Yes I feel useless.

.....

Interviewer: "Is that uhm, the tube feeding that makes you feel that way or is it everything?"

Larry: "Oh, everything I guess but uh, you know, being dependent on the tube feeding is, is uh, makes me feel helpless. Uh..... you know, I could uh, you know, I just like, you know, I, I wish, I wish I could be every other day. You know, then I could, you know, do what I want, but uh. This is all right I guess. I, I'm going to start eating but uh, I can't, I don't feel like it."

Wendy has a debilitating disease that one would assume limits her mobility and activities immensely. She never mentions that her illness may contribute to her limitations. All her responses are as if both are included. Her illness and tube feeds intermeshed so strongly they are one in the same.

Interviewer: "Has the tube feeds affected your social life?"

Wendy: "I'm very limited."

Interviewer: "Very limited you're very limited ... is that what you are saying?"

Wendy: "Uh ... no social life. The problem is I'm limited because the only thing that's limited is.... uh I can't go to people's ... well I guess I could go to people's dinners.... have my own things, but bringing the pole and the bag to ... I would choke on that."

When Audrey was asked the question "Has tube feeding changed the way you think of yourself?", she responds by explaining that:

Audrey: "Oh yes, I'm not me.....Not the way I used to be. Uh, I'm a different person all together... than I was before all this."

Interviewer: "In what way are you different?"

Audrey: "Well nobody else sees it, but I do. Uh, even my actions, mostly I think. The way I do things now."

Interviewer: "Your actions are different?"

Audrey: "MmmMmm."

Interviewer: "Can you give me an example.... of what you're thinking?"

Audrey: "Well what I was doing right now."

Interviewer: "Holding on to that." (refers to covering the tracheostomy hole to talk)

Audrey: "So holding it so I can talk to you."

Interviewer: "Okay, the mechanics of how you have to talk...."

Audrey: "Yeah, I have to close it, put my tongue over, like so, so I can talk to you."

The question pertained to tube feeds but the response was that she finds herself to be a 'different person'. Whether this is due to her tube feeds or her illness is not differentiated but the example provided was not a tube feed situation.

Social Functioning:

Seven of the respondents contribute the impact on their lives due to a combination of everything. This combination includes illness, treatments, the tube feeds and their current life situation. One area of their lives that are impacted by this combination include their social life. Most respondents find that their social lives are limited to visiting only close family. Jim's narratives discusses the fact that he can not go on fishing trips with his friends because he lacks the energy and the health.

Jim: "Well there's social activities, we don't do anything really other than uh maybe go visit the families, you know, one of the siblings or something like that but uh or the odd friend, but uh, other than mostly people come here or, or uhm, we have no social life really at all any longer. And I'm not suggesting that that's necessarily the tube feeding but it's just a result of everything. "

Interviewer: "How you're feeling and health..."

Jim: "How I'm feeling and health, yeah, yeah. Uhm.... uhm little bit.... uhm yeah quite limited..... There's, you know, there's... Yeah, it's, it's a combination of health and the tube feedings cause I know there's a fishing trip coming up and my friends trying to talk me into going out and he says lets hang your tube, you know, up in a tree or something. You know, it's not just the tube, it's you know, if it were as easy as that, you know, I may be able to go but I don't think I can, you know, sit in a boat or you know, go in a plane or something. I'm just not strong enough or feeling good enough to do that. You know, sitting out in the sun isn't good for me right now so, so uhm, you know, it's not just the tube feeding aspect. It's a combination of the treatment and the tube feeding for me anyway. "

Traveling:

Another social function involves traveling as discussed in chapter seven. Lucy comments that she does not see herself traveling in the future as a result of her tube feeds and her tracheostomy.

Interviewer: ".....So the reason you don't travel is due to this tube feeds and the"

Lucy: (points to tracheostomy)

Interviewer: "tracheostomy and your health, your energy level, does that play a role?"

Lucy: (nods yes)

Interviewer: "So it's a combination of"

Lucy: "Everything. The whole picture.....Not being able to swallow saliva is embarrassing if people don't know my problem."

Working Life:

Another area of their lives that are impacted by this combination include their work life or activities.

Interviewer: "How has the tube feeds affected your activity?"

.....
John: "Well it's cut it right out."

Interviewer: "Cut it right out. Yeah, we've, we've talked about it before."

John: "Yeah. Between the medical condition and the tube feeds, it just stopped everything."

John explains that the impact on his life is not just due to the tube feeds, his weakened condition plays a role as well.

Interviewer: "You, you mentioned just a little earlier that, tube feeds were a real burden, you can't really do anything, they take up a lot of time..... is that...."

John: "Well, mind you, it's uh it's medical too, it's uh my condition is so weakened by this happening. After Thursdays, uh, it's maintained my progress, but I'm in a weakened condition. I can't do anything. I can't pick up my hand. I can't build a house or anything."

Interviewer: "Yeah, so would you say it's more your condition than the tube feeds?"

John: "I would say so....Yeah, I don't, I don't blame the tube feeds for everything."

His energy level plays a role as well.

John: "....I guess the main thing is the movement, you can't, you can't find the energy to do the things you used to be able to do."

.....
Interviewer: "So one of the reasons you feel you don't have that much energy is because of the tube feeds?"

John: "Yeah..... and my condition."

Barb also commented that the tube feeds affected her working life. When probed further she did mention that it was a combination of everything.

Interviewer: "How has the tube feeds affected your working life?"

Barb: "It stopped it."

Interviewer: "Was that due to your tube feeds or"

Barb: "No. Everything."

Jim also mentions how he had to stop working but it was due to a combination of everything.

Interviewer: "So did you stop working so you could tube feed yourself?"

Jim: "Uh well, it would just would be... difficult to try and keep... first of all I wasn't feeling up to it, physically I was unable to work and uh, uhm it just wouldn't, I don't know, it would be pretty difficult to be toting this around (looks at pole) and trying to uh manage working and tube feeding at the same time."

Interviewer: "Okay."

Family: "He had full intentions at the beginning that he would take it to work and feed, but he just hasn't been feeling well."

Jim: "I just haven't been... it's a combination of both, it's not just the tubefed, its that I couldn't push himself and uh do it, but uh, physically I'm weak and tired, and just sapped out and I have a lot of appointments that I seem to go to and it seems to be there's something all the time happening and uhm, realistically my mind wouldn't be, you know, on the job it would be very difficult to try to accomplish much."

Paul was the only respondent that separated the impact from the tube feeds and stated that it was due to his cancer.

Interviewer: "Okay.... You mentioned a bit about your work. The question here is How has home tube feeds affected your working life?"

Paul: "Well the tube feeds haven't really. Because uh it's mostly because uh the cancer that has affected my work life more than the tube feeds. Okay, so because of my disability and everything else I can really only go around and check and see what's going on and advise a little bit and stuff. So I just more and less drop in.... so that, that has affected it more. The tube feeds wouldn't have affected it because by the times I would be off the machine I would be there. So if I had to have this for a longer period and I was back at work the tube feed wouldn't really affect me personally."

Quality of Life:

Quality of life is another area of their lives that the combination of everything impacts. Here are some examples when respondents were asked to describe their quality of life.

Lucy: I would think just fair is probably best description of how I feel about my quality of life right now. I really can't blame the tube feeding for this, it is my health in general that is not what I would like it to be.

Jim mentions that his quality of life is low right now due to the fact that they are doing very little socially or with regards to family activities. The weather and the flood situation in Winnipeg may have caused some of this as well.

Jim: "Pretty low."

Interviewer: "Very low?"

Jim: "Yeah, yeah we're not.... we're surviving but we're.... I shouldn't say surviving that's, that's not very fair. We're, you know, it seems to be like more day to day existence, we're not planning, you know, uhm what we are going to do this weekend or what we are going to do with the kids, we're just not living, you know, living life to the fullest. We're not doing things that we should be, I'm feeling that uh ...once I have a big hang-up, you know, I'm feeling that I'm missing out on the kids doing stuff and they realize it is only a short period of time and uh, and uh, you know, their at a young age that they're not really likely to remember, T— probably won't remember any of this, but uh... uhm..... it makes me feel like I'm robbing them of some opportunities to do things. I don't know, I don't know if we would do anything anyway, you know, with the way the weathers been and everything, there's not a lot of people doing things out there. (both laugh)

Interviewer: "Sitting in their home, going through their stuff, getting ready for the flood..."

Jim: "That's right you can't uh, you know, you can't tell, you know, you can't do things either way. But again, it's not just the tube feed that's the overall thing. You know, everything's seems to apply to the overall picture but I think that's true for probably anyone who's on the tube feeds, they have an overall picture so."

Summary

When trying to understand what life is like on home enteral nutrition, it is important to realize that the tube feeds is only a small part of one's entire situation.

Tube feeds have become a part of that individual as much as their illness has and that the two cannot be separated.

IX. Positive Aspects of Tube Feeding

The negative aspects of tube feeding are mentioned several times throughout the report, in other themes, whereas the positive aspects are not as strongly conveyed.

“What are the positive aspects of tube feeding yourself?” Common responses included: the tube feeds kept them alive, the tube feeds were considered nutritious, provided them with strength and energy and the tube feed regimen was simple and easy to do. Eleven out of the twelve respondents are represented in the following comments.

Alive:

Six respondents commented that the tube feeds kept them alive.

Lucy: But the plus side is knowing you would probably not be alive today if there wasn't some way to substitute for not being able to eat and drink normally and the tube feeds seem to be the best way to accomplish this.

Interviewer: “What about the tube in your stomach?..... Does that bother you?”

Larry: “Yeah. But not, not so much now. I'm used to it. Uh..... it's uh, it's sore around here.....You know, it's uh, I can't say anything, you know it's good to have, you know or I'll be dead, you know. So I when I think that, I think good things about it.”

Adequate Nutrition:

Six respondents commented that the tube feeds gave them adequate nutrition when asked ‘what are the positive aspects of tube feeding?’.

Barb: "I've never been, uhm, never before in my life have I had such nutritious food in me..... 'm mean, I imagine this is more healthy than anything else in the entire world. (both laugh)

Jim: "Well from my point of view, I feel like I'm getting the proper nutrition for my body to do what needs.... that's, that's why, what sold me on it. So it makes me overcome looking at things sticking out of my stomach and, you know, that's I know that it's the best thing for me."

Interviewer: "Okay."

Jim: "And that's, that's what sold me."

Interviewer: "So why would getting the proper nutrition be important?"

Jim: "Because it's important for the body to heal, it's needs the nutrition to heal, it needs, it needs nutrients. Well at least I believe it does, or I've been told it does. (both laugh) I wouldn't want to.....But uh, it makes a lot of sense, and uh, you know, makes sense that if you're not eating properly helping your body heal itself it will be weaker and run down and it won't be at it's peak. You know, you need to be as strong as I can, so....it takes off whatever it needs."

Source of Energy or Strength:

Six respondents commented that the tube feeds provided them with strength and/or energy when asked 'What are the positive aspects of tube feeding?'

Lucy: I know the tube feeding is the only way I can keep up my strength so am content I have to stay on the tube feeding.

Allan: "I never thought that it would come the day that where I would have to take three meals with uh liquid.....You know, but.... (holds both arms up and flexes muscles)"

Interviewer: "Keeps you strong."

Other: "He's a strong man."

Interviewer: "Do you find that stuff keeps you strong?"

Allan: "Oh, yeah."

Nutrition is linked to the amount of energy the respondents felt.

Larry (written): *1. I get enough nutrition to live.*

Interviewer: *"You mention that you get enough nutrition to live. Okay. Do you find uh, I think we mentioned a little earlier about your energy...Do you notice a difference in how much energy you have in relation to how much tube feed you feed?"*

Larry: *"Yeah, the more tube feed you do, the more energy you have."*

In actuality the three positive aspects, keeping alive, adequate nutrition and strength/energy are inter-related. The tube feeds provide enough nutrition to keep one stronger and more energetic and also keep one alive.

