

**DECISION-MAKING BY HEALTH CAREPROVIDERS  
ON BEHALF OF PROFOUNDLY IMPAIRED PERSONS:  
QUALITY OF LIFE CONSIDERATIONS**

BY

BEVERLY JOAN HENDERSON

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  
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| Marketing            | 0338 |
| Histoire             |      |
| Histoire générale    | 0578 |

|   |      |
|---|------|
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| Moderne   | 0582 |
| Histoire des noirs  | 0328 |
| Africaine   | 0331 |
| Canadienne  | 0334 |
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| Latino-américaine   | 0336 |
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| Histoire des sciences   | 0585 |
| Loisirs   | 0814 |
| Planification urbaine et régionale                            | 0999 |
| Science politique   |      |
| Généralités   | 0615 |
| Administration publique                                       | 0617 |
| Droit et relations internationales                            | 0616 |
| Sociologie  |      |
| Généralités   | 0626 |
| Aide et bien-être social                                      | 0630 |
| Criminologie et établissements pénitentiaires                 | 0627 |
| Démographie   | 0938 |
| Études de l'individu et de la famille                         | 0628 |
| Études des relations interethniques et des relations raciales | 0631 |
| Structure et développement social                             | 0700 |
| Théorie et méthodes   | 0344 |
| Travail et relations industrielles                            | 0629 |
| Transports  | 0709 |
| Travail social  | 0452 |

### SCIENCES ET INGÉNIERIE

#### SCIENCES BIOLOGIQUES

|   |      |
|---|------|
| Agriculture                             |      |
| Généralités                             | 0473 |
| Agronomie                               | 0285 |
| Alimentation et technologie alimentaire | 0359 |
| Culture                                 | 0479 |
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| Exploitation des pâturages              | 0777 |
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#### SCIENCES DE LA TERRE

|                     |      |
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| Biogéochimie        | 0425 |
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|                        |      |
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#### SCIENCES DE LA SANTÉ ET DE L'ENVIRONNEMENT

|                                 |      |
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| Orthophonie                     | 0460 |
| Pathologie                      | 0571 |
| Pharmacie                       | 0572 |
| Pharmacologie                   | 0419 |
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| Statistiques                    | 0463 |

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|              |      |
|--------------|------|
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| Ingénierie   |      |
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| Automobile   | 0540 |

|                                      |      |
|--------------------------------------|------|
| Biomédicale                          | 0541 |
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| Psychologie expérimentale    | 0623 |
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| Psychologie physiologique    | 0989 |
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| Psychométrie                 | 0632 |





DECISION-MAKING BY HEALTH CAREPROVIDERS  
ON BEHALF OF PROFOUNDLY IMPAIRED PERSONS:  
QUALITY OF LIFE CONSIDERATIONS

by

BEVERLY JOAN HENDERSON

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

MASTER OF SCIENCE

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## ABSTRACT

This thesis describes the dimensions of quality of life as they are defined, weighted and prioritized by health careproviders who are involved in proxy decision-making on behalf of profoundly impaired persons.

The project involved a descriptive study and utilized qualitative methods. Multiple methods, including semi-structured interviews, in-depth case studies, and participant-observation were employed in order to triangulate on the decision-making process.

In the analysis stage, data from all sources was coded thematically, indexed, and themes pertaining to quality of life decision-making were extracted. In-depth analysis of qualitative data describing decision-making suggests that the definition and application of quality of life criteria vary with the personal values and professional ideologies of the careproviders. Macro-level analysis indicates, however, that there are some dimensions of quality of life of concern to all careproviders. Focusing on these dimensions can provide common ground for treatment intervention decision-making.

To Stanley, with gratitude for sharing his simple, yet  
profound, understanding of quality of life with me.



... We're not in a position to cure people or to make them that substantially different than what they are, but we're here really to improve whatever we can in their day-to-day living. And of course... the scope of each department is different in attaining or achieving that end of quality of life....

*Quotation from one of the careproviders at St. Amant Centre*

## **CHAPTER 1**

---

### **INTRODUCTION**

#### **Purpose and Objectives**

This thesis describes dimensions of quality of life as they are defined, weighted and prioritized by health careproviders and family members who are involved in making treatment decisions on behalf of profoundly impaired persons. The research objectives are:

- 1) To describe the concept of quality of life as it is defined by health careproviders and parents, and applied in interpreting the experience of people with profound impairment.
- 2) To describe the process through which specific dimensions of quality of life are weighted and prioritized in the decision-making process.
- 3) To describe the influence of careprovider priorities associated with the impact of alternative interventions on the ease of providing care.
- 4) To describe the influence of more general societal values defining social worth and the application of the principles of distributive justice in the allocation of health care resources.
- 5) To describe the process of evaluating or assessing the effects of specific interventions on quality of life when the client is unable to communicate his/her own evaluation.

## Research Questions

In achieving the above objectives, a number of research questions were posed:

- (a) What factors do careproviders consider in assessing both the potential effects and the actual effects of specific interventions on another person's quality of life?
- (b) Is the concept of quality of life defined differently by each careprovider in accordance with individual subjective criteria?
- (c) Are there systematic variations in the ways in which careproviders from different professional disciplines define quality of life?
- (d) Is there consensus about the minimal requisites for sustaining quality of life, and the relative importance of its individual dimensions among nurses, psychologists, therapists, and other careprovider groups?
- (e) Are the effects of specific interventions on the ease of care factored into the decision-making process?
- (f) Do societal and professional values about the relative worth of profoundly handicapped individuals influence resource allocation decisions?

The theoretical framework for this research program is constructed around dilemmas which confront health careproviders involved in using quality of life assessments to assist in proxy decision-making on behalf of profoundly impaired people. The central research question originated in conversation with a clinician who is a participant in this type of decision-making. A detailed account of the origin and formulation of the research question is the subject of the next section.

## **The Origin and Formulation Of The Research Question**

The central question addressed by this research program was initially raised in a conversation with a professional colleague who is presently the Director of Physiotherapy at a residential care facility for individuals who are severely mentally and physically handicapped. During that conversation, our discussion centred around the need to develop outcome measures which could be used to evaluate the effects of some of the treatment interventions initiated by the physiotherapy staff at that particular facility.

My colleague's perception of the need for outcome measures was partially a response to the anticipation of future cost constraints, which she felt might change the criteria used to allocate health care resources. She expressed concern that outcome measures which would demonstrate the efficacy of expensive items such as spinal jackets and elaborate modified wheelchairs, might become necessary to ensure continued funding for this type of equipment.

My colleague also noted that, while careproviders within the facility frequently cited improved quality of life as an indication of the benefit afforded by specific interventions, there was no working definition of quality of life as the concept is applied to profoundly impaired persons. She expressed concern that appropriate objective assessment tools, which would evaluate the impact of specific treatments or programs on quality of life, had not been developed.

The problem of proxy assessment of quality of life as described by my friend was intriguing, both in terms of my perspective as a rehabilitation professional, and because of current interest in health-related quality of life. I was in the process of completing a course entitled "Measurement of Health Status and Disability," and had been assigned readings dealing with the measurement of quality of life. Upon conducting a bibliographic search and developing a paper on a utility-based approach to quality of life measurement, it became apparent that there was a rapidly growing body of literature focusing on the measurement of health-related quality of life.

It also became apparent, however, that much of the research in this field was constrained by

methodological limits associated with the researchers' failure to define and apply an operational definition of quality of life before attempting to use the concept in outcome measurement. Investigators identified what they believed to be dimensions of quality of life in the context of specified measurement objectives, but by focusing on individual dimensions such as function, they sometimes failed to capture the essence of the concept as a whole. In terms of my own research problem, it became evident that documenting definitions of quality of life, as described by people who care for severely handicapped individuals, would be a necessary pre-requisite to any attempt at developing a measurement tool for use in proxy assessment of quality of life.

In expanding the literature review to deal with applications of quality of life measurement to special needs people, it became clear that most of the existing indices had not been applied to, or validated for, use with people who were severely disabled. The gap in the measurement literature reflected the unique problems of assessing quality of life in this special situation where it is necessary to substitute proxy evaluation.

An appreciation of some of the legal and ethical problems inherent in incorporating subjective evaluations of quality of life into the proxy decision-making process was gained during the subsequent development of a paper on medical-legal decision-making. This appreciation, in combination with a recognition of the limitations of current quality of life measurement approaches to the situation under consideration, contributed to an understanding of the problems of proxy assessment of quality of life as they had been described by my colleague. A desire to explore the ways in which careproviders integrate quality of life considerations into the clinical decision-making process provided the basis for the research program which is the subject of this thesis.

As little previous research focusing on the problems of proxy evaluation of quality of life has been published, it was decided to develop a descriptive account of decision-making as it is carried out on behalf of profoundly handicapped individuals. The use of in-depth interviews and other qualitative methods enabled the researcher to explore careproviders' definitions of quality of life as they are applied in proxy decision-making situations. The use of this methodology also provided descriptions of the ways in which the dimensions of quality of life are assessed by careproviders, and

the process by which these assessments are subsequently incorporated into the clinical decision-making process.

The next sections will describe the problems which confront careproviders when they attempt to use quality of life considerations in making decisions on behalf of clients who are unable to participate in the decision-making process. After a brief discussion of the difficulties which are inherent in proxy decision-making, a case example which illustrates quality of life decision-making as observed in the facility which provided the setting for this research program, will be presented.

### **An Introduction to Quality of Life Decision-Making**

Arriving at a decision is never easy in cases where the individuals who are the subjects of decision-making are unable to express their views and preferences. The process of weighing the burdens of a specific intervention against the potential benefits is a complex one. In their accounts of proxy decision-making, careproviders frequently cite potential improvement in quality of life as justification for treatment decisions made on behalf of clients who are profoundly cognitively and physically impaired. A procedure may thus be performed with no participation on the part of the client, on the basis of a proxy decision-maker's assessment that quality of life would be improved as a result of that particular procedure.

The gaps alluded to previously, in terms of research addressing the definition and evaluation of quality of life, leave decision-makers with few established criteria for quality of life decision-making. Despite the emphasis on the importance of improving quality of life, the concept as applied to the experience of individuals with profound impairment, has not been defined. In individual careproviders' assessments of the potential for improving quality of life by specific interventions, the dimensions of quality of life which are considered are frequently not specified. In group decision-making situations, it is uncertain whether or not the participants have used similar or different criteria in their assessment of quality of life.

The next section describes a case example which illustrates some of the difficulties experienced by health careproviders attempting to make proxy decisions in situations where the outcome cannot be predicted with certainty. The case is a composite example, drawing on information from field notes describing the experiences of a number of individuals who live in a local residential care facility. The investigator observed the interaction involved in treatment decision-making over a six-month period, and obtained additional information from follow-up interviews. A composite case, containing elements of several different cases, was subsequently developed to preserve the anonymity of individual residents. Although the composite case integrates elements from case examples involving both male and female residents, the individual described in the following section will be referred to as male. A glossary of terms and procedures which may be unfamiliar to some readers, is contained in Appendix A.

## **A Composite Case Illustration**

### **General Information**

As indicated in the previous section, this case example is a composite re-construction integrating information from a number of cases observed by the researcher during a six-month period at St. Amant Centre, a residential facility for people who are mentally and physically handicapped. Careproviders who participated in decision-making on behalf of the residents of this facility included both professional and non-professional staff members, as well as medical and surgical specialists who provided regular consulting services. One of these consultants was an orthopedic surgeon who conducted rounds, referred to as Orthopedic Clinics, at St. Amant Centre twice monthly. These Orthopedic Clinics were the primary decision-making forums observed by the researcher.

Orthopedic Clinics took place in a large treatment room in the Physiotherapy Department. The physiotherapy staff was responsible for scheduling and organizational details. Careproviders and parents/guardians sat around a low plinth. Residents were brought into the room individually, and the

physiotherapists made brief verbal presentations outlining the person's medical history, and the problem(s) under review. If a detailed physical examination was required, the therapists lifted non-ambulant residents from their wheelchairs, and transferred them to the plinth.

A core group of careproviders attended Orthopedic Clinics on a regular basis. This group included the consulting orthopaedic surgeon, physiotherapists, occupational therapists, and an orthotist. The head nurses from the residents' living units frequently attended, when residents under their care were reviewed at the clinic. Other careproviders such as social workers, community-based health care workers, and students from a variety of health-related disciplines, were also present for some of these rounds.

Parents and/or guardians were notified of the clinics by the Physiotherapy Department, and were invited to attend. Those who were closely involved with ongoing decisions involving treatment plans for their children often chose to be present, to ask questions, and to express their views regarding any interventions which were proposed.

### **The Resident**

At one particular clinic, a teenage resident was pushed into the room in a wheelchair. The child was accompanied by both parents, and the head nurse from the living unit. The parents were introduced to the orthopedic surgeon by one of the physiotherapists. The parents were then greeted by other careproviders who were closely involved with the child's care, and were directed to some of the chairs which circled the plinth.

The resident was positioned in the wheelchair, facing the surgeon. The careproviders observed the child. The living unit staff had obviously paid careful attention to grooming and dressing the teenager. His wheelchair had been modified with a special insert which provided support for the head, and positioned him/her securely in the chair by means of straps around the chest, pelvis, and feet. A lap tray was attached to the wheelchair.

The child appeared small for someone who was fourteen years old. Uncontrollable writhing



movements of the arms, and involuntary facial grimaces were constantly present. The child's gaze was persistently directed upward. Periodic spasms caused the child to extend his body against the straps which were securely fastened to the wheelchair insert.

The physiotherapist who worked with the child provided a brief history. The child had been a resident of St. Amant Centre since three years of age. His diagnosis was spastic quadriplegia and profound mental retardation. Seizures occurred frequently. The child was cortically blind, and was unable to communicate verbally, or to use any type of communication device. He attended school for half-days, and participated in a number of other programs and activities within the Centre. Sometimes the parents took him home on weekends, or for special occasions.

### **The Problems**

The specific problems which had resulted in the consult to the orthopedic surgeon were decreased range of movement in one of the child's hips, and an apparent increase in discomfort when the affected leg was moved. The physiotherapist reported that, during activities which were part of the child's school therapy program, careproviders had noted a progressive decrease in range of motion. They had observed that the child became agitated and moaned when the hip muscles, particularly the adductors, were stretched. The head nurse concurred with these observations, noting that activities such as bathing and diapering, which required abduction of the hips, produced similar responses. The aides and nurses on the living unit had interpreted these responses as expressions of discomfort.

The surgeon approached the child, held one of the child's hands, and addressed him. The child responded with apparent excitement. Involuntary movements of the arms and head increased for a short time. The child smiled and uttered a sound.

The surgeon then turned to examine the child's x-rays, which were placed on a screen at the front of the room. The x-ray findings were discussed with the careproviders and parents. Radiological examination showed that one of the child's hips was subluxated, or partially dislocated. The surgeon

suggested that a physical examination of the child's hip be performed.

The physiotherapists removed the wheelchair straps and lifted the child to the plinth. The child lay on his back with both legs flexed and rotated to one side. The surgeon examined the child's hips, compared passive range of motion in both hip joints, and observed his face for expressions of discomfort. When the muscles in one hip joint were stretched, the child moaned and grimaced. The surgeon drew the parents' attention to the movements which appeared to elicit pain, and demonstrated the differences in range of movement between the child's hips.

The surgeon then raised the question of whether or not surgical release of shortened structures around the hip joint would serve to prevent an inevitable dislocation. With this surgical procedure, it might also be possible to slow the progression of deformities such as pelvic obliquity and scoliosis, which are frequent sequelae to unilateral hip dislocation. The surgeon expressed concern that a future hip dislocation, and the subsequent progression of skeletal deformities, might cause the child to experience an increasing amount of pain.

### **The Implications of Non-Intervention**

During physical examination of the child's hip, the surgeon commented that the progressive pain and deformity associated with hip dislocation might eventually compromise the child's ability to sit upright in a wheelchair. The ensuing discussion among the careproviders who were present, centered on the implications associated with the potential loss of the ability to be seated in a wheelchair.

The occupational therapist reported that the child was participating in a program designed to promote improved oral feeding skills. The child's ability to sit upright in a special wheelchair, which had been modified to provide total body support in the sitting position, was an essential pre-requisite to the continuation of this program. The physiotherapist reported that the child seemed to enjoy school activities. Should the ability to be seated in the chair be lost, attending school or other programs within the facility would be compromised. The head nurse noted that it would also be difficult or impossible for careproviders and family members to take the child out of the facility for special events, or on weekends, if he were unable to sit comfortably.

The occupational therapist then observed that a decision not to intervene via surgery, might ultimately result in a diminished quality of life for the child. The other team members expressed agreement with the therapist's observation regarding quality of life.

### **The Parents' Viewpoint**

The surgeon then spoke directly to the child's parents. Although the parents had made a decision to choose institutional care when their child was very small, they had continued to visit him regularly, and were involved in making decisions about the care which he received. They had retained legal guardianship of the child and, consequently, the ultimate decision regarding surgery rested with them. The parents had been silent to this point, but had nodded in acknowledgement as the surgeon explained the problems involving the child's hip.

The surgeon reviewed the reasons for considering surgery, and outlined what would be involved in the procedure under consideration. The child would have to be transferred to an acute care hospital for surgery. After a few days, he would return to St. Amant Centre, where the regular careproviders would resume his care. The child would experience some pain as a result of the surgery, but as his general health was good, the risks associated with the surgery were not considered to be extraordinary.

The parents responded by articulating their concerns. These included the short-term impact of the procedure, and the more general risks associated with the proposed surgery. They observed that the child did not exhibit signs of discomfort while sitting in the wheelchair. They asked how much pain would be associated with the surgery. They expressed concern over the child's cognitive inability to understand that the pain associated with an immediate surgical procedure, would prevent or minimize pain from progressive skeletal deformities in the future. They asked the surgeon to describe what potential complications might ensue as a consequence of surgery.

The parents also expressed concern that the proposed surgery required the child to be transferred to an unfamiliar acute care centre. They noted that the child would not know anyone in that centre, and that the staff would be unfamiliar with the care routines which are regularly carried out at St.

Amant. They expressed their fear that the child would be emotionally upset by the transfer.

The parents then raised a number of concerns about the potential long-term consequences of both non-intervention and surgical intervention. They asked the surgeon to clarify the likely consequences of non-intervention. They asked if the surgeon could be sure that the child's quality of life would be compromised through the progression of deformity, and loss of mobility which the careproviders had described. They asked if the surgeon could guarantee that the surgical intervention would have the desired outcome. Finally, they asked whether the long-term benefits of intervention justified the physical and emotional trauma which their child might experience as a result of the surgery.

#### **A Delayed Decision**

The surgeon responded to the parents' questions by explaining that there were no guarantees, and that the eventual outcomes of either surgical intervention or of non-intervention could not be predicted with certainty. The parents indicated that they would prefer to "wait and see" whether the child's hip problem became progressively worse. They asked the surgeon if the decision could be delayed for a while longer. The surgeon recommended that the child be reviewed in Orthopaedic Clinic in two months, and requested that the parents make a decision regarding surgical intervention by that time. The parents were invited to contact the surgeon directly if other questions or concerns arose in the interim.

### **Research Questions Raised by the Composite Case**

Decision-making in problematic situations like this composite case, involves consideration of scenarios in which neither the burdens nor the benefits of a surgical procedure can be predicted with certainty. My observations indicated that these cases are among the most difficult to resolve. In order to reach a decision, proxy decision-makers must weigh the potential risks of the intervention against

the potential benefits, without knowing what the client might choose if he were able to participate in the decision-making process.

In a situation such as that described in the preceding composite of elements from several cases observed, careproviders emphasized the potential benefits to be derived from the proposed surgery. They perceived, as a result of past experience, that the temporary burdens associated with the procedure are usually outweighed by long-term benefits such as improved care, a delay in the development of painful deformities, and the ability to continue to participate in programs and activities.

The parents, however, placed more emphasis on the short-term burdens of a painful and invasive surgical procedure, especially since the outcome of a decision against surgery could not be predicted with certainty. Together, with the health careproviders, they had to determine which course of therapy was in the child's best interests.

Maintaining or improving the resident's quality of life is often identified by careproviders as the most important consideration in the decision-making process. The ways in which health careproviders define and weight quality of life considerations in situations involving proxy decision-making, is the focus of this thesis. If quality of life considerations are to be used effectively as outcome measures for assessing the effects of alternate care programs and treatment interventions, the ways in which careproviders define quality of life, the relative weighting of the dimensions of quality of life in the decision-making process, and the ways in which careproviders assess potential or actual improvement in quality of life, must be understood. Subsequent chapters will address these issues.

## Synopsis

Chapter 2 of this thesis provides a summary of the literature pertaining to issues which are relevant to this research program. The evolution of quality of life considerations as outcome measures is summarized, as are the problems of definition and measurement which have been identified in quality of life research. Issues surrounding the dilemmas associated with proxy decision-making in legal jurisdictions are also discussed. Literature pertaining to temporal trends which have impacted on the survivorship and life chances of severely disabled people, as well as literature focusing on society's obligation to disabled people, will also be referenced.

In Chapter 3, the theoretical and conceptual framework of this research project is presented. The numerous variables which were expected to impact upon the proxy decision-making process are described. These include variables associated with decision-making at an individual level, as well as those impacting upon decision-making at inter-individual or team levels. The potential influence of considerations pertaining to the impact of alternate interventions on careprovider workload, as well as that of societal views pertaining to the valuation of disabled people, will also be considered.

Chapter 4 presents details of the methodology used in completing the fieldwork. The design of the project, as well as details related to access, fieldwork, data collection and analysis are summarized. The process by which participants and case examples were selected, as well as consent procedures and issues of confidentiality, will be described. Validity and reliability issues will also be addressed.

In Chapter 5, a description of specific aspects of the facility selected as the setting for the fieldwork, will be presented. A profile of the resident population, an outline of the roles and responsibilities of staff members in service delivery, and a brief discussion of how the responsibility for proxy decision-making is shared between careproviders and parents/legal guardians provide a contextual framework for interpreting the proxy decision-making process as it is carried out by careproviders on behalf of residents.

Finally, four chapters are devoted to a description of quality of life decision-making as presented by the parents and careproviders who participated in this project. Chapter 6 outlines the various

dimensions of quality of life as they were described by respondents during in-depth interviews. Chapter 7 describes four decision-making scenarios involving increasing degrees of complexity and uncertainty, in which quality of life considerations were used to balance decisions. Chapter 8 describes the ways in which considerations related to careprovider workload, as well as considerations related to the social valuation of profoundly handicapped people, influence the proxy decision-making process. Finally, Chapter 9 provides a description of the problems associated with proxy evaluation of the impact of specific interventions upon other people's present and/or future quality of life.

## **CHAPTER 2**

---

### **QUALITY OF LIFE ASSESSMENT AND PROXY DECISION-MAKING: A REVIEW OF RELEVANT LITERATURE**

The problems associated with quality of life assessment and proxy decision-making encompass a wide range of issues in the clinical, medical-legal and social sciences literature. Relevant literature was drawn from a variety of sources in several disciplines. Primary themes include:

- 1) The evolution of health-related quality of life as an outcome measure.
- 2) Problems of definition and measurement in quality of life research.
- 3) The use of quality of life criteria in legal decision-making.
- 4) Temporal trends affecting the survivorship and life chances of severely handicapped people.
- 5) Society's obligation to disabled people.



## **The Evolution Of Health-Related Quality Of Life As An Outcome Measure**

The term "quality of life," while achieving recent popularity in health care research, has a more lengthy history in lay usage. Originally the term was used in reference to material well-being and, although this connotation has persisted to the present time, the scope of the concept has been broadened through several decades of use to include a wide range of dimensions.

Following World War II, when the term "quality of life" was popularized in lay language, it was used in reference to possession of the material items considered necessary for a good life (Ebbs et al. 1989). Quality of life was evaluated by markers of material success such as a home, a car and the latest appliances. If, in addition, one could afford to travel and to provide an education for one's children, then by extension, the quality of life was considered to be "good" (Alexander and Willems 1981).

During the era of cultural and political change in the 1960's, the concept of quality of life was extended to incorporate psychosocial dimensions such as emotional health (de Haes and van Knippenberg 1985). These added dimensions were thought to be important contributions to a satisfying and enjoyable life. There was a movement away from the more materialistic view, and a movement towards focusing on subjective indicators such as enjoyment, personal caring, and intensity of experience (Alexander and Willems 1981).

In the 1970's, health-related quality of life began to be used as a outcome measure in the evaluation of medical treatment regimens (e.g. Burge et al. 1975; Priestman and Baum 1976). Interest in quality of life measurement continued to swell during the 1980's, and was reflected in the growth of a substantive body of literature dealing with the application of quality of life measurement techniques to the clinical evaluation of treatment programs for chronic diseases such as cancer (e.g. Ebbs et al. 1989; Edlund and Tancredi 1985; Najman and Levine 1981; Schipper and Levitt 1985; Spitzer 1987).

### Concerns About the Quality of Extended Lives

The exponential growth in efforts to use health-related quality of life as an outcome measure has occurred primarily in response to a broadening of the concept of health. This broadening conceptualization has, in turn, paralleled the epidemiological transition from infectious to chronic disease which has occurred over the past 150 years (Dever 1980; Gordon 1950; Mausner and Kramer 1985; McKinlay and McKinlay 1975; Orman 1977; Peron and Strohmenger 1985).

In times when infectious diseases were the most prevalent causes of death, measures of mortality were used as indicators of health status. In societies in which life expectancy has increased significantly, however, and the burden of morbidity associated with an increased prevalence of chronic disease is of equal or greater concern than premature death from infectious disease, conventional mortality measures do not always accurately reflect the health status of the population (McKinlay and McKinlay 1975; Peron and Strohmenger 1985). In these circumstances, there is a growing concern for, not only the ability to survive, but the quality of that survival (Chambers 1988; Gerhardt 1990; McDowell and Newell 1987; Miettinen 1987). More inclusive definitions of health, and measures of health status which incorporate considerations beyond reducing mortality or extending life, have been introduced to provide a more accurate reflection of the current health status of the population (Croog and Levine 1989; Katz and Akpom 1979; McDowell and Newell 1987; Ware 1987).

An expanding body of literature acknowledges, therefore, that the effects of treatment regimens which serve to prolong life in the presence of chronic diseases such as cancer, cardiovascular disease, and chronic neuromuscular disorders, must be balanced against the quality of an extended life (Cohen 1982; de Haes and van Knippenberg 1985; Schipper 1985; van Knippenberg et al. 1992). Increasingly, contemporary researchers and clinicians recognize that quality of life considerations should be taken into account when decisions are made about which course of treatment would best serve the patient's interests (Guyatt et al. 1986; O'Young and McPeck 1987; Schipper 1983). Quality of life considerations are particularly important in decisions where there is little difference in the effect of alternate treatment interventions on the duration of life (Ebbs et al. 1989).

Insights about the importance of considering the impact of medical treatment upon quality of life, are reflected in the growing body of research and clinical studies oriented towards developing ways of using quality of life indices as outcome measures (Cohen 1982; Schipper 1985; van Knippenberg et al. 1992). Quality of life criteria have been used to assess outcomes in the treatment of chronic disorders such as cancer and chronic renal failure (e.g. Churchill et al. 1987; Schipper et al. 1984), and to assess the effects of some surgical procedures (e.g. Troidl et al. 1987).

### Measurement Tools

Despite the interest in quality of life measurement which has been demonstrated by both researchers and clinicians, finding appropriate ways of evaluating health-related dimensions has proven to be difficult. Early measurement approaches emphasized the assessment of functional limitations (Karnofsky and Buchenal 1949; Katz et al. 1963). These assessments were often completed by a physician or other health care professional on behalf of the client. Later, it became apparent that many people with physical impairments and associated functional limitations perceived their quality of life to be quite high. Measurement indices were extended and re-focused, therefore, to incorporate a variety of psychosocial factors (Brook et al. 1979; Chambers et al. 1982; Gibson, Gibson and Bergner 1975, Kaplan, Bush and Berry 1976). In conjunction with this increased emphasis on psychosocial factors, clinicians and researchers began to rely more heavily on self-assessment of quality of life by their clients (Alexander and Willems 1981; van Knippenberg et al. 1992).

Most recently, multi-dimensional models of quality of life which incorporate physical, emotional, social, and intellectual or cognitive dimensions, have been developed (Croog and Levine 1989; Hornquist 1982; Schipper and Levitt 1985; Spitzer 1987; Ware 1987). Attempts to measure quality of life have utilized different combinations of these dimensions and sometimes others, as well (Croog and Levine 1989; Ebbs et al. 1989). As a consequence, however, many existing measurement indices are designed to assess specific dimensions of

quality of life, rather than to capture the essence of the total concept (Alexander and Willems 1981; Edlund and Tancredi 1985; Katz 1987; van Knippenberg and de Haes 1988).