Interviewer: *"What are the positive aspects of tube feeding yourself?"*

Paul: *"Okay,...keeps me alive."*

Interviewer: *"Keeps you alive."*

Paul: *"Keeps me uh, uh,.... you know I end up with enough energy that lasts sort of through the day. Kind of peeters out some days around five but, but uhm, yeah it gives you your energy, it gives you uh your uh.....your liquids I guess, it gives you enough liquids out of that, it's not it's not too bad. I'd rather do that than through my veins.... like you say. Yeah, I guess that's about it for positive aspects. I can't see anything else, I can't stand the smell of it. (both laugh). Other than that it keeps me alive."*

Interviewer: *(laughs) "Keeps you alive, keeps your health?"*

Paul: *"My health, my energy, I get enough vitamins out of it, you know..."*

Quality of Life:

Having more energy to do things they enjoyed improved their quality of life.

Interviewer: “Okay. And the tube feeds, has that affected your quality of life?”

Mike: “No, it’s probably made it better because I’m able to do stuff, cause I have enough energy to do things.”

Simplicity:

Another positive advantage to the tube feeds were that they were considered simple and easy. Four respondents commented regarding the ease of implementing this technology when asked ‘What are the positive aspects of tube feeding yourself?’..

Audrey: “ It’s easy and convenient.”

John: “Well, if you want to be realistic about it, uh, I suppose it’s easier than preparing a meal. Attach a hose to your stomach and sit down and wait, that’s all there is to it. No dishes to wash. Just throw the cans in the garbage. That’s all it takes. Well you need to wash the equipment and stuff, tubes and everything.”

Wendy also mentions that a positive aspect of tube feeding is that she no longer has to plan and prepare meals. She finds it comforting that she knows she’s getting adequate nutrition through her enteral products.

Wendy: “The only positive thing I can think of, with having the feeding I don’t have to decide what I’m going to eat. Same for supper, I don’t have to worry about preparing.”

.....

Interviewer: “What about the nutrition you get from the product the your weight, being able to”

Wendy: “Well, I know the girls there, looking after that, so I don’t have to worry about that, I just, I don’t have to plan metrying to make sure that you get your meat and vegetables and all that. It’s all there. My only... like in the morning if I have a, well an average day, every meal I have fiber but sometimes, whether it has fiber or no fiber. That’s the only decision.”

.....

Interviewer: "So does that give you a, a good feeling that you know that you're getting what you need and you don't have to eat it?"

Wendy: "Well, I can relax a lot, and I know that I won't have that trouble like I had before. So ... it's good that way."

Summary:

The positive aspects of tube feeding are few but are very well supported by respondents. The strongest message is the ability of the tube feeds to keep them alive. The tube feeds also provide enough nutrition which enables one to feel stronger and more energetic to continue with activities that they are able to do. Another advantage is that the tube feeds are easy and simple to implement.

Strauss (1984, 45) comments that "if life is at stake..... then the ill person is likely to consider that the entire regimen is binding." It is quite evident that respondents know that they have to keep tube feeding themselves in order to stay alive. This may contribute to the level of commitment these individuals have with maintaining this regimen.

X. Quality of Life

How do respondents living with home enteral nutrition perceive their quality of life? Qualitative analysis of the respondents' narratives are reported in this chapter. These narratives reveal how informants rate their quality of life and what aspects of their lives they mention when discussing their quality of life.

Every respondent was asked the question "I realize that quality of life is difficult to define, but in your own words how would you describe your quality of life currently?" Numerous respondents provided answers that could be grouped into four categories: poor, fair, good and very good.

Table 3: Quality of Life Qualitative Responses

Respondents	Comments	Categories				Rating
		Poor	Fair	Good	Very Good	
#001	good			x		3
#002	pretty low	x				1
#003	the pits (cries)	x				1
#004	not good		x			2
#005	good			x		3
#006	fair		x			2
#007	fair/ very poor	x				1
#008	very good				x	4
#009	not good		x			2
#010	fair		x			2
#011	good			x		3
#012	good			x		3
Mean						2.25 ± 0.93

(1=poor; 2=fair; 3=good; 4=very good)

Comments such as 'pretty low' and 'pits', were documented as poor quality of life. In one case a respondent commented that his quality of life was fair in one answer and very poor in another. This response was averaged as poor. If the individual commented that his/her quality of life was not good that was assumed to be fair. No assumptions had to be made for those who commented with the specific category responses. Limitations to these assumptions could have been corrected if the individuals were actually asked to rank their quality of life on a scale of poor, fair, good and very good. Some respondents were probed for this ranking but not all respondents answered with a specific rating. If one applies a rating to the above responses the mean response for the group is 2.25. This indicates that on average the group felt their quality of life is fair to good.

Impact of Enteral Nutrition on Quality of Life:

What did respondents state when asked "Did home tube feeds change your quality of life?" Five respondents stated that the home tube feeds did not change their quality of life. Seven respondents felt that it had changed their quality of life. Out of those seven respondents, three felt it improved their quality of life. Two individuals explained that it kept them out of the hospital and allowed them to come home.

Interviewer: "... has home tube feeds changed your quality of life?"

Jim: "MmmMm I'd say, I think I'd be in the hospital or something worse, you know,Worse than being in the hospital, I don't know if there is such a thing. But uh, yeah, it changed the quality of life, it's allowed me to come home and uh, and uh be with my family. So uh, you know, it's improved my quality of life. But uh, cause uh, I don't know what they we have in store with me but I wouldn't have been able to eat or anything so... there would have been something, I'm sure they had something planned or they had

something up their sleeve. But uh, so it's improved that from that perspective."

Mike: "Oh yeah, it makes it much easier so I don't have to go into the hospital every few months and I can do it at my own rate, get a better nights sleep, don't have to go by uh hospital regulation on how it works."

Another reason one felt quality of life was better with the tube feeds was because it gave them enough energy to do the things they liked to do.

Mike: "No, it's probably made it better because I'm able to do stuff, cause I have enough energy to do things."

Getting nourishment into their bodies has also made their lives better.

Lucy: I would say home tube feeding has made my life better in that I can now get food into my body without choking as I did earlier.

Out of the seven respondents that felt tube feeds did impact on their quality of life, two felt it had a negative effect. When the respondents were probed further as to why, this was their responses:

Larry: "Well, I've always got a pole next to my bed, uhm, I've got to sleep, you know, on my back, you know, facing up to the, and uh, I don't know."

Interviewer: "Has it made it better, has it made it worse?"

Larry: "Oh it's made it worse. But then again it's keeping me alive, so it's better,..."

The next respondent is unable to speak and his wife offers this explanation:

Question 17. Did home tube feeds change your quality of life?

Tom (written): Yes, very definitely, although my age has quite a bearing on my life now.

(phone)

Interviewer: "For the question, Did home tube feeds change your quality of life? he answered 'Yes, very definitely'... in what way has it affected his quality of life? Has it improved it or decreased it I know it has affected it but in what way?"

Wife: "It has withdrawn him from staying home. He hears about people he's worked with. He will not go out and talk to people. He's just withdrawn himself."

Interviewer: "Is that due to the tube feeds or ..."

Wife: "Due to his mouth which is part of the tube feeds. He would not visit and have to have a tube feed there."

For these individuals it was difficult for them to pin point why they felt tube feeds had a negative impact on their quality of life. One respondent did write that age was a confounder that also contributed to his change in quality of life. This respondent's spouse felt that his social life was quite different now and that probably contributed to his quality of life. The researcher was unable to confirm this with the respondent.

In Larry's narrative he mentions that the tube feeds have a dual effect on his quality of life. In some ways it was worse and in some ways it was better. This is also supported by the following narrative. Mike reflects on his future quality of life compared to his current.

Mike: "Cause I think it's not great but I'm sure it can always get, always can get worse."

Out of the seven respondents that felt the home tube feeds did change their quality of life, two felt that it did not improve or decrease their quality of life. One commented that it just made them slow down a little and the other commented that he had accepted the change and went on with his new life.

Allan: "But uh, as far, as far as I'm concerned, I'm happy, I'm happy..... I have to be happy the way I'm living because I can't be otherwise. I can't go and to other people and say 'Okay give me a plate and some steak and potatoes and'.....So I have to use this.....And I accept that.....And uh, that's good because if I didn't, didn't accept this, it would be, it would be hard, harder on my system."

Issues related to Quality of Life:

When discussing their quality of life, what issues were raised most frequently by the respondents? Issues that were mentioned by more than one respondent included: 1) activities that they were able or no longer able to do (feeling restricted); these activities may include work, social activities, hobbies and daily activities; 2) family; 3) food; 4) mental health and acceptance of their situation; 5) general health; 6) pace of their new lifestyle and 7) aging.

Activity:

The respondents rating of their quality of life depended, for some, on whether they were able to continue with activities that they found enjoyable. Activities may include work, social activities, hobbies, and daily activities. George rated his quality of life as very good.

George: I'd say it was very good because I'm still able to eat and drink. Play golf in summer and curl and bowl in winter. Shovel snow - cut grass and work at my hobbies.

It is important to note that George consumed a pureed diet and did not experience pain or discomfort while eating and still found eating enjoyable. Audrey also considered her quality of life to be good because she was still able to go out and do whatever she liked to do.

Audrey: "Oh, yeah. I still enjoy myself, I mean....."

Interviewer: "You still enjoy yourself..."

Audrey: "Oh yeah I go out and do whatever the heck I like as long as I don't over do, uh, it hasn't stopped me from doing anything. So, I guess nothing really has changed"

Interviewer: "So would you say your quality of life is, is poor, fair, good, very good?"

Audrey: "I think I have a good life. Like I said I do as I darn well please."

Interviewer: (laughs) "I do what I darn well please."

Audrey: "And don't tell me that I can't do it." (both laugh)

Larry on the other hand stated that his quality of life was fair or very poor and finds his day lacking in activity. This is how Larry describes his quality of life:

Larry: Fair. My day is very uneventful..... My health has improved but quality of life is very poor.

Family:

Family was mentioned in three respondents comments when discussing quality of life. Jim feels his quality of life is pretty low and comments that he feels some guilt when he sees the impact his health has on his family especially his young children.

Jim: "Pretty low.....Yeah, yeah we're not.... we're surviving but we're.... I shouldn't say surviving that's, that's not very fair. We're, you know, it seems to be like more day to day existence, we're not planning, you know, uhm what we are going to do this weekend or what we are going to do with the kids, we're just not living, you know, living life to the fullest. We're not doing things that we should be, I'm feeling that uh ...once I have a big hang-up, you know, I'm feeling that I'm missing out on the kids doing stuff and they realize it is only a short period of time and uh, and uh, you know, their at a young age that they're not really likely to remember, T— probably won't remember any of this, but uh... uhm..... it makes me feel like I'm robbing them of some opportunities to do things."

Allan is an elderly gentleman who is satisfied socializing with family and has rated his quality of life as good.

Allan: "My quality, my quality of life. Like I say, okay,the fact I had to have these at meal times, kinds of restricts me, uh restricts my activity some, in a way, you know, but uh I don't go, I don't go out to strangers too much. I go to my relatives, my children and my relatives, I go to their homes and they all know my case and so I'm satisfied that they would, they would sympathize with me rather than 'Oh look, look guys, look at him', you know."

Food:

George, in the previous quote mentioned that his quality of life is very good and one reason is that he is still able to eat. Audrey, on the other hand, is no longer able to eat and has not consumed food for several years. She also mentions food when discussing quality of life. Audrey has rated her quality of life as good.

Interviewer: "Did home tube feeds change your quality of life?"

Audrey: "No."... "Oh, like I said it can be inconvenient at times, but I wouldn't do it now, but before when I down somewhere shopping I could go have a coffee and sandwich, whatever, now I can't but you know it's different. Uh, I'd say it's the same."

As Audrey discusses her quality of life she does reflect back to the beginning when she first started tube feeds and comments that her quality of life has improved.

Interviewer: "How about when you look at your quality of life or now compared to that first year when you came home?"

Audrey: "It's got a lot better.".... "Oh yeah. And getting back my self confidence again. I lost it for a long time, I didn't care if I came out of the hospital or not. When I think back now, it just goes through my mind about what I was thinking then, my God are you stupid."