### Situation-Specific Indices

In the past decade, a number of measurement indices have been developed which purport to measure health-related quality of life in relation to the impact of specific chronic disease states, and the effects of particular treatment interventions. Examples of the application of quality of life measurement indices can be found in literature pertaining to the treatment of cancer (Schipper et al. 1984; Selby et al. 1984; Spitzer et al. 1981; van Knippenberg and de Haes 1988; van Knippenberg et al. 1992), rheumatoid arthritis (Chambers et al. 1982), end-stage renal disease (Churchill et al. 1987), and stroke (Ahlsio et al. 1984). Examples evaluating the success of surgical procedures include total gastrectomy (Troidl et al. 1987), bone marrow transplants (Baker, Curbow and Wingard 1991), and coronary artery bypass surgery (LeMendola and Pellegrini 1979). The instruments used by these researchers and clinicians are but a few of the steadily growing number of situation-specific or disease-specific measurement tools available (Guyatt, Bombardier and Tugwell 1986; Spitzer 1987).

Even in situations where specific measurement indices have not been developed, the term "quality of life" frequently emerges in discussions about the benefits of treatment interventions. This less systematic application of the concept is practised by health careproviders in long-term care facilities which serve the needs of individuals who are profoundly physically and mentally handicapped. As most of these individuals are unable to communicate their own perceptions of quality of life to their careproviders, quality of life and the potential for improving quality of life through specific interventions, is assessed by family members, guardians and/or health careproviders on the clients' behalf. To date, however, there has been little formal effort to describe the criteria which are used to evaluate quality of life in such situations. Systematic research has also not been conducted to measure the degree of consensus among proxy decision-makers defining the factors which are perceived to contribute to a good quality of life. The project under consideration will attempt to address these deficits.

## **Problems of Definition And Measurement**

The second body of literature reviewed in preparation for this research program, was that related to the definition and measurement of quality of life. Because the concept of quality of life can encompass virtually every facet of human existence and is influenced greatly by individual subjective criteria, definition and measurement of this concept have proven to be challenging (Edlund and Tancredi 1985; Najman and Levine 1981; Schipper 1985; van Knippenberg and de Haes 1988; van Knippenberg et al. 1992). As indicated in the previous section, researchers have developed indices which are designed to measure quality of life in the presence of diseases such as rheumatoid arthritis and cancer. In doing so, however, these investigators have frequently failed to provide a definition of what they are attempting to measure (Miettinen 1987; Spitzer 1987).

Specific dimensions of quality of life have been emphasized by researchers in the development of measurement indices, but there is a wide variation in the dimensions which have been weighted most heavily in the various situations under study (Alexander and Willems 1992; Croog and Levine 1989; de Haes and van Knippenberg 1985; Ebbs et al. 1989; Katz 1987). For example, while measures of physical well-being were assessed by Karnofsky and Buchenal (1949), Priestman and Baum (1976), and Spitzer (1981), psychological well-being was considered by only two of these investigators (Priestman and Baum 1976; Spitzer 1981), and social functioning by only one of them (Spitzer 1981).

### **Proxy Assessment**

The difficulties in using health-related quality of life as an outcome measure are compounded in situations where surrogates are required to make treatment intervention decisions on behalf of profoundly impaired individuals who have never been able to express their views (Degner and Beaton 1987; Loewy 1989; Swazey 1980). Widely-used definitions of quality of life have incorporated a variety of elements, including the ability of patients to manage their own lives or to lead a normal life, the satisfaction of human needs or human values, the fulfilment of personal goals, and measures of

social utility (Edlund and Tancredi 1985; van Knippenberg and de Haes 1988). Most of these definitions presume that independent functioning is possible, that the individual in question can participate in decision-making, or that there is at least some degree of conscious self-awareness (Brody 1976). Measurement indices which have been developed in efforts to assess quality of life are based on these definitions and are, therefore, only readily applicable to the assessment of persons who are capable, or have been capable in the past, of expressing what this concept means to them as individuals.

Table I contains three selected examples of widely used measurement indices described in the literature. The table summarizes the dimensions of quality of life which were evaluated, the method of evaluation, and the limitations of the indices for applications involving quality of life assessment among profoundly impaired individuals. The instruments selected include one which attempts to evaluate overall quality of life by using both objective and subjective criteria (Spitzer et al. 1981), one which focuses on the client's subjective evaluation of life satisfaction (Andrews and Withey 1976), and one which assigns utility values to various health states (Feeny and Torrance 1989).

Limitations of application similar to those described in Table I are to be found in other quality of life indices as well. There have been few formal attempts to consider the concept of quality of life as it is applied to profoundly physically and cognitively impaired persons who are unable to communicate their viewpoints. Although some researchers have asked surrogates to rate the quality of life of others, most of these assessments have been carried out in situations where the client's rating of quality of life could be compared with that made by the surrogate decision-maker. Some of these studies serve to reinforce the problems inherent in proxy assessment of quality of life by documenting significant differences between the measures of quality of life as rated by careproviders, and the client's self-rating (Janssens 1986; Pearlman and Speer 1983; Starr, Pearlman and Uhlmann 1986; Zweibel and Cassel 1989). Other validity studies have noted that not only do assessments differ, but the components of quality of life judged to be of primary importance by careproviders and family members do not always correlate with those selected by patients as being most important (Starr, Pearlman and Uhlmann 1986).

**TABLE 1**  
**The Limitations of Selected Measures of Quality of Life when Applied to the**  
**Assessment of Profoundly Impaired Persons**

| INDEX OR MEASURE  | QUALITY OF LIFE DIMENSIONS   | METHOD OF ADMINISTRATION   | REASONS WHY INAPPROPRIATE   |
|---|--|--|---|
| <b>QUALITY OF LIFE INDEX</b><br>(Spitzer et al. 1981)                         | Activity level<br>Activities of daily living<br>Feelings of healthfulness<br>Social support<br>Psychological outlook | Health care provider or client   | Attributes not sensitive to subtle indicators of change used in assessment of profoundly impaired individuals |
| <b>FOUR SINGLE ITEM INDICATORS OF WELL-BEING</b><br>(Andrews and Withey 1976) | Life satisfaction  | Interviewer uses scales to obtain self-evaluation by client                                  | Self-assessment not possible in this population   |
| <b>TIME TRADE-OFF APPROACH</b><br>(Feeny and Torrance 1989)                   | Health state utility values provide single summary statistic   | Interviewer presents subject with two hypothetical scenarios and utility values are assigned | Difficult to use in proxy decision-making unless concept of quality of life in this situation is understood   |

### Perceived Limitations

The subjectivity inherent in the assessment of quality of life has caused some health care providers to hesitate to use criteria based on quality of life considerations in treatment decision-making. Some clinicians have concerns about the moral and ethical basis of such decision-making, while others may be concerned with legal liability, particularly when the decision involves the withholding or withdrawal of treatment (Thomasma 1984). Still others consider the concept to be undefinable and unmeasurable and feel, therefore, that it may be considered "unscientific" to use quality of life considerations as outcome measures in clinical trials (Schipper and Levitt 1985).

In addition to the reservations articulated by health care providers, advocacy groups representing disabled people have expressed concerns about the use of quality of life criteria as a basis for proxy decision-making. Members of such advocacy groups have stated unconditionally that no one should consider themselves capable of deciding another person's present or future quality of life (Baker 1989; Bopp 1990; ILSMH 1992; Koster-Dreese 1989). Concerns such as these have served to slow the acceptance of outcome measures based on surrogate assessment of quality of life.

The difficulties experienced by people who attempt to make decisions on behalf of individuals who cannot speak for themselves, are reflected in the increasing number of cases referred to the Courts. Recourse to the legal system may also reflect the inherent uncertainty and likelihood of disagreement among decision-makers about the criteria which should be used in making proxy decisions (Ball 1984; Sinclair 1990; Sneiderman 1991). The body of case precedents illustrates many of the difficulties inherent in attempting to incorporate quality of life considerations into decision-making for individuals who are legally incompetent.

### **The Use of Quality of Life Criteria in Legal Decision-Making**

The third body of literature which was considered in developing this research program was drawn from the legal and ethical literature. The Courts have utilized a variety of tests and standards in deciding cases involving surrogate decision-making on behalf of legally incompetent individuals for whom medical or surgical interventions have been contested. The standard of substituted judgment, in which surrogates attempt to make decisions based on what they believe the incompetent person would choose for him/herself has been, and still is, used in some cases. In others, the best interests test has been used in an effort to ensure a greater degree of objectivity in the decision-making process (Weir 1989).

Application of the best interests test requires that surrogates weigh the benefits of treatment (or non-treatment) against the burdens (Buchanan and Brock 1989). This type of decision-making has



been hailed by some authors as a preferable alternative to decision-making based on the criterion of substituted judgment, particularly in cases where the client has never been competent (Beauchamp and Childress 1989). This approach has also been advocated as a mechanism for avoiding judgments based solely on either "sanctity of life," or "quality of life" considerations (Weir 1989). The legal record shows, however, that determining the best interests of an incompetent client can be somewhat problematic. It is very difficult to completely exclude subjective factors such as quality of life considerations from the decision-making process.

### **Substituted Judgment or Best Interests?**

Some of the earliest cases in which the best interests of clients who were unable to participate in the decision-making were considered, involved situations in which family members had requested kidney transplants from incompetent, institutionalized relatives. The case of *Strunk v. Strunk* (1969), and the case of *Lausier v. Pescinski* (1975), both involved proxy transplant decisions. In the *Strunk* case the substituted judgment test was ultimately used to decide in favour of allowing the incompetent client to be a donor. One of the dissenting judges, however, indicated that he was not convinced that the transplant would be "of significant benefit to the incompetent" person (*Strunk v. Strunk* 1969:151). In the *Pescinski* case, the request for donorship was denied on the basis that "an incompetent particularly should have his interests protected" (*Lausier v. Pescinski* 1975:182).

Other notable cases in which the best interests of the legally incompetent client were considered to take precedence over the interests of others, involved minor children with disabilities of congenital origin. The use of the best interests test in such instances was prompted by a number of cases in which infants born with Down's Syndrome or other congenital impairments were denied surgery for associated correctable medical problems, and allowed to die (Cohen et al. 1987; Freeman and McDonnell 1987). In some of these cases, parents or health care providers decided against allowing the surgery on the basis that the lives of such infants were not worth preserving (Kuhse 1987; President's Commission 1983). In cases where such decisions were contested, however (Maine

Medical Center v. Houle 1974), judges have ruled that decisions not to perform "medically necessary and medically feasible" treatment are not justified simply on the basis of a "qualitative evaluation of the life to be preserved" (as discussed by Cohen et al. 1987; Maine Medical Center v. Houle 1974:265-266).

Courts have reached similar conclusions in cases involving older children, notably the Dawson case in British Columbia (as discussed in Degner and Beaton 1987: preface). The decision in this case was that the presence of a pre-existing impairment, such as mental retardation, does not justify the denial of treatment for a correctable medical condition.

The aforementioned cases have dealt primarily with the rights of permanently impaired individuals to receive treatment which has been determined to be in their best interests. A landmark case in 1976, however, dealt with the right of a never competent individual to refuse unwanted treatment (Superintendent of Belchertown State School v. Saikewicz 1976). Although the use of the substituted judgment test by the Supreme Court of Massachusetts in deciding this case has been criticized by some authors as being inappropriate (Buchanan and Brock 1989; Ellman 1990; Weir 1989), there was at least one notable strength in this decision (Keyserlingk 1979). The Court stated that "the substantive rights of the competent and the incompetent person are the same in regards to the right to decline potentially life-prolonging treatment" (Weir 1989:111).

Subsequent court decisions have also applied the substituted judgment test in cases involving persons who have been declared legally incompetent. Other courts, however, rejected the use of the standard of substituted judgment, at least in cases where the client had never been competent to make decisions. In the Stonar case in 1979, the New York Court of Appeals ruled that no one could make a substituted judgment on behalf of a person who had never been legally competent. In doing so, however, the Court failed to use the best interests test as the appropriate alternate standard (Weir 1989). In 1983, in the Hamlin case, the Washington Supreme Court ruled that decisions for individuals who had never been competent should be made "on a case-by-case basis with particular consideration of the best interests and rights of the specific individual" (Weir 1989:157-158). Despite this recognition that the best interests of the individual should be the primary decision criteria, there

were still no established criteria governing the appropriate use of either the standard of substituted judgement, or the best interests test.

In an attempt to define the appropriate standards for application in specific situations involving proxy decisions, the New Jersey Supreme Court in the Conroy case in 1985, laid out three alternative standards which could be used by surrogate decision-makers (Weir 1989:158-159). These included:

- 1) a subjective standard to be used when the wishes of a previously autonomous patient were known to the surrogate,
- 2) a limited-objective standard to be used when there was some evidence of the wishes of the patient, and
- 3) a purely objective standard which could be applied in the absence of any information about the patient's perspective on the decision.

In a 1987 case, *In The Matter of Beth Israel Medical Center*, the presiding judge provided a list of criteria which should be considered in weighing the benefits and burdens of life-prolonging treatment. It can be noted by reviewing the criteria applied in the judgment (*In The Matter of Beth Israel Medical Center* 1987:517), that no clear dividing line could be defined between subjective criteria (e.g. application of the standard of substituted judgment), and objective criteria (e.g. application of the best interests test). In this case, the New York Supreme Court recognized the difficulties inherent in making proxy decisions based on either purely subjective or purely objective criteria.

### **Acceptance of Quality of Life Criteria**

In keeping with the hesitancy in legal jurisdictions to accept the use of subjective criteria in surrogate decision-making situations, some courts have stated unequivocally that quality of life considerations should not be factored into the decision-making process (*Cruzan* as discussed in Bopp 1990; *Maine Medical Center v. Houle* 1974:265-266; *Superintendent of Belchertown State School v. Saikewicz* as quoted in Keyserlingk 1979:165). As noted *In The Matter of Beth Israel Medical*

Center, however, other courts have clearly recognized that it is very difficult to completely exclude subjective factors. Subjective factors relating to potential improvement in quality of life often do enter into the decision-making process, particularly in cases where the surrogate decision-makers are closely associated with the day-to-day care of the incompetent individual and know him/her well (Law Reform Commission of Canada 1982; Veatch 1989; Weir 1989).

The process of factoring quality of life considerations into decision-making has been partially facilitated by the gradual acknowledgement that the term "quality of life" can be interpreted very differently by decision-makers in different situations. Because of the likelihood of wide variability in individual characterizations of the concept of quality of life, some authors have emphasized that it is imperative that distinctions be made between these different interpretations before arriving at a decision (Buchanan and Brock 1989). The interpretation found most acceptable for deciding legal cases, involves consideration of the quality of a legally incompetent individual's life only in intrapersonal or noncomparative terms, and not in terms of social worth (Keyserlingk 1979). Accordingly, some scholars have concluded that use of "quality of life criteria which have not been purged of any connotations of social utility, relative worth or merely subjective considerations" should be rejected (Keyserlingk 1979:188).

Based on the above interpretation of quality of life, proxy decision-making for treatment interventions on behalf of those who are legally incompetent should proceed by determining whether the intervention will alleviate a particular problem or correct a specific deficit, regardless of any pre-existing mental and/or physical impairment (Beauchamp and Childress 1989; MacKenzie in the case of Steven Dawson 1983). The best interests of the individual in question then become the focal point for decision-making.

### **Best Interests in Medical Decision-Making**

While attempts are frequently made to apply the principle of the client's best interests to decision-making in medical as well as legal jurisdictions, there continues to be a great deal of uncertainty in

the process of making treatment decisions on behalf of people who cannot participate in the decision-making process (Canadian Paediatric Society 1986; Nolan 1987). While consideration of quality of life in "non-comparative or intrapersonal terms" is certainly appropriate in medical decision-making as well as legal decision-making, the concept of quality of life within those terms, and as applied to individuals with profound cognitive and physical impairment, has not been defined. There is no systematic indication about which factors are considered in health professionals' definitions of quality of life in these circumstances. It is also unclear how these factors are subsequently weighted in the decision-making process.

This project will address the lack of definition of quality of life as the concept is applied to people who are profoundly physically and cognitively handicapped. If quality of life considerations are to be used effectively as outcome measures in situations where proxy decisions about medical and surgical interventions are made, it is important to determine if there is a consensus among decision-makers regarding the minimal requisites for sustaining quality of life and the relative importance of its individual dimensions.

### **Temporal Trends Affecting the Survivorship and Life Chances of Severely Handicapped People**

The fourth body of literature which was reviewed in the preparation of this thesis, is that which places the central research question in epidemiological context. In the next sections, temporal trends affecting infant mortality rates, life expectancy, and mortality rates from both infectious and chronic diseases, will be described with reference to severely handicapped people. The implications associated with an increasing prevalence of people with profound physical and mental impairment, in terms of health care needs and the types of decisions which must be made by proxy decision-makers, will also be addressed.

### Increased Survival of Disabled Infants

In most industrialized nations, stable socio-economic environments with access to adequate resources, in addition to health care systems which combine a high standard of public health with the latest in Western medical technology, have created conditions which ensure the survival of most infants (Arras et al. 1987; Cohen et al. 1987; Dubos 1959; Eidelman 1986; Mitchell 1988). In Canada, infant mortality rates have decreased from 92.7 deaths per 1000 live births in 1925, to 7.0 deaths per 1000 live births in 1985 (Crichton and Hsu 1990).

A decrease in the infant mortality rate has been noted to affect not only healthy infants, but those with very low birthweight, and/or serious mental and physical impairments (Cluff 1985; Cohen et al. 1987; Diamond et al. 1988; Fox 1987; McCormick 1987; Zola 1990). The numbers of infants and young children who have been enabled to survive with significant congenital impairments have been slowly increasing over the past three to four decades (Pharoah et al. 1987; Richards and Baker 1988; Windham and Edmonds 1982). This increase in survivorship has stimulated a corresponding increase in the demand for improved care for these children, whether they reside in the community or in long-term care facilities.

### Parallel Temporal Trends

A decreased infant mortality rate, and improved care for children surviving infancy with severe handicap have, in many instances, resulted in a gradual increase in post-neonatal survival rates, and an extension of the average maximum lifespan for the profoundly impaired institutionalized population (Balakrishnan and Wolf 1976; Dayton et al. 1932; Grant 1987; Heaton-Ward 1968; Richards and Baker 1988; Richards and Sylvester 1969). This increase in life expectancy is reflected in temporal trends which parallel those described for the general population earlier in this chapter.

Infectious diseases, and particularly respiratory infections have, historically, been the most common cause of mortality among people living in residential health care facilities (Carter and Jancar 1983; Chaney, Eyman and Miller 1979; Dayton et al. 1932; Eyman et al. 1990; Grant 1987; Richards and Sylvester 1969). The advent of antibiotics and other improvements in medical care for this

population have, however, contributed to a decreased mortality rate from infectious diseases, especially within the younger and healthier segment of this population (Carter and Jancar 1983; Grant 1987). Life expectancy has, subsequently, shown a gradual increase.

With increased longevity, however, there is an associated increase in the number and complexity of potential medical problems. Disorders commonly associated with aging become more prevalent (Balakrishnan and Wolf 1976; Burns et al. 1990; Carter and Jancar 1983; Zola 1990). An increased prevalence of chronic disorders results in the creation of additional situations which necessitate proxy decision-making about medical and surgical interventions (Arras et al. 1987). Surgery for cholecystitis, and pain control for severe arthritic conditions are two examples of decision-making situations which are more likely to arise in an aging population than in a younger group of people.

Life-threatening situations which require proxy decisions about medical or surgical treatment also arise more frequently in an aging population of persons who have pre-existing congenital impairment in addition to acquired chronic or degenerative conditions. Technology exists which can prolong life in the presence of severe impairment almost indefinitely (Edlund and Tancredi 1985). Health careproviders are often required to decide whether prolonging life through the use of various technologies is in the best interests of the client (Croog and Levine 1989; Freeman and McDonnell 1987).

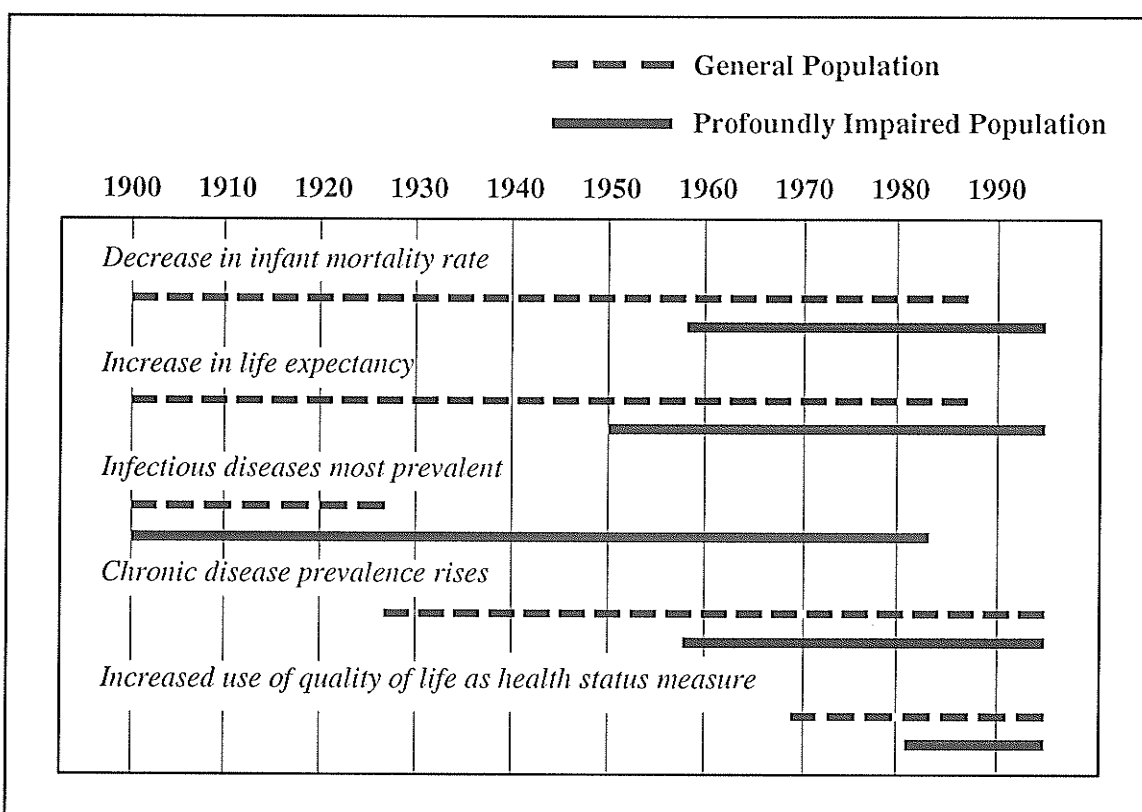
Not surprisingly, an increase in the number and complexity of situations requiring careproviders to make decisions about medical and surgical treatment on behalf of profoundly handicapped people, has sparked an interest in using quality of life considerations as outcome measures. The potential effects of treatment programs or surgical procedures on quality of life, are of particular concern to careproviders in situations where clients are unable to communicate their own perspective. The growing interest in using quality of life considerations as outcome measures in long-term care facilities, parallels the interest which has been demonstrated by researchers and clinicians in other health care settings (as discussed earlier in this chapter).

Figure 1 illustrates the parallel temporal trends which have affected both the general population, and the population of profoundly impaired people living in residential care facilities. Decreased infant mortality rates, increased life expectancy, and the transition from infectious to chronic disease

are illustrated within the approximate time frames which are relevant for each population. The increasing interest in using quality of life considerations as outcome measures which has accompanied the epidemiological transition from infectious to chronic disease is also illustrated.

Figure 1

**PARALLEL TEMPORAL TRENDS IN THE  
GENERAL AND PROFOUNDLY IMPAIRED POPULATIONS**  
(illustrated within approximate time frames)



Sources: Balakrishnan and Wolf 1976; Burns et al. 1990; Carter and Jancar 1983; Chaney, Eyman and Miller 1979; Dayton et al. 1932; Dever 1980; Eyman et al. 1990; Gordon 1950; Grant 1987; Heaton-Ward 1968; Mausner and Kramer 1985; McDowell and Newell 1987; McKinlay and McKinlay 1975; Peron and Strohmenger 1985; Richards and Baker 1988; Richards and Sylvester 1969; Ware 1987; Zola 1990.



## **Society's Obligation to Disabled People**

The final body of literature which provides the context for this thesis is that pertaining to society's obligation to disabled people. Decisions made by careproviders on behalf of profoundly handicapped individuals may be influenced by more general societal attitudes about the valuation of disabled people, and the application of the principles of distributive justice.

### **The Demand For Health-Related Services**

As indicated in the previous section, the increased survivorship and improved life expectancy of infants with low birthweight and/or congenital impairments, has contributed to an increased prevalence of individuals who have some degree of disability, or some type of activity-limiting condition (Barker and Rose 1984; Cluff 1985; Morris 1975; Newacheck et al. 1986). One result of this increase in prevalence is an associated increase in the demand for various types of health-related services (Canadian Hospital Association 1984).

The availability of health-related services is sometimes inadequate to meet these increased service demands. Health careproviders are sometimes forced to make decisions involving the allocation of services and specialized equipment for the disabled. At the present time, no set criteria exist for making these decisions, and this ambiguity is compounded by the wider context of uncertainty created by the absence of a societal consensus (Freeman and McDonnell 1987). Despite public and professional assertions that disabled persons should not be refused medically necessary treatment on the basis of a pre-existing disability, there remains a great deal of uncertainty as to what constitutes necessary and appropriate treatment for seriously impaired newborns, and what society's obligation should be to those who survive infancy with severe-profound handicaps.

### **The Status of Disabled Persons**

To ensure that disabled persons are guaranteed equitable access to specialized equipment and services, non-disabled members of society must recognize the status of disabled persons as equivalent to their own (Eidelman 1986). Today, even in societies where there is a firm belief in the value of children, some infants, including those with disabilities, remain less valued than others. Consequentially, these children may not receive life sustaining or life enhancing care (Eidelman 1986; Kimura 1986; Korbin 1981; Subramanian 1986; Waxler-Morrison, Anderson and Richardson 1990).

In industrialized countries with abundant resources and advanced health care systems, preliminary steps have been taken to ensure that infants born with impairments are granted a status more equivalent with that of healthy infants. Widely held beliefs emphasizing the "sanctity of life," (Arras et al. 1987; Post 1988; Singer 1983) have influenced the expanded application of technology-based neonatal care to save the lives of infants born with serious congenital impairments. Ethical, medical and legal precedents assert that disabled individuals should not be refused medically necessary treatment on the basis on a pre-existing disability (Freeman and McDonnell 1987). This trend is reflected in the growing number of problematic court cases described in the previous review of the medical-legal literature (earlier in this chapter).

Despite preliminary steps to ensure that disabled people are ensured equitable access to health care resources, however, there continues to be uncertainty in the minds of people who care for individuals who are permanently and profoundly impaired, as to whether society at large is committed to providing unlimited access to health care resources for this particular group of people.

### **Issues of Resource Allocation**

The dilemmas inherent in treatment decision-making on behalf of disabled persons become even more complex as concerns about the just allocation of diminishing health care resources are heightened (Schwartz and Aaron 1984). Constraints on health care spending have been imposed by the provincial government in Manitoba, as well as in other provinces. While the need to restrict

spending and to balance obligations to all areas of health care is generally recognized, there is a reluctance among health care workers to accept budget reductions, and a vested interest in maintaining existing levels of service delivery.

The imposition of budgetary restraints has sparked debates among health care providers and policy-makers about the need to develop consensus-based decision criteria governing the allocation of "scarce" health care resources (Friedman 1986). Such debates have raised concerns among people who care for the profoundly impaired institutionalized population about the definition and application of quality of life criteria in resource allocation decisions. Their concerns focus on the possibility that care for profoundly and permanently impaired persons could be reduced or withheld in favour of providing better quality care for those whose prognosis is more favourable, and for whom existing measures of cost-effectiveness and social worth can more readily be applied (Edlund and Tancredi 1985; Friedman 1986; Robertson 1975). At the same time, however, care providers have difficulty accepting the idea that disproportionate amounts of resources would be withdrawn from such a vulnerable group of people.

### **Society's Obligation and Quality of Life Considerations**

Quality of life issues are often raised in discussions centering on society's obligations to people who are profoundly and permanently impaired. Decision-making based on the concept of quality of life is often considered to be somewhat tenuous, however, due to the inherent subjectivity involved in the process (Arras et al. 1987; Freeman and McDonnell 1987). Are decision-makers judging the quality of life of disabled persons in comparison to that of unimpaired people (Arras et al. 1987)? Are the attitudes and opinions of the various decision-makers based upon moral or cultural biases towards the status of disabled persons within society which may be at odds with one other (Asch et al. 1987; Eidelman 1986)? Are social worth criteria being incorporated into the concept of quality of life (Arras et al. 1987)? And finally, are the "burdens" imposed by seriously disabled persons upon care providers and society being factored into decision-making based on quality of life criteria (Brock 1989; Post 1988).