Mental Health and Acceptance:

Audrey makes reference to how she was thinking during her hospital stay. How one accepts this new lifestyle has an effect on how they perceive their quality of life. In a previous quote Allan comments that he has accepted his new way of life and has gone on with things. Allan has rated his quality of life as good. John, on the other hand has recently found out that he may remain on tube feeds for the rest of his life. Since he is at the early stages of this realization he has not accepted this fact, he still hopes that he will get off the tube feeds. John has rated his quality of life as 'not good'.

Interviewer: "So, would you say your quality of life is good or"

John: "No, I would say it's not good right now. Very hard on the nerves."

Interviewer: "Hard on the nerves?"

John: "Of course it is. Sure. The sooner I get off it the better I'll like it."

General Health:

Two respondents actually stated that their health or illness had an impact on their quality of life.

Lucy: I would think just fair is probably best description of how I feel about my quality of life right now. I really can't blame the tube feeding for this, it is my health in general that is not what I would like it to be.

Mike also comments that his illness impacts his mental health as well as his quality of life. When Mike is asked to describe his quality of life this is his response:

Mike: "Not good because of the way my [illness] is holding me back. Also it's trying to make me depressed."

Pace of Their New Lifestyle:

Some individuals did comment that they noticed a difference in the pace of their new lifestyle. Things have definitely slowed down for some. Their lives slowed down in areas of various activities such as work, social activities and daily activities.

Paul: "Well uh before I was uh a very busy person, always very busy, workaholic I guess, you know and some, some days guess uh you know when days I wasn't working I'd come home and cut the grass or get the river boat working or mix cement or do something you know, I like doing things but uh now since the tube feeds, well ever since the cancer I got to slow down because I got to be on the tube feeds for a certain amount of time so I'm forced into doing something uh of a lesser nature, you know. Yeah, and uh..."

Interviewer: "Think that will improve your quality of life?"

Paul: "It might slow me down a bit."

Interviewer: "Is that a good thing....?"

Paul: "Maybe."

Interviewer: "....bad thing?"

Paul: "Maybe being so busy all the time might of contributed to getting my cancer, I don't know, but uh, I think slowing down is a necessity. Yeah, I got to slow down a bit, so I do and now maybe I'll keep it up.

Aging:

Pace of one's lifestyle and quality of life can be affected by age. Three respondents did comment that their quality of life has probably changed due to their age. Some found it difficult to distinguish between the effects of tube feeds on their quality of life and the effects of aging. This is Tom's description of his quality of life:

Tom: fair - I really do not have the same quality of life that I used to have. Age also plays a factor in the quality of my life. As I get older I am unable to do things as I did in the past.....Yes the health survey pointed out the problems I have encountered in the past couple of years. I do feel however the my age - getting older, is diminishing my quality of time and life.

Summary:

In summary, the respondents ranked their quality of life somewhere between fair and good. Seven respondents commented that the tube feeds did change their quality of life. Three respondents said it improved their quality of life, two felt that it decreased their quality of life and two felt it had a dual effect. Issues that were important to these individuals when considering their quality of life included: the ability to do activities such as social activities, work, daily activities and hobbies; spending quality time with their family; being able to eat food or accept the fact that they no longer can eat; mental health and acceptance of their situation; general health ; getting used to the pace of their new lifestyle and their aging process.

XI. SF-36 Health Survey

Quality of life can be quantified using a generic health measure that assesses health-related quality of life outcomes (see supporting literature in chapter three). For the purposes of this research project the SF-36 Health Survey was selected. This chapter reports the quantitative analysis of the SF-36 results and therefore reports how the Manitoba Home Nutrition Program respondents perceive their quality of life.

When designing the SF-36 Health Survey, eight health concepts were selected out of more than 40 concepts and scales studied in the Medical Outcomes Study (Ware 1993). The SF-36 (see Appendix B) includes one multi-item scale measuring each of these eight health concepts:

- 1) physical functioning - performance of a range of physical activities such as self-care, walking, climbing stairs and vigorous activities
- 2) role functioning: physical - impact of physical health on performance of work or other regular daily activities
- 3) bodily pain - severity of bodily pain and its interference with work inside or outside the home
- 4) general health - evaluations of general health including current health, health outlook and resistance to illness
- 5) vitality - frequency of feeling full of energy versus feeling tired and worn out

- 6) social functioning - extent and frequency of limitations in social activities with friends/relatives due to health problems
- 7) role functioning:emotional - the impact of emotional problems on performance of work or other regular daily activities
- 8) mental health - general mental health including four major mental health dimensions (anxiety, depression, loss of behavioral-emotional control and psychological well-being).(Ware 1993)

The survey questions are grouped into the eight health concepts according to the following table:

Table 4: Item Groupings and Abbreviated Item Content for the MOS SF-36 Survey (McHorney, Ware and Sherbourne 1994, 45)

Health Scale	Item	Abbreviated Item Content
Physical Functioning (PF)	PF1	Vigorous activities, such as running, lifting heavy objects, strenuous sports
	PF2	Moderate activities, such as moving a table, vacuuming, bowling
	PF3	Lifting or carrying groceries
	PF4	Climbing several flights of stairs
	PF5	Climbing one flight of stairs
	PF6	Bending, kneeling, or stooping
	PF7	Walking more than a mile
	PF8	Walking several blocks
	PF9	Walking one block
	PF10	Bathing or dressing yourself
Role Physical (RP)	RP1	Limited in the kind of work or other activities
	RP2	Cut down the amount of time spent on work or other activities
	RP3	Accomplished less than would like
	RP4	Difficulty performing the work or other activities

Bodily Pain (BP)	BP1 BP2	Intensity of bodily pain Extent pain interfered with normal work
General Health perceptions (GH)	GH1 GH2 GH3 GH4 GH5	Is your health: excellent, very good, good, fair, poor My health is excellent I am as healthy as anybody I know I seem to get sick a little easier than other people I expect my health to get worse
Vitality (VT)	VT1 VT2 VT3 VT4	Feel full of pep Have a lot of energy Feel worn out Feel tired
Social Functioning (SF)	SF1 SF2	Frequency health problems interfered with social activities Extent health problems interfered with normal social activities
Role Emotional (RE)	RE1 RE2 RE3	Cut down the amount of times spent on work or other activities Accomplished less than would like Didn't do work or other activities as carefully as usual
Mental Health (MH)	MH1 MH2 MH3 MH4 MH5	Been a very nervous person Felt downhearted and blue Felt so down in the dumps nothing could cheer you up Been a happy person Felt calm and peaceful
Reported Change	TRAN	Rating of health now compared to one year ago

Other important health concepts that were not included in the SF-36 Health Survey include: health distress, family functioning, sexual functioning, cognitive functioning,

and sleep disorders.(Ware and Sherbourne 1992). On each dimension of the SF-36, the respondent receives a score from 0 to 100. A higher score indicates better health.

The survey was constructed for self-administration by persons 14 years of age and older and for administration by a trained interviewer in person or by telephone. (Ware and Sherbourne 1992). “The SF-36 can also be included as one part of a longer interview, questionnaire, or other data collection effort.”(Ware 1993, 4:1). The focus of this survey is on the patient’s point of view of their health status and its impact on these eight dimensions.

The SF-36 has proven itself reliable and valid in numerous studies.(Ware 1993; McHorney, Ware and Sherbourne 1994; McHorney, Ware and Raczek 1993). Reliability examines the consistency of results from the same measurement tool designed to evaluate the same variable. “Estimates of score reliability for the SF-36 scales have been reported in 14 studies All estimates exceeded accepted standards for measures used in group comparisons. For each scale, the median of the reliability coefficients across studies equals or exceeds 0.80, with the exception of the Social Functioning scale(the median for this two-item scale is 0.76).” (Ware 1993, 7:4). “Most studies used the internal consistency method and Cronbach’s coefficient alpha..... A range of patient populations and situations are represented.” (Ware 1993, 7:6). Internal consistency is an issue in multiple item scales. How consistently does each item in the scale measure the same phenomenon.

Validity is the extent to which the score means what it is supposed to mean. “Two kinds of strategies were used to evaluate the validity of the SF-36..... First, [they] judged content validity by comparing it with other widely used survey forms. Second, [they] used empirical approaches including factor analytic tests of construct validity, ‘criterion-based’ approaches, and numerous correlational studies.” (Ware 1993, 8:3). Three steps are needed to accumulate evidence of validity related to theoretical constructs.(Nunnally 1964). These steps are: 1) specifying the domain of variables; 2) establishing the internal structure of observed variables; and 3) verifying theoretical relationship between scale scores and external criteria. The domains are established as the eight most frequently represented health concepts. The two major dimensions of health are physical and mental. The scales that measure physical health include: physical functioning, role-physical and bodily pain. These scales were shown to best distinguish groups differing in severity of chronic medical conditions. (McHorney, Ware and Raczek 1993). The scales that measure mental health include: mental health and role-emotional. These scales best distinguished groups differing in the presence and severity of psychiatric disorders.(McHorney, Ware and Raczek 1993). The scales that measure both physical and mental health include: social functioning, vitality and general health perceptions. These scales had the most complex interpretations.(McHorney, Ware, and Raczek 1993). This demonstrates convergent and discriminant validity. “Convergent validity is supported when different methods of measuring the same construct provide similar results.

Discriminant validity examines whether a measure of one underlying construct can be differentiated from another construct.”(Ware 1993, 8:2).

SF-36 Results:

All twelve individuals completed the SF-36 Health Survey. Eleven questionnaires were conducted using self administration and one was read to the respondent by the interviewer since the individual was blind. Only one value was missing out of 432 items (0.23% missing data). This value was in the General Health score which is a five-item scale. Therefore 1.67% (1/60) of the data was missing for this dimension.

Table 5 : SF-36 Health Status Survey Results

SF-36 HEALTH STATUS SURVEY RESULTS								
Subject #	PF	RP	BP	GH	VT	SF	RE	MH
1	80	25	74	47	50	75.0	100.0	80
2	35	0	72	62	30	25.0	100.0	68
3	5	25	41	37	25	75.0	66.7	68
4	5	0	74	35	10	0.0	0.0	56
5	40	100	51	82	75	100.0	100.0	80
6	20	0	62	25	20	25.0	66.7	68
7	90	0	51	32	50	62.5	66.7	52
8	95	75	100	57	70	100.0	100.0	92
9	55	0	1	25	40	37.5	33.3	68
10	15	0	41	82	35	25.0	100.0	72
11	75	50	80	60	45	75.0	100.0	84
12	35	0	41	50	40	37.5	0.0	80
MEAN	45.83	22.92	57.33	49.50	40.83	53.13	69.45	72.33
S.D.	32.60	34.47	25.55	19.81	18.85	32.48	38.82	11.50

(PF=physical functioning; RP=role-physical; BP=bodily pain; GH=general health; VT=vitality; SF=social functioning; RE= role-emotional; MH=mental health; S.D.= standard deviation)

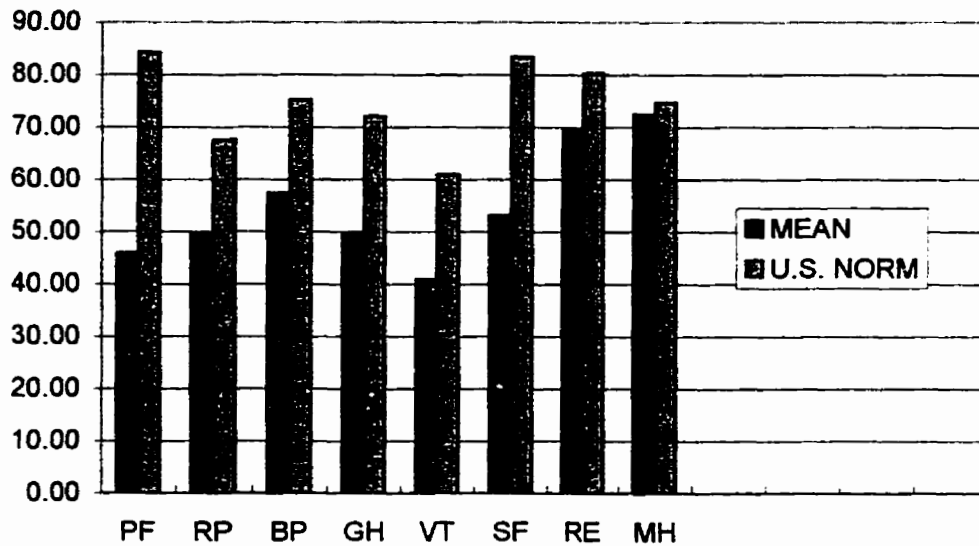
Comparing SF-36 Results to U.S. Population Norms:

To interpret the SF-36 results one can compare the group means to a population norm. “The SF-36 provides a common yardstick to compare those patients with chronic health problems to those sampled from the general population.” (Ware 1993, 2:4). The sample means were compared to the U.S. population norms using t-tests (see Methods section for equation).