It is because of such questions that the dimensions of quality of life in the presence of severe-profound impairment must be defined, and the ways in which quality of life considerations are factored into proxy decision-making situations must be described. If a consensus of opinion regarding criteria for assessing quality of life in the presence of profound impairment can be identified, and if outcome measures can subsequently be developed which would demonstrate to society how various interventions improve quality of life for severely disabled individuals (Mosteller 1987), the rationale for the provision of invasive and/or expensive treatment procedures should become clearer.

Chapter 3 provides the conceptual and hypothetical framework for this thesis. The potential sources of variation which may serve to complicate proxy decision-making will be described. Some of the issues which have been identified in reviewing the literature, will re-emerge in Chapter 3 as potential sources of variation which may influence the proxy decision-making process.

## CHAPTER 3

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### THEORETICAL AND CONCEPTUAL FRAMEWORK FOR PROXY DECISION-MAKING BASED UPON QUALITY OF LIFE CONSIDERATIONS

As noted in Chapter 2, evaluation of the impact of specific interventions on health-related quality of life has frequently been advocated as a mechanism for improving both clinical decision-making and public policy development (e.g. Hadorn 1991; Kuhse 1987; Mosteller 1987; Schipper 1985). While this is, seemingly, a viable idea in instances where information concerning clients' perspectives on quality of life and their preferences regarding various treatment options is available, assessment of the potential for improving quality of life by surrogate decision-makers presents a number of problems (Swazey 1980).

In decision-making situations involving individuals who were previously competent to make their own decisions, surrogates can sometimes draw upon prior knowledge of the expressed feelings and attitudes of those individuals towards various interventions. This is not possible, however, in the situation under consideration, where the individuals in question have never been able to make their own decisions. Theoretically, decision-making should then proceed by weighing the burdens of treatment against the potential benefits. This can be a complex and difficult process, however, particularly when the outcomes of treatment or non-treatment cannot be determined with any certainty, or when decisions may affect the length of life (Alberta Educational Communications Corporation 1983; Degner and Beaton 1987; Freeman and McDonnell 1987; Loewy 1989; Robertson 1980).

As an example, re-consider the process of weighing the burdens of surgery against the potential benefits, as they were presented in the composite case example in Chapter 1. In this case, a profoundly handicapped individual was assessed regarding the feasibility of carrying out a surgical procedure which might prevent a hip dislocation. Some careproviders emphasized the potential benefits of the procedure, knowing from past experience that the burdens imposed by the surgery are usually short-term. While they acknowledged the pain that the individual would experience with surgery, and recognized the emotional trauma of being transferred to an unfamiliar acute care facility to undergo surgery, they felt that potential long-term benefits such as delaying the onset of pain and deformity, outweighed these short-term burdens. Other careproviders, particularly the child's parents, were more concerned with the pain and other short-term burdens associated with an invasive surgical procedure. Their concerns were heightened because the eventual outcome of the surgical procedure could not be predicted with certainty.

The process of making decisions in circumstances such as those described above can, therefore, become very complex. The numerous sources of variation which may influence proxy decision-making will be considered in the following sections.

## **Sources of Variation Affecting Decision-Making**

### **Introduction**

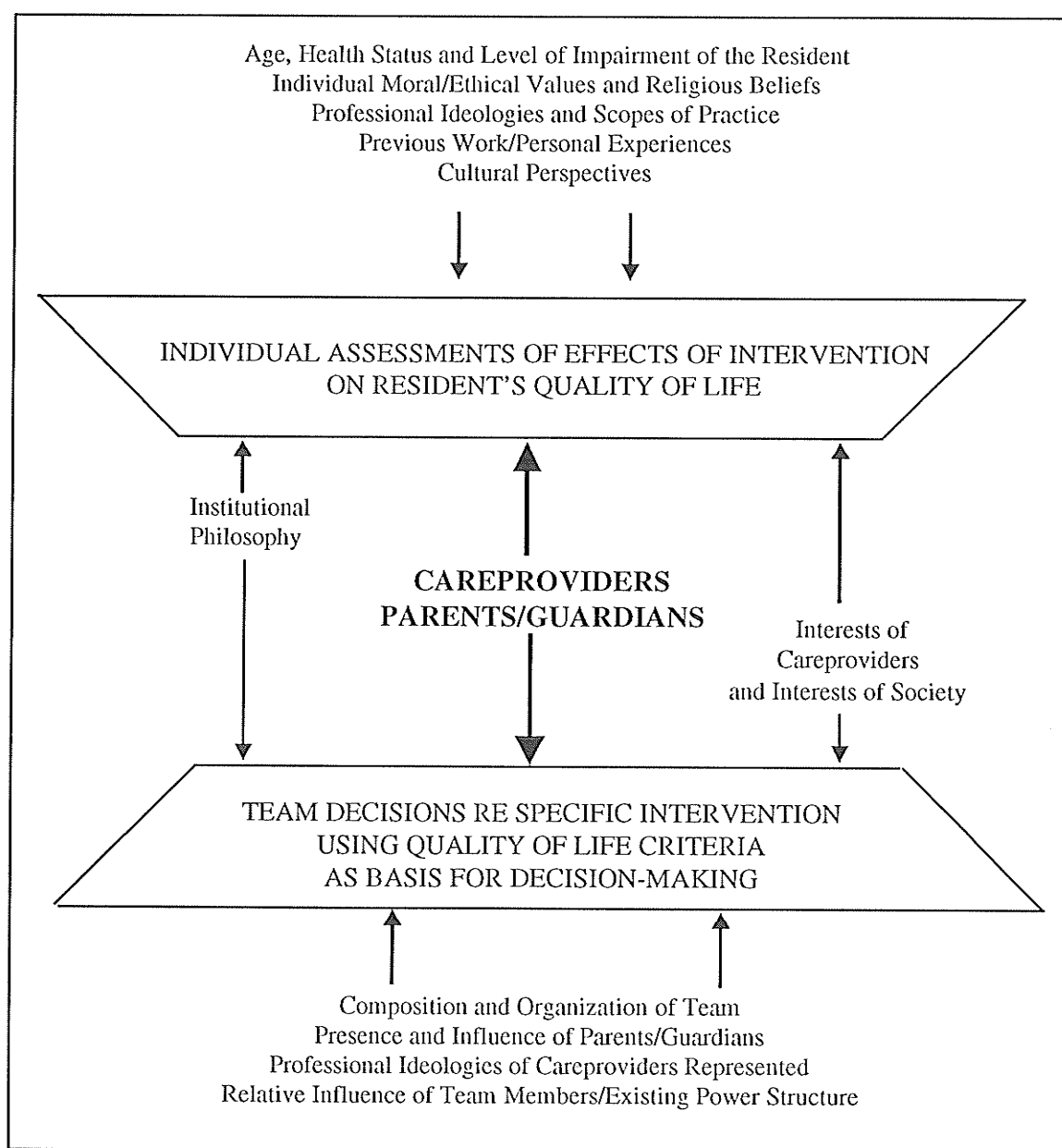
A review of the literature has identified several sources of variation which are expected to influence the process of proxy decision-making as careproviders attempt to decide which course of treatment is in the best interests of their clients. Some sources of variation are anticipated to influence decision-making at an individual level, while others are expected to exert an influence in group or inter-individual decision-making situations.

Additional sources of variation are expected to influence both individual and inter-individual decision-making. These include considerations related to the impact of alternative interventions on careprovider workload, and issues related to society's valuation of disabled people. The institutional

philosophy of St. Amant Centre is also expected to impact on decisions made on behalf of the residents of this facility. The anticipated influence of these multiple sources of variation on careproviders and parents involved in proxy decision-making, is schematically represented in Figure 2, and discussed in the sections which follow.

Figure 2

## SCHEMATIC REPRESENTATION OF CONCEPTUAL FRAMEWORK



### Individual Level Variation

At an individual level, it is anticipated that indicators of quality of life as applied to profoundly impaired individuals, will be influenced by a number of variables. The lack of an existing consensus regarding the definition of quality of life encourages individual characterizations of this concept, as discussed previously in Chapter 2 (Edlund and Tancredi 1985; Najman and Levine 1981; Schipper 1985).

First, the priorities of the professionals involved, in keeping with their respective professional ideologies, may be reflected in the differential weighting of the various factors which are considered in the course of the decision-making process. Literature relating to the sociology of professions would lead one to expect that the themes which emerge will reflect the professional ideologies and scopes of practice of the respondents (Caplan, Callahan and Haas 1987; Friedson 1970; Kottke 1982; Safilios-Rothschild 1970; Sussman 1965). For example, the nursing staff may tend to weight factors affecting the client's comfort and physical care more heavily than do other careproviders. Similarly, rehabilitation professionals may tend to emphasize factors related to independent functioning.

A number of other factors are also expected to influence day-to-day decisions about programming and treatment interventions, as they are made by clinicians and/or family members. Individual moral, ethical and religious values, may influence decision-making at a personal level (Dunstan and Seller 1983; Hoffmaster 1982; Holmes, Margetts and Gibbs 1979). The previous work experience of the careproviders involved may also influence their assessments of the potential for improving quality of life by specific interventions. In addition, the age, level of impairment, and health status of the residents in question may receive consideration.

Finally, the cultural background of various decision-makers may influence their assessments of quality of life. Cultural perspectives on the acceptance and care of profoundly impaired children have been noted to vary (Gan 1991; International Rehabilitation Review 1989; Korbin 1981; Miles-Tapping 1989; Waxler-Morrison, Anderson and Richardson 1990). Additionally, there is currently little knowledge of medical ethics in cross-cultural context (Kunstadter 1990; Marshall 1992).



### **Inter-Individual Level Variation**

The individual and/or professional agendas emphasizing different dimensions of quality of life (as discussed in the previous section), are also expected to influence decisions which are made jointly by groups of health careproviders and parents/guardians. At an inter-individual level, therefore, it is anticipated that factors such as the organization and composition of the health care teams which are responsible for making specific decisions, will influence both the nature and the weighting of quality of life considerations which are raised in these situations. The professions represented, their respective professional ideologies, their relative influence in a particular group, and any pre-existing power structure within the team, may influence both the indicators of quality of life used, and the final decisions regarding specific interventions (Angrosino 1987; Barry 1982; Caplan, Callahan and Haas 1987; Friedson 1987; Marshall 1989; Safilios-Rothschild 1970; Sussman 1965; Wolinsky and Marder 1985).

### **Additional Sources of Variation**

The nature of decisions made by health careproviders on behalf of persons who are profoundly physically and cognitively impaired, is expected to be influenced by a number of additional sources of variation which will increase the complexity of the decision-making process. These sources of variation are related to careprovider priorities, as well as more general societal interests, and may be represented at both individual and inter-individual levels of decision-making. Dilemmas routinely associated with proxy decision-making in situations involving uncertainty may be complicated, therefore, by consideration of:

- 1) Careprovider priorities which take into account the impact of alternative interventions on careprovider workload.
- 2) Societal views pertaining to the valuation of disabled people.
- 3) Issues related to the effects of rapid advances in technology
- 4) Issues related to the application of the principles of distributive justice.

The next sections are devoted to a discussion of these additional sources of variation.

### **Careprovider Priorities**

It is anticipated that, in individual discussions as well as in group forums, there may be some discussion as to the ways in which particular interventions affect careprovider workload, and how such considerations should be weighted in the decision-making process.

One of the problems which arises in the type of proxy decision-making situation under consideration, stems from the difficulty of considering the interests of careproviders in isolation from the interests of the profoundly impaired individual who relies on those careproviders for all of his daily needs (Beauchamp and Childress 1989; Croog and Levine 1989; Swazey 1980). A surgical procedure which preserves mobility in the hip joint, thus facilitating bathing, diapering and other daily care activities, has definite benefits in terms of easing careprovider workload. At the same time, however, the procedure serves to increase client comfort, and to improve the quality of care received. This same surgical procedure may also enable the individual involved to continue to sit upright in a wheelchair or seating system. He can then be moved from place to place, and can participate in various programs to the best of his ability. While this may be seen to contribute to an improved quality of life for the resident, it may also be seen to contribute to a feeling of careprovider satisfaction.

### **Society's Valuation of Disabled People**

It can be equally as difficult to consider the best interests of a profoundly impaired person in isolation from the interests of society at large (Beauchamp and Childress 1989; Freeman and McDonnell 1987; Swazey 1980). As indicated previously, there are concerns among those who care for profoundly impaired institutionalized individuals, about society's level of commitment to this group of people (Buchanan and Brock 1989). Such concerns are often founded upon a recognition of the potential for making quality of life decisions based on social utility or social worth (Brody 1976; ILSMH 1992).

Those who care for, and/or advocate for, individuals who are permanently and profoundly impaired, believe that the lives of these individuals have inherent value, and that resources should not be rationed simply on the basis of these pre-existing impairments. They have a genuine commitment to protect the rights and interests of institutionalized individuals. At the same time, however, there is a recognition that there are limits to morally justifiable and socially responsible treatment, especially in life-threatening situations where prolongation of life would not appear to be in the patient's best interests (Callahan 1990; ILSMH 1991; MENCAP 1990).

### **The Effects of Rapid Advances in Technology**

Society's level of commitment to provide infinite numbers of health care dollars for care of permanently impaired, institutionalized individuals is of particular concern to careproviders when they consider the level of impairment of some of the individuals currently being admitted to long-term care facilities (Robertson 1975). They have noted that, since the advent of advanced technological support systems in the newborn intensive care nurseries, the level of impairment of some surviving infants and children is virtually unprecedented (Richards and Baker 1988; Zola 1990). Successive invasive surgical interventions are often required to ensure continuation of life and/or client comfort. Uncertainty regarding society's willingness to condone the provision of expensive procedures and equipment for such individuals may be especially intense in such situations (Weir 1989).

An additional problem related to the technological advances which have enabled profoundly impaired infants to survive infancy and early childhood, is the momentum associated with the acceptance of technological intervention in the life cycle. Efforts to improve care for impaired infants and children, and to sustain this level of care as they grow older, have resulted in the implementation and acceptance of a wide variety of medical and surgical interventions (Arras et al. 1987; Freeman and McDonnell 1987). Surgical procedures such as gastrostomies which, in past years, were rarely performed on profoundly impaired institutionalized people, are now carried out with increasing frequency. In some instances, gastrostomies have improved nutrition and general health so signifi-

cantly that it is subsequently possible to consider additional surgical procedures such as spinal stabilizations. Orthopaedic interventions of this nature were often considered to be too risky and not medically feasible, before the advent of the use of gastrostomies in this particular population.

In addition to more invasive clinical interventions, technological change has influenced the equipment which is currently available for the ongoing care and education of individuals with severe impairment. Technologically advanced orthotic devices and mobile seating systems, some of which cost several thousand dollars, are frequently prescribed with the objective of ensuring that individuals with severe physical impairment can be seated in wheelchairs rather than being cared for in bed. Communication systems utilizing the latest in computer technology, which enable profoundly impaired individuals to participate in educational and work-related programs, have also been developed. Care of the permanently impaired institutionalized population is, therefore, no longer synonymous with maintenance care, but increasingly involves the use of a wide array of technologically advanced equipment, and the skills of a variety of medical specialists and other professionals (Grant 1987).

### **The Principles of Distributive Justice**

An associated source of concern for careproviders stems from the realization that access to various types of specialized equipment (e.g. electric wheelchairs and technologically advanced communication systems), is already restricted for the profoundly impaired institutionalized population. This restricted access exists by virtue of the fact that such items require the assessment and recommendation of various health professionals (Friedson 1981; Kaufert and Kaufert 1989), and are distributed through public reimbursement systems (Brooks 1991; Mechanic 1977). There are long waiting lists for equipment such as electric wheelchairs, and members of the community compete with institutionalized persons for access to such equipment. There are also periodic shifts in the allocation of resources as various advocacy groups succeed in prioritizing programs for persons with specific disabilities. These shifting priorities raise questions as to whether those who are institution-

alized are at a permanent disadvantage in terms of resource allocation, due to lack of strong advocacy groups (Mather 1989). Additionally, there may be concerns expressed regarding limited access to treatment or equipment as a consequence of allocation decisions which are made by policy-makers outside the institution in question.

Restricted access to health care resources exists in other areas as well. There are definite differences of opinion amongst members of the medical profession regarding the appropriateness of specific medical and surgical interventions for those who are profoundly cognitively and physically impaired (Faulder 1985; Freeman and McDonnell 1987; ILSMH 1991; ILSMH 1992). Some orthopedic surgeons, for example, refuse to consider operating on mentally retarded spastic quadriplegics, particularly older adults (Drummond 1979; Moreau et al. 1979; Sherk et al. 1983). To some extent, then, physicians are rationing the allocation of certain resources for particular groups of people on behalf of society, even though a social consensus regarding such practices has not been attained (Robertson 1980). While many physicians do not feel that it is their responsibility to be gatekeepers of health care resources, and advocate for the best possible treatment for their clients despite pre-existing mental and physical impairment (Drummond 1987; Hiatt 1975), others practice implicit rationing through the discriminatory selection of patients for treatment (e.g. Lorber 1972 and 1975). This practice will continue in the absence of guidelines from government funding agencies (Mechanic 1977).

### **Institutional Philosophy**

A final source of variation which may be expected to influence decision-making at both individual and inter-individual levels, exists because the institution selected as the setting for this project is administered by the Sisters of Charity of Montreal (the "Grey Nuns") of the Roman Catholic Church. St. Amant Centre thus abides by the Catholic Medico-Moral code in providing medical care for the residents (St. Amant Centre MISSION Booklet).

A visitor to St. Amant Centre cannot help but notice the visible signs of Catholic identity.

The prominence of Christian symbols, the Chapel, and the presence of the Sisters as they serve in both administrative and careprovider capacities serve as tangible reminders that St. Amant Centre is a Catholic health care facility. In addition, the visitor is made aware that pastoral care services and religious education are integral components of the Centre's total care program.

The traditions and moral principles of the Roman Catholic Church are reflected in the institutional philosophy and Mission Statement of St. Amant Centre. A belief in the dignity of each person, respect for life as a gift from God, and a commitment to quality care for the whole person are outlined as fundamental principles (St. Amant Centre MISSION booklet and Fact Sheet; Sisters of Charity of Montreal Booklet 1991). Adherence to these principles is expected to influence both the type of care provided, and the nature of decisions made on behalf of the residents. The Centre's commitment to maintaining family involvement and respecting parents as primary decision-makers is also a fundamental principle of Catholic teaching (Catholic Health Association of Canada 1991; Dunstan and Seller 1983).

Finally, the Roman Catholic Church has, historically, voiced strong opinions about a number of bioethical issues (Callahan and Campbell 1990). The Catholic Health Association of Canada has produced a Health Care Ethics Guide which is designed to assist health careproviders in making informed ethical decisions (Catholic Health Association of Canada 1991). The principles outlined in this book, particularly as regards the care of the dying person, were observed to exert a significant influence on the type of care which is offered at St. Amant Centre.

## Summary

This chapter has provided an outline of the theoretical and conceptual framework upon which this research program is based, and has summarized the numerous sources of variation which may influence proxy decision-making in the setting under study. Chapter 4 provides a description of the research design which was developed and the methodology which was used to carry out the research program.

## CHAPTER 4

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### METHODOLOGY

#### Project Design and Data Sources

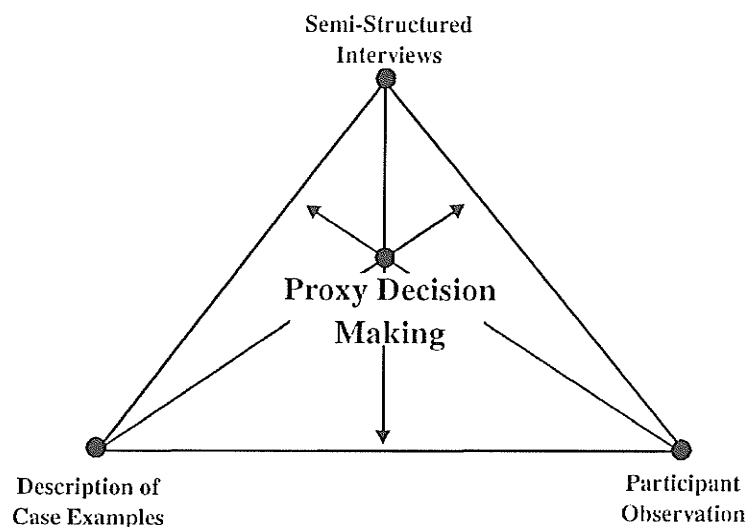
The research program investigating the assessment of life quality in preparation for proxy decision-making utilized a design format involving descriptive ethnography and other qualitative methods (Agar 1980; Diamond 1986; Glaser and Strauss 1967; Hammersley and Atkinson 1983; Locke, Spirduso and Silverman 1987; Marshall and Rossman 1989; Spradley 1979; Stern and Pyles 1985; Stone 1991). Triangulation methodology, a technique in which data is elicited from several different sources and/or collected using multiple methods, was used (Denzin 1978; Guba and Lincoln 1989; Marshall and Ross 1989; Parry 1991; Smith and Kleine 1986; Zelditch 1962). For this particular research program, data drawn from three different sources allowed the researcher to document different dimensions of proxy decision-making and, subsequently, to triangulate on the decision-making process.

The three data sources were:

- 1) The transcripts from in-depth, semi-structured interviews with careproviders and parents.
- 2) Case examples developed from multiple data sources, including descriptions provided by careproviders during in-depth interviews, and information on treatment decisions involving selected residents which was recorded via participant-observation.
- 3) Field notes taken as a participant-observer in various decision-making forums where quality of life issues were considered.

A detailed description of these three data sources follows. A schematic representation of triangulation methodology is contained in Figure 3.

Figure 3  
METHODOLOGY UTILIZING THREE SOURCES OF DATA TO TRIANGULATE  
ON THE PROXY DECISION MAKING PROCESS.



Sources: Denzin 1978; Guba and Lincoln 1989; Marshall and Rossman 1989; Parry 1991; Smith and Kleine 1986; Zelditch 1962

### Semi-Structured Interviews

The primary source of data is contained in the transcripts of in-depth, semi-structured interviews which were conducted with special education teachers, health careproviders from different disciplines, and family members (Langness and Frank 1981; Williams and Wood 1986). In their roles as careproviders or as family members, all respondents were involved in proxy decision-making at some level. Interviews were scheduled at each participant's convenience. With two exceptions, interviews and discussions of case studies with staff members at St. Amant Centre were carried out during the course of the participants' daily work activities. Two of the respondents chose to be interviewed before or after working hours. Interviews with parents/guardians were completed in their homes, at a mutually agreed-upon time.



The average duration of the interviews was forty-five minutes. Interviews were audio-taped, and transcribed verbatim in all but three cases. These three respondents refused to consent to have their comments tape-recorded. The investigator, therefore, recorded the informants' responses through detailed field notes.

In the course of the interviews, respondents were asked to describe what they felt was important to providing or maintaining a good quality of life for the residents for whom they provided care. Respondents were also invited to describe how the various dimensions of quality of life are weighted and prioritized in the process of making treatment decisions. Finally, they were asked to express their perceptions of the ways in which different dimensions of quality of life are assessed or measured in the absence of subjective input from the residents.

In the course of the interviews, participants were also asked how internal organizational considerations, such as the effects of specific interventions on careprovider workload, influence the decision-making process. In addition, caregivers were invited to describe their perceptions of how external societal values defining quality of life for persons with profound physical and mental impairment, might affect the allocation of health care resources.

### Case Examples

The second data source comprised information which was assembled from multiple sources to document the experience and care decisions for designated residents. Information used to develop the case examples was obtained from transcripts of interviews, as well as field notes taken by the researcher during participant-observation of both formal decision-making, and informal interaction.

In the course of in-depth interviews, participants were asked to describe case examples of individual residents who were perceived to have experienced improved or diminished quality of life as a result of various treatment interventions. The purpose of focusing on these examples during interviews, was to elicit careproviders' perceptions of the dimensions of quality of life which were perceived to have been affected by specific programs or procedures. In their narrative, respondents

referred to cases involving invasive interventions such as orthopedic and gastrointestinal surgery, as well as clinical programs with which the respondents were directly involved. The latter included sensory stimulation programs, feeding programs, behaviour modification programs, school programs, adult work programs, and various therapeutic interventions such as the prescription of special equipment and devices. Decisions about the care of the residents at the end of life were also discussed.

### **Participant Observation**

The third source of data consisted of observations made as a participant-observer in various group forums where quality of life issues were raised (Agar 1980; French, McDowell and Keith 1972; Spradley 1979). These forums included (1) Orthopedic Clinics, (2) Restraint Committee Meetings, (3) Residents' Rights Council meetings and (4) Annual IPP (Individual Program Planning) Meetings. Orthopedic Clinics were the primary forums where decisions involving surgical interventions and the prescription of orthoses and seating systems were made by careproviders. Restraint Committee Meetings were the primary forums where decisions to initiate or discontinue the use of restraints were discussed. Residents' Rights Council meetings were forums where issues affecting the quality of life of the residents were discussed by some of the residents who were able to communicate. Annual IPP (Individual Program Planning) meetings were forums where each resident's programs and progress were reviewed with all involved careproviders, as well as parents or legal guardians.

The researcher was also granted permission to observe interaction in a sensory stimulation program involving some of the adult residents, in order to witness first-hand the nature of the residents' responses towards this type of intervention.

During participant-observation, field notes were taken documenting the style of discourse, and the dimensions of quality of life which were considered. In these various forums, the way in which quality of life considerations were weighted and prioritized in the process of making decisions was also observed.

## Setting

The setting for this project was St. Amant Centre Inc., in Winnipeg, Manitoba. St. Amant Centre is a residential facility for people who are permanently physically and mentally impaired, and is currently home to approximately 265 children and young adults. The natural beauty of its riverside location, in combination with the attractiveness of the interior of the buildings, effectively erases the negative images which are frequently associated with this type of long-term care institution. (A brief history of St. Amant Centre is contained in Appendix B).

The Centre, which was incorporated in 1978 is, and has always been, owned and operated by the Sisters of Charity of Montreal (the "Grey Nuns"). The Sisters of Charity of the Council of the St. Boniface Province are members of the corporation and ensure that the Centre fulfils its corporate objectives. They appoint a Board of Directors which, acting through an Executive Director, is responsible for the direction and operation of the Centre. As indicated in the previous chapter, the influence of the traditions of the Roman Catholic Church contributes to the creation of a unique care environment.

Administrative duties are carried out by the Executive Director, an Assistant Executive Director, a second Assistant Executive Director responsible for nursing services, and a third Assistant Executive Director responsible for clinical services. Professional and non-professional staff from a variety of disciplines deliver a wide spectrum of services and programs to the residents at St. Amant Centre. Each department is headed by a director, and staffed according to the needs and requirements of the Centre. Chapter 5 provides a descriptive profile of St. Amant Centre which includes a summary of staff roles and responsibilities in the delivery of services and programs.

Although the structure and function of St. Amant Centre are similar, in some respects, to those of other facilities devoted to the care of individuals who are ill and/or disabled, the fact that this is a residential facility which is home to many individuals for most or all of their lives contributes to the creation of the care environment which is, in many respects, unique. Many of the residents are admitted to the Centre when they are small children and, in some cases, contact with family

members following admission is infrequent or non-existent. Staff members at St. Amant consequently assume roles which are much more than those of health careproviders. In the absence of family contact, they provide the residents with stable and secure relationships and, in some cases, form deep emotional attachments. It is not uncommon to hear a staff member refer to a particular child as "my baby." The illness or death of a resident with whom careproviders have had a close and/or long-standing relationship can affect them deeply.

### Negotiating Access

In Chapter 1, the contribution of the Director of Physiotherapy at St. Amant Centre Inc., in originating the central question for this research program, was acknowledged. As a physiotherapist, I had worked with this individual in a number of capacities, and in a number of different settings. My ongoing contact with her, as well as my professional affiliation with other members of the physiotherapy and occupational therapy staff of St. Amant Centre, served to facilitate access to the research setting.

My experience as a rehabilitation professional offered some advantages in completing the research program. My presence at Orthopedic Clinics was readily accepted due to my familiarity with members of the physiotherapy and occupational therapy staff. The therapists subsequently provided introductions to staff in other departments, and facilitated my access to meetings and sensory stimulation sessions. My previous work experience in other health care settings enabled me to more easily comprehend discussions during Orthopedic Clinics and other team meetings, but also enabled me to appreciate the uniqueness of St. Amant Centre.

The insider relationship afforded to me as a consequence of my familiarity with health care settings, is thought to have facilitated the development of a negotiated trust during in-depth interviews. Staff members expressed a great deal of interest in the project, were extremely willing to offer assistance in any way possible, and spoke frankly and openly about both the challenges of quality of life decision-making on behalf of the residents. One possible disadvantage of this insider

relationship was that I may not have maintained as critical a perspective as would an outsider. This may have contributed to a tendency to over-look potential conflict situations, and to emphasize the formation of consensus in decision-making situations.

### **Institutional Approval**

The formal process of negotiating access to St. Amant Centre for purposes of fielding the research program began in March 1991. An initial letter describing the program of research, and requesting access to interview and observe both residents and staff members, was sent to the Executive Director. That letter was subsequently referred to the Assistant Executive Director of Clinical Services, who forwarded a reply and a Research Review Form. This form was completed and submitted as requested. In May 1991, a letter indicating preliminary approval for the project was received from the Research Review Committee of St. Amant Centre.

In accepting the research proposal, the Research Review Committee stipulated that separate letters explaining the research program, as well as separate consent agreements for in-depth interviews, be prepared for staff members and for parents or guardians. The Committee also specified that parents or guardians who were not participating in in-depth interviews be requested to sign a consent agreement allowing the investigator to observe residents at clinics or annual review meetings. Lastly, the Committee indicated that its final approval would be subject to approval of the proposal by the Human Subjects Committee of the University of Manitoba, Faculty of Medicine.

### **Human Subjects Approval**

A proposal was sent to the Human Subjects Committee of the Faculty of Medicine at the University of Manitoba, and received approval in June, 1991. A copy of the letter of approval was forwarded to the Research Review Committee at St. Amant Centre, along with parental and staff versions of the explanatory letter and consent agreement.

## **Funding**

In October, 1991 an application for research funding was made to the Friends of St. Amant Centre. The application was successful, and grant money was subsequently obtained which covered general expenses, and transcription of some of the audio-tapes.

## **Chronology of Fieldwork**

Fieldwork began in September 1991. A preliminary meeting was held with the Assistant Director of Clinical Services, and introductions were made to other staff members. At this time, the Medical Director suggested that Orthopedic Clinics, where decisions were made about orthotic devices, wheelchair seating modifications, and orthopedic surgery, would provide an interesting forum for an investigator with a background in physiotherapy to begin observing interactions and decision-making.

The Director of Physiotherapy, who was responsible for the scheduling and organization of Orthopedic Clinics, was subsequently contacted regarding the researcher's attendance at these clinics. It was determined not to be practical for the investigator to obtain parental permission in advance of specific clinic dates, because the schedule was prepared only two weeks before cases were reviewed. The Director of Physiotherapy suggested that the researcher attend the clinics as an observer, identify cases appropriate for follow-up, and then contact parents to request their permission for the various activities entailed in the project. This arrangement was documented in a letter to members of the Research Review Committee, and was mutually agreed-upon.

In October 1992, the investigator began to attend Orthopedic Clinics on a bi-weekly basis. Both informal interaction between careproviders, as well as formal decision-making about specific equipment and surgical procedures were observed. The physiotherapy and occupational therapy staff, who were regular participants at Orthopedic Clinics, facilitated the researcher's access to other decision-making forums through personal introductions to other staff members who attended the Clinics.

Following introductions to staff members from other departments in the Centre, access was negotiated to observe decision-making in a variety of other settings. These settings included IPP meetings, Resident Rights Council meetings, and Restraint Committee meetings.

As contact with staff members from different departments was made, consent agreements and letters which explained the objectives of the research program and invited careproviders to participate in in-depth interviews, were sent out. These letters were sent initially to physiotherapists, occupational therapists, and physicians; then to nurses, aides, psychologists, and social workers; and finally to recreation staff members, adult program instructors, and special education teachers in the on-site school. These groups of careproviders were selected as they were all involved in delivering services which might affect the residents' quality of life. Explanatory letters and consent agreements were also mailed to parents and/or guardians of residents whose cases were reviewed at Orthopedic Clinics. In December 1992, the first signed consent agreements were received from parents and staff, and semi-structured, in-depth interviews were begun.

Fieldwork was completed in May, 1992, and the process of analysis and writing began. The chronology of field events is schematically represented in Figure 4. A more detailed chronology of the fieldwork is contained in Appendix C.

Figure 4

**STEPS INVOLVED IN NEGOTIATING ACCESS AND COMPLETING FIELDWORK.**

|                 |  |
|-----------------|--|
| MARCH 1991      | - Letter to Executive Director, St. Amant Centre             |
| MAY             | - Approval of St. Amant Research Review Committee            |
| JUNE            | - Approval of Human Subjects Committee                       |
| SEPT            | - Preliminary meetings and organization of fieldwork process |
| OCT             | - Commenced participant-observation at Orthopedic Clinics    |
| NOV             | - Approached parents and staff re participating in project   |
| DEC             | - In-depth interviews commenced                              |
| JAN- MAY 1992   | - Continued fieldwork  |
| FEB-SEPT        | - Literature search and completion of formal proposal        |
| OCT - JUNE 1993 | - Analysis and preparation of final report                   |

## Selection of Participants and Case Examples

### Participants

Health careproviders from disciplines involved in treatment decision-making and/or direct resident care were contacted to ascertain their willingness to participate in semi-structured interviews. When the number of potential respondents within each professional discipline or treatment department was small (six or less), each member of the department was invited to participate. On the living units where the numbers of staff members are large, the head nurses were requested to inform their staff about the project, and to identify to the researcher any nurses or aides who indicated an interest in participating. Approximately one-half of the education staff were contacted. Any parents/guardians who were approached for consent to have the researcher observe rounds, clinics and meetings at which their son/daughter/ward was presented or discussed, were also asked about their willingness to be interviewed.

### Case Examples

Case examples were selected by two different methods:

- 1) Through observation of residents attending Orthopedic Clinics, and yearly review meetings (IPP).
- 2) From transcripts of in-depth interviews in which careproviders described treatment programs or procedures involving specific residents, and provided assessments of how quality of life was perceived to be improved or diminished by these particular interventions.

Whenever possible, decision-making situations involving specific residents which were observed at Orthopedic Clinics, were also discussed with the relevant individual careproviders during in-depth interviews.



## Consent Procedures and Ethical Considerations

All participants, including staff members and parents and/or guardians, were asked to sign consent agreements indicating their willingness to be interviewed. Parents and/or guardians of residents who were selected for follow-up, were also requested to sign agreements indicating that they consented to have the researcher attend IPP meetings, as well as clinics and other meetings at which their child's case was reviewed. The consent agreement also requested parental permission to allow the investigator to discuss the process of treatment decision-making for specific residents with the individual careproviders who were involved. The consent agreements prepared for use by parents/guardians and health careproviders, as well as the explanatory letters describing the research program, are appended as Appendix D.

Information obtained from all methods of data collection is confidential and the names of residents, parents or health careproviders will not be used at any time. Field notes, audiotapes, and transcripts of in-depth interviews have been indexed and stored so that the sources can only be identified by the investigator. No one else has access to this data. Names of staff members and/or residents which were used inadvertently in in-depth interviews, and for whom a consent agreement was not obtained, have been deleted from the transcripts.

In the analysis and final writing, a consistent effort has been made to ensure that information used in verbatim quotations is disguised so that the informants cannot be identified. Although it was stipulated in the careproviders' consent agreements that the professional affiliation of the respondents could be specified, this has not been done in selected instances, as it was felt that job identity would serve to identify the speakers. As indicated in the introductory chapter, the case example which was presented is a composite re-construction integrating information from a number of cases observed at Orthopedic Clinic. This format was selected in order to preserve the anonymity of individual residents.

## Response Rate

The response rates of parents/guardians and health careproviders who were included in the initial qualitatively defined sample were monitored in an effort to detect systematic self-selection bias in the patterns of response.

### Parents/Guardians

A master list was generated which contained the names of parents/guardians of all residents who were scheduled for review at Orthopedic Clinic in a three month period. After consulting with the Director of Physiotherapy and the Head of Medical Records, this master list was shortened by excluding the names of parents who had previously indicated that they did not wish to be contacted in regard to projects of this nature. Families who were known to be experiencing difficult personal problems, and parents of residents who were considered to be medically fragile, were also excluded.

Forty-seven (47) letters requesting permission for the researcher to observe residents at meetings and clinics, and to discuss their cases with relevant careproviders during in-depth interviews, were subsequently sent to parents/guardians of residents of St. Amant Centre. Reminder letters were mailed if no reply was received within a month of the initial contact. This protocol generated replies from twenty-eight (28) out of the forty-seven individuals/couples to whom letters were sent. This constitutes a response rate of sixty percent (60%). Only four (4) of those who replied did not give their consent, resulting in twenty-four (24) positive responses. The response rate of parents/guardians is summarized in Table II.

TABLE II  
RESPONSE RATE OF PARENTS/GUARDIANS

|  |        |          |
|--|--------|----------|
| Replies received after initial contact | (n=47) | 15 (32%) |
| Replies received after reminder        | (n=32) | 13 (41%) |
| Total replies received                 | (n=47) | 28 (60%) |
| Total "yes" responses                  | (n=28) | 24 (86%) |
| Total "no" responses                   | (n=28) | 4 (14%)  |

The majority of replies were received from parents/guardians living in, or in close proximity to, the City of Winnipeg (68%). As a number of the letters to rural areas were addressed to remote communities, and the cultural/linguistic background of the intended recipients was often unknown, it was not possible to monitor how many of these letters actually reached their destination, or were understood by the recipients. The rural/urban response rate is summarized in Table III.

TABLE III  
RURAL/URBAN BREAKDOWN OF PARENTAL RESPONSES

|                           | URBAN<br>(Winnipeg) | RURAL<br>(Outside Winnipeg) |
|---------------------------|---------------------|-----------------------------|
| Total letters sent (n=47) | 29 (62%)            | 18 (38%)                    |
| Replies received (n=28)   | 19 (68%)            | 9 (32%)                     |
| Yes (n=24)                | 15 (62.5%)          | 9 (37.5%)                   |
| No (n=4)                  | 4 (100%)            | 0                           |

Considering the manner in which the original sample was defined, a high rate of parental response was not anticipated. Those to whom letters were mailed included parents who do not maintain regular contact with St. Amant Centre. As mentioned previously, some letters were sent to remote areas of the province. Two of the four parents/couples who refused their consent called the researcher by phone, and indicated an unwillingness to participate in any sort of research project which involved their children. It is possible that some of the non-respondents had similar reservations concerning research.

### Parent Interviews

Of the 24 parents/guardians who consented to allow the researcher to observe clinics and meetings where residents' care was discussed, eight (33%) indicated that they would be willing to

participate in follow-up interviews to discuss parental perspectives on decision-making. Six of the consenting respondents were from the Winnipeg area, and two lived in rural areas.

Interviews were subsequently scheduled with six of the eight consenting parents, and five were eventually completed. Three of the completed interviews involved only the mother of the resident. One interview involved both mother and father, and the fifth was completed with both the natural mother and foster father. A sixth interview with the mother of another resident was scheduled, but was cancelled by the respondent due to an urgent family matter. A father whose signed consent form was not received until the fieldwork was essentially completed, was not contacted for an interview.

The small number of parents agreeing to be interviewed was not considered surprising. In addition to the factors affecting parent/guardian response rate which were mentioned in a preceding paragraph, there may have been other reasons why parents were hesitant to participate in interviews. The sensitive nature of the subject matter, and possible uncertainties as to whether the research project incorporated an evaluative component which might affect their relationship with St. Amant Centre, may have increased the reluctance of some parents. One parent who contacted the researcher by phone indicated that she was simply unable to discuss her child's case, and that the only way she was able to cope with the experience of having a profoundly handicapped child was to avoid contact with St. Amant Centre. Finally, individuals who worked for Child and Family Service agencies and the Office of the Public Trustee were not expected to participate in interviews.

Those parents who did agree to be interviewed had very little in common in terms of their level of involvement with St. Amant Centre. Some maintain regular contact with their children and are actively involved in volunteer work, while others frequent the Centre only for annual review meetings. All of these parents expressed a genuine concern about the welfare of their children, however, and indicated a deep regard for St. Amant Centre and the health care workers who work there. All of these parents also expressed a desire to be involved in decision-making on their children's behalf, even though some of them indicated that they would, generally, act upon the recommendations of the regular careproviders.

### Staff Members

A good rate of response was obtained from letters requesting participation of the staff of St. Amant Centre. Thirty-five (35) of the forty-four (44) individuals contacted agreed to participate in in-depth interviews, one (1) chose not to be interviewed but indicated a willingness to assist the researcher in gaining access to some of the group forums, and eight (8) did not reply. Thirty-five (35) interviews were subsequently scheduled, and thirty-three (33) were eventually completed. This information is summarized in Table IV.

TABLE IV  
RESPONSE RATE OF HEALTH CAREPROVIDERS  
CONTACTED FOR INTERVIEWS

|                              | (n=) | YES      | NO      | NO REPLY |
|------------------------------|------|----------|---------|----------|
| Adult Program Instructors    | 3    | 3(100%)  |         |          |
| Aides                        | 3    | 3(100%)  |         |          |
| Head Nurses                  | 6    | 4 (67%)  |         | 2 (33%)  |
| Nurses (other)               | 2    | 2(100%)  |         |          |
| Occupational Therapists      | 3    | 3(100%)  |         |          |
| Physicians                   | 4    | 2 (50%)  |         | 2 (50%)  |
| Physiotherapists             | 5    | 5(100%)  |         |          |
| Psychologists                | 4    | 4(100%)  |         |          |
| Social Workers               | 3    | 2 (67%)  | 1 (33%) |          |
| Speech/Language Pathologists | 2    |          |         | 2 (100%) |
| Recreation Staff             | 2    | 2(100%)  |         |          |
| Teachers                     | 7    | 5 (71%)  |         | 2 (39%)  |
| TOTALS                       | 44   | 35 (80%) | 1 (2%)  | 8 (18%)  |

In Table IV, "n" refers to the number of persons in each professional group who were contacted regarding the project. In the case of departments with a relatively small number of staff (e.g. physical therapy, occupational therapy, speech/language pathology, social work, and psychology), "n" was also equal to the total number of professional staff within that department.

The final total of completed interviews with the addition of the five (5) interviews conducted with parents, was thirty-eight (38). In the process of interviews with careproviders, two of the thirty-three staff respondents indicated that they were also parents of children with special needs. Both parental and professional perspectives were, therefore, incorporated in their responses.

### **Validity and Reliability**

Criteria for assessment of validity and reliability in quality of life research have been inadequately addressed (Drummond 1987; Katz 1987; Spitzer 1987; Torrance 1987; van Knippenberg and de Haes 1988). Measurement of validity and reliability presented initial challenges in this research endeavour, as the literature review did not identify published research which focused on the problem of proxy assessment of quality of life, and the decision-making process which is used to evaluate the potential for improving quality of life through specific medical or surgical interventions.

Basic validity issues were compounded, therefore, by:

- 1) The absence in the clinical or research literature of an operational definition of quality of life.
- 2) The absence of validated measurement instruments for use in decision-making situations requiring proxy assessment of quality of life.
- 3) The absence of baseline standards for comparison and validation of results among equivalent populations.

External validity has been improved to some extent by including representatives from a number of professional disciplines and careprovider groups, and by having as many participants as possible from each profession/group represented (Angrosino 1987; Guba and Lincoln 1989). Participant-observation was carried out in a variety of group decision-making settings, and over an extended period of time, in order to reduce reactivity and improve internal validity (Agar 1980; Angrosino 1987). Validity was also improved by using a grounded theory approach to test the hypotheses generated from the information obtained through in-depth interviews, against data obtained through participant-observation (Glaser and Strauss 1967; Stern and Pyles 1985; Strauss and Corbin 1990).

Internal reliability was achieved by eliciting and recording a consistent set of information during both in-depth interviews, and individual discussions of specific case studies (Fowler 1988). Comparison of the actual decision-making process as documented during participant-observation in group decision-making forums, with the decision-making process as described during in-depth interviews by the individuals who were participants in this process, also served to improve reliability (Langness and Frank 1981).

## **Data Analysis**

Data available for analysis included transcripts from audiotaped interviews with family members and health careproviders, notes on specific case examples, and field notes from participant-observation of rounds and clinics. In the process of analysis, data from all sources was coded thematically, indexed, and common themes were extracted (Brent 1984; Glaser and Strauss 1967; Marshall and Rossman 1989; Stern and Pyles 1985; Strauss and Corbin 1990; Williams and Wood 1986). For purposes of this thesis, themes defining the definitions and primary dimensions of quality of life among people with severe-profound impairment, references to how these dimensions were weighted and prioritized in specific decision-making situations, and methods of assessing either improvement or deterioration in quality of life following specific interventions, were identified. The

degree to which information elicited in relation to specific case examples as well as observations made at clinics and meetings was consistent with information recorded during the in-depth interviews, was then assessed.

In presenting an analysis of this data, it is recognized that the viewpoints and attitudes of careproviders who choose to work in a setting such as St. Amant Centre may be significantly different than those of health careproviders who work in other settings. The conclusions may not, therefore, be generalizable to decision-making situations involving other groups. It is also recognized that some staff informants are also parents of special needs children, and that their opinions may reflect their own personal experiences.

The next five chapters provide a descriptive analysis of the data which was collected during the research process. Chapter 5 provides a descriptive profile of the residents of St. Amant, a summary of staff roles and responsibilities in the delivery of programs and services, and a brief discussion of the ways in which responsibility for decision-making is shared between careproviders and parents/legal guardians. The various dimensions of quality of life in the presence of severe-profound impairment, as defined by the careproviders and parents who participated in in-depth interviews, is summarized in Chapter 6. In Chapter 7, the ways in which quality of life considerations are weighted and prioritized in a number of proxy decision-making scenarios are described. Considerations related to the influence of careprovider priorities, as well as that related to societal views about the valuation of disabled people, are described in Chapter 8. Finally in Chapter 9, the methods used to measure or evaluate quality of life in the presence of profound physical and cognitive impairment, the limitations and strengths of the evaluation process as described by the respondents, and the ways in which these assessments are factored into the decision-making process, are discussed.



## **CHAPTER 5**

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### **A DESCRIPTIVE PROFILE OF THE RESIDENTS AND STAFF OF ST. AMANT CENTRE**

A descriptive profile of both the resident population and the roles and responsibilities of careproviders in delivering the various services and programs provided at St. Amant Centre, is a necessary pre-requisite to presenting an analysis of the information obtained through in-depth interviews and participant-observation. In addition, a brief account of the way in which the responsibility for decisions made on behalf of the residents is shared between careproviders and parents/legal guardians, is provided. These descriptions serve to inform the decision context of both the careproviders' narratives, and the group interactions observed by the researcher.

#### **Population Profile**

In order to provide a contextual framework for interpreting the proxy decision process as it is carried out by careproviders at St. Amant Centre, it is necessary to provide a descriptive profile of the resident population. This profile will include statistical information pertaining to temporal trends which have affected both the composition, and the current demographic characteristics of the population at this particular facility. Specific reference will be made to the changing age structure of the residents, changing levels of impairment, and possible future trends which may affect discharge statistics.

### Changing Age Structure

The changing survivorship patterns of profoundly handicapped people as described in Chapter 2, are reflected in the changing age structure of the population at St. Amant Centre. An appreciation of this changing age structure is fundamental to understanding the nature of care decisions which are made on behalf of an aging resident population.

In the early years of St. Amant Centre, children were transferred to the Manitoba Developmental Centre in Portage la Prairie, Manitoba after they reached twelve years of age. Due to a change in policy in 1974, however, the Centre currently provides care for residents of all ages. The fact that children are no longer transferred to Portage la Prairie, in combination with the gradual increase in the life expectancy of individuals with severe to profound impairment over the past three-four decades, has served to markedly change the age structure of the population at St. Amant Centre.

In 1976, only 4% of the residents at St. Amant Centre were over the age of 18. In 1990, 50% of the residents were over the age of 18 with 39% being over the age of 21. The Centre's own projections for 1995 indicate that over 75% will be over the age of 18, and 61% will be more than 21 years of age. This information is summarized in Table V.

TABLE V  
CHANGING ADULT POPULATION AT ST. AMANT CENTRE  
(based on a total population of 254 residents)

|                | 1976    | 1990      | 1995      |
|----------------|---------|-----------|-----------|
| Adults over 18 | 10 (4%) | 127 (50%) | 191 (75%) |
| Adults over 21 | -       | 99 (39%)  | 156 (61%) |

Source: St. Amant Centre "Five Year Plan - Statistics Update," October 1, 1990.  
Used with permission.

The increasing number of adults in the resident population has necessitated some program changes at the centre. Programming for young adults over the age of twenty-one who have completed their schooling has had to be increased. The demand for some type of programming for older adults who have been admitted to the Centre from other facilities or the community in recent years, or for adults who finished school several years ago, has also increased. The increased demands for the placement of adults currently exceeds the space available in the adult programs at St. Amant, and has necessitated the creation of a waiting list. Residents who graduate from school in the Centre tend to continue on with various adult programs, but those who have not been in school for some time, or who have been recently admitted, may have to wait.

### Level of Impairment

The level of cognitive impairment of the residents at St. Amant Centre has also changed over time. In 1976, only 68% of the residents were considered to be severely-profoundly mentally retarded (defined as IQ below 25-35 in Grant 1987). With the recent trend to provide care for less severely impaired children in the community, 94% of the residents at St. Amant Centre were assessed as being severely-profoundly mentally retarded in 1990.

The degree of physical impairment has also increased over time. This change has implications in terms of the functional abilities of the residents. As an example, 33% of residents were ambulatory in 1976, as opposed to 22% who were ambulatory in 1990. Information summarizing changing levels of impairment is presented in Table VI.

TABLE VI  
CHANGING LEVELS OF IMPAIRMENT OF RESIDENTS AT ST. AMANT CENTRE  
(based on a total population of 254 residents)

|   | 1976      | 1990      |
|---|-----------|-----------|
| Severely-Profoundly Mentally Retarded Residents | 173 (68%) | 239 (94%) |
| Ambulatory Residents                            | 84 (33%)  | 56 (22%)  |

Source: St. Amant Centre "Five Year Plan - Statistics Update," October 1, 1990.  
Used with permission.

Increasing levels of physical and cognitive impairment create demands for heavier nursing care, and may require the provision of more specialized equipment, such as modified wheelchairs and communication systems (e.g. Bliss symbol boards). The development of therapeutic, educational and work-related programs which will meet the needs of a group of people with significant physical and cognitive impairment provides an ongoing challenge for the staff at the Centre.

### **Discharge Statistics**

The aforementioned increases in the average age and level of impairment of the residents at St. Amant Centre may eventually have an impact upon the number of residents who are able to be discharged back to the community. Many of the adult residents who have been admitted in recent years, resided in the community until such time as this was no longer feasible. Aging parents who could no longer provide the necessary physical care, increased medical problems which were not easily managed at home, and/or lack of community based resources, made it necessary for many of these individuals to be admitted to St. Amant Centre. The probability of these individuals returning to live in the community is low. Younger, profoundly impaired residents who require high levels of care, or who are considered to be medically fragile, may also not be candidates for community living, considering the current availability of community based support services.

Discharge statistics for St. Amant Centre are presented in Table VII. Residents who are able, and for whom appropriate community living arrangements can be made, can be discharged either to group homes, foster homes, or their natural home. It will be interesting to compare these figures with corresponding statistics in future years, to observe any longitudinal changes in discharge patterns which might be related to increases in the average age and level of impairment of the resident population.

TABLE VII  
NUMBER OF RESIDENTS DISCHARGED TO COMMUNITY LIVING SETTINGS  
FROM ST. AMANT CENTRE

|                 | FOSTER<br>HOME | NATURAL<br>HOME | GROUP HOME<br>APARTMENTS | TOTAL |
|-----------------|----------------|-----------------|--------------------------|-------|
| 1980            | 1              | 4               | 0                        | 5     |
| 1981            | 3              | 2               | 3                        | 8     |
| 1982            | 1              | 2               | 3                        | 6     |
| 1983            | 0              | 2               | 10                       | 12    |
| 1984            | 1              | 4               | 3                        | 8     |
| 1985            | 1              | 3               | 1                        | 5     |
| 1986            | 0              | 1               | 3                        | 4     |
| 1987            | 3              | 1               | 7                        | 11    |
| 1988            | 0              | 1               | 4                        | 5     |
| 1989            | 0              | 1               | 2                        | 3     |
| 1990 (1/2 year) | 0              | 1               | 0                        | 1     |

Source: St. Amant Centre "Five Year Plan - Statistics Update," October 1, 1990.  
Used with permission.

### Summary

In summary, both the composition and the characteristics of the people who are residents of St. Amant Centre have changed significantly over the past 15 years. The number of adult residents has increased dramatically, and the current resident population is assessed as being more severely mentally and physically impaired than that of 1976. These changes have necessitated expanded programming for the growing adult population, and have increased the level of physical care required. The eventual result of these trends may be a more stable population over time, as fewer residents may be candidates for discharge to community living settings.

## Careprovider Roles and Responsibilities in Service Delivery

The clinical services and programs which are available to the residents, and the various roles and responsibilities of the staff members of St. Amant Centre in delivering these services and programs, also constitute part of the decision context for proxy decision-making on behalf of the residents. The next subsections provide a description of those departments whose members actively participated in this project, and summarize the responsibilities of the members of these Departments in a number of team decision-making situations. A brief summary of St. Amant Centre's role in the wider Winnipeg community is also included.

### Medicine

The medical team is headed by the Medical Director, and includes two pediatricians. These physicians are responsible for the ongoing care of the residents of St. Amant Centre, in cooperation with a variety of other careproviders. Other medical specialists provide regular consulting services, including a neurologist, an orthopedic surgeon, and a psychiatrist.

### Nursing

St. Amant Centre is organized into a number of living units or wards for those who require a high level of care, and three attached cottages for ambulatory residents who are able to function somewhat more independently. The residents are assigned to specific living units primarily on the basis of age criteria. A person's level of functional and/or cognitive impairment, however, may also influence placement. For example, ambulatory residents tend to live in the same units, as do adult residents who are less cognitively impaired.

Nursing care is provided around the clock by registered nurses, licensed practical nurses, psychiatric nurses and aides, under the direction of the head nurse on each living unit. Nursing care activities include bathing, diapering, grooming and feeding for those residents who are totally dependent, and the provision of assistance in such activities for those residents who are able to help

themselves to some degree. Nursing staff also dispense medications, and attend to any other medical needs of the residents.

Members of the nursing staff have frequent contact with family members of residents when they come to visit. Nurses may be responsible for setting up necessary meetings with parents/guardians, and for communicating information regarding ongoing changes in residents' treatment programs. They also participate in decision-making about programming changes and surgical procedures such as gastrostomy. Because of their close involvement with the residents, members of the living unit staff are also able to provide valuable feedback regarding equipment or programming which has been recommended by clinical staff from departments such as physiotherapy, occupational therapy, and psychology.

### **Clinical Services**

A number of clinical services, including psychology, occupational therapy, and physiotherapy are available within the Centre.

The Psychology Department offers a variety of consultation services and programming, and assumes special responsibility in the case management and treatment of behavioural problems. Members of the Psychology Department are actively involved with many of the Centre's committees. For example, psychologists are involved in the decisions of the Restraint Committee which examines possible alternatives to physical or chemical restraints for residents who may endanger themselves or others by inappropriate or aggressive behaviour. Research is also a primary function of this department.

The Occupational Therapy Department also provides a number of services to the residents at the Centre. These include splinting, electric wheelchair assessment and instruction, and a variety of activities designed to facilitate sensorimotor development. One of the main objectives of the occupational therapy staff is in developing oral feeding skills or self-feeding skills, through working with residents who are capable of performing these functions.

As a consequence of their involvement in feeding programs, members of the Occupational Therapy Department serve on the Feeding Assessment Team at the Centre. The function of this team is to provide an evaluation of feeding skills which may assist with decision-making regarding gastrostomy surgery. Occupational therapists also participate in Orthopedic Clinics, offering their assessments of the individual's need for orthotic devices as well as modifications to wheelchair seating which will serve to accommodate environmental controls and augmentative communication devices.

The Physiotherapy Department offers programming which is designed to provide residents with a variety of sensory and motor experiences. One of the objectives of this Department is to enable residents to experience movement in any way possible. Another is to enable the resident to experience normal sensory experiences such as touch and handling. Increasing the resident's independence in functional activities wherever possible, is also stressed. In addition, members of the physiotherapy staff are responsible for scheduling Orthopedic Clinics. They actively participate in decision-making involving the prescription of seating and orthotic devices, and recommendations about orthopedic surgical procedures.