Table 6: SF-36 Health Status Survey Results Compared to U.S. Norms

SF-36 HEALTH STATUS SURVEY RESULTS COMPARED TO U.S. NORMS			
Dimension	Sample (mean & S.D.)	U.S. Population Norms (mean & S.D)	Statistical Significance
Physical Functioning	45.83 : 32.60	84.15 : 23.28	$p < .002$
Role-Physical	22.92 : 34.47	80.96 : 34.00	$p < .001$
Bodily Pain	57.33 : 25.55	75.15 : 23.69	$p < .05$
General Health	49.50 : 19.81	71.95 : 20.34	$p < .005$
Vitality	40.83 : 18.85	60.86 : 20.96	$p < .005$
Social Functioning	53.13 : 32.48	83.28 : 22.69	$p < .01$
Role-Emotional	69.45 : 38.82	81.26 : 33.04	NS
Mental Health	72.33 : 11.50	74.74 : 18.05	NS

Figure 1: SF-36 Health Status Survey Results Compared to U.S. Norms



Therefore, we can state that this group statistically had a lower score than the U.S. population for physical functioning, role-physical, bodily pain, general health, vitality, and social functioning dimensions. There was a statistically significant difference for all dimensions except for the role-emotional and mental health dimensions. This result is predictable since none of the respondents had known psychiatric disorders. For those dimensions that were lower than the norm, what is the meaning of low or high scores?

Table 7: Information About SF-36 Health Status Scales (Ware 1993, 3:5)

Concepts	Meaning of Low Scores	Meaning of High Scores
Physical Functioning	Limited a lot in performing all physical activities including bathing or dressing due to health.	Performs all types of physical activities including the most vigorous without limitations due to health.
Role-Physical	Problems with work or other daily activities as a result of physical health.	No problems with work or other daily activities as a result of physical health.
Bodily Pain	Very severe and extremely limiting pain.	No pain or limitations due to pain.
General Health	Evaluates personal health as poor and believes it is likely to get worse.	Evaluates personal health as excellent.
Vitality	Feels tired and worn out all of the time.	Feels full of pep and energy all the time.
Social Functioning	Extreme and frequent interference with normal social activities due to physical or emotional problems.	Performs normal social activities without interference due to physical or emotional problems.

In other words, according to the SF-36 results, the respondents' health impacted negatively on their ability to perform physical activities; their physical health impacted on their work or daily activities; they experienced more pain than the average individual; they perceived their personal health to be below average; they felt more tired than the average person; and their health interfered with their social activities.

SF-36 scores decline with increasing age (Ware 1993). The respondents were slightly older than the general U.S. population. When we correct for age, by

comparing the group means to the U.S. norm for the age group 55 to 64, (group mean age = 58.42) these are the results:

Table 8: SF-36 Health Status Survey Results Compared to U.S. Norms for Age Group 55-64, Males & Females.

SF-36 HEALTH STATUS SURVEY RESULTS COMPARED TO U.S. NORMS FOR AGE GROUP 55-64, MALES & FEMALES			
Dimension	Sample (mean & S.D.)	U.S. Population Norms (mean & S.D)	Statistical Significance
Physical Functioning	45.83 : 32.60	76.24 : 26.32	$p < .01$
Role-Physical	22.92 : 34.47	73.66 : 38.39	$p < .001$
Bodily Pain	57.33 : 25.55	67.51 : 25.63	<i>NS</i>
General Health	49.50 : 19.81	64.62 : 23.37	$p < .05$
Vitality	40.83 : 18.85	60.37 : 22.59	$p < .005$
Social Functioning	53.13 : 32.48	81.37 : 24.81	$p < .02$
Role-Emotional	69.45 : 38.82	80.26 : 34.29	<i>NS</i>
Mental Health	72.33 : 11.50	75.01 : 19.30	<i>NS</i>

When comparing the sample to the U.S. population norms for this age group, the only dimension that is no longer statistically different is bodily pain. That means that the sample group has a similar score for bodily pain as does the U.S. population for this age group. The other dimensions: physical function, role-physical, general health, vitality, and social function are all statistically lower for the home enteral nutrition group compared to the U.S. norms for persons aged 55 to 64 years.

Health Transition Scores:

The second question in the SF-36 Health Survey is the health transition item.

This question asks respondents how they would compare their health in general to one

year ago. This item is not used to score any of the eight multi-item scales. "It is based on the hypothesis that self-reported transitions reflect true changes in health during the recall period." (Ware 1993, 9:15). The results of the health transition scale are as follows:

Table 9: Health Transition Item Results

Respondents	Health Transition Scores		
	Total Group	Long Term (>1 yr)	Short Term (<1 yr)
#001	4		4
#002	5		5
#003	1	1	
#004	5		5
#005	1	1	
#006	5		5
#007	2	2	
#008	4		4
#009	4	4	
#010	3	3	
#011	3	3	
#012	5		5
MEAN +/- SD	3.5 +/- 1.5	2.33 +/- 1.21*	4.67 +/- .51*

(1 = much better; 2 = somewhat better; 3 = about the same; 4 = somewhat worse; 5 = much worse)

* $p < .001$

Those individuals that had recently started tube feeds (mean length of time on tube feeds = 4.3 months) scored their health as somewhat worse to much worse than one year ago. Those individuals that have been on tube feeds for greater than a year (mean length of time on tube feeds = 54.2 months) scored their health as somewhat better or about the same as one year ago. The two groups were compared using a t-test and it was shown that those who were on enteral nutrition for a short term scored their health lower than those who were on enteral nutrition for a long term compared to one

year ago. It makes sense that those individuals who have recently started tube feeds have recently had a change in their health status due to an illness. Those individuals who remain on tube feeds for longer than one year, either continue to have the illness that necessitates enteral feeds or their health has improved.

Comparing SF-36 Results to Other Patient Populations:

Home Parenteral Nutrition Patients

No studies to date have looked at measuring health status or quality of life of patients on home enteral nutrition using the SF-36 Health Status Survey. One study, recently published in 1997 by Richards and Irving assessed the quality of life of 51 patients with intestinal failure on home parenteral nutrition using the SF-36 and the EuroQol instruments (Richards and Irving 1997). Home parenteral nutrition is used for patients who are unable to absorb adequate nutrients through the digestive system. These patients are fed via an intravenous placed in a large vein. This is different from enteral nutrition which involves feeding directly into the stomach or small bowel with a feeding tube.

Richards and Irving (1997) documented that the home parenteral nutrition scores were below United Kingdom norms for physical functioning, role-physical, bodily pain, general health, vitality and social functioning. The home enteral nutrition group scores were compared to the home parenteral nutrition group scores as follows:

Table 10: Home Enteral Nutrition Scores Compared to Home Parenteral Nutrition Scores

Health Dimension	Patients on HEN Sample N=12	Patients on HPN N= 51	Difference in Scores
Physical functioning	45.83	45.53	+0.30
Role-physical	22.92	25.0	-2.08
Bodily pain	57.33	46.12	+11.21
General Health	49.50	36.33	+13.17
Vitality	40.83	37.87	+2.96
Social Functioning	53.13	50.37	+2.76
Role-emotional	69.45	58.67	+10.78
Mental Health	72.33	66.68	+5.65

Unfortunately Richards and Irving did not publish the standard deviations, therefore a t-test was not done comparing these two groups. As a result the variability of their data is not known to the reader. One limitation to comparing these two groups is that both groups contain small patient numbers (N=12, N=51). There is no current literature with larger group norms for comparisons in nutrition support.

Hemodialysis Patients:

Some quality of life studies have compared home parenteral nutrition to hemodialysis due to the fact that patients are dependent on medical technology for survival and it is believed that both populations are faced with similar challenges (Smith 1993; Burnes et al. 1992). Recently some studies have used the SF-36 Health Survey to study quality of life or health status in hemodialysis patients (Kurtin et al. 1992; Meyer et al. 1994; Merkus et al. 1997). The study by Kurtin et al. (1992) used the SF-36 Health Survey in an outpatient dialysis unit and determined it's practicality with regards to patient acceptance, timing of administration during the dialysis session,

respondent burden and staff burden. The investigators reported strong evidence of patient acceptance. The same researchers reported two years later on their experience with the SF-36 Health Status form and documented scores for 112 patients who had completed the SF-36 on at least one occasion, for a total of 496 responses. The mean initial scores for the 112 patients were lower for all health dimensions when compared to the general U.S. population. These results are similar to those reported by Merkus et al. (1997) in the United Kingdom. How does our patient group compare? The American group was chosen for comparison since this researcher is using U.S. population norms versus United Kingdom population norms.

Table 11: Home Enteral Nutrition Scores Compared to Outpatient Dialysis Scores

Health Dimension	Patients on HEN Mean & SD Sample N=12	Patients on Dialysis Mean & SD N=112	Statistical Significance
Physical functioning	45.83 : 32.60	48.5 : 31.2	NS
Role-physical	22.92 : 34.47	33.4 : 38.7	NS
Bodily pain	57.33 : 25.55	60.1 : 27.4	NS
General Health	49.50 : 19.81	43.7 : 23.9	NS
Vitality	40.83 : 18.85	44.5 : 21.4	NS
Social Functioning	53.13 : 32.48	65.1 : 27.6	NS
Role-emotional	69.45 : 38.82	55.2 : 45.1	NS
Mental Health	72.33 : 11.50	69.6 : 17.5	NS

Not one health dimension was scored significantly different between these two patient groups. Therefore, this information suggests that people on home enteral nutrition and those on dialysis report similar perspectives on their health and its impact on their lives.

Ventilator Dependent Patients:

Ventilator dependent patients are also dependent on technology for survival. Smith and Shneerson (1995) published a report on patient outcomes in a progressive care program in England, for prolonged ventilator support. One outcome that was measured in this study was their health status using the SF-36 Health Status Survey. The SF-36 questionnaire was sent to the 28 surviving patients and 20 completed replies were received, giving a response rate of 71.4%. The study concluded that the patients had low scores for physical function and physical role limitation. How does our patient group compare to ventilator dependent patients? Results from the study were presented in graph form and therefore the scores were interpreted from the graph.

Table 12: Home Enteral Nutrition Scores Compared to Ventilator Dependent Scores

Health Dimension	Patients on HEN Sample N = 12	Ventilator Patients N = 20	Difference in Scores
Physical functioning	45.83	30	-15.83
Role-physical	22.92	38	-15.05
Bodily pain	57.33	75	-17.67
General Health	49.50	40	+9.50
Vitality	40.83	58	-17.17
Social Functioning	53.13	65	-11.87
Role-emotional	69.45	75	-5.55
Mental Health	72.33	80	-7.67

Unfortunately the authors did not publish the actual means and standard deviations for each health dimension. Consequently, statistical comparison of the data is not

possible. Further research would be needed to compare similarities and/or differences between these two technology dependent groups.

Conclusion:

The SF-36 Health Status Survey results indicate that the home enteral nutrition group reported lower levels of physical functioning, physical role, general health, vitality, and social functioning than the average U.S. population.

When compared to other technology dependent patient groups it is difficult to determine differences between this group to those on total parenteral nutrition or to those whom are ventilator dependent due to lack of statistical data. Statistical analysis of the dialysis sample compared to the home enteral nutrition sample did not find any significant differences in any of the eight health dimension scores.