### **Social Work**

Other departments whose members actively participated in this project included the Department of Social Services. Social workers assist families with the emotional and social dimensions of caring for handicapped people. They also serve as liaisons between the Centre, the parents, and the community. In the event that parental consent for medical or surgical procedures which careproviders consider important to a resident's comfort or well-being is not forthcoming, social workers may take an active role in contacting the agency under which the resident was admitted to the Centre (such as Child and Family Services) in order that they can try to obtain parental consent.

In reference to the role of social workers in the specific decision-making scenarios which are described in Chapter 7 of this thesis, one of the social workers who was interviewed referred to her



role as that of a "facilitator." In this capacity, social workers are responsible for bringing appropriate people together for meetings at which information is shared, and team decisions are made.

### **Recreation**

The Recreation Department offers a wide variety of programming for residents in all age groups. The Department develops regular programs which incorporate activities such as swimming, games, and arts and crafts. The staff also sponsor special events throughout the year (e.g. a winter carnival). Activities outside the Centre include shopping, hockey games, the zoo and visits to a cottage at a Lake Winnipeg beach.

### **School**

Children begin to attend the Centre's nursery school when they are three years old. Once they reach statutory school age, they attend school five days a week for either half or whole days. Students graduate from the school program when they reach twenty-one years of age.

The school is located within St. Amant Centre, but the responsibility for its administration rests with the St. Vital School Division. The school provides educational programming to children who are residents of the Centre, as well as a few students from the community who have high medical and/or physical needs. The staff are special education teachers, and the programs are uniquely designed to accommodate the needs and abilities of the residents of the Centre. The curriculum incorporates four domains: vocational, domestic, recreational and community based. Teaching objectives for each student incorporate these four domains to provide a well-rounded program adapted to meet the individual's unique needs. The child's future development, as it enables the individual to live in the community or to attend programs like Adult Program within the Centre, are also considered in curriculum development.

Children who are in school fulltime are often seen on site during the day by physiotherapists and occupational therapists, psychologists, and/or speech and language pathologists. These specialists

serve as consultants, providing periodic evaluations, recommending ways in which treatment objectives can be achieved through modification of classroom activities, and providing training to enable the school staff to implement specific treatment programs.

### **Adult Programs**

Because of the increase in the proportion of young adults who currently reside at St. Amant Centre, an Adult Program with three streams has been established for residents who have completed their schooling. The pre-vocational stream provides training in work skills and work habits. The developmental stream is designed for those residents who have the potential to develop work skills, but have never done any work. The sensory stimulation stream is for those who need to "experience more of the world," and to be part of an activity program.

Although many of the adults who are over twenty-one years of age attend one of the half-day Adult Programs, there are some adults who are not presently included in any adult programming. This is due either to lack of space within the programs, or to the severity of their disability. The absence of program opportunities for these individuals is of particular concern to many of the staff members. Some of the adult residents who have been bedridden and unable to participate in activities for several years, are currently undergoing assessments to see if they can tolerate being seated in upright seating systems. Provision of seating systems may enable residents to attend programs, or at least to be taken outside on nice days by volunteers or family members. A sensory stimulation program has been developed on one living unit for some of the adults who are not presently involved in programs. A few residents who are too medically fragile to attend any kind of programming are provided with comfort care on the living units.

### **Community Programs**

St. Amant Centre staff and volunteers actively interact with the Winnipeg community. Members of the residents' families, as well as other people from the community, provide volunteer services to

the residents. Group homes have been established for residents who are able to function in a community setting. A Developmental Day Program is available for children from the community who have delayed development and/or physical, behavioural or sensory handicaps. In addition, the Centre acts as a resource for those who care for multiply-handicapped children in the community through their Community Outreach Program. The Centre also offers intermittent respite admissions for non-resident children and young adults, in order to provide relief for families in the community who are caring for individuals with multiple handicaps.

### **The St. Amant Society**

The St. Amant Society is an auxiliary organization which takes an active role in both fundraising and public relations activities on behalf of the Centre. Some of the parents who participated in this project are actively involved in this organization. The work which they do on behalf of St. Amant is important, in that it allows them to provide a direct contribution to maintaining quality care for their children.

## **Responsibility for Decision-Making**

As has been noted in the previous sections, careproviders at St. Amant Centre are active co-participants in proxy decision-making on behalf of the residents, even though the legal responsibility for decision-making rests with the residents' parents or legal guardians. Parents and/or guardians often act upon the advice of careproviders, particularly if they do not maintain regular contact with their children, and are unfamiliar with their programs and progress.

Most of the children who become residents of the Centre are admitted under a voluntary placement agreement which is negotiated between the parents and an agency such as one of the branches of Child and Family Services. Upon signing this agreement, parents relinquish the responsibility for the ongoing care of their child but, providing that they remain as legal guardians,

they are consulted regarding any decisions which must be made on the child's behalf. A few children are placed at St. Amant under the provision of a Court Order. In these cases guardianship is transferred, and families are not involved in decision-making. Under such circumstances, the child becomes a ward of an agency such as Child and Family Services. The Child and Family Services Worker responsible for a particular resident would then be contacted for consent for surgical procedures, research projects, and in any other situations requiring legal consent.

Adults are admitted under either a committee ship, or an order of supervision. Parents can go to Court and apply for a Committee ship in which case they manage the person's estate, but do not have the legal right to make decisions on their behalf. Often, however, the parents continue to function as the resident's guardian, and are consulted regarding major decisions. Adult residents who are admitted under an order of supervision, are under the care of the Public Trustee. In these instances, the Public Trustee is committee of the person's estate, as well as their affairs. The Office of the Public Trustee is then contacted for consent to perform surgical procedures, for permission to undertake research involving particular residents, or in any other situation in which legal consent must be obtained.

### Summary

The preceding descriptive profile has been provided for three reasons. First, the description serves to illustrate how decisions about programming and service delivery may be influenced by the changing composition and demographic characteristics of the resident population. Second, it illustrates how the quality of life decision-making which will be described in the following chapters, occurs in the context of the organizational structure which has been outlined. In this regard, the ways in which teams are organized, and the roles and responsibilities of the individual members of those teams, are important factors in the decision-making process. Third, it serves to remind the reader that decision-making is governed, to some extent, by the circumstances under which residents are admitted to St. Amant Centre, and the perceived roles of the individuals who possess the legal authority for decision-making on their behalf.

## CHAPTER 6

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### THE CONCEPT OF QUALITY OF LIFE AS APPLIED TO THE EXPERIENCE OF PEOPLE WITH PROFOUND IMPAIRMENT

This chapter will examine the dimensions of quality of life as they were defined and/or described by careproviders and parents during in-depth, semi-structured interviews. Although the interviews were open-ended and relatively unstructured, participants were specifically asked to define or describe quality of life, as it applies to the experience of profoundly impaired people who are unable to express their own viewpoints. The subject was introduced with a prefacing statement:

Interviewer:

I've been asking people for their views on quality of life as it applies to some of the more profoundly impaired residents at the Centre- the ones who can't really speak for themselves. It's my understanding that quality of life considerations are very important when you are making decisions on behalf of the residents. What I'm trying to get is a description of quality of life as you define it for the residents.

As indicated in Chapter 2, the literature on the measurement of health-related quality of life would lead one to anticipate that careproviders' narratives would incorporate a wide range of individual characterizations of the concept of quality of life (Edlund and Tancredi 1985; Najman and Levine 1981; Schipper 1985; van Knippenberg and de Haes 1988; van Knippenberg et al. 1992). Similarly, the literature on the sociology of professions would lead one to expect that the themes

which emerged would reflect the professional ideologies and scopes of practice of the respondents (Caplan, Callahan and Haas 1987; Friedson 1970; Kottke 1982; Safilios-Rothschild 1970; Sussman 1965). Members of the nursing staff, therefore, might be expected to express concerns that the residents receive the best physical care available, and to stress the importance of cleanliness and comfort. Physiotherapists might be expected to focus on objectives emphasizing the importance of enabling residents to achieve the highest level of independence possible. Each of the other professions (e.g. psychology, recreation and education), would also be expected to focus on specific agendas.

Transcripts of the interviews were initially examined, therefore, in order to extract themes related to individual definitions and descriptions of quality of life. The transcripts were then re-examined to determine the presence of systematic variation in the statements of members of the same professional group, as well as to extract common themes which cross-cut professional groups.

As anticipated, the concept of quality of life as applied in decisions involving persons with profound physical and cognitive impairment, was described differently by individual careproviders. A number of themes emerged as respondents described what they felt contributed to a good quality of life. There were references to the importance of physical comfort and freedom from pain, as well as to mobility and the development of sensorimotor skills. Careproviders frequently emphasized happiness and security in relationships. They described the importance of social interaction, both within and outside the Centre. Choice-making, and enabling residents to exert some control over their environment were also stressed. Finally, enhancement of both the residents' self-esteem and their social status were described as vital to overall quality of life.

The anticipated differences between professional groups were also reflected in the themes which emerged from the data. Systematic intraprofessional comparisons revealed that some themes were emphasized consistently by specific careprovider groups. Inter-professional comparisons demonstrated, however, that there were also themes which were identified by informants from virtually all disciplines as being important to a good quality of life. These widely

agreed-upon themes provided a foundation for consensus in treatment decisions, among professionals who emphasized differing treatment priorities.

The sections which follow will systematically explore themes which emerged from the data, as they were described by the careproviders and parents who were interviewed. Thematic categories which are similar to those published in other health-related quality of life research utilizing a multi-dimensional approach will serve to group the various themes (e.g. Croog and Levine 1989; Hornquist 1982; Schipper and Levitt 1985; Spitzer 1987; Ware 1987). These categories are physical health or well-being, emotional well-being, social interaction, intellectual or cognitive development, and overall self-esteem.

### **Physical Well-Being**

When respondents were asked to identify what they thought contributed to a good quality of life for the residents under their care, various factors relating to physical health and well-being were frequently cited. Although the importance of physical health was described by respondents from a number of disciplines, nurses and physiotherapists raised issues relating to this theme more frequently than respondents from other professional groups.

#### **Comfort and Cleanliness**

The importance of keeping the resident comfortable, and the contribution of cleanliness and appearance in enhancing social interaction and integration, was described by several members of the nursing staff. An excerpt from the narrative of one of the nurses emphasized the comfort theme.

...If you're not comfortable, you're not going to be able to enjoy your environment....Nobody will come to them if they're not clean ...and not looking appealing, which is terrible, but it's the facts of life. They won't get the attention others do.

Another of the nurses echoed the theme of comfort, and cited ways in which she was able to assess a client's comfort.

We measure quality of life in terms of comfort, whether the person - if they're acting out; or [in the case of] someone who is profoundly handicapped, if perhaps they're crying, expressing their needs in that way.

### **Mobility and Function**

The physiotherapists who were interviewed stressed mobility, and achieving the highest possible degree of physical function. These themes were emphasized as important contributory components of physical well-being and overall quality of life.

Just basically from our training, quality of life for us is movement. It's attaining the highest physical level that the child can. That's what we're striving for with many.

The importance of achieving or maintaining mobility was frequently emphasized in discussions concerning the importance of preventing residents from becoming bed-ridden, and of enabling them to be seated in wheelchairs or other types of mobility systems.

From our point of view, and I don't know if this would be the position of the client themselves, but we feel that one of the major factors contributing to quality of life is the ability to be in the upright position and be mobile. Once people can't sit up and enjoy that mobility then you take away, I feel, from a lot of the quality of life that they can enjoy, really; on a social basis, even from a work-related basis- which happens in some of our clients....Just being able to go outside, enjoy the fresh air, being pushed by somebody else, makes a tremendous difference, I think, in their day-to-day quality instead of just looking at the four walls of their room.

### **General Good Health**

Members of other professional disciplines, although not as directly involved in the day-to-day physical care of the residents, nonetheless recognized the contributions of the staff who were involved in personal care. These informants acknowledged the importance of health or physical well-being to overall quality of life. One of the psychologists stated:



... If you have good health then your quality of life is going to be better than if you don't. Therefore, anything that the medical people, the nursing folks can do that contributes to good health [is important to maintain a good quality of life].

One of the teachers also emphasized the importance of physical well-being, noting that the alleviation of physical discomfort might serve to enhance opportunities for development in other areas.

...I have so many children that are medically fragile that number one for me is always their health, well-being and comfort. For example, I have one student whose hip is literally going out of it's socket and my thought for this... young girl is to be comfortable, to have changes in position, and that's a very important part of her program. She's supposed to go in for surgery and once that problem is alleviated, hopefully then other things will be focused in on.

### **Physical Well-Being Summarized**

These examples illustrate two points in quality of life assessment involving proxy decision-making. First, the specific components of physical well-being considered to be most important reflected the professional ideologies of the respondents. The nursing staff tended to emphasize personal care, cleanliness and appearance; the physiotherapy staff mobility and function. These systematic differences in the emphasis of careproviders from different disciplines must be recognized as potential complicating factors in attempts to achieve consensus formation in team decision-making situations.

Second, some of the above statements suggest that professionals who were not directly involved in physical care were not hesitant to recognize the contribution of good health to overall quality of life, and to acknowledge its importance in providing a solid foundation upon which to develop the resident's potential in other areas. Shared recognition of the centrality of good health was one of the factors which appeared to facilitate consensus formation in decision-making. This theme will be discussed in more detail in Chapter 7.

## Emotional Well-Being

Themes relating to emotional well-being were consistently identified by representatives from all professional groups as making a vital contribution to overall quality of life. These themes included references to happiness, and to security and stability in relationships. The following excerpts from the narrative deal with the dimensions of happiness and security, and illustrate care providers' emphasis on the importance of emotional well-being.

### Happiness

Some care providers considered the attainment of happiness to be the primary objective for the clients with whom they worked. This was described by one of the occupational therapists.

Quality of life for our kids? Their happiness would be the first indicator. A lot of people don't expect our kids to even show their happiness, but I think they do in a lot of different ways a lot of people may not really see. Smiling is obvious; not crying, cooperating.

One of the teachers in the St. Amant School also stated that her students' happiness was of fundamental importance to quality of life.

How I judge that their quality of life has improved is by the change in their own demeanour, their happiness. You can tell they're happier. In a lot of them it reduces the self-abuse.

A member of the physiotherapy staff noted that, in some cases, the happiness of the residents might take precedence over the achievement of goals related to physical well-being.

... I have some kids that come down for my maintenance classes that I'm sure are going to keep getting worse range [of movement] even if they're seen twice a week, but when they're down they're smiling, they're happy on the way down, they love being handled and they love being touched, and the fact that I'm not getting any increase in range probably doesn't mean that much to them... So it makes me think that if I'm not getting my physio goal of increasing range of movement, at least I'm getting a personal goal of making somebody happy.

The acknowledgement by the speaker in the previous statement suggests that, occasionally, some dimensions of the residents' quality of life may take precedence over others. In this case, happiness was considered to be an equally or more significant intervention goal than improvement in physical or functional status. This emphasis upon the centrality of maintaining the resident's happiness in the process of weighting and prioritizing quality of life considerations in decision-making will be discussed in greater detail in Chapter 7.

### **Security and Stability**

Happiness was not the only factor which informants considered to contribute to emotional well-being. The importance of developing significant relationships with other people was emphasized by several of the respondents. One of the social workers expressed this viewpoint.

From my point of view, the primary importance is that residents have significant relationships with- have significant people in their lives; that they have relationships with people- intimate relationships. Because they're not living with their family, that at least...there are people on the unit that they can be close to; if there is family, that those relationships be maintained and encouraged as much as possible. So that's what I would see as number one; intimate relationships with people.

Another of the social workers also indicated that emotional well-being was considered to be important, both in terms of security, and of happiness.

... On a personal level, I think a good quality of life is to be comfortable, to be safe and secure, and a degree of happiness is pretty important.

The importance of considerations such as stability and happiness, was reinforced by one of the careproviders who was the parent of a child with special needs.

I guess if I was going to look at quality of life I would first look at stability. I think whether you're handicapped or not, you have a right to as stable, and troublefree, and happy a life as is in the realm of possibility.

Achieving emotional well-being was considered to be important, not just in its own right, but as a pre-requisite for improving quality of life in other dimensions. One of the teachers described happiness as the foundation for cognitive or intellectual development.

I think the things that I would use to measure whether their- what their quality of life is, perhaps first of all, are they enjoying what we're doing in the classroom. I think unless we're having fun that we're missing the potential for a lot of learning that could happen otherwise....So I would see dancing eyes, smiles, laughter as being a major indicator of whether I'm providing a quality program with these children.

### **Emotional Well-Being Summarized**

The achievement of emotional well-being was, therefore, the first priority of many careproviders in enhancing quality of life for the residents under their care. In some situations, maintaining or achieving happiness was described as being more important than improving physical function. In other situations, happiness and security in relationships were considered to be fundamental pre-requisites to the development of social and/or cognitive skills. The contribution of emotional well-being, in terms of security, stability in relationships and happiness, to overall quality of life was recognized across disciplines. As in the case of physical health or well-being, this consensus of opinion was considered to be a potentially important factor in treatment intervention decision-making.

### **Social Interaction**

Although themes related to physical and emotional well-being emerged most frequently as components considered necessary for a good quality of life, other themes were also identified in the respondents' narrative. One dimension of quality of life which was frequently discussed was that of social interaction. Enabling residents to interact socially both within and outside the Centre was consistently stressed.

One of the Adult Program staff emphasized the importance of social contact, and the development of relationships.

Social - and that can mean friendships or families - having social contact [is important]....I think quality of life for people here too might include having relationships with unpaid people - people who are there just because - not because they're getting paid to be there. I can't imagine what it would be like being around paid people all the time - people who are paid to be with them.

Social interaction was also recognized as an important consideration by careproviders who were primarily concerned with interventions designed to improve the physical well-being of residents. One of the physiotherapists spoke of the importance of sociability, citing as an example, the impact of maintaining one resident's ability to sit upright in a wheelchair.

...I think she's very sociable. She really likes being chatted with. And I think once you're stuck in bed, you can't look anybody in the eye, and they can't look at you in the eye either. So I think she'd probably get passed by on the ward quite a bit, whereas if she's up in the chair, everybody stops to chat with her. So that's probably the biggest thing. There are other things like her chest. I think maybe she would have a problem with her chest because she drools quite a bit when she's lying down where it doesn't give her much of a chance to clear her chest....

### **Social Interaction Summarized**

As indicated in the previous statements, enhancement of opportunities for social interaction was considered by careproviders to be of significant importance. In certain situations, opportunities for social interaction might assume greater importance than considerations such as physical well-being. In the above quotation, the speaker noted the importance of seating to maintaining capacity for social interaction, before alluding to the physical benefits of being in an upright position for part of the day. The relative importance of enhancing opportunities for increased social interaction in the process of decision-making will be considered later from the perspective of careproviders.

## Intellectual and Cognitive Development

Other themes which were identified in content analysis from the respondents, reflected the priorities of some careproviders in the area of intellectual and/or cognitive development. Many respondents spoke of enabling residents to make choices, to express preferences, to be able to exert some degree of control over their environment, and to exercise a measure of self-determination. Such themes were most frequently emphasized by careproviders involved in various types of programming.

### Choice-Making and Control

Choice-making and control were two dimensions of quality of life which were emphasized repeatedly by careproviders from all disciplines, but particularly those from education, psychology, adult program and recreation. The importance of enabling children to make choices, with particular reference to its role in facilitating communication, was described by one of the teachers.

... Even at the most basic level, if the kids are able to indicate a choice in some way or other between two things, that gets me on the first tiny step to establishing a communication program for them that, hopefully, will ultimately lead into something functional where they can make a lot of choices, and tell us a lot of things....

The same speaker emphasized the importance of choice-making in stimulating cognitive development.

The kids start to count on that [making choices]. I see that very quickly becoming very important to them. If they're used to making choices between things and all of a sudden they're just given something- it's a totally different situation. In one situation you have an active, thinking, operative human being, and in the other you have a passive receiver of service.... The quality of your life is measured by the extent to which your brain is working, and it's making choices, and it's finding things that give pleasure and fun, give satisfaction to your life.

A member of the Adult Program staff re-iterated the theme of enabling people to make choices, in reference to the adult population at St. Amant Centre.

Choice making, I think, is really important even for someone who is not able to communicate very well- maybe through eye glances or smiles. For people who can indicate a choice, I think that's pretty important for quality of life. Not to be stuck with what the staff decide to give you; to be given the opportunity to make choices wherever possible in things like clothing, hair cuts, food choices.

Another member of the Adult Program staff emphasized the importance of enabling the residents to make choices and, in doing so, of opening up the opportunity for them to exert a measure of control over their lives.

They love the [adult] program because they're doing things, they're actually participating, and they're given choices- more choices here. On the living unit, basically you're fed when it's time to eat because the cart comes up at a certain time, so they don't have much control in their lives.... Whereas here, we definitely can't give them choices all the time, of course, because we have a five to one ratio, but there are so many things that they can do independently or that they are taught to do.... It's the highlight of their day.... It really improves their quality of life having that little bit of control in some part of their day.

A member of the recreation staff expressed similar priorities, stressing the importance of allowing the residents to make choices, of treating them with respect, and of encouraging independence.

The most important thing to me is that the resident be given a choice, that he has rights, and that he be treated as - like if he's an adult, be treated like an adult - not as a kid just because he's mentally delayed. Letting him do what he can on his own. A lot of times staff do things for the residents and they don't have to do it.... I try to let the resident do as much as he or she can do.

Expanding upon the theme of enabling the residents to exert a measure of control in their lives, one of the psychology staff emphasized the importance of creating an environment which provides the resident with opportunities for self-determination, and for participation in normal life experiences without compromising safety.

Those things that to me are indicators [of quality of life]: that we are allowing as much self-determination as is reasonable, that that person has a secure environment in terms of the kinds of relationships that they have, and that they are safe, but in a dignified way, without removing all the normal risks and challenges.

The themes of choice-making and control were also raised by careproviders who, although their principal role was in the domain of physical care, recognized the importance of facilitating the development of potential in other areas. One of the physiotherapists, while acknowledging the priority that children achieve the highest possible degree of physical function, recognized that the ultimate benefit of this achievement was increased happiness, and the development of potential in other areas.

I look at some of the kids that we've got walking in the last few years, that were strictly in wheelchairs before. Improvement for their quality of life as I see it, is not being pushed to and from school. It's walking to and from school, whether it be with a hand held, or with a walker, or pushing the wheelchair with another child in it, or whatever.... The benefits are there. The child is much happier because they have some control over their environment, and they produce a lot better.

### **Intellectual and Cognitive Development Summarized**

Enabling residents to make choices, and providing opportunities for them to exert a measure of control over their lives through programs and activities which stimulate cognitive development, were described by many respondents as their ultimate goals for the residents. Although professionals from disciplines such as education and psychology tended to place more emphasis on these considerations, there was acknowledgement across disciplines of their importance. This agreed-upon consensus of opinion will emerge in Chapter 7 as the basis for some treatment decision-making.



## Self-Esteem and Social Status

While all of the dimensions of quality of life which have been described thus far could be considered to contribute to increased self-esteem, themes relating to this area were specifically raised by some of the respondents. These careproviders attributed a great deal of importance to the residents achieving not only an increase in self-esteem, but an increased status in the eyes of other members of society. The programs in which the residents participated were viewed as vital to achieving both increased self-esteem and social status. One of the Adult Program staff described how she felt the residents' status could be raised when visitors or other careproviders recognized that the residents were capable of cognitive and/or physical skills of which they were previously unaware.

We teach them work skills, which for me definitely improves their quality of life, because people that they know or people around them... see them in a different light.... When people walk into our program and they see somebody who they always thought of as being very severely disabled, mentally or physically, and they see them operating the computer by simply pressing a head switch, their status goes up with that individual like, one hundred times. The status that comes along with giving them that little bit of independence.

One of the psychologists also described how the process of enabling residents to do as much as possible on their own is attributed to increase the respect which they get from other members of society.

...Just by the mere fact that we're teaching people to do things, and if they're involved in programs like this, it allows people to think of them differently and that improves their quality of life, I'm sure. They get more esteem. I don't know if they get more self-respect. They certainly get more respect from other people.

It is interesting to note that careproviders referred to an external locus of control in describing potential sources of increased self-esteem. This is probably due to the difficulty inherent in assessing increased self-esteem on behalf of non-communicative residents. As careproviders were often unable to verify an actual increase in a resident's self-respect, they tended to focus on the importance of elevating the resident's status in the eyes of other careproviders, visitors and family members. This

increased status was perceived to be an important contribution to improved quality of life for the residents, although it could also be interpreted as playing an important role in contributing to the self-satisfaction of careproviders.

### **Quality of Life Summarized**

Themes defining quality of life in terms of physical and emotional well-being, social interaction, cognitive or intellectual development, and increased social status and self-esteem, were repeatedly emphasized by individuals from a variety of disciplines. Although the professional ideologies of careproviders from different disciplines appeared to influence the specific components of quality of life used to establish immediate priorities, virtually all professional groups considered physical and emotional well-being as fundamental pre-requisites to the enhancement of quality of life in areas such as social interaction, cognitive development and increased self-esteem. This suggested a more generalized interprofessional recognition of a hierarchial arrangement of the various dimensions of quality of life, in which there was significant agreement on the primary dimensions.

### **The Hierarchy Of Quality Of Life Dimensions**

It can be noted from the discussion in the preceding sections that, despite the influence of a variety of professional ideologies, respondents noted that the attainment of goals which they considered to be of immediate importance in terms of treatment objectives, did not necessarily fulfil their ultimate goals in terms of improved quality of life for the residents. Thus, careproviders who were involved in the provision of medical, nursing, or other clinical services, agreed that their ultimate goals went far beyond the attainment of physical health or well-being. Similarly, careproviders involved in programming designed to stimulate cognitive development and social interaction, recognized the importance of physical and emotional well-being as necessary pre-requisites to the success of such programming.

One of the physicians interviewed summarized the goals used to justify medical and/or surgical interventions as follows:

...In all situations, ultimately the quality of life, if you want to call it that, that is the psychological, sociological benefits are what you're really striving for.

Other medical professionals expressed similar viewpoints. Although nursing staff members emphasized the achievement of physical comfort, they also recognized that, having achieved this end, enabling the residents to interact socially, to participate in programs, and to enhance their cognitive development was also important. One of the nurses expressed her feelings regarding the ultimate goals for the residents.

I think we can provide a very good quality of life. If they're looking comfortable that's a criteria - they're looking clean and they're comfortable and not complaining of pain. Then take that one step further - they're accomplishing certain tasks, they communicate back to you by smiles and laughter. That's an indication of quality of life to me.

The viewpoint that there should be more to life than physical care, no matter how good that care might be, was also expressed by one of the occupational therapists.

I think there's more to life than physical care. And there's loving and everything in that too - I mean people are very kind to the residents that aren't going anywhere or doing anything but - just in terms of a change of position or a change of place - a change of ceilings to look at - you know there's got to be something said for that in terms of their lives.

One of the Adult Program staff echoed this viewpoint, stressing that dimensions of quality of life other than those related to physical care are probably most important in the final analysis, and suggesting that emphasis should be re-directed to focus on those dimensions.

... I think now if we focused a little more on quality of life, not so much just physical needs, but some emotional and some of the other needs you have in life, that I think it would stand us in good stead....It's not as much as it was years ago - but we would dress people up nicely, and they look nice, and their clothes are always pressed freshly, stuff like that- that's the most important. I don't think fancy hairdos and pressed clothes are everything.

While the two quotations immediately above could be interpreted to reflect a belief in the importance of the work done by the professional disciplines represented by the speakers, there were indications that, in the minds of many of those interviewed, the various components of overall quality of life formed a hierarchial system with physical and emotional well-being as the foundations upon which other components could be developed more fully. Reference to this hierarchy was made by some of the respondents quoted in previous sections, and was expressed very clearly by one of the teachers.

Well, I guess it's like a tiered system in a way... I have so many children that are medically fragile, that number one for me is always their health, well-being and comfort.... Once that [physical problem] is alleviated, hopefully then other things will be focused in on.

One of the psychologists summed up the feelings of many of the careproviders, stating that good health is important, but not as an end in itself.

Generally you want people healthy for a reason. Like there has to be a life to live and that's what you're getting people healthy for. Good health is not an end in itself. If that's all that we provide here is good health, then we're missing the boat by a long shot. Because I think if you again look at quality of life for the average person, a lot of people who have their health would rate their quality of life low because of misses of other important ingredients.

These narratives suggest that, while the various careproviders who contribute to treatment decision-making may want to give priority to interventions emphasized by the treatment philosophy of their specific disciplines, most agree that their ultimate goals in improving overall quality of life for the residents, are achieved by providing opportunities for social interaction, the development of significant relationships with other people, and the development of cognitive/intellectual skills. The existence of this consensus of opinion is an important factor in the proxy decision-making process, and contributes significantly to the ability to make decisions based on the best interests of the client. Examples of the ways in which these various quality of life considerations are weighted and prioritized in specific decision-making situations, will be the focus of the next chapter.

## CHAPTER 7

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### WEIGHTING AND PRIORITIZING QUALITY OF LIFE CONSIDERATIONS

This chapter will focus on themes from the respondents' narrative describing the ways in which the component dimensions of quality of life are weighted and prioritized, in the process of proxy decision-making on behalf of residents who are unable to communicate their wishes. Respondents were introduced to this subject as follows:

Interviewer:

During this interview, you have indicated that there are a number of dimensions which are incorporated into your definition of quality of life. When you are making decisions on behalf of the residents here, do certain quality of life considerations receive greater priority than others?

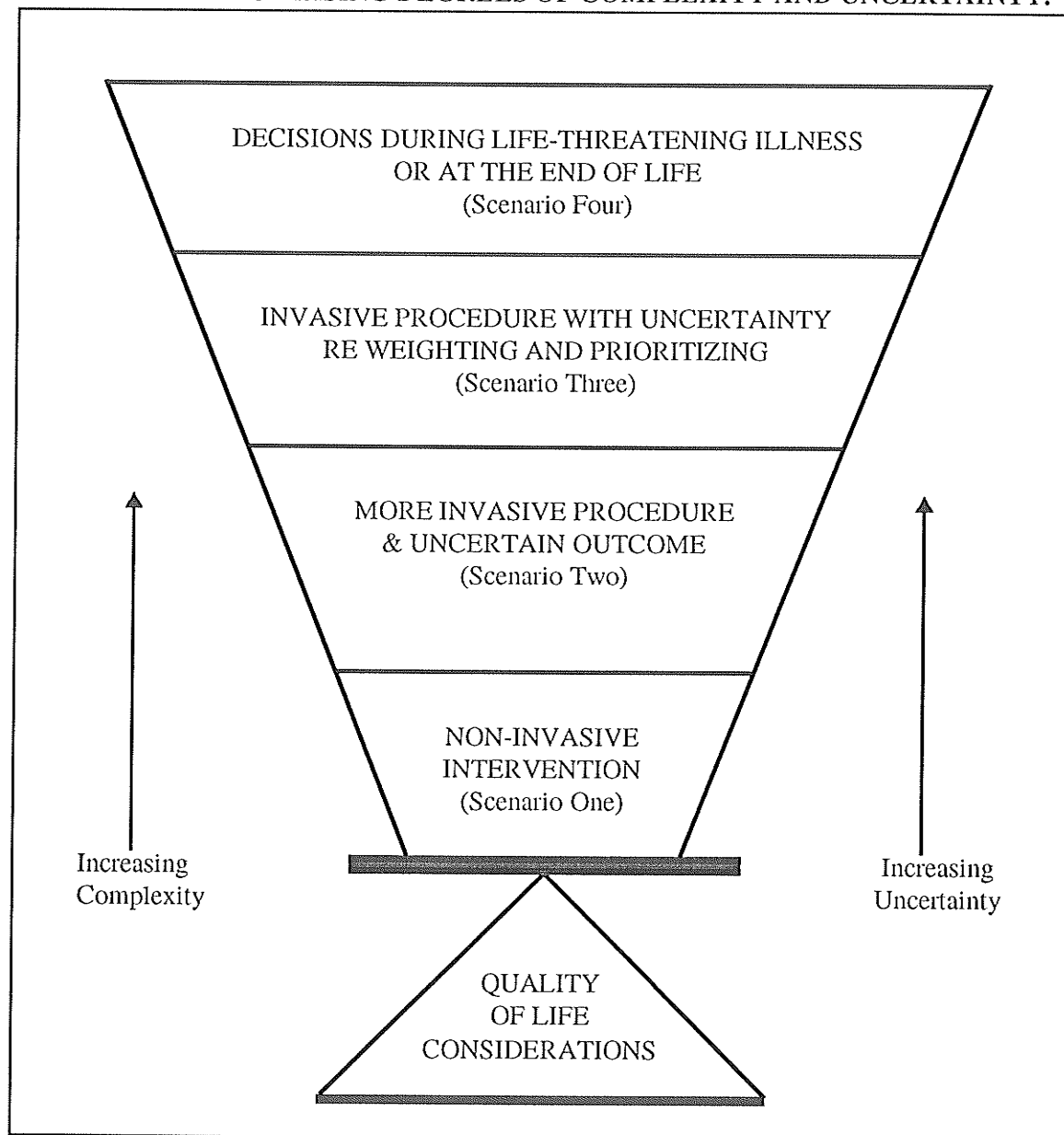
In the process of identifying the factors which they believed were most important in quality of life decision-making, participants made reference to a number of problematic decision-making situations which frequently arise at St. Amant Centre. Scenarios illustrating four of the most significant dilemmas in decision-making have been selected for inclusion in this thesis. These four examples were selected to represent a continuum of decision scenarios, in which the degree of uncertainty and complexity associated with the weighting and prioritizing of quality of life considerations progressively increases. They are:

- 1) An example of decision-making involving a non-invasive intervention in which careproviders weighted short-term burdens against potential long-term benefits.
- 2) An example involving an invasive intervention, where neither the outcome nor the impact of the intervention on specific dimensions of quality of life could be predicted accurately.
- 3) An example of an invasive intervention in which there was greater uncertainty among careproviders about which quality of life criteria should be weighted most heavily in decision-making.
- 4) Examples of dilemmas associated with decisions regarding intervention or non-intervention in life-threatening situations.

A schematic representation of these decision scenarios, illustrating the progressive increase in the uncertainty and complexity associated with using quality of life considerations as a basis for proxy decision-making, is provided in Figure 5.

Figure 5

**SCHEMATIC REPRESENTATION OF QUALITY OF LIFE  
CONSIDERATIONS BEING USED TO BALANCE DECISIONS  
IN PROXY DECISION-MAKING SCENARIOS  
INVOLVING INCREASING DEGREES OF COMPLEXITY AND UNCERTAINTY.**



The four decision scenarios outlined in Figure 5, will be described using narrative text obtained during in-depth interviews with the respondents. The quality of life considerations which are weighted and prioritized in each of the decision-making scenarios will also be described.

Respondents frequently illustrated their discussion of quality of life decision-making by referring to specific case examples from their own experience. These case examples have been included in the descriptive narrative which follows, in cases where the permission of parents/guardians was obtained. Information about case studies describing the experience of specific residents, involved comparison of information from parents and careproviders with observations made by the researcher at Orthopedic Clinics, IPP meetings, and sensory stimulation programs involving some of these residents.

### **A Non-Invasive Intervention: Scenario One**

The initial decision scenario involves decisions relating to the use of external orthotic devices. As orthotic intervention is non-invasive, the central research question focuses on the ways in which proxy decision-makers apply quality of life criteria in deciding whether the possible short-term burdens imposed by the wearing of an orthosis justify the potential long-term benefits of the device.

Orthotic devices which are frequently used at St. Amant Centre include various types of splints, as well as a spinal jacket called the Soft Boston Orthosis. Orthoses are prescribed with the objective of slowing or preventing the progression of skeletal deformities through proper positioning.

Although it is the therapy staff and the consulting orthopedic surgeon who recommend and order orthotic devices, the staff on the living units are responsible for correct and regular application of the orthoses, and for monitoring the residents' responses. During in-depth interviews, members of the nursing staff often expressed concerns about the potential discomfort experienced by residents who use these devices. As one of the foremost priorities of the nursing staff is to assure the resident's comfort, some careproviders perceived that the use of orthoses was sometimes not in the resident's best interests.

This apparent conflict of priorities was described by one of the living unit staff in reference to splints which had been recommended for a specific resident.



...[W]e were supposed to put these on- like apply these, and he wasn't comfortable and you could tell 'cause he was always crying or whining. And, you know, to me comfort care for him would be taking him out of the splints, even though he's supposed to have them on.

This type of concern was most frequently expressed by careproviders in reference to the Soft Boston Orthosis. In addition to concerns about potential discomfort, members of the living unit staff recognized that the contribution of the orthosis in preventing deformity in later life has not been demonstrated in longitudinal studies. The following is an excerpt from an interview with one of the aides who questioned the use of these orthoses or body jackets, especially for the older residents.

Even with a lot of these body jackets, I think these things should have been done when the kids were much younger. At this point I say, are you really doing a kid any good any more, when they're twenty-two, putting them in a body jacket, after they've been like this for so many years? I think it should be done at a much younger age. Not that I'm blaming anybody. If I'm told to put them on, I'll put them on, but I can't say that at this age it's going to do any good, other than preventing them from getting worse.

One of the nurses expanded upon these concerns in the narrative excerpt which follows.

I'm having a lot of problems with the appliances right now - having a lot of difficulty accepting those for various reasons. I'm not sure that they are serving any purpose, and I'm not sure that anyone has been able to prove that they serve a purpose. I think they add to the discomfort in many instances. Again, that's very subjective on my part. They do help some of the children with seating, but whether or not they prevent scoliosis from becoming worse, I don't really know if I'm convinced of that. As I say, no one has ever proven it yet to my knowledge.

The speaker also recognized, however, that there was at least one advantage to using the orthosis; that being its contribution in assisting the resident to sit better in a wheelchair. Reference to the impact of the Soft Boston Orthosis in improving the resident's sitting posture was also made by another member of the nursing staff.

I think the residents that are in the body jackets, they sit a lot straighter in their wheelchairs- they're not flopping over the side.

The contribution of the appliance to improved sitting posture was most strongly emphasized by the physiotherapists. An excerpt from an interview with one of the therapists is presented below:

Soft Boston Orthoses - we've incorporated into seating a lot - have made a big difference, I think, in the quality of many of the resident's lives, because sitting isn't nearly as big a hassle or as stressful for them as it was. Many of them didn't have control to be able to hold their heads upright, or to use their arms, and with good supportive seating, it's given them the ability to move their arms and to hold their heads up and do other things.

One of the parents who was interviewed stressed both the potential future value of the orthosis in preventing or limiting deformities, as well as its current value in maintaining her daughter's ability to sit upright.

... Her body jacket that she wears- heavens, if she wouldn't have that, I'm sure her spine would be way worse than it is, 'cause it's bad enough without it. But with it, it makes it much, much straighter, so that gives her a chance that it would maybe stay at that, hopefully. Because some of the children, as it gets worse, they have to lay all the time - they can't even sit.

These several examples illustrate the contradictions and trade-offs in decision-making involving non-invasive interventions. Soft Boston Orthoses are provided to residents to help maintain erect posture when the individuals are seated. They are also provided to prevent or slow the progression of future skeletal deformities such as scoliosis. Some careproviders, particularly members of the nursing staff, asked whether the orthoses caused the residents some degree of discomfort, but admitted that they were unable to assess the severity of the discomfort. The dilemma for the decision-makers is whether the potential, but as yet undocumented long-term benefit of the device in preventing or limiting spinal deformity, outweighs the perceived short-term burden of discomfort. Careproviders from different professional backgrounds were observed to place a greater emphasis on either the burdens or the benefits of particular interventions. The dilemma of choosing whether or not to intervene cannot, therefore, be resolved simply through weighing short-term burdens against potential long-term benefits.

Careproviders and parents who were interviewed did, however, reveal one area of consensus. Shared recognition of the contribution of the Soft Boston Orthosis in assisting residents to sit better, enabled careproviders with different agendas to agree to use this appliance. In order to resolve the dilemma of how to most effectively weigh short-term burdens against long-term benefits, careproviders tended to focus on the most visible and consistently recognized benefit to the residents; that of improving their ability to sit upright.

The next section will describe the nature of quality of life considerations related to the ability to sit upright, and explore the reasons why careproviders considered this ability to be important enough to justify an intervention which may cause discomfort, and for which the long-term benefit is essentially unproven. Discussion will focus specifically on the ways quality of life criteria are incorporated into decisions to use Soft Boston Orthoses.

### **Weighing Quality of Life Considerations: Scenario One**

The narrative presented in the last section emphasized that the ability to sit upright in wheelchairs or other types of mobile seating systems was considered to be of fundamental importance by many of the respondents. It is a widely accepted practice in health care that the capacity to maintain non-ambulatory people in an upright position for at least part of the day has physiological benefits, such as improving digestion and aiding in the prevention of respiratory problems associated with being bed-ridden. As indicated in Chapter 6, however, benefits related to the maintenance of physical well-being do not always carry the most weight in the process of prescribing and evaluating treatment interventions. In discussing the value of orthoses in supporting residents in the seated position, respondents verified that other quality of life considerations were of equal, or greater relative importance, than criteria involving maintenance of physical health or well-being.

The contribution of appropriate seating to quality of life was described by one of the nurses, who initially emphasized the physiological benefits, and subsequently recognized the importance of seating in assuring the resident's mobility. She then identified some of the additional opportunities which were afforded by enabling residents to be seated in wheelchairs.

I think that they should be seated. For meals it's only normal that your digestive system is going to work better if you're in the upright position. And mobility - it's good for the family to have mobility, just stroll around the grounds in the summer....It gives them a chance to experience other things....There'll be more opportunities for them.

One of the physiotherapists focused on the opportunities for functional and cognitive development which were possible when an individual is well-supported in an upright position.

...They're able to attend better in school when they're in a good supportive seating position- to do more quality type things, or to manipulate switches, or whatever it may be.

In the narrative which follows, two other members of the physiotherapy staff also commented on the benefits of seating. In the first excerpt, the respondent emphasized the vital role of wheelchair seating in achieving the treatment objectives established by the Physiotherapy Department. In the second excerpt, the therapist stressed the importance of seating in terms of providing increased opportunities for residents to see and experience more of the world.

#### **Excerpt #1**

We feel that it's [seating] a very basic necessity for any quality of life that we can offer to the individual. I guess from a movement point of view, a lot of our treatment philosophy is really based on providing an opportunity for severely handicapped people to experience movement, experience different positions, experience being handled, all those kinds of things- rather than directing our treatment towards improving the physical capabilities. It's more allowing for some of the normal experiences that every person should be able to have.

#### **Excerpt #2**

...It's [seating's] the link between people being stuck in bed, and people being able to be up and see the world or see other parts of the world instead of just their room. And some of the ones that are not able to sit up end up in bean bag beds basically, and look at the ceiling all the time.

Although careproviders from all disciplines agreed on the central contribution of seating to improving the residents' quality of life, they acknowledged the problems of assessing the more subjective aspects of the intervention from the resident's perspective. They recognized that

determining whether the ability to sit contributed primarily to improved physical well-being, or to the enhancement of other dimensions of quality of life, was virtually impossible. One of the physicians articulated this problem in describing decisions to re-seat individuals who had been bed-ridden for several years. He/She noted that it was difficult to assess the benefits, but stressed that the value of the intervention in terms of improving "human interaction" aspect was probably of primary importance.

I would say that the short answer to that is that you get people up for the "human interaction" rather than just the physiologic benefits, but again I emphasize that I'm not diminishing the physiologic benefits of that. It's still very helpful. The other thing you have to remember is that sometimes you can't separate the two at all.

One of the physiotherapists also expressed uncertainty in assessing whether the physical or the social aspects of seating were the most important considerations. The informant indicated, however, that the potential for facilitating social interaction was probably the primary consideration in decisions involving one particular resident.

I think she's very sociable. She really likes being chatted with. And I think once you're stuck in bed you can't look anybody in the eye and they can't look you in the eye either. So I think she'd probably get passed by on the ward quite a bit. Whereas if she's up in the chair, everybody stops to chat with her. So that's probably the biggest thing. There are other things like her chest. I think maybe she would have a problem with her chest because she drools quite a bit when she's lying down where it doesn't give her much of a chance to clear her chest.... Probably sociability is the biggest thing.

The range of opinions expressed in the narrative of these careproviders reflects their evaluation of the vital contributions of seating to maintaining dimensions of residents' quality of life other than physical well-being. These contributions included improving social interaction through the development and maintenance of relationships with other people, and maximizing the residents' cognitive development by providing the opportunity to attend school, workshops and other programs. Seating was perceived by the respondents to be the "link" to enabling the residents to experience more of life. Devices such as the Soft Boston Orthosis are accepted, therefore, despite some careproviders'

misgivings about the degree of comfort afforded, and despite uncertainty about the long-term benefits. The contribution of the orthosis to the client's ability to sit, and the subsequent opportunities afforded by this ability are recognized by all careproviders. This area of consensus is thus an important factor in decisions to use the orthoses.

The emphasis on seating as a means of creating opportunities for social and cognitive development, reinforces the idea that physical well-being or health, while important, may be considered of less importance than other factors pertaining to a resident's quality of life. If physical comfort were the only consideration weighted in this decision-making process, then it would seem likely that keeping residents comfortable in bed without using orthotic devices which might be deemed uncomfortable, or seating systems which rigorously support them in the upright position, would maximize their quality of life. Other factors, however, were considered by careproviders from all disciplines to be of equal, or greater importance than physical comfort. Decisions involving the provision of orthoses and seating systems would, therefore, appear to reinforce the existence of a hierarchial arrangement of criteria defining the dimensions of quality of life, as described in the previous chapter. As will be noted in the next sections describing decision scenarios involving greater degrees of uncertainty and complexity, however, a model describing quality of life decision-making would be much more complex than a simple hierarchial arrangement.

### **A More Invasive Intervention: Scenario Two**

In the course of in-depth interviews, careproviders described other proxy decision-making scenarios in which the invasiveness of the intervention necessitated the weighting of a number of additional quality of life factors, and increased both the complexity and the uncertainty of decision-making. One scenario centered on decision-making about the surgical management of progressive skeletal deformities.

Progressive skeletal deformities tend to occur in the presence of severe neurological impairment, even among residents who are well-managed clinically. Hip dislocations, pelvic

obliquity and progressive scoliosis can cause pain, and make it difficult for staff to carry out routine care activities. Severe deformity can also compromise the residents' functional capacity to sit comfortably in a wheelchair.

In situations where the development of deformity is observed, surgical procedures including soft tissue releases, reduction of hip dislocations, and spinal stabilizations are sometimes proposed as mechanisms to delay or arrest the progression. Decisions involving such surgical interventions are usually made at Orthopedic Clinics by the orthopedic surgeon in consultation with the therapy staff and the head nurses. Final consent for surgical procedures must be obtained from the parents or legal guardians.

As in the first decision scenario, the central question in decision-making centers around the problem of weighing short term burdens against potential long-term benefits and an uncertain outcome. Careproviders and parents must, however, consider a number of additional quality of life factors in situations where orthopedic surgery is contemplated. The procedure is much more invasive than the provision of an external orthotic device. A decision to perform orthopedic surgery requires that the resident be transferred to an unfamiliar acute care facility, and be subjected to a painful surgical procedure. Careproviders are uncertain as to the amount of physical pain experienced by the resident, and are also unsure about the extent of the emotional trauma caused by transfer to an unfamiliar facility where care is provided by unknown careproviders. As with any surgical procedure, the possibility of complications during or after the surgery must also be weighted in the decision-making process. The specific nature of these uncertainties will be described in more detail in the following section.

### **The Impact of Surgery on Physical Well-Being**

Prevalent surgical interventions which were proposed included soft tissue releases and/or varus osteotomies, both of which were recommended as ways of preventing or reducing hip dislocation. One of the nurses summarized some of the concerns articulated by careproviders in discussions related to decisions to perform hip surgery.

Hip surgery, I'm not sure, because we've had some really unfortunate results here. On one child- he had a really rough time in surgery- it set him way, way back in everything and he lost all of his skills. He was sick for about a year and a half. It was a real problem for him.

Maybe in the long run it has benefitted him, I don't know. You have nothing to compare it to. You don't have two children that are identical - one you send for surgery and one you don't- then you compare the results. It just doesn't happen that way. I can't say that had they not done it, he would be sitting or not sitting. We just don't know. But I suppose there's been enough in the past where they haven't done this surgery and have shown that they end up not being able to sit or whatever.

In this statement, the informant describes: (1) the short-term burdens associated with the procedure, (2) the problems of uncertainty in assessing the future benefit of the procedure for the resident, and (3) the problems of decision-making in situations where there is minimal objective evidence to verify the efficacy of the intervention. On the positive side, the potential contribution of the procedure in maintaining the resident's ability to be seated was also acknowledged.

One of the physiotherapists elaborated on the reasons for recommending surgery, referring to the unchecked progression of severe deformities which has been observed among residents who have not been treated surgically. The long-term benefits which were anticipated to be a consequence of the intervention were noted, and a reference was made to the secondary benefit of enabling residents to sit better.

We know that one of the most frequent reasons why people develop deformity is because of a dislocated hip, and this is why surgical management of a dislocated hip or a subluxating hip we feel is indicated, because we've seen the deformities that people do develop without surgical intervention.

I can't say right now whether or not that surgical intervention is - 10 years from now- is going to actually show a decrease in the number - not the number but the severity of the deformities....But hopefully when we look at our population 20 years from now, we'll see a decrease in the number of bedridden individuals, the number of individuals who have deformities to the severity that they aren't able to sit up any longer, and you know we have a population of those individuals right now.

Another surgical procedure which was sometimes considered was that of spinal stabilization.

Another of the physiotherapists discussed the long-term problems which are frequently associated



with severe progressive spinal deformity. In the narrative, reference is made to a decision involving a particular resident who was a candidate for spinal stabilization surgery.

...I think it will definitely be a big improvement in the long run because her curve is progressing at such a rate that in another few years the spine is going to be on the pelvis, and it's going to very drastically restrict her respiratory status, and then we're going to run into problems with things like pneumonia. If she picks up an infection, she's not going to be able to have the resistance or the lung capacity....

The informant elaborated on the potential improvements which were anticipated to result from performing spinal stabilization surgery. The effects of the surgery on the client's future quality of life in terms of preventing pain and respiratory distress were emphasized. The therapist also stressed that the surgery would improve the resident's quality of life because the individual would no longer require a body jacket to stabilize her spine.

I would think, in somebody like her case, that it would - the quality of life would improve. Because I would think that even from a comfort care standpoint that should - as they deteriorate when they get older - if her chest is so that she can't breathe easily, she's going to be in a lot of pain.

Also it means too that if she has surgery now, then once she's through the convalescent stage she won't have to wear a body jacket any more. She hates a body jacket - she's a child who is very uncomfortable - they're not made for everybody - not all children tolerate them....

### **The Impact of Transfer on Emotional Well-Being**

Although the preceding narratives indicate that improvement in the physical well-being of residents through the prevention of pain and deformity weighed heavily in decision-making about surgical interventions, it did not represent the only factor considered by careproviders. Respondents also expressed their concerns about the impact of surgical intervention on residents' emotional well-being. A decision to perform surgery necessitates transfer of the individual to an unfamiliar acute care centre where he/she does not know anyone. One of the aides from the living unit staff articulated her concerns, describing the possible effects of transfer from the perspective of the resident.

We've had a few cases where it seemed the kids were happy to come back- back home sort of thing. Familiar faces and all that. I think it must be scary for them to be sent out to a strange place. It would be like sending a two year old. It's a certain amount of security for them. You're used to the routine and all of a sudden your whole routine is changed.

One of the nurses expressed the anxiety which she perceived that the residents experienced when they are transferred to an unfamiliar setting, and were unable to comprehend the reasons for the change.

It's a big thing for them. They have to go to a strange place, and strange things are going to happen to them that they don't understand and you can't explain. It must be frightening in some instances for some. The ones that are really low functioning perhaps don't even have a clue what's going on. I really don't know. Who's to say?

Similar concerns were expressed by one of the physiotherapists, who stressed the inability of residents with profound cognitive impairment to understand the reasons for performing surgery.

I don't think that they [the residents] have the capacity to be told that it's something that's going to improve them, or they don't have the understanding that this was a necessary step.

This speaker also observed, however, that the residents may be cognizant of the fact that they are in strange surroundings when they are transferred. Periodically, during the time the investigator was observing Orthopedic Clinics, careproviders observed that some residents appeared to be angry or withdrawn for a period of time when they returned to St. Amant Centre after surgery which involved transfer to an acute care facility. In this excerpt from the narrative, the speaker attributes reasons for observable changes in the behaviour of the residents.

...They know they were taken away somewhere, they know that they were somewhere where no one knew them, and it was almost like we were getting rid of them and then subjecting them to so much pain.

Another theme was identified by several respondents when they referred to the problems which they perceived might be experienced by residents who were transferred to other facilities.

They realized that careproviders in other facilities were not familiar with the residents, and perhaps had little experience caring for people with severe-profound impairment. The aide quoted previously in this section alluded to the potential difficulties which might be experienced by staff in acute care centres.

...If you haven't dealt with any of these [individuals] in the hospital, and one of these kids are brought in, you don't know what the child likes or what the child doesn't like.

The observations of this speaker were verified by both other careproviders, and by parents of residents who were transferred to acute care facilities for surgery. One of the parents described her daughter's response to transfer.

I know when [my daughter's] at \_\_\_\_\_ Hospital, it appears to me that she's been crying all the time, or weeping all the time, and I'm sure that she's really unhappy when she's there.

The speaker continued, reflecting upon possible reasons for her daughter's response, and noting that different careproviders who were unfamiliar with the child and her daily care routines could make the experience an emotionally traumatic one.

It's really different when you're in a hospital. I mean it's not that there's anything wrong with the people that work there, but St. Amant is home and the people that work there- that's like their Mom and Dad and everybody all wrapped into one, you know. They depend so much on them. So if you take them away from there, I'm sure it's like taking you out of your home and plunking you into a strange place....

...The people there don't know her, and they don't know what she likes or dislikes, and it's hard. And people from St. Amant can't be there to tell them.

The potential physical and emotional trauma associated with invasive surgical procedures, adds to the complexity of proxy decision-making in situations where decisions about surgery must be made. The weighting of specific quality of life considerations which are incorporated into the decision-making process will be described in the following section.

### **Weighing Quality of Life Considerations: Scenario Two**

Decision-making about surgical interventions is a complicated process. The potential long-term benefits of orthopedic surgical procedures cannot be predicted with certainty. Short term burdens, such as the amount of pain and the possibility of complications after surgery also cannot be accurately predicted. The emotional effects associated with transfer to other centres were also identified by many respondents as primary areas of concern.

Frequently, however, both the short-term burdens associated with the surgery, as well as the uncertain long-term preventative effects, were outweighed by other considerations. Careproviders emphasized the need to prevent the pain associated with progressive skeletal deformities. They stressed the importance of maintaining range of motion so that basic care activities such as bathing and diapering could be provided without subjecting the resident to significant discomfort. Finally, they recognized the importance of enabling the resident to be seated comfortably in a mobility system, and to continue to attend programs both within and outside the Centre.

One of the physiotherapists discussed the indications for orthopedic surgery, emphasizing the importance of the roles of careproviders in relieving pain and ensuring that they can maintain adequate physical care for the residents.

There's actually two classifications, I think, of individuals for whom surgery is indicated. One is the severely affected residents where we are actually trying to decrease the amount of pain that a person is having through surgical intervention, or for those who are so severe that perineal care becomes a problem when they're moved, and trying to put a diaper on, the patients themselves are in pain.

These comments, describing the criteria used to recommend surgical interventions, emphasize the immediate or short term goals of surgery. The physiotherapist went on to describe a second set of evaluation criteria, justifying orthopedic interventions in terms of their longer-term benefits in minimizing progressive deformities such as scoliosis. The benefits of surgical intervention in terms of preventing future deformities, were perceived to accrue over the life course.

I would say in the past 10 years, there's been more and more aggressive surgery done to try and minimize the deformities that we see, ... just because with our adult population we know the problems that most of these individuals are going to run into in a few years.

The speaker then noted that, by minimizing severe pain and deformity, careproviders hope to prevent individuals from becoming bed-ridden, to enable them to sit upright in a wheelchair or seating system, and to participate in life as fully as possible.

For our population, if they can't be seated comfortably during the day, it precludes them from so many other activities. I mean a big part of the quality of life for a lot of our individuals is just being able to get out of their rooms, and unless they have adequate seating, they can't get out of their rooms, they can't attend workshops, they can't attend all the other special activities that occur outside the Centre, go to the Jets games. You know, what are they going to do if they can't sit?

So, in terms of quality of life, I think it's [seating's] a very big issue....and surgical intervention, because it does facilitate, or may facilitate seating, is another big issue.

Surgical intervention, therefore, by virtue of its potential role in preventing or minimizing pain and deformity and facilitating seating, was ultimately considered to enhance the quality of life of the residents.

Some of the respondents' preferences for interventions which enabled residents to sit upright and avoid being bed-ridden, developed from their observations about the quality of life of individuals who were re-seated after being confined to bed for several years.

I think when we look at some of the individuals who, in the past, we've given up on in terms of seating and are now starting to re-seat again, when we look - at least from a subjective point of view- at someone who has had to lie on either a bean-bag chair or a bed all day who can now be taken off the ward, taken outside for walks. You know, you can't ask that individual whether or not their quality of life - I wish we could - but from an observational point of view you have to admit that that kind of life would be much better, especially for those who you feel really enjoy being moved around, enjoy being pushed.

Respondents asserted that enabling residents to be seated and mobile allowed them to see more of the world than just the four walls of their rooms. They observed that the sense of pleasure or satisfaction which this ability was perceived to provide, was an important consideration in

decisions to carry out surgical procedures. Often, such considerations outweighed concerns about the physical and emotional discomfort associated with the procedures. Although respondents emphasized that appropriate orthopedic intervention could prevent future painful deformities and compromised respiratory systems, they also recognized that increased comfort in later life could not be guaranteed. The immediate benefits of facilitating the residents' physical care, preserving their ability to sit upright, and maximizing mobility and program participation, were part of the careproviders' subjective evaluations of the requisites for maintaining or improving quality of life. These considerations provided common ground for consensus in proxy decisions where careproviders decided in favour of surgical intervention.

Quality of life considerations pertaining to the physical and emotional well-being of the residents, assumed greater importance in decision-making about orthopedic surgery than in decisions about the use of orthoses (as discussed in Scenario One). Although such considerations were not necessarily the most important criteria in decision-making involving orthopedic surgery, they assumed a more significant role because of the invasiveness of the intervention. The emotional well-being of the resident also assumed greater importance in this decision-making example, because of the necessity of transferring the resident to an unfamiliar acute care facility.

As in the previous scenario, however, if the decision to perform or not to perform surgery were based solely on considerations pertaining to the resident's physical and emotional comfort, non-intervention might seem to meet those needs more fully. My observations suggest that it was the combined recognition that the intervention should reduce future pain, ensure increased comfort for basic care procedures, and enhance the residents' abilities to be seated in a mobility system, that ultimately formed the basis for the careproviders' decisions. Consensus on this combined set of criteria ultimately allowed careproviders to agree on the need to perform a particular intervention. Once again, quality of life considerations pertaining to the enhancement of the individual's ability for social interaction and intellectual/cognitive development are important decision criteria. The significant weighting given to physical and emotional well-being in decisions surrounding orthopedic surgery indicate, however, that decision-making in some situations cannot proceed on the basis of a simple hierarchial arrangement of the various dimensions of quality of life.

### **A More Controversial Intervention: Scenario Three**

As noted in the previous section, the process of deciding to perform orthopedic surgery when there is a significant amount of uncertainty about the potential risks and outcomes of the procedure, can be problematic. A consensus can be usually be developed, however, on the basis of quality of life considerations which are recognized as being important by all decision-makers. The following section describes a decision scenario in which the complexities of decision-making about an invasive surgical intervention are significantly increased, due to uncertainty among careproviders as to which quality of life considerations should receive primary consideration. This decision scenario exemplifies the potential for conflict, in situations where careproviders disagree about the relative contribution of specific dimensions of quality of life to the enhancement of overall quality of life.

The intervention considered in this third scenario is gastrostomy, a surgical procedure through which a feeding tube is inserted directly into the stomach. Gastrostomy is frequently performed on residents who have been fed for long periods of time through naso-gastric tubes, as well as on residents who experience significant difficulties with oral feeding. Decision-making about gastrostomy surgery involves considerations which are similar to those described in decision-making surrounding orthopedic surgery. The physical pain imposed by the procedure, the emotional trauma associated with transfer to another facility, and the possibility of complications during or after surgery are all taken into account by decision-makers.

An additional element of uncertainty is often introduced as careproviders express differing opinions as to the impact of the procedure on specific dimensions of the residents' overall quality of life. As will be illustrated in the narrative of informants describing their decisions, there was a significant degree of consensus among careproviders and parents as to the physical benefits which could be derived from gastrostomy. There was also general agreement among decision-makers that performing a gastrostomy enhanced quality of life in cases where residents had been subjected to long-term naso-gastric tube feedings. In cases where gastrostomies were performed on residents who were previously orally fed, however, and where a decision in favour of gastrostomy would result in a loss of oral feeding skills, there was less agreement about the effects of the procedure on overall quality of life.

### Naso-Gastric Tubes vs. Gastrostomy

Two of the nurses who were interviewed summarized their perceptions of the physical benefits which were derived from gastrostomy, and compared the benefits of the procedure with those of naso-gastric (levine) tube feedings.

#### Excerpt #1

There's problems with levine tubes with aspirations, excessive mucous. With the gastrostomies there's less chance of aspiration and they're not as mucousy because they don't have that tube going down their nose. When they get mucousy you have to suction them and I'm sure that's not comfortable for them.

#### Excerpt #2

When you put in a gastric tube, it can go into the lung. They kept pulling them out as well. A lot of them don't touch their G-Tubes. They think they're comfortable.

Another of the nurses described what she perceived to be additional benefits of gastrostomy feeding for residents who experienced difficulty with oral feeding and who, in the past, would have been fed via a naso-gastric tube.

People who are no longer able to eat orally used to receive nasogastric feedings, and the tube was really visible and irritated the mucosa and it often necessitated having the person's hands having to be restrained so that they wouldn't pull the tube out. So when we started doing gastrostomies it meant the person gained weight, had use of their hands, the catheter wasn't as evident, and I think that contributed to the quality of life. Once they gained weight they seemed to get more ambitious, they were nourished and they were more aware.

The contribution of the gastrostomy to normalization of the residents' appearance was described by one of the parents, on the basis of observing her daughter's transition from a naso-gastric tube to a gastrostomy tube.

The tube in her nose was- well, it wasn't nice to look at either and- it's okay for us to get used to it, but some of my family had a hard time, or have a hard time still to accept those things, if they don't see them all the time. So actually having the tube where it is now is good because it's out of the way and nobody sees it and it makes her look more normal.



These narratives suggest that the benefits to the client of having a gastrostomy rather than a naso-gastric tube were generally recognized. As mentioned previously, however, there was much less agreement regarding the insertion of a gastrostomy tube for individuals who were fed orally.

### **Oral Feeding vs. Gastrostomy**

Several careproviders expressed concerns about the loss of oral feeding skills, which resulted from a decision to perform a gastrostomy and the impact of this loss on the residents' quality of life. To some extent, the focus on specific aspects of quality of life again reflects the specific professional ideology and scope of practice of the careproviders who were interviewed. While the nursing staff focused on the benefits of the procedure for improving nutrition and decreasing the risks of aspiration associated with oral feeding, careproviders from other disciplines emphasized the loss of the pleasurable and social aspects of feeding. The informants who emphasized social interaction and increased pleasure also recognized the potential physical benefits of gastrostomy, but indicated their conviction that the impact of the procedure on other dimensions of quality of life should be considered in decision-making.

A number of issues were raised by careproviders who were hesitant to condone the widespread use of gastrostomies. In the following statement, one of the occupational therapists expressed concerns about the loss of oral stimulation which is a consequence of feeding a person via a tube which goes directly into the stomach.

...So what happened was, a lot of people went... for gastrostomies, which was great, but none of these people were ever on any sort of oral stimulation program. So at mealtimes, basically what happened was, they'd get hooked up to their tube and that was it....

This informant also noted that performing gastrostomies resulted in a loss of interaction time between the resident and the person feeding the resident.

It just to me makes common sense that you make it seem like a mealtime because these people get so few one-to-one interactions living in this sort of atmosphere. I mean it's an institution, so mealtimes ... should be a pleasant one-to-one interaction.... That's what mealtimes are is a social time, and they weren't getting that.

One of the physiotherapists also cited loss of resident and careprovider interaction time as a significant consideration in decision-making.

With regards to gastrostomy, the minute that you've done it, you've taken away perhaps 4 half-hour times of one-to-one contact that that child would have had while they were being fed. You have to very carefully weigh the fact that you're going to lose that, and whether or not that was quality time, or whether that half hour was spent fighting to get it done.

The importance of considering the effects of the procedure on all dimensions of quality of life was reiterated by one of the psychologists. This respondent emphasized that the physical benefits might not be the most important considerations in all cases.

I don't think that the personal aspects of feeding were looked at as closely a few years ago as they are now. These are being used to balance decisions. Even if it may benefit a person from a health perspective to go to gastrostomy feeding, if people feel they're going to lose important social opportunities, or if feeding is something that they still seem to enjoy, then I think that's offsetting the health considerations.

The specific quality of life considerations which were discussed in the process of decision-making about gastrostomy, and the relative weighting of these considerations will be discussed in the next section.

### **Weighing Quality of Life Considerations: Scenario Three**

Quality of life criteria, other than those centering on the impact of gastrostomy on physical health, were observed to be applied in situations where careproviders agreed that it was inappropriate to perform a gastrostomy. One of the careproviders described a situation involving a resident who was able to communicate his own consent in a decision involving a proposed gastrostomy. The informant

used the case description to illustrate a situation where social interaction considerations were given higher priority than physical safety or comfort. The careprovider concluded that this particular resident's decision reinforced the preferences of some careproviders to ensure that such considerations be given appropriate weighting in gastrotomy decision-making.

...I know we had one individual, he was able to communicate, tell us when he was having feeding problems. So he was given the choice, "Do you want the gastrostomy?" We showed him what it looked like and how it was in your stomach- hooked up for feeding, and he did have a choice whether he wanted to continue having problems, and aspirating, and getting pneumonia, or having a gastrostomy.

He opted not to have it. So it proved to us that for him it was a nicer experience choking and gagging than being hooked up to a tube. That was his choice because he enjoyed the taste, he enjoyed the social climate. He didn't want to be an outcast and be the only one that had a bottle.

One of the parents interviewed described her decision to refuse a gastrostomy on behalf of her son, emphasizing the enjoyment which he gained from eating.

As far as choosing for him because he can't choose - things like when they wanted to do the stomach thing - I didn't feel that that was something that he needed to have, and that we could work around that in a different way....That was one of his best things was eating....That was his big thing. I mean what else has he got?....

This parent also stressed the importance of allowing her son to exert some control over his life by being able to indicate preferences for different types of food.

I think it's a control thing too. I mean what control has he got over his life other than keeping his lips shut when somebody's trying to stuff something into them that he doesn't like?

The differences of opinion over which considerations should receive priority in decisions about gastrostomy surgery, illustrate how proxy decision-making situations can become very complex. In the case of decisions about gastrostomy, careproviders from different disciplines and with varying intensities of service involvement, may tend to weight specific aspects of quality of life

more heavily than others. Careproviders who are most intimately involved with the physical care of the resident (e.g. nurses) perceive that the physical benefits of the procedure are of primary importance in decision-making, and that the short-term burdens imposed by the surgery and the transfer to another facility are outweighed by the long-term benefits. The narrative of members of the nursing staff, who emphasized weight gain, prevention of vomiting and aspiration, decreased mucous production and general indicators which they perceived to reflect increased comfort, exemplify this viewpoint. Other careproviders, while acknowledging the physical benefits of gastrostomy, were concerned that the procedure resulted in trade-offs involving diminished quality of life in other dimensions. They emphasized the pleasurable and social aspects of feeding, and the importance of enabling the resident to exert some degree of control by indicating preferences for specific types of food. These respondents stressed that the potential effects of the procedure on other dimensions of quality of life should not be overlooked by decision-makers and, in some cases, believed that such considerations outweighed those related to physical well-being. These fundamental differences of opinion are reflected in a later section of this paper where careproviders describe how gastrostomies are sometimes performed despite a lack of consensus.

### **Life Threatening Situations: Scenario Four**

A fourth type of decision scenario which was identified in the narrative, involved the type of care which is offered to residents in life-threatening situations. These scenarios often reflected situations presenting the greatest level of complexity and uncertainty. Although the Roman Catholic Church has developed guidelines about the care of the dying person in accordance with its traditions and moral principles, the individual moral, ethical, and religious beliefs held by the careproviders and parents who participate in decision-making can create situations which are unexpectedly complex. In some situations, there is uncertainty as to whether aggressive intervention or non-intervention best meets the needs of specific residents during life-threatening illness or at the end of life. The intimate

relationships which often develop between staff members and residents can also increase the difficulty associated with end-of-life decision-making.

Despite the overlying dimension of neurological impairment, many of the residents at St. Amant are assessed as having a stable medical status and, overall, are in fairly good health. Some residents, however, have irreversible medical problems. These individuals are considered medically fragile, and may experience repeated life-threatening episodes. Older residents who have surpassed average life expectancy for this population, or whose cardiovascular and respiratory systems are compromised by advanced skeletal deformities, are also prone to experience complications which may threaten life.

Several of the careproviders discussed their perspectives on aggressive treatment intervention for chronically-ill residents in the event of serious medical problems. In particular, they discussed cases where there was little or no hope of maintaining the minimal requisites which were perceived to be necessary in sustaining an acceptable quality of life. These cases included residents who were perceived to have little quality of life because of the effects of ongoing medical problems and/or recurrent acute illnesses, and cases where profoundly impaired infants had been admitted to St. Amant Centre for palliative care without the expectation of long-term survival.

In discussing cases involving life-threatening situations, respondents described the difficulties associated with setting agreed-upon limits to active intervention in cases where prolongation of life was not perceived to be in the best interests of the client. The influence of the guidelines which have been developed by the Catholic Church concerning proportionate and disproportionate means of treatment for the dying person is reflected in the following excerpts from an interview with a member of the psychology staff.

...In the Centre here it's a quality of life issue. Is that life a quality life? Should we try and maintain it at all costs? My views may have changed a little bit in the last few years in the sense that I think we don't necessarily have to keep people alive at all costs. But when you come right down to it, what are the boundaries?

This person went on to discuss differences in the management of an acute episode which can be treated with full expectation of the client's recovery to their former state, and a situation in which there is little hope for recovery.

...The natural thing is when someone gets sick, you treat them....If you have pneumonia, we treat you with antibiotics and the pneumonia would go away. The person will usually be functioning like they were before. It's not a chronic sickness. In most cases, it's curable.

With residents here... because of the physical impairments, it's much more serious and they may not ever get back to be what they were. But that's not possible to tell ahead of time. If there's no hope for a person, that might be one thing, but if it's an acute illness that can be cured, it's not really a contentious issue.

A member of the physiotherapy staff articulated her personal perspective on decisions to aggressively intervene in cases where residents experienced recurrent life-threatening episodes, and where there was little or no potential for recovery to a state of overall health.

When I do see people struggling with their breathing, when you see somebody in the final stages - I've personally treated three or four of them in the last stages - and at that point I would think it would be cruel to intervene because that particular person is suffering and it's not as if life is going to be that much different. And it's likely that they're going to be going through that over and over again, because they have very compromised respiratory systems.

One of the resident's parents stated that she would base a decision about allowing aggressive intervention for her daughter on her projection of what she would want for herself in a similar situation. She emphasized that prolongation of life by artificial means was not something she would choose for herself.

As far as directives, should [my daughter] become ill or anything, I would think it would be probably similar to what I would want for myself. If she's going to be in a lot of pain and suffering, then certainly none of this keeping her on life-support machines and this kind of thing....I don't want to be in a hospital hooked up to machines for ions.

## Comfort Care Guidelines

In the preceding section, a consensus of opinion can be identified in the views of careproviders and parents with regards to aggressive intervention, in cases where there is little or no potential for recovery to the resident's former state. This consensus about the desirability of less aggressive intervention has resulted in the implementation and development of specific "Comfort Care Guidelines." These guidelines present four optional types of care which can be provided in life-threatening situations.

The guidelines were summarized by one of the physicians who was interviewed.

...[W]e explain to them [parents] what kind of care we can offer at St. Amant. We don't run IV's, we don't ventilate, we don't have heart monitors. That's what we view as comfort care and is what we provide at St. Amant.

If they're happy with that, we would have a "No Resuscitation" order and a "No Transfer From Centre - Comfort Care Only" guideline....That would be a Level I. Level 2 would be transfer to hospital, but no CPR - for stabilization only...and transfer back immediately.... Third level would be transfer to hospital, stabilization and treatment of the condition, but no ICU and no resuscitation. And the fourth level would be full care including resuscitation.

Parents/guardians are made aware of these options and can decide, in consultation with staff at the Centre who know the resident well, what they feel would best meet the needs of each particular individual.

One of the nurses described the philosophy underlying the development and implementation of these guidelines.

...In the community, in long term facilities, there is a lot of thought being given to comfort care, using directives, and it's okay not to treat. We have adopted some of those philosophies so that if there is no cure for the person, if there is no chance for his condition to improve then, with a joint conference including the parents - the public trustee- we have opted to keep the resident here and provide comfort care.

The criteria used in deciding whether quality of life is sufficiently compromised to justify non-intervention and the provision of comfort care only, were outlined by one of the physicians. This

speaker emphasized that not only are aspects of physical health considered when assessing diminished quality of life, but also factors such as the resident's inability to attend programs.

We wouldn't go to somebody who's going to workshop every day, happy, cheerful, loving life- we would not accept a "comfort care only, don't treat" kind of option for a person like that. So we wouldn't seek them [advance directives] from those parents.

...[A]gain it's a judgment of quality of life. It's where we think that there is little quality: they're sick all the time, they're deteriorating in their health, they rarely leave the ward cause they're not well enough to go to workshop or anything. We use those all as indicators of health or of well-being, and we try to obtain it [a directive].

The preceding narrative indicates that, once careproviders have assessed a resident's quality of life as being significantly compromised, they are able to initiate discussion with the parents about the options available under the comfort care guidelines. One of the parents discussed her decision to opt for "comfort care only" after her daughter had experienced one of several recurrent life-threatening episodes.

I made that decision after the last - well, she was really really sick a year ago...they didn't think she'd live through the night. And we came and stayed with her the night at the hospital and she got better by morning - a little bit better- she never really gets better.... So before they sent her back, I spoke to doctors at \_\_\_\_\_ Hospital and decided that if she gets sick again, or if anything happens again, they don't have to do anything. Cause to me she's not living, she's existing,...and she can't get better. ... I don't want her to go through any more of that. I just don't. I don't want us to go through any more of that either.

#### **Weighing Quality of Life Considerations: Scenario Four**

In accepting the use of the "Comfort Care Guidelines," both careproviders and parents were adamant that, in the event that a decision against aggressive intervention was reached, the resident's physical and emotional comfort must be given priority. Respondents alluded to the importance of good palliative care, and spoke of their willingness to provide physical and emotional support to the residents until the end of life. One of the physicians described the Centre's commitment to good palliative care.



Most families opt for comfort care only here. And we're very comfortable with that, and I think we do that really well....we provide one-on-one staffing, whereas hospitals would never be able to do that even for people who were dying.

Several careproviders linked statements of their commitment to provide good palliative care with descriptions of their reservations about transferring residents to other centres for care at the end of life. This reluctance to see terminally-ill residents transferred was supported by the perception that staff in other institutions were often less aware of the non-communicative individual's needs and, consequently, would be less able to provide adequate emotional support. Two of the nurses interviewed expressed the importance of meeting the resident's emotional needs at the end of life. Both careproviders' narratives reflect the uniqueness of the care environment of St. Amant Centre, and the expertise of the staff which enables them to interpret the resident's needs.

#### **Excerpt #1**

Most [parents] opt for comfort care here because of the expertise of the staff. When they go to another institution, they become just another patient. We know their crying and what it means.

#### **Excerpt #2**

...A lot of them [parents] say, "Let's keep them here, let's not transfer them to another hospital in the event that they have acute pneumonia because they don't know them, they don't know what is normal for them."...This way our resident doesn't get left alone when he needs the most attention.

The staff's concern for the residents' emotional well-being was summarized by one of the psychologists, who commented on the trade-offs which were made in choosing between care regimes emphasizing technologically-based life support, and comfort care at the end of life. This respondent indicated that careproviders felt that maintaining existing relationships, and providing emotional support through good palliative care, were of primary importance for the residents under their care.

One of the big considerations that led to the development of advance directives was the sense that we weren't doing residents any big favour either from a health or a comfort point of view when we transfer them off to acute care centres during the time of a medical emergency. While there may be a better technology in terms of equipment and facilities at acute care

centres, there certainly wasn't the knowledge base in terms of people with profound disabilities....

That was one of the factors that really started people to think. More important than technology - we have the basic technology, maybe that's adequate - and what we're gaining by transferring people for a bit more technology, we're losing as a tremendous amount of comfort and family involvement, and involvement of staff that they're already having relationships with.

The type of decision-making that surrounds life-threatening situations, and the very existence of the comfort care guidelines, serve to re-emphasize those dimensions of quality of life which careproviders and parents feel to be most important in decision-making. Criteria centering on the residents' continuing ability to maintain relationships with people, to experience some degree of social interaction, and to participate in the programs and activities which they enjoy, were rated as the most significant criteria. When residents are no longer able, or have never been able to participate in these types of interactions, quality of life is considered to be severely compromised. If, in addition, residents experience recurrent illness and/or irreversible physical suffering, quality of life is seen to be further compromised. Careproviders and parents are then able to decide, generally with the support of all concerned, that non-intervention in the event of a life-threatening acute episode is in resident's best interests. At the same time, however, respondents expressed profound concerns for the residents' emotional and physical well-being, and recognized that meeting their needs in these dimensions is essential to providing quality care at the end of life.

Chapter 8 describes some additional considerations which frequently complicate decision-making for careproviders involved in making proxy treatment decisions. One group of considerations is related to internal organizational factors. Discussion of these considerations will center around the impact of alternative interventions on careprovider workload. A second group is related to external societal views about the valuation of disabled people. Discussion will focus on issues pertaining to the application of the principles of distributive justice in the allocation of health care resources, and the impact of rapid advances in technology on the decisions which are made on behalf of profoundly impaired people.

## **CHAPTER 8**

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### **CAREPROVIDER PRIORITIES AND SOCIAL WORTH CONSIDERATIONS**

#### **Introduction**

Before systematic data-collection was started, it was hypothesized that both internal organizational factors and external societal values would influence proxy decision-making (Chapter 3). Internal organizational factors included considerations pertaining to the impact of alternative interventions on careprovider workload. External societal values included considerations related to the valuation of disabled people, and the application of the principles of distributive justice in the allocation of health care resources.

During in-depth interviews, therefore, respondents were invited to share their views of the ways in which these additional considerations were perceived to influence proxy decision-making. Narrative relating to the impact of specific interventions on careprovider workload will be presented in the first section of this chapter. The second section will present careproviders' concerns about issues related to society's perception of the value of disabled people.

#### **Careprovider Workload and Decision-Making**

In the process of describing how specific considerations are weighted and prioritized in the process of making decisions about treatment interventions such as orthopedic surgery and gastrostomy,

participants were asked to discuss the impact of these procedures on careprovider burden. The subject was introduced with the following statement:

**Interviewer:**

I've been trying to get a feeling for how particular considerations are weighted in the decision-making process. Is the resident's quality of life the only consideration, or are factors related to careprovider workload also considered? As interventions such as soft tissue releases can be seen to make caring for that resident easier, can you separate the benefits to the resident from the benefits to the careproviders who care for that resident?

Some of the respondents indicated that careprovider burden was considered either directly or indirectly, depending on the proposed intervention. There was a recognition that, since determining what was best for the resident was often very difficult, careproviders sometimes had to assume that procedures which made caring for that person easier, would have the indirect benefit of improving their quality of life. One of the psychologists described the difficulty which he/she experienced in separating the resident's best interests from careprovider interests.

I think it would be nice if they could [separate the interests of caregivers from the interests of residents]. I'm not sure if it's possible. I think in all decisions like that, everyone has a resident's agenda. I think everyone does have their view of the resident's best interest. Personal circumstances and agendas always confound in what we think is going to be in the resident's best interest. So I'm not sure if it's possible to totally rule out staff interest.

The speaker went on to state that the effects of various interventions on careproviders were at least recognized in the decision-making process.

I think that on the positive side, it is acknowledged. I think all that people can do is reasonably acknowledge that there are benefits or disadvantages to staff, and try to consider those benefits or disadvantages as part of the whole equation, rather than pretend that they don't exist.

Another of the psychologists expanded upon this theme by describing the process which was used in an attempt to separate staff interests from the interests of the client when a referral for behaviour modification was received.

When I get a referral, though, the first thing I would look at is, would carrying out this request improve the person's quality of life...? Sometimes, of course, the request might be only for staff convenience. It wouldn't really have much effect on the resident's quality of life. That kind of thing can still be important in terms of staff satisfaction, but I would think that has a much lower priority than things that directly affect the resident's quality of life....

This speaker then commented that the process of determining whether the careprovider and/or the resident has benefitted most from a specific intervention is often a difficult, if not impossible, task.

Sometimes they're related; if staff find it especially difficult to work with a person for example, and they ask me for some procedure to deal with the problem, the dealing with the problem might not be directly related to the person's quality of life, but if it affects the kinds of programs that the person can take part in, who is willing to work with them, the attitudes that the staff have towards that person, there might be an indirect relation to the person's quality of life.

Other careproviders concurred with this viewpoint stating, in essence, that what was good for the careprovider should also be good for the resident. One of the physician's stated:

...I don't see anything wrong with saying, "If a careprovider's happier and finds it easier to take care of somebody who's completely disabled -," that that's not in fact good for the patient or the person - the disabled person. Unless of course you can see that for some reason it's in fact harming them.

### **Specific Interventions and Careprovider Workload**

Interventions which were discussed by the careproviders with respect to their effects on workload and ease of care, included the use of various orthotic devices, as well as surgical procedures. Specific interventions were noted to affect careprovider workload in different ways.

Some interventions, such as the use of orthotic appliances and seating systems, served to increase careprovider workload because of the time spent in applying the orthoses, or positioning the client properly in a seating system. One of the head nurses discussed the effects of such appliances on the workload of the staff on one living unit.

I find that the staff eventually does adjust to it. They are sometimes reluctant at first, but I think I'm fairly blessed with a really good staff who see almost always what we're telling them, and they believe us that we're doing it for the benefit of the resident. They will go along with it. Yes, it definitely adds to the care, makes it much heavier- much more difficult, but they are always willing to try. Eventually they become accustomed to it like anything else. They just adjust.

Other interventions, such as soft tissue releases, could be seen to decrease careprovider workload. Soft tissue releases are sometimes performed when spastic muscle groups in the lower limbs become shortened, creating problems in the performance of routine care activities such as bathing and diapering. The importance of factoring considerations pertaining to careprovider workload into decision-making about orthopedic surgery, was openly acknowledged by individual careproviders during in-depth interviews. One of the physiotherapists described the importance of considering ease of care in decisions regarding soft tissue releases.

There's actually two classifications, I think, of individuals who surgery is indicated for. The one is the severely affected ones where we are actually trying to decrease the amount of pain that a person is having through surgical intervention, or for those who are so severe that perineal care becomes a problem. When they're moved, and trying to put a diaper on, the patients themselves are in pain. It's very difficult for caregivers themselves to keep residents adequately cleaned, and so soft tissue releases or even a varus osteotomy may, in fact, facilitate careproviders. So that's one area- to facilitate careproviders and to decrease pain.

One of the nurses concurred with this assessment, noting that what was good for the careproviders in this situation was also good for the resident, and that it was difficult to separate these two considerations. This speaker recognized that increased difficulty in providing adequate nursing care for residents might eventually contribute to the development of additional problems.

Thinking of one child in particular..., he could really use it [soft tissue releases]. It's getting to the point where putting a diaper on this child is extremely difficult. That's not just for ease of care, that's for the child himself.

Once you get to the point where you can't put a diaper on them, how are you going to maintain skin integrity, and all that other kind of stuff? It's very difficult if you're not going to be able to get in there to clean them. Looking at it that way, I can see the soft tissue releases as being a benefit.

This attention to careprovider considerations was also noted in observations made at Orthopedic Clinics. A short conversation which was recorded in the field notes will serve to illustrate the linkage between careprovider considerations, and client-oriented considerations. The speakers were discussing the pros and cons of a specific surgical procedure for one of the residents:

Speaker #1. "How would it help her quality of life?"

Speaker #2. "It would help her caregivers and that's part of quality of life, whether right or wrong."

### **Balancing Client and Careprovider Considerations**

Even though the necessity of factoring careprovider considerations into the decision-making equation was generally recognized, some respondents expressed concern that undue attention to such factors might lead to situations where careprovider convenience becomes the primary consideration in decision-making. Some of the informants were adamant that this should not be allowed to occur. One of the careproviders referred to the potential changes in decision criteria which could occur, in situations where gastrostomy surgery was increasingly being used as the treatment of choice.

Now that we've become a little more accustomed to seeing the gastrostomy, and it doesn't seem as invasive or whatever to people, the main thing that I'm concerned is that we would err in the other way, and again to accommodate other priorities like getting people fed and maintaining body weight etc., that people might get gastrostomies before they really have other options exhausted.

Another of the careproviders reiterated the importance of ensuring that decisions to perform gastrostomies were not made primarily on the basis of criteria emphasizing the convenience of the procedure in terms of facilitating subsequent management of feeding for careproviders.