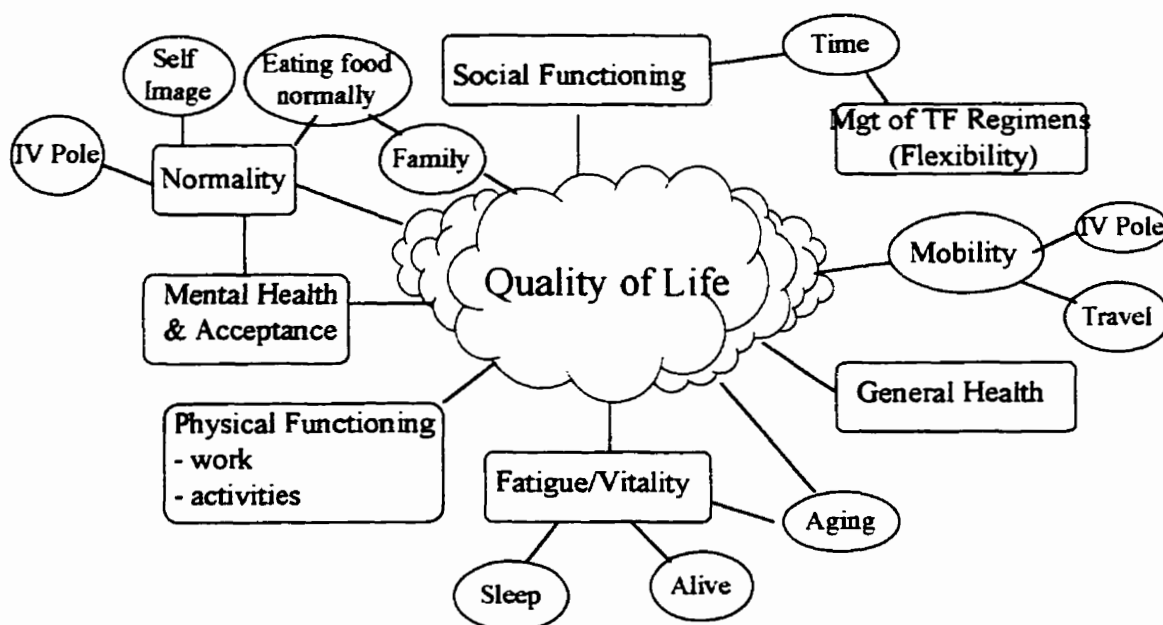
XII. CONCLUSION

What is it like to live on home enteral nutrition? What is it like to receive eighty to one hundred percent of your food via a tube? This is the first research of its kind to examine quality of life with home enteral nutrition.

A multimethod approach was used to determine quality of life of those, within the Manitoba Home Nutrition Program, living with home enteral nutrition. Ethnographically oriented interviews, using a structured interview guide, were used to capture qualitative data. Four illness narratives illustrate the diversity of life with home enteral nutrition. Despite these diversities, common themes emerge from the structured interviews (see Figure 2).

Individuals living on home tube feeds are dependent on technology for survival. One component of this technology is the intravenous pole. This pole was frequently mentioned as being restrictive or cumbersome. Individuals felt that it not only restricted them to their homes but restricted them to a specific area within their home. The pole's wheel base is large, and when manipulating the pole around their homes, the respondents bumped into furniture, had a difficult time moving the pole up and down stairs and rolling it on carpet is a challenge. Respondents stated that they were tied or nailed to their poles.

Figure 2: Common Themes Identified in Qualitative Interviews



Kaufert and Locker (1990) identified that improvements in mobility impacted positively on quality of life. Therefore, a more portable system of tube feed administration, on a regular daily basis, warrants further investigation. For instance, the tube feed travel pack consisting of a knapsack that holds the enteral pump, bag and tube feed product may provide an alternate choice for individuals to increase their mobility within their homes as well as outside of their homes

Another common theme, when describing what life is like on home tube feeds, is the fact that the tube feed regimen is time consuming. Individuals perceive that the tube feeds consume a large portion of time regardless of the actual amount of time that is required to administer their tube feeds. This time impacts on many aspects of their

lives including their ability to continue favourite activities such as hobbies, sports, and social activities. The organization of this time and one's ability to be flexible with this regimen seems to enable the individual to better cope with this new lifestyle. The more control one had with adjusting their tube feed regimen the better their quality of life. Control is an important aspect of quality of life (Laskiwski and Morse 1993).

Impact on normality is a common issue with chronically ill persons (Strauss 1984). For this group, the behavior associated with eating was most identified with normality. Self image was also mentioned but was limited to respondents under the age of 50 who had only been receiving tube feeds for a short time period. Accepting these new life changes was important in order to enhance their quality of life.

When assessing quality of life in persons living with home enteral nutrition, one cannot separate technology from the illness state. Respondents had a difficult time separating descriptions of life with home enteral nutrition from their experience of illness and health. Hence, tube feeds and the illness state are intertwined in terms of their impact on quality of life.

The positive aspects of tube feeding are few but are very well supported by respondents. The strongest message is the ability of the tube feeds to keep them alive. Other benefits of enteral nutrition include the provision of adequate nutrition which improves energy levels in a convenient, simple form of technology.

In the qualitative data, respondents ranked their quality of life somewhere between fair and good. Issues that were important to these individuals when considering their quality of life included: the ability to do activities such as social activities, work, daily activities and hobbies; spending quality time with their family; being able to eat food or accept the fact that they no longer can eat; mental health and acceptance of their situation; general health; getting used to the pace of their new lifestyle and their aging process. Seven out of the eight dimensions in the SF-36 Health Survey are mentioned in the qualitative interviews. These include: physical functioning, role-physical, mental health, role-emotional, social functioning, general health and vitality.

This multimethod research design combined ethnographically oriented semi-structured interviews with a standardized health survey to capture quality of life. Did each method confirm findings from the other? Did the SF-36 results support the qualitative data for each of the health dimensions?

The SF-36 results indicate that the respondents' health or tube feed regimen impacts negatively on their ability to perform physical activities. Problems with work or other daily activities exist as a result of physical health. This impact on ability to perform activities was mentioned by several respondents during the qualitative interviews.

General health is perceived by these respondents to be below normal as measured by the SF-36 Health Survey. Health is raised in the narratives as impacting on their quality of life and on their ability to perform favourite activities. Age is also mentioned to impact on general health.

The SF-36 results indicate that respondents feel more tired than the average person. Qualitative data supports this. Respondents comment that they did not have the energy to do the things they used to do. On the other hand, the tube feeds also provided them with energy to continue some activities. Age also impacts on their vitality. This technology had minimal impact on sleep for most. Individuals with gastrointestinal problems had the most difficulty with sleeping and feeding simultaneously.

The SF-36 results indicate that the respondents' health or tube feed regimen interferes with their social activities. Impact on family is raised when discussing quality of life issues. The time management of the tube feed regimen; the immobility of the equipment; and the inability to consume food normally; is stated to interfere with social activities leading to social isolation for some.

After the SF-36 results were corrected for age, the Manitoba Home Nutrition Program participants scored within normal for bodily pain. This is supported by the limited comments in the narratives with regards to pain.

As one would predict the Manitoba Home Nutrition Program respondents scored within normal for the mental health and role-emotional dimension. Narratives did reveal that mental health contributes to one's quality of life with regards to acceptance of this new lifestyle.

Throughout the thesis comparisons are made to parallel technologies. Similarities are found between populations living with home parenteral nutrition, renal dialysis and ventilator support to those living with home enteral nutrition. In all these situations individuals are dependent on medical technology for survival; there exists a physical connection to equipment; the method of treatment is invasive; and the frequency of treatment can be on a daily basis. The management of these regimens impact on their quality of life.

Future Research:

This research project brings us one step closer to unraveling the mystery of quality of life with home enteral nutrition. Generalizations can be made from this data only to individuals who are followed by established Home Nutrition Programs in

Canada. Many individuals are believed to live with home enteral nutrition without follow up from established home enteral nutrition programs.

Further research is needed to determine if similar narratives are found in different home enteral nutrition populations in the world. All respondents in this study were adult, Caucasian and the majority had family incomes greater than \$40,000 per annum. Other populations to research include pediatrics, aboriginal, and the poor.

This multimethod design approach could be used to investigate quality of life of those living with parallel technologies. Further comparisons can then be made between home enteral nutrition, home parenteral nutrition, hemodialysis or ventilator dependent populations. Establishing similarities and differences between these patient groups will improve our understanding of what life is like for this population. Once similarities and differences are established there is a huge resource of comparable research that can be tapped.

Further research is needed to investigate the daily use of travel packs with regards to increasing portability/mobility and the impact on quality of life. Re-engineering and developing an intravenous pole that is more compatible for the home setting and flexible for transport will also increase mobility.

Further examination of the various methods of tube feed administration and its impact on quality of life is also needed. Flexibility, portability and time consumption are important factors to consider when selecting methods of tube feed administration. Syringe feedings meet this criteria but are very seldom used.

Travel packs, re-engineered intravenous poles or syringe feedings may all need to be considered to accommodate the needs of this diverse patient population.

Overall, quality of life as perceived by those living with home enteral nutrition is rated somewhere between fair and good. Home enteral nutrition impacts on many aspects of peoples lives including their physical functioning, social functioning, families, favourite activities, ability to consume foods normally, and acceptance of their new life situations. Managing the tube feeds regimen poses many challenges to individuals when balancing their priorities. Those individuals that are able to adjust and adapt their own treatments to fit their lifestyles report less restraints imposed by this technology.

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September 16, 1996

Brenda Hotson
Health Sciences Centre
Attn.: Receiving
59 Pearl Street
Winnipeg, Manitoba R3E 0M1
CANADA

RE: PO# E122622

Dear Ms. Hotson,

The Medical Outcomes Trust is pleased to provide the enclosed information about the SF-36™ Health Survey as specified on your Request Form received September 16, 1996.

We are please, by this letter, to grant permission to you to use the SF-36™ Canada - English Health Survey. Enclosed are copies of both the more commonly used 4-week recall format and the acute 1-week recall format, either of which you may reproduce for your use. Also enclosed is a copy of *SF-36 Health Survey: Manual and Interpretation Guide* as well as reprints of publications that may be of interest to you. The scoring algorithms printed in *How to Score the SF-36™ Health Survey* should be used for translations of the SF-36™ Health Survey. Additional foreign language versions of this document are forthcoming.

When reproducing the SF-36™ Health Survey please include an identifier as follows:

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If you add any questions to it, as users often do, or embed it in a larger questionnaire, please give the larger questionnaire its own name and indicate the following in small type anywhere on the form including at the end: *This questionnaire includes the SF-36™ Health Survey, item numbers X to Y in this questionnaire, Reproduced with permission of the Medical Outcomes Trust, Copyright © 1992.*

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APPENDIX A

If for any reason you change the wording of any part of the SF-36™ Health Survey, or delete any questions or responses, please do not refer to it as the SF-36™ Health Survey. This is for purposes of standardization of content, scoring, and labeling. We wish to assure users that the designation SF-36™ Health Survey refers to the identical instrument and scoring rules in all cases. This will allow comparison of scores across multiple reports.

In addition to the *SF-36 Health Survey: Manual and Interpretation Guide*, two other books related to the Medical Outcomes Study and to the SF-36™ Health Survey have been published commercially. *Measuring Functioning and Well-Being: The Medical Outcomes Study Approach*, Stewart, A.L. and Ware, J. Jr., Editors, Duke University Press, 1992 and *SF-36 Physical & Mental Health Summary Scales: A User's Manual*, Ware, J.E. Jr., Kosinski, M., and Keller, S.D., The Health Institute, New England Medical Center, Boston, Massachusetts.

The information you have provided on the Project Registration Form will allow the Trust to keep apprised of current projects. If you should later plan to use the SF-36™ Health Survey in additional outcomes measurement activities, we ask that you simply complete a Project Registration Form and forward it to the Trust. I have enclosed a blank Project Registration Form. The Trust in this way can be informed of progress in the field, be alert to the need for new technology and information, promote standardization, and generally serve to advance the field.

Also enclosed with this mailing are the Consumer/Patient Satisfaction Information and November, 1994, *Bulletin*. A brochure describing the Trust's Membership Program has been included for your review. If you have any questions about the materials you received, please contact Daniel W. Krueger at (617) 426-4046.

We wish you the best of good fortune in pursuing your goals in outcomes measurement. Please contact us if we can be of further assistance.

Respectfully,

Lyn Paget

Lyn Paget
Director of Operations

Enclosures

This portion of the letter will also serve as your receipt.

Awaiting Method Of Payment:	<input type="checkbox"/> Check	<input type="checkbox"/> Visa	<input type="checkbox"/> M/C	<input type="checkbox"/> AMEX
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AMOUNT:	\$126.00 US	ORDER #:	0001763
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APPENDIX B

INTERVIEW GUIDE

ID# _____

1. Date of interview: Month/Day _____ Year _____
 Start time _____ End time _____ Length ___ hours _____ minutes

2. Physical Setting:
 - Respondent's Home
 - MHNP Clinic Room _____
 - Other _____

INTRODUCTION

Very often health professionals will recommend that individuals receive daily tube feeds for home but no one ever asks those individuals what it is like to live on artificial nutrition support? What is it like to receive most of your food in the form of a liquid that you put down a tube? The purpose of my visit with you today is to ask questions regarding these issues and find out what you think and feel about this way of life.

There are three sections to this interview. First, I'm going to ask you to complete a short health survey which will take approximately 10 minutes. After the survey, I'm going to ask you a few questions about yourself. It will be easier to talk about how the tube feeds have affected or changed your life if I know a little bit about your background. In the last section, I'll ask you questions regarding your experiences with tube feeds. What is it like to live on tube feeds? Can you describe a typical day with tube feeds? How has tube feeds affected your family, work and social life?

SF-36 HEALTH SURVEY

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

- | | |
|----------------|---|
| Excellent..... | 1 |
| Very good..... | 2 |
| Good..... | 3 |
| Fair..... | 4 |
| Poor..... | 5 |

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

- | | |
|--|---|
| Much better now than one year ago..... | 1 |
| Somewhat better now than one year ago..... | 2 |
| About the same as one year ago..... | 3 |
| Somewhat worse now than one year ago..... | 4 |
| Much worse now than one year ago..... | 5 |

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a) Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b) Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c) Lifting or carrying groceries	1	2	3
d) Climbing several flights of stairs	1	2	3
e) Climbing one flight of stairs	1	2	3
f) Bending, kneeling, or stooping	1	2	3
g) Walking more than a kilometre	1	2	3
h) Walking several blocks	1	2	3
i) Walking one block	1	2	3
j) Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a) Cut down on the amount of time you spent on work or other activities	1	2
b) Accomplished less than you would like	1	2
c) Were limited in the kind of work or other activities	1	2
d) Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a) Cut down the amount of time you spent on work or other activities	1	2
b) Accomplished less than you would like	1	2
c) Didn't do work or other activities as carefully as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(circle one)

Not at all..... 1
 Slightly..... 2
 Moderately..... 3
 Quite a lot..... 4
 Extremely..... 5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

None..... 1
 Very mild..... 2
 Mild..... 3
 Moderate..... 4
 Severe..... 5
 Very severe..... 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

- Not at all..... 1
- A little bit..... 2
- Moderately..... 3
- Quite a bit..... 4
- Extremely..... 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a) Did you feel full of pep?	1	2	3	4	5	6
b) Have you been a very nervous person?	1	2	3	4	5	6
c) Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d) Have you feel calm and peaceful?	1	2	3	4	5	6
e) Did you have a lot of energy?	1	2	3	4	5	6
f) Have you felt downhearted and blue?	1	2	3	4	5	6
g) Did you feel worn out?	1	2	3	4	5	6
h) Have you been a happy person?	1	2	3	4	5	6
i) Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

All of the time.....1
 Most of the time.....2
 Some of the time.....3
 A little of the time.....4
 None of the time.....5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely True
a) I seem to get sick a little easier than other people	1	2	3	4	5
b) I am as healthy as anybody I know	1	2	3	4	5
c) I expect my health to get worse	1	2	3	4	5
d) My health is excellent	1	2	3	4	5

BACKGROUND INFORMATION

ID# _____

1. Sex: Male Female
2. What is your age? _____ years
3. How long have you received tube feeds? _____ years _____ months
4. How often do you feed yourself with the tube? _____ times per day
5. How long does it take per feed? _____ hours _____ minutes
6. Do you require assistance with the feedings? Yes No
7. How long have you been followed by the Manitoba Home Nutrition Program?
_____ years _____ months _____ weeks
8. What tube feed product do you use? _____
9. What volume do you administer per feed? _____
10. How has your weight been in the past 3 months?
 - same
 - gained weight how many pounds? _____
 - lost weight how many pounds? _____
11. What is your usual weight? _____
12. How tall are you? _____
13. Where do you live? (if not at informant's residence)
 - neighborhood _____
 - city _____
 - dwelling _____
14. How long have you lived here?
 - _____ years
 - _____ months

ID # _____

15. Have you moved since you started on tube feeds? Yes No

a) If YES, where did you live before?

- neighborhood _____
- city _____
- dwelling _____

b) If YES, why did you move?

16. What is your marital status?

- Single Married Divorced/Separated
 Widowed Common Law

17. Do you have any children? Yes No

Number of children _____ Ages _____

Number of children living with you? _____

18. Who else lives in your household? (specify number of each)

- spouse/partner _____
 mother / mother-in-law _____
 father / father-in-law _____
 other _____

ID # _____

19. Do any of your relatives live here in Winnipeg? Yes No
Have you seen or talked to any of your relatives in the past month? Yes
 No
20. How much formal education do you have?
- Less than grade 7
 - Junior High School (grade 7-9)
 - Partial High School (grade 10 or 11)
 - High School Graduate
 - Partial college or university
 - College or university graduate
 - Postgraduate studies
 - Graduate degree
21. Are you currently:
- working full time retired
 - working part time homemaker
 - unemployed student
 - on leave due to illness

ID # _____

22. What is your present occupation? (work place including home, type of work, if no longer working e.g. retired / disabled include prior occupation)

23. What is the annual Household Income

- < \$20,000
- \$20,000 to \$40,000
- \$40,000 to \$60,000
- >\$60,000

24. What are your present religious beliefs?

- Protestant (Denomination: _____)
- Catholic
- Jewish
- None
- Other _____

ID # _____

EXPERIENCE QUESTIONS

1. Can you describe to me what it is like to live on tube feeds?

2. Why do you need home tube feeds? (include disease/medical background re: reason for tube feeds)

3. What were your thoughts when they first told you that you would need to go home on tube feeds?

ID# _____

4. Have those thoughts changed now that you are living the experience?

5. Can you describe for me a typical day and how you incorporate your feedings into you daily routine?

6. What do you usually do while you're feeding? (probe re: mobility with tube feeds)

ID# _____

7. How has home tube feeds affected your family life?

8. How has home tube feeds affected your working life? (if retired: your activity)

9. How has home tube feeds affected your social life?

ID# _____

10. Do you consume food as well as the tube feeds? Yes No

If YES, do you consume regular meals?

If YES, do you enjoy eating?

If NO, what is it like to never eat food? (probe re: cravings, compensated activities)

11. Do you ever feel hungry?

ID# _____

12. What are the positive aspects of tube feeding yourself?

13. What are the negative aspects of feeding yourself?

14. Has tube feeding changed the way you think of yourself?

ID# _____

15. Has tube feeding changed the way you think of your body?

16. I realize that quality of life is difficult to define, but in your own words how would you describe your quality of life currently? (If the answer is poor, good, etc. ask WHY?)

17. Did home tube feeds change your quality of life?

ID # _____

18. At the beginning of the interview you completed a written questionnaire. Did the written questionnaire represent how you feel about your quality of life? Did the questions represent how you feel about your health? How did the written questionnaire compare to the verbal questions with regards to capturing how you felt about your quality of life? and How you felt about your health?

APPENDIX C

INTERVIEW GUIDE FOR WRITTEN RESPONDENTS

ID# _____

1. Date of interview: Month/Day _____ Year _____
 Start time _____ End time _____ Length ___ hours _____ minutes

2. Physical Setting:
 - Respondent's Home
 - MHNP Clinic Room _____
 - Other _____

INTRODUCTION

Very often health professionals will recommend that individuals receive daily tube feeds for home but no one ever asks those individuals what it is like to live on artificial nutrition support? What is it like to receive most of your food in the form of a liquid that you put down a tube? The purpose of this research project is to ask questions regarding these issues and find out what you think and feel about this way of life.

There are three sections to this interview. First, please complete the short health survey which will take approximately 10 minutes. It is very important that this survey is completed first and not changed after you complete the rest of the questionnaire. After the survey, please complete the background information section. It will be easier to understand how the tube feeds have affected or changed your life if I know a little bit about your background. In the last section, are questions regarding your experiences with tube feeds. What is it like to live on tube feeds? Can you describe a typical day with tube feeds? How has tube feeds affected your family, work and social life?

SF-36 HEALTH SURVEY

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

- | | |
|----------------|---|
| Excellent..... | 1 |
| Very good..... | 2 |
| Good..... | 3 |
| Fair..... | 4 |
| Poor..... | 5 |

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

- | | |
|--|---|
| Much better now than one year ago..... | 1 |
| Somewhat better now than one year ago..... | 2 |
| About the same as one year ago..... | 3 |
| Somewhat worse now than one year ago..... | 4 |
| Much worse now than one year ago..... | 5 |

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a) Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b) Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c) Lifting or carrying groceries	1	2	3
d) Climbing several flights of stairs	1	2	3
e) Climbing one flight of stairs	1	2	3
f) Bending, kneeling, or stooping	1	2	3
g) Walking more than a kilometre	1	2	3
h) Walking several blocks	1	2	3
i) Walking one block	1	2	3
j) Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a) Cut down on the amount of time you spent on work or other activities	1	2
b) Accomplished less than you would like	1	2
c) Were limited in the kind of work or other activities	1	2
d) Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a) Cut down the amount of time you spent on work or other activities	1	2
b) Accomplished less than you would like	1	2
c) Didn't do work or other activities as carefully as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(circle one)

Not at all.....1
 Slightly.....2
 Moderately.....3
 Quite a lot.....4
 Extremely.....5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

None.....1
 Very mild.....2
 Mild.....3
 Moderate.....4
 Severe.....5
 Very severe.....6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

- Not at all..... 1
 A little bit..... 2
 Moderately..... 3
 Quite a bit..... 4
 Extremely..... 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a) Did you feel full of pep?	1	2	3	4	5	6
b) Have you been a very nervous person?	1	2	3	4	5	6
c) Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d) Have you feel calm and peaceful?	1	2	3	4	5	6
e) Did you have a lot of energy?	1	2	3	4	5	6
f) Have you felt downhearted and blue?	1	2	3	4	5	6
g) Did you feel worn out?	1	2	3	4	5	6
h) Have you been a happy person?	1	2	3	4	5	6
i) Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

All of the time.....1
 Most of the time.....2
 Some of the time.....3
 A little of the time.....4
 None of the time.....5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely True
a) I seem to get sick a little easier than other people	1	2	3	4	5
b) I am as healthy as anybody I know	1	2	3	4	5
c) I expect my health to get worse	1	2	3	4	5
d) My health is excellent	1	2	3	4	5

BACKGROUND INFORMATION

ID# _____

1. Sex: Male Female
2. What is your age? _____ years
3. How long have you received tube feeds? _____ years _____ months
4. How often do you feed yourself with the tube? _____ times per day
5. How long does it take per feed? _____ hours _____ minutes
6. Do you require assistance with the feedings? Yes No
7. How long have you been followed by the Manitoba Home Nutrition Program?
 _____ years _____ months _____ weeks
8. What tube feed product do you use? _____
9. What volume do you administer per feed? _____
10. How has your weight been in the past 3 months?
 - same
 - gained weight how many pounds? _____
 - lost weight how many pounds? _____
11. What is your usual weight? _____
12. How tall are you? _____
13. Where do you live?
 - neighborhood _____
 - city _____
 - dwelling _____
14. How long have you lived here?
 - _____ years
 - _____ months

ID # _____

15. Have you moved since you started on tube feeds? Yes No

a) If YES, where did you live before?