...I know the attitude a lot of times from the nurses's aides is that it is difficult to feed the child, takes too long, we have lots to feed. But I don't really think that's a reason to give the kid a gastrostomy. I think they felt that it was just a minor kind of surgery...,

but it's still a surgery. It still means the child has to go to the hospital and get all of this done. One of my kids died - not as a result of the surgery, I guess, that's what I've heard - but it may not have happened if she hadn't gone in. I think the seriousness of gastrostomies is a little more clear now. It's not just a tube, easier for everyone.

Thus, while the benefits and burdens of specific interventions as they affected careproviders were acknowledged as legitimate factors to be considered in the decision-making process, there was also a recognition that decision-makers must be cautious, and ensure that factors related to careprovider workload do not become the primary motivation for deciding in favour of a particular intervention. In times of imposed spending restraints, procedures which save time and have the effect of decreasing careprovider workload, could also be construed as measures which would cut costs. The effects of specific procedures, in terms of their relative impact on the quality of life of the residents and the workload of the careproviders, must be carefully assessed.

The next section will present themes from the respondents' narrative in which they discussed how society's views about the valuation of disabled people are perceived to influence decision-making. Careproviders' concerns about the application of the principles of distributive justice and the impact of rapid advances in biotechnology are also presented.

### **Social Worth and Decision-Making**

In the course of the in-depth interviews, some careproviders expressed concerns that decision-makers outside St. Amant Centre might use social worth criteria as a basis for evaluating the quality of life of the residents. Informants articulated the fear that institutionalized individuals who are permanently and profoundly impaired might be denied access to specific services and adaptive equipment. Careproviders felt that external decisions to withhold resources could be based on the public's perception that the residents would never be "contributing members" of society, and that resources might be more appropriately concentrated on the care and rehabilitation of individuals whose impairments were less severe. Such viewpoints were perceived to be in direct opposition to St. Amant's philosophy regarding the dignity of the person and respect for human life.



In order to elicit more information about social worth considerations, participants were asked to describe their perceptions of society's views of quality of life as applied in evaluating the experience of people with profound impairment. The subject was introduced with the following statement:

Interviewer:

I want to get a feeling as to whether people think that there are any kinds of limitations to the amount of treatment, or the number of interventions you might use with residents who are profoundly impaired. Does society's notion of quality of life, or I suppose the social worth of the individuals who are in this kind of institution, affect decision-making at all?

Many of the respondents prefaced their answers by stating that they felt most people outside the Centre had very little knowledge either of the level of impairment of the residents, or of the nature of the care and programming which was provided. One of the parents who was interviewed expressed this viewpoint:

I think that most people don't have a clue about what's going on unless they're involved in it....Lots of people have big ideas on it- you know if you were to ask them about it I'm sure they'd have something to say; but until they've actually been in that situation, what they have to say isn't valid anyway as far as I'm concerned, because they don't know.

Some of the respondents stressed, that because most outsiders had no emotional relationship with people who are impaired to the extent of the residents at St. Amant Centre, they would experience little difficulty in making decisions based on more generally-held beliefs about social worth. One of the physiotherapists made the following observations:

Some people, especially people who've had no contact with residents - with people who live in an institution - or this type of resident for example, they have no emotional contact with it. It's very easy for them to say, "They're not contributing members of society. Isn't it terrible they were born this way? Isn't it too bad they had to live? It would be a blessing if they would go." I think people like that really don't think about what they're saying because they really never had the experience.

The speaker went on to say that those who had experience working with individuals who were profoundly impaired, saw them in a different light, and were more readily able to accept them as people with different levels of ability.

I think it's harder for people in society who have had contact with those types of individuals or have worked with those types of individuals, because they see them as people with feelings.... These other people, it's just that their life is sort of on a different scale, that's the way I see it. Everything is relative to what you're used to.

### **Application of the Principles of Distributive Justice**

As indicated previously, some careproviders expressed concerns that social worth criteria (criteria which might be used in assessing one's actual or potential value to society), might someday be used to govern the distribution of expensive or "scarce" health care resources. In this event, it was perceived by some of the careproviders at St. Amant Centre, that rationing of some services to permanently and profoundly impaired institutionalized individuals might be instituted. This perception was intensified by the current environment of health policy in Manitoba, in which concerns about the nature of health care reform and resource cutbacks are affecting careproviders in all health care settings.

Although many of the careproviders at St. Amant indicated their commitment to ensuring that the residents have equal access to equipment and services, they recognized that society outside the institution might have different views. They also recognized that competition for health care resources is increasing, and articulated concerns that the principles of distributive justice might someday be ignored in favour of saving money. One of the occupational therapists stated:

... Some people, also, that I've spoken to, wonder about the value of doing this because it's competing - we're using money that they feel could be otherwise used to help somebody who could contribute to society, and that's often a measure that's used for determining, I guess, worth to society. What can you do for society? What kind of status can you attain? So if the resident can never contribute and will always be dependent, some people would rather see the money go somewhere else....

We're on dangerous territory when we try and do that, because we use the indicators of productivity.

In discussing the potential use of social worth criteria, it was recognized by some of the respondents that health careproviders in facilities other than St. Amant Centre might also define quality of life as applied to people with profound impairment using criteria based upon popular values defining social worth. This recognition was noted in the earlier analysis of careprovider narrative which emphasized the concerns of St. Amant staff about transferring residents to other centres for procedures such as gastrostomy surgery. There were several more specific references to the attitudes of careproviders outside the Centre, as well. One of the nurses described the reaction of acute careproviders when gastrostomies were first performed on residents of St. Amant Centre, and indicated the difference in attitude between St. Amant careproviders and others regarding the valuation of persons who are profoundly impaired.

When we started doing gastrostomies, it was in '88 I guess, and we got a lot of flack from the other hospital. "Why are we doing this? Who did we think we were, God or what? What's going on?" To the point where \_\_\_\_\_ had to go and speak to them, and I had to go and speak to the nurses. I guess we never thought otherwise, because most people that work here accept them and get annoyed when these things happen and shouldn't happen, but I guess it's part of life. I think it's going to be more and more so which is unfortunate.

Another of the nurses commented on the difficulty of obtaining treatment interventions for severely impaired infant who had been sent to St. Amant Centre for palliative care, but who had continued to live for a number of years. The informant notes, however, that despite this sort of difficulty, St. Amant is often successful in its efforts to obtain outside treatment for the residents.

We also have a young child here who came from the acute care centre for comfort care. We had to do a lot of "politicking" in order to get some treatment for her and she's thriving. Sometimes the intervention is really beneficial.

Other careproviders noted that it was sometimes difficult to find specialists who will agree to perform various types of surgical procedures for the residents of St. Amant Centre. The following excerpt from the narrative of one of the psychologists exemplifies the viewpoint of several of the careproviders who were interviewed.

...I have, for example, seen physicians who are not interested in treating this population and I think their biases are reflective of the biases of a small group of society. Within society there are people who don't value those people with disabilities. I think we would expect to see that represented to some extent in all professions. I'm sure they are represented in the medical profession.

Other careproviders noted that the difficulty in obtaining what was considered to be necessary and appropriate treatment was increased when treatment was requested for one of the adult population. The needs of the rapidly growing group of older adults in the Centre are of increasing concern to the careproviders. Some informants described the difficulties they experienced in locating facilities or physicians who would admit and provide continuing care for this group of people. One of the physicians alluded to this problem, contrasting the difficulty in securing treatment for adult residents with the relative ease of obtaining services for children.

...It's funny how also age comes into the consideration. For example, if I want to transfer a child to [a particular hospital] who is very ill- they may have severe cognitive dysfunction- I get a grumbling on the other end of the phone but I never get a no- or rarely-I have once. If I transfer a 25 year old to a hospital who has profound cognitive dysfunction, very limited ability to get out of bed, presumed very poor quality of life- I will probably spend half a day trying to find a hospital that will take them....

Society says that if you're over a certain age - if you're not a child any more and you still have this terrible impairment - then you're not worth anything.

The increased difficulties associated with obtaining treatment for aging residents who have been profoundly handicapped since birth was described by other respondents. The unique problems associated with aging in cases where individuals have pre-existing mental and physical impairments would merit additional consideration in future research.

Finally, some of the respondents acknowledged that the de-valuation of profoundly disabled persons was reflected, not only in the attitudes of health careproviders in other centres, but by some within the institution itself. The excerpt which follows serves to illustrate this acknowledgement.

...It's apparent that there are quite a few employees here that do use worldly standards in terms of judging people or assessing people.

Once again, the moral philosophy of St. Amant Centre is perceived to conflict with widely-held views of society at large.

### **The Impact of Increased Technological Intervention**

Respondents' narratives centering on resource allocation and the principles of distributive justice, sometimes reflected concerns regarding the impact of increased technological intervention. Procedures such as gastrostomy which, at one time, were rarely performed on institutionalized people are now prescribed with increasing frequency. In the event that one or more procedures are performed successfully, it sometimes becomes possible to consider additional treatment options. The problems associated with setting limits to intervention can then become more complex. This dilemma was described by one of the physicians.

[Technological advances] also end up changing what you have to offer and, in some cases, make the decision about treatment a lot more difficult. If you take all the kids where the risks of a major surgery were felt to be too great because they were relatively malnourished and had a lot of respiratory problems, many of them now with augmented nutrition and having gastrostomies and fundal bifurcations, all of a sudden are in a situation where their general health has improved dramatically. And a situation where there was no question that the risk of surgery- for example doing a spinal fusion- was too great to consider the potential benefits, ... now health improved, the potential risks are less, ... and all of a sudden the balance is now swung such that you may have to re-consider.

Thus, as the general health of profoundly disabled people improves through the provision of better care, and as technological advances expand available treatment options, successive technological interventions may be performed with increasing frequency and increasing acceptance.

When do you say when? That's a problem that everybody faces all of the time and... my own personal approach to it - at least on a basic level - is that you have to say as a doctor, or as a therapist, or as any person who is going to treat somebody or who is going to suggest treatment for somebody, is that you have to consider that to be a one-on-one situation and

that you have to do as much as you can do towards betterment of that person's life, again considering this balance of benefit and risk and everything else.

The speaker continued, observing that if health care resources become inadequate to meet service demands, it should be the responsibility of society, and not the individual careproviders, to make decisions about the distribution of resources.

Now, if the society is in a situation where there are not the resources in society to allow everybody to have the nth degree of treatment, then the decision has to be made by society, and not by the individual treating an individual patient....The individual physician or individual therapist or whatever cannot be the person who's the gatekeeper by themselves.

In their narrative, informants acknowledged that external forces in decision-making, such as policy decisions based on societal valuation of disabled people and the application of the principles of distributive justice, serve to increase both the uncertainty and the complexity of the proxy decision-making process. They felt the process was complex because of ambiguity in the criteria used in the allocation of resources, and because rapid technological advances encourage the routine application of interventions without benefit assessment. Informants expressed their conviction that access to available resources and technology should not be rationed simply on the basis of severe, pre-existing impairment. Finally, some of the careproviders expressed a commitment to establishing outcome measures which would enable them to provide clear and convincing evidence to decision-makers outside the Centre that the interventions and programs which are provided do improve quality of life for the resident population.

### Summary

Careproviders discussed a number of issues relating to both careprovider burden, and public or professional valuation of social worth in decision-making on behalf of the residents for whom they care. They identified some interventions which increased careprovider burden, and others which facilitated care. They noted that factors affecting workload did enter into the decision-making

process, but were aware of these factors and recognized the dangers of them becoming the primary criteria for decision-making.

Social worth was discussed in terms of society's ignorance of both the level of impairment, as well as the level of ability of the residents at St. Amant Centre. Careproviders noted that they were concerned that social worth criteria would be used to determine access to resources in the future, when it is anticipated that monetary considerations may play a bigger role in resource allocation decision-making. They related instances where they felt residents are denied equitable access to resources on the basis of pre-existing impairment. They also expressed concern over dilemmas created by the increasing acceptance of technological intervention.

In the following chapter, the ways in which careproviders described their abilities to assess or measure the effects of various interventions on the residents' quality of life will be summarized. The various indicators which were used in the assessment process, the strengths and weaknesses of proxy evaluation of quality of life, and the manner in which the evaluations are factored into the decision-making process will be the focus of discussion.

## **CHAPTER 9**

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### **QUALITY OF LIFE ASSESSMENT: A BASIS FOR DECISION-MAKING**

The data presented thus far, has served to address the original objectives of this research project (as outlined in Chapter 1), with one exception. The concept of quality of life as defined by careproviders, and applied in interpreting the experience of people with profound impairment, was described in Chapter 6. In Chapter 7, the process through which specific dimensions of quality of life are weighted and prioritized in a number of decision-making scenarios was discussed. The influence of careprovider priorities associated with the impact of alternative interventions on the ease of providing care, and the influence of more general societal values defining the application of the principles of distributive justice in the allocation of health care resources, were described in Chapter 8.

To address the final objective of describing the process through which careproviders evaluate or assess the impact of specific interventions on the resident's quality of life, data from both participant-observation and in-depth interviews was used. This chapter describes some of the difficulties experienced by careproviders in their efforts to incorporate quality of life assessments into the proxy decision-making process.



## Introduction

In their narratives, respondents alluded to a number of factors which, from their own experience, contributed to the complexity of assessing or evaluating changes in residents' quality of life. First, they emphasized that the ability to assess the effects of particular treatment interventions upon specific dimensions of quality of life requires time, experience, and the intuitiveness which develops as a consequence of close and long-standing relationships. These pre-requisites enabled them to develop a unique understanding of the residents' needs, likes and dislikes. Second, they stressed the need to make assumptions, based upon their own definitions of quality of life, in the decision-making process. Third, they recognized that it is difficult to determine the exact nature, and also the specific source of apparent improvement, in cases where the resident cannot readily communicate. In conjunction with this recognition, they described the difficulty of identifying appropriate objective indices which could be used to measure improvement, and the subsequent necessity for subjective evaluation.

Careproviders also made references to the importance of team assessments in protecting the best interests of the resident, and emphasized the need to consider the impact of interventions on all dimensions of a resident's quality of life. They indicated the need for careproviders to assume advocacy roles on behalf of the residents, so as to ensure that the benefits of providing these people with quality care and programming would be apparent to policy-makers outside the Centre. Finally, they expressed personal commitments to the residents with whom they worked, demonstrating a profound belief that the lives of these people were as important as those of other members of society.

The sections which follow provide a more detailed description of the difficulties experienced by careproviders involved in proxy decision-making on behalf of profoundly handicapped people. In their narrative, careproviders often referred to specific case examples. These have been included in cases where the consent of parents and/or guardians was obtained.

## Proxy Assessment of Quality of Life

### The Importance of Insider Relationships

Participants in this study emphasized repeatedly, that the process of assessing or measuring the ways in which specific interventions or care plans affect the quality of residents' lives, required spending extended periods of time, and developing a close relationship with the residents. These requirements were vital to the development of careproviders' capacity to interpret the residents' subtle responses to both physical care and program participation.

The aides on the living units who provide basic personal care to the residents, often know them very well. Their intimate relationships with the residents enable them to provide unique assessments of the ways in which residents communicate or respond to the care they receive. The following are excerpts from interviews with two of the aides. Both of these speakers stressed the need to spend time with the residents in order to elicit responses, and to be able to recognize what sort of interaction had prompted those responses.

#### Excerpt #1

Our kids really do communicate. It may be by a twitch, or smile, or their eyes. If you really spend the time, it doesn't matter how profoundly retarded, they'll show you they like something or don't like something. That's the biggest factor in your quality of life is the time factor.

#### Excerpt #2

As you get to know them, as you're doing your work,....you spend some time with them, and all of a sudden you see that they are responding. It might be a sound you make, or it might be touching.

The importance of a close and/or long-standing relationship to the careproviders' capacity to determine the significance of the limited responses of the residents, was illustrated by one of the physiotherapists in discussing an incident with a resident with whom she was relatively unfamiliar.

I was doing [his] treatment on the table in the bathroom every morning. One morning they [the aides] were finished [his bath] early and they had put him back to bed. He has no way to indicate his likes or dislikes or desires, except by shivering when he's afraid, or crying. He was relatively new to me, and I could not tell that morning what his behaviour was. So I went and got one of the aides who knew him really well, and she came in and she took one look and she said, "He's afraid you're not going to take him to school because he's back in bed."

The therapist acted upon the advice of the aide, and described the resident's response to her actions.

So it was simple to improve his quality of life that morning. I picked him up and took him back into the bathroom and did his treatment on the table that I always would have done it on, and his whole tone and demeanour changed immediately....But it took someone who knew him well to make the decision.

Other careproviders agreed that interpreting the meaning of residents' responses is a time-consuming process. A member of the recreation staff emphasized that there was always a response to be found if the careprovider was able to spend sufficient time with the resident. The speaker also indicated that the resident's response was often subtle and difficult to interpret.

There always is one [a response], positive or negative. It's just a matter of taking time to find out what it is....You have to look for those subtle gains or those subtle appreciations by the residents and it is very, very hard.

The process of eliciting some type of response from the residents and of, subsequently, being able to establish communication with them, was described by one of the teachers. This speaker verified the observation that each resident will respond in some way, to some form of stimulation. The challenge for careproviders and teachers is to identify which type of interaction will unlock the door to establishing a connection with that person.

I've yet to see a child that didn't react some way physically that you couldn't read to what's going on....I've had kids who were stiff as a board who just alternately stared, or had their eyes closed because they couldn't make sense out of what was coming in, and they were

shutting it out because it was just confusing information for them. Even with those kids, physical closeness, being held and put in a rocking chair, and doing some stimulation things with them, ultimately got some kind of physical response that let you know you made a connection, and that there's some pleasure in the process that was being gone through.

An appreciation of the subtlety of the residents' responses was gained when the researcher was allowed to observe a sensory stimulation program which was started on one of the living units. This particular program was designed to provide stimulation to adult residents who are not involved in any other type of programming. Prior to attending some of these sessions, one of the nurses was asked how she could tell whether the residents enjoyed or disliked the various types of sensory stimulation which were used in this program. She made the following observations.

...The expression on their face, because you can tell a tense person from a relaxed person, and it's amazing. You can put [their] hands in water, and a lot of these residents, even though they're very seriously handicapped, just love the water. You can see them just stretch their fingers. With the massage, they like that as well. All of the residents' responses may be minimal, but they do [respond] to music, they really do.

The nurse's comments were verified when the investigator observed some of the sensory stimulation sessions. The aides who are members of the living unit staff, interact with the residents on a one-to-one basis during these half-hour sessions. It was apparent that the aides knew the residents very well, and that they had developed an appreciation of the meaning of the residents' subtle responses to modalities such as massage and foot baths. After only a few sessions, the aides could describe what sorts of stimulation the residents most enjoyed or disliked, and even what type of music elicited a response.

In the case of some residents, it was not difficult for even an outside observer to differentiate between obvious expressions of pleasure or anxiety. In other cases, however, the response was extremely subtle, and essentially imperceptible to an unfamiliar observer. Careproviders who were familiar with the residents and accustomed to handling and observing them, however, were able to appreciate, describe, and even demonstrate body language responses, changes in facial expression, and subtle differences in the sounds which the residents made.

The ability to interpret the residents' subtle responses provides a unique advantage to the staff at St. Amant Centre. Careproviders recognized this advantage, and also recognized that staff members in other institutions to which residents were admitted for medical or surgical problems, were placed at a disadvantage. This recognition was frequently expressed in concerns regarding transfer of residents to other facilities. One of the parents verified that admission to an acute care facility can be problematic.

Going to the hospital was a tough thing for him 'cause he'd been in twice, and the first time it wasn't a good experience. The second time was much better because we were prepared for it, and knew how to prepare the people that were working with him ... a little better.

The speaker returned to this subject later in the interview, describing the lack of awareness on the part of the acute care centre staff as to the abilities of her son, who was unable to walk and required support to sit in a wheelchair.

...The first time he went in, I just assumed they would know what to do with him. But...when I come back and find him hanging out the side of a wheelchair 'cause they think he can sit up,... And then when one of the residents comes by and is telling you that this operation will help him to walk better, and you just laugh at him, and he looks at you like, "What'd I do?"

### **The Importance of Long-Term Evaluation**

Some careproviders stressed that, even after they had developed a relationship and established communication with a resident, it could take years before any measurable progress could actually be documented. This was particularly true in areas such as social development, and the acquisition of intellectual/cognitive skills. One of the teachers described the nature of progress evaluation with students, and emphasized that it can be a long-term process.

I see them paying attention to the rest of the world that's going on around them, becoming involved with the other children in whatever way they can. Sometimes it's very little; it might

just be laughing at what is going on. They become involved, they begin to notice what is going on out there and it can take forever to do it, it seems, years and years. To me, that is an improved quality of life.

One of the Adult Program staff discussed the changes that are observed in people who have behaviour problems, once they begin to demonstrate an interest in the activities which are offered through this program. Once again, it was emphasized that measurable progress can take years.

You often see people who have a lot of behavioural problems - like they'll be self-abusive - stopping a lot of those behaviours during adult program time.... They start to wait for you to do something with them so that they don't even bother with the other things, because they know that there's other stuff happening....

Those kinds of changes that we notice, they take years sometimes till somebody really gets enjoying that and looking for it, but it's still years that are saved from more self-abuse.

A lengthy evaluation period was also required to assess changes in physical or functional development. One of the physiotherapists noted that years can pass before the results of programs designed to maintain joint range of motion are apparent.

...I'm seeing the results now after four, five years, but I do see the results. When I do assessments on these children I can see whether they're maintaining a range or not. I can see that many of them are maintaining a range in spite of growth, in spite of tighter muscles. Or in some cases, they've even gained.

The need for long-term evaluation places careproviders who have worked at St. Amant Centre for a number of years at an advantage. Staff members who spend only a short time in this setting find it difficult to evaluate changes in functional or cognitive abilities. Similarly, careproviders in acute care settings who are involved with residents when they are transferred for medical or surgical treatment, may have a difficult time to appreciate that the benefits of the procedures which are performed may not be apparent for several years. In some cases, however, it is uncertain whether the changes noted by long-term careproviders are actually indicative of changes in function or cognition, or whether they are the result of increased perceptual and observational skills which are heightened during the course of lengthy relationships with residents.

### The Importance of Intuition

Sometimes the process of assessing either improvement or deterioration in an individual's quality of life is an intuitive one. Respondents, particularly parents, noted that they sometimes "just knew" that there was something wrong, or that there had been an improvement in some aspect of a resident's life. One of the parents who had cared for her daughter at home for several years before her admission to St. Amant Centre, discussed how she felt she could intuitively determine her daughter's level of comfort.

...I don't think she's comfortable, I don't. And I guess I take it on myself because I'm her mother and I think that I can - I may be wrong - but I think I can feel what she's feeling.

Another parent, who has maintained regular contact with her daughter since her admission to the Centre, indicated that she had little difficulty in determining what the child's crying meant.

When you've known her for so long, you just know [what her crying means], just like any other kid.

Careproviders within the Centre also relied upon intuition when working with residents with whom they had a long-standing relationship. One of the teachers described this dimension of intuitive interpretation.

...Sometimes you know just instinctively that a student's not well or not feeling well. You become very close to them. I've had some of my students for three to four years and I feel I know them very well. I know them like my own children at home, and you can make value statements on that basis as well.

The intimate and intuitive relationships which develop between careproviders and residents at St. Amant Centre were described as being extremely important to the emotional well-being of the residents. The temporary loss of these relationships during a resident's admission to other health care facilities, was perceived to be a potential source of emotional upset. As described in Chapter 7,

concerns that careproviders in acute care centres would be unable to intuitively determine the resident's needs were important considerations in the decision-making process surrounding surgical procedures. Such concerns were also foremost in decisions not to transfer residents to other centres for care at the end of life.

### **The Importance of Shared Baseline Assumptions**

The development of close, long-standing relationships was not the only pre-requisite which facilitated the process of proxy quality of life assessment. Careproviders noted that there are also certain assumptions which needed to be accepted before they attempted to evaluate the effects of specific treatment interventions on dimensions of another person's quality of life. These assumptions are based on careproviders' definitions of what they consider to be important to enhancement of the quality of their own lives. One of the physicians described this process.

...The first thing that I would say is that all of this depends on definition....I mean we make assumptions about what quality of life is, but we have to recognize that they are assumptions. So first of all you have to sort of define quality of life, and then you have to make an assumption that what you think is going to be important for somebody's quality of life, is what is important.

One of the nurses expressed a similar viewpoint, noting that what she perceived to be of importance to the residents was probably based on considerations which were important to the quality of her own life.

Everyone has their own personal opinion of what they consider quality of life, and I guess they compare it to themselves. I'm my own criteria, I suppose, for the residents, to an extent.

Some of the respondents made reference to the ways in which proxy decision-making for interventions, such as gastrostomies, could proceed by deciding which type of treatment they would choose for themselves, in similar circumstances. Narrative illustrating the tendency for careproviders to reflect upon what they might choose if they were placed in the resident's position, was previously



presented in the decision-making examples discussed in Chapter 7, and is described here by one of the nurses.

As far as gastrostomies go, I think they're absolutely necessary for quality of life. The residents that have them are residents that absolutely refused to eat, could not eat....

If they could make that decision and say, "No, I don't want a gastrostomy, I want to waste away," then fine. I would have to go along with that. If I could give them that choice, I would certainly give them that choice. But because I can't give them that choice, I have to base the judgment on what, perhaps, I would want if it were me.

One of the occupational therapists expressed a similar viewpoint in discussing a decision to involve a particular resident in one of the Adult Programs.

...We don't know right away if it's improving her quality of life- and I guess that's so subjective. I just know if I was in that situation I'd want to be involved in something - I wouldn't want to sit in my room all day long and the only difference would be to bed or up, and not even being out of my room.

The existence of shared assumptions, based on definitions of what careproviders felt contributed to an enhanced quality of life, was important in the process of planning various programs and interventions. A member of the psychology staff described this process.

In general we would assume that things that lead to more independence on a person's part lead to increased quality of life. So if we can't measure quality of life we would say, "Well, does this improve the person's independence?" We would assume that that improves the quality of life.

We might think of normalization, what would this person do if they were living out in the community? So then we might say, "Well, we don't really know if it's a better quality of life, but at least it's more normal."

Proxy decision-making could proceed, therefore, on the basis of careproviders' own definitions of quality of life, and shared assumptions that similar criteria could be used in proxy decision-making on the residents' behalf. As some of the careproviders pointed out, however, they

often had to make an additional assumption that an apparent improvement in a resident's quality of life was directly related to the implementation of a specific program or intervention. These assumptions were made necessary due to the difficult, if not impossible task, of identifying the nature and source of the improvement, and of providing objective evidence that the intervention in question had actually produced the changes which were observed.

## **Measurement Issues**

### **The Nature and Source of Improvement: A Case Example**

As described in the preceding section, decisions made by careproviders on behalf of residents were often based on individual definitions of quality of life, and shared assumptions that residents would benefit from interventions designed to enhance quality of life according to those definitions. However, many careproviders expressed feelings of uncertainty about the specific mechanisms by which quality of life was improved by specific interventions, even though they were certain that there had been an improvement. For example, it was often difficult to determine whether the resident's physical health was most improved as a consequence of a specific intervention, or whether the primary benefit was in the area of enhanced emotional well-being. In cases where residents participated in programs in a number of different departments, it was also difficult to determine which of several interventions might have contributed most significantly to improved quality of life.

The following case example illustrates the difficulty of assessing the contribution of a particular intervention on what was considered to be an improvement in a client's overall quality of life. In this example, one of the occupational therapists describes a situation in which a relatively simple intervention created additional opportunities for a particular resident and, in doing so, had an apparently profound effect on her quality of life.

I did one thing that I think improved her quality of life, but it was something very simple.... She is somebody that doesn't have a lot of functional movement. I mean she's very severely disabled.... Anyway, I tried her with a head switch with some music 'cause she loves music and battery operated toys, and she had no problem with it. Figured it out right away and understood that concept. And so - she used to participate in music - she'd go down to music class and because she can't physically really play any instruments, they'd have her playing the background music. So they'd set her up with a tape recorder and a timer and she'd just have to hit the switch to keep the music going. And she really got a kick out of it and you could see that she enjoyed doing it....

The speaker went on to describe some of the benefits of the intervention, but indicated that other programs which were put in place for this resident may also have contributed to the improvement in quality of life.

...It's given her something that she can kind of control. Now I don't know if that's made her happier. She also got put in half-time school. She's just brightened up - I don't think it's cause of that - I think she's just brightened up. But now she's at the point where, in the afternoon, she doesn't like staying on the ward.... She really puts up a fuss now and wants to go somewhere and this is somebody who never got to go anywhere. But I think, in my eyes, at least doing one little thing for her made a difference for her certainly and she's able to participate in class and that's one of her objectives....

The benefits of this simple intervention were then described in more detail. The speaker noted that, while there were obvious emotional and perhaps physical benefits to be derived, the primary benefit was perceived to be the degree of control which it gave the client.

...She tends to keep