- neighborhood _____
- city _____
- dwelling _____

b) If YES, why did you move?

16. What is your marital status?

- Single Married Divorced/Separated
- Widowed Common Law

17. Do you have any children? Yes No

Number of children _____ Ages _____

Number of children living with you? _____

18. Who else lives in your household? (specify number of each)

- spouse/partner _____
- mother / mother-in-law _____
- father / father-in-law _____
- other _____

ID # _____

19. Do any of your relatives live here in Winnipeg? Yes No
Have you seen or talked to any of your relatives in the past month? Yes
 No
20. How much formal education do you have?
- Less than grade 7
 - Junior High School (grade 7-9)
 - Partial High School (grade 10 or 11)
 - High School Graduate
 - Partial college or university
 - College or university graduate
 - Postgraduate studies
 - Graduate degree
21. Are you currently:
- working full time retired
 - working part time homemaker
 - unemployed student
 - on leave due to illness

ID # _____

22. What is your present occupation? (work place including home, type of work, if no longer working e.g. retired / disabled include prior occupation)

23. What is the annual Household Income

- < \$20,000
- \$20,000 to \$40,000
- \$40,000 to \$60,000
- >\$60,000

24. What are your present religious beliefs?

- Protestant (Denomination: _____)
- Catholic
- Jewish
- None
- Other _____

ID # _____

5. Can you describe for me a typical day and how you incorporate your feedings into your daily routine? (Include timings of feedings, common activities that you might do during the day and evening.)

6. What do you usually do while you're feeding?

APPENDIX D

**MANITOBA HOME NUTRITION PROGRAM ANNUAL
REPORT***

**Primary Disease for the Period 01/04/95 to 31-03-96
Enteral Patients**

Primary Disease	# patients
ENTERAL	88
ALS	2
Bartter's Syndrome	1
Broncho Pulmonary Dysplasia	1
Cancer	27
Chronic Denervation Disease	1
Chronic Pancreatitis	1
Congenital Heart Disease	1
Crohn's	3
CVA	7
Diabetes	1
Encephalopathy	2
Head Injury	1
Hypoxic Injury	1
Intestinal Lymphangectasia	1
Lennox-Gestault Seizure	1
Miller Kieker Syndrome	1
Motility Disorders	4
Motor & Development	1
Muscular Sclerosis	1
Neurological Disorders	24
Parkinson's Disease	1
Pierre Robin Syndrome	2
Trisomy 18, Spinabifida	1
Vater Syndrome	2

PATIENT STATISTICS

**For the period 01/04/95 to 31/03/06
Enteral Patients**

Sex		Age				Location	
Female	Male	<20	20-39	40-59	60+	Urban	Rural
38	50	42	4	13	29	49	39

* Reproduced with permission from the Manitoba Home Nutrition Program.

APPENDIX E

UNIVERSITY OF MANITOBAFACULTY COMMITTEE ON THE USE OF HUMAN SUBJECTS IN RESEARCH

NAME: Ms. B. Hotson

REFERENCE: E97:27

DATE: 24 April 1997

YOUR PROJECT ENTITLED:Protocol Title: Quality of Life of Persons Receiving Long Term
Tube Feeds at Home

Revised Consent Form (undated)

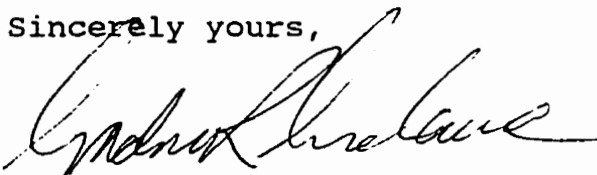
HAS BEEN APPROVED BY THE COMMITTEE AT THEIR MEETING OF:

Approved by Dr. G. Grahame on behalf of the Committee on April 22,
1997COMMITTEE PROVISOS OR LIMITATIONS:

Approved as per your letter dated April 2, 1997

You may be asked at intervals for a status report. Any significant
changes of the protocol should be reported to the Chairman for the
Committee's consideration, in advance of implementation of such
changes.****THIS IS FOR THE ETHICS OF HUMAN USE ONLY. FOR THE LOGISTICS OF
PERFORMING THE STUDY, APPROVAL SHOULD BE SOUGHT FROM THE RELEVANT
INSTITUTION, IF REQUIRED.****

Sincerely yours,

Gordon R. Grahame, M.D.,
Chairman,
Faculty Committee on the Use of
Human Subjects in Research

GRG/tk

Telephone Inquiries should be directed to Theresa Kennedy
Telephone: 789-3255 or
E-mail: kennedy@bldghsc.lan1.umanitoba.ca

APPENDIX F

MANITOBA HOME NUTRITION PROGRAM

January 14, 1997

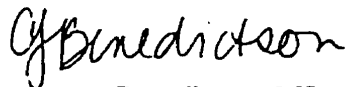
Brenda Hotson
34 Sasaki Crescent
Winnipeg, Manitoba
R2P 1P8

Dear Brenda:

As requested, I am forwarding you a letter on behalf of the MHNP team expressing our support of your research project entitled, "Quality of Life of Person's Receiving Long Term Tube Feeds at Home."

We feel that this investigation and its results will be of value to the MHNP. We appreciate the opportunity to participate in this study.

Sincerely,



Gabriella Benedictson, MSc, RD
MHNP Team Coordinator

/at

CK477 - 848 Sherbrook Street, Winnipeg, MB R3A 1S1
Phone: 787-1831 / Fax 787-1647

APPENDIX G

QUALITY OF LIFE OF PERSONS RECEIVING LONG TERM TUBE FEEDS AT HOME

Very often health professionals will recommend that individuals receive daily tube feeds for home but no one ever asks those individuals what it is like to live on artificial nutrition support? What is it like to receive most of your food in the form of a liquid that you put down a tube? Very little is known regarding “What it is like to live on home tube feeds?”

The **purpose** of this research project is to find out **what life is like for people who are receiving tube feeds at home from the individual’s perspective**. This will be achieved by talking to people, like yourself, who receive home tube feeds.

You have been asked to participate since you are followed by the Manitoba Home Nutrition Program, you are over the age of eighteen and are currently receiving home tube feeds. The Manitoba Home Nutrition Program was approached since they are the only program within the province that has a registry of people receiving home tube feeds.

You will be asked to **participate in an interview** which could take place at your home, at the Manitoba Home Nutrition Clinic or any setting that you find comfortable. The interview will be approximately one and a half to two hours in length. There are three sections to the interview. The first section is a short written health survey that you will complete. This will take approximately ten minutes. The next two sections require no writing. In the second section the researcher will ask you questions about your age, marital status, education, family, occupation, type and

amount of tube feeds, and number of feedings per day. In the last section, the researcher will ask you questions regarding your experiences with tube feeds. Questions such as “What is it like to live on tube feeds? How has tube feeds affected your family, work, and social life?”

With your permission the last two sections of the **interview will be tape-recorded**. The information revealed in the interview will be **confidential**. The records of your interview will be number coded and your name will be erased. Therefore no one will be able to identify your record except for the researcher. You will not be identified in any report by name, occupation or by any identifiable features. Results will be reported in a graduate paper as group results. The Manitoba Home Nutrition Program will not have access to any individual results. Your participation in this research project will not affect the care you already receive from the Manitoba Home Nutrition Program.

The **researcher** is a Community Sciences Graduate Student at the University of Manitoba. The researcher is not affiliated with the Manitoba Home Nutrition Program in any way. This research is not funded or initiated by the Manitoba Home Nutrition Program.

Joining the research is completely **voluntary**. If you do not wish to participate in this research project, it will not affect the care that you receive and you may withdraw from the study at any time.

There are no known **risks or discomfort** to participating in this research project other than 1) taking up your time to answer questions, and 2) asking questions that may bring up personal problems or remind you of past difficulties. The benefits to you may be that this will provide a chance to tell your story of what life is like on tube feeds. When completed, this research will help both individuals receiving home tube

feeds and health care workers to understand more about how home tube feeds has affected individuals' lives.

If you have any questions, please contact Interviewer Hotson at 694-8456.

I have been fully informed regarding the above research procedures and have had the purpose of this study explained to me. I have been provided with the opportunity to ask questions and these questions have been answered satisfactorily. I agree to participate in this research and understand that I may withdraw this consent and discontinue participation at any time without affecting my health care received from the Manitoba Home Nutrition Program.

Date: _____

Signature: _____

APPENDIX H

May 1, 1997

To Patients of the Manitoba Home Nutrition Program:

Very often health professionals will recommend that individuals receive daily tube feeds for home but no one ever asks those individuals what it is like to live on artificial nutrition support? What is it like to receive most of your food in the form of a liquid that you put down a tube? **Very little is known regarding “What it is actually like to live on home tube feeds?”**

I am currently conducting a research project to find out **what life is like for people who are receiving tube feeds at home from the individual’s perspective.** This will be achieved by talking to people, like yourself, who receive home tube feeds.

In the next couple of weeks you will be contacted by someone from the Manitoba Home Nutrition Program to ask if you would be willing to participate in this research project. The reason the Manitoba Home Nutrition Program will be contacting you is to keep your identity confidential to the researcher until you agree to participate. This letter has been written by the researcher but mailed by the Manitoba Home Nutrition Program staff.

The **researcher** is a Community Sciences Graduate Student at the University of Manitoba. The researcher is not affiliated with the Manitoba Home Nutrition Program in any way. This research is not funded or initiated by the Manitoba Home Nutrition Program.

You have been asked to participate since you are followed by the Manitoba Home Nutrition Program, you are over the age of eighteen and are currently receiving home tube feeds. The Manitoba Home Nutrition Program was approached since they are the only program within the province that has a registry of people receiving home tube feeds.

You will be asked to **participate in an interview** which could take place at your home, at the Manitoba Home Nutrition Clinic or any setting that you find comfortable. The interview will be approximately one and a half to two hours in length. There are three sections to the interview. The first section is a short written health survey that you will complete. This will take approximately ten minutes. The next two sections require no writing. In the second section the researcher will ask you questions about your age, marital status, education, family, occupation, type and amount of tube feeds, and number of feedings per day. In the last section, the researcher will ask you questions regarding your experiences with tube feeds.

Questions such as “What is it like to live on tube feeds? How has tube feeds affected your family, work, and social life?”

With your permission the last two sections of the interview will be tape-recorded. The information revealed in the interview will be confidential. The records of your interview will be number coded and your name will be erased. Therefore no one will be able to identify your record except for the researcher. You will not be identified in any report by name, occupation or by any identifiable features.

Joining the research is completely **voluntary**. If you do not wish to participate in this research project, it will not affect the care that you receive and you may withdraw from the study at any time.

There are no known **risks or discomfort** to participating in this research project other than 1) taking up your time to answer questions, and 2) asking questions that may bring up personal problems or remind you of past difficulties. The benefits to you may be that this will provide a chance to tell your story of what life is like on tube feeds. When completed, this research will help both individuals receiving home tube feeds and health care workers to understand more about how home tube feeds has affected individuals' lives.

If you have any questions, please contact Interviewer Hotson at 694-8456 or 787-2343 or contact the Manitoba Home Nutrition Program.

Sincerely,

Brenda Hotson
Graduate Student
University of Manitoba
Department of Community Health Sciences

APPENDIX I

INFORMATION RE: GRADUATE STUDENT'S RESEARCH PROJECT

PURPOSE:

To determine "What life is like for people who are receiving tube feeds at home" from the individual's perspective.

IMPORTANCE OF THIS RESEARCH:

There is currently nothing written in the medical literature to help health professionals understand "What it is like for people to live on tube feeds at home?" This research provides a vehicle for people like yourselves to express your story and inform health professionals what it is like to live on tube feeds at home. When completed, this research will help both future individuals receiving home tube feeds and health care workers to understand more about how home tube feeds has affected individuals' lives.

METHOD:

- **Interviews**

- **Setting:** conducted either at the individual's home, at the Manitoba Home Nutrition Clinic or whatever setting the individual finds comfortable. The researcher is flexible and wants the participant to feel at ease.

- **Length** of interview: approximately one and half to two hours

- Interview is **tape recorded** so the participants message is clearly and accurately conveyed. This is to avoid misunderstandings. All interviews are transcribed and common themes of the entire group are reported.

- Number of participants: approximately 10 to 19 people will be interviewed.

INCLUSION CRITERIA:

- Registered with the Manitoba Home Nutrition Program
- Receiving home tube feeds for a minimum of 1 month
- Physically/mentally able to participate in a one and half hour interview as judged by the MHNP professional staff
- Age > 18 years
- Male or female
- Fluent in English
- Resides in Winnipeg or willing to be interviewed in Winnipeg
- Agreeable to consent

IF INTERESTED IN PARTICIPATING:

Name and phone number will be forwarded to Interviewer Hotson. Interviewer will contact participant by phone to arrange convenient time and place for the interview.

IF NOT INTERESTED IN PARTICIPATING:

Joining the research is completely voluntary. If the participant does not wish to participate in this research project, it will not affect the care they receive .

CONFIDENTIALITY:

The information revealed in the interview will be confidential. The participant will not be identified in any report by name, occupation or by any identifiable features.

MORE QUESTIONS:

Please feel free to contact Interviewer Hotson at 694-8456 or 787-2343.

**APPENDIX J
CODES**

269

ACCEPT (resigned)	EAT.SOCIAL
ACTIVITIES	EAT.SWALLOW
ACTIVITIES.MISS	EMOTIONAL
AGE	ENERGY
ALIVE	ENJOY
ANNOYING (bothersome, hate)	ERROR
APPETITE	EXPENSIVE
ASSISTANCE.PUBLIC	FAMILY
ASSISTANCE.TF	FATHER
ASSISTANCE.WALK	FEAR
B1 - B24	FEED.CONTINUOUS
BACKUP	FEED.DAY
BORING (monotonous)	FEED.INTERMITTENT
BOWELS	FEED.NIGHT
BURDEN (inmate,nailed down)	FEMALE
CARE.ADJUST	FIGHT (convince)
CARE.ALTERNATE	FLEXIBLE
CARE.RIGID	FLOOD
CAREFUL	FLUIDS
CLOTHES	FOOD
COMBO	FOOD.CRAVING
CONFIDENCE	FOOD.FAVOURITE
CONVENIENT	FOOD.MISS
COOK	FOOD.PRESENCE
CUMBERSOME	FOOD.SOLID
DECISION.NO	FOOD.TERMINOLOGY
DEMONSTRATE	FUTURE
DEPENDENCE	GOVT
DETERMINED	HANDICAP
DEVELOP	HAPPY
DIAGNOSIS	HEALTH
DIARRHEA	HEALTH.PRO
DIFFICULT (hard,terrible)	HELPLESS (useless)
DISAPPOINT	HOME
DISFIGURE	HOMECARE
DISRUPT	HOSPITAL
DOWN	HOSPITAL.OUT
E1-E18 (experience questions)	HUNGER
EAT	IMPROVE
EAT.ENJOY	INCONVENIENT
EAT.FALSE TEETH	INDEPENDENCE
EAT.MISS	ISOLATED (separated)
EAT.NOTENJOY	LONG TERM
EAT.NOTMISS	LUCK
EAT.PAIN	MALE

APPENDIX J
CODES

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MD.NEG	SELF.OUTER
MD.POS	SELFIMAGE
MEAL	SHORT TERM
MEAL.PREP	SIMPLE
MEALTIME	SISTER
MEDICAL.CARE	SLEEP
MEDICAL.CONDITION	SLEEP.CUDDLE
MEDICAL.THERAPY	SLEEP.DISEASE
MEDS	SLEEP.WASHROOM
MENTALHEALTH	SLOWEDDOWN
MHNP	SMELL
MOBILE	SOCIAL
MOM	SOCIAL.FAMILY
MOTHER	SOCIAL.FRIENDS
NEGATIVE	SOCIAL.RESTAURANT
NORMAL	SON
NUTRITION	SPOUSE
OUT	STRENGTH
PAIN	SUPPLIES
PAST	SUPPORTGROUP
PERMANENT	SURVEY
PHYSICAL	SWALLOW
POLE	SYMBOLIC
PORTABLE	TASTE
POSITIVE	TEMPORARY
PRESSURE	TF.CLEANING
PRETEND	TF.DIFFERENT
PRODUCTIVE	TF.GRAVITY
QOL	TF.OUTSIDE
QOL.FAIR	TF.PUMP
QOL.GOOD	TF.PUMPMANUAL
QOL.POOR	TF.SYRINGE
QOL.TF	TF.TASTE
QOL.TF.DECREASED	TFACT.
QOL.TF.IMPROVED	THERAPY
RELIEF	THIN
RELIGION	THOUGHTS
RESTRICT	TIME
ROLE.ACTIV	TIME.#HOURS
ROLE.WORK	TIME.ADJUSTMENT
ROUTINE.DAY	TIME.BEGINNING
ROUTINE.HOMECARE	TIME.CONSUMING
ROUTINE.VON	TIME.CUTSINTO
SCHOOL	TIME.FASTER
SELF.INNER	TIME.RATE

APPENDIX J
CODES

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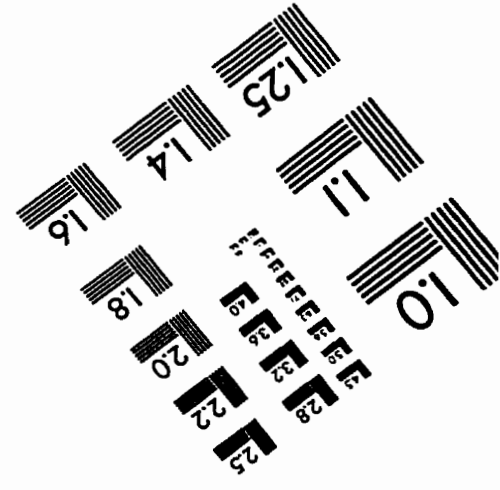
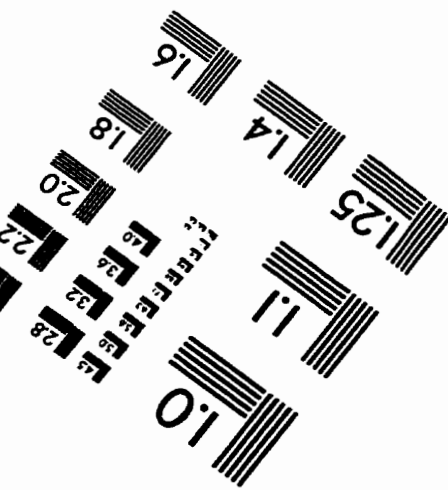
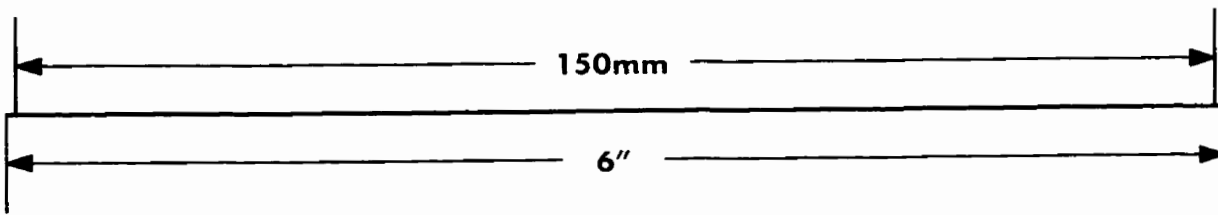
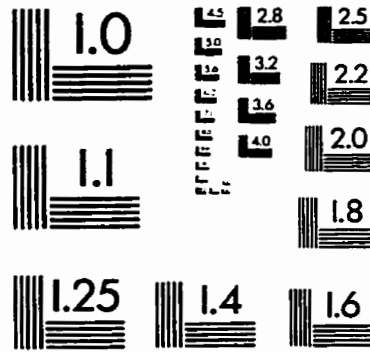
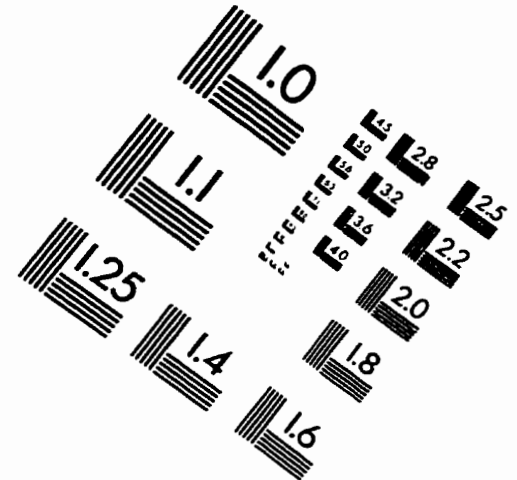
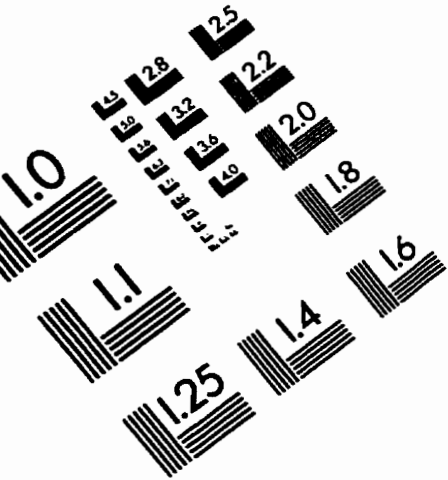
TIME.TF	UNCOMFORTABLE.DIARRHEA
TIME.WAIT	UNCOMFORTABLE.GAS
TIRED	UNCOMFORTABLE.INDIGESTION
TRACH	UNCOMFORTABLE.REGURG
TRAVEL	UNEVENTFUL
TUBE	VACATION
TUBE.BALLOON	VENT (ventilator)
TUBE.BLOCKAGE	VERBAL
TUBE.BUTTON	WASHROOM
TUBE.GASTROSTOMY	WEIGHT
TUBE.JEJUNOSTOMY	WEIGHT.GAIN
TUBE.LOOKS	WEIGHT.LOSS
TUBE.NG	WEIGHT.STABLE
UNCOMFORTABLE	WITHDRAWN
UNCOMFORTABLE.BLOATED	WORK
UNCOMFORTABLE.CONSTIPATIO	WORSE (could be worse)
N	WRITTEN

Quality of Life Domains in Quantitative Literature (cont.)

Domains	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z	%	
Socio-Economic Status												X						X									X	11.5
Financial adequacy				X	X					X			X			X	X				X							30.8
Neighborhood					X																	X						7.7
City or Country					X																							3.8
Housing				X	X				X			X																15.4
Education				X	X				X	X											X							15.4
Standard of Living					X				X				X					X										19.2
Age											X	X																7.7
Sex											X	X																7.7
Race												X																3.8
Sexual Satisfaction				X					X									X										11.5
Availability of Transportation											X	X																7.7

(A= Aronson 1989, B= Bergner 1985, C= Bowling 1991, D= Burkhardt et al 1989, E= Campbell, Converse and Rodgers 1976, F= Ferrans 1992, G= Goodinson 1989, H=Hadorn and Hays 1991, I= Horngquist 1982, J= Jenkins et al. 1990, K= Knapp 1976, L= Larson 1978, M= McDowell and Newell 1987, N= Meeberg 1993, O= Mor 1987, P= Moinpour et al. 1989, Q= O'Young and McPeck 1987, R=Packa 1989, S=Pocock 1991, T= Schumacher Olschewski and Schulgen 1991, U= Stewart 1992, V= Szalai and Andrews 1980, W= Tarter et al 1988, X= Warc 1987, Y= et al 1984, Z= Zhan 1992)

IMAGE EVALUATION TEST TARGET (QA-3)



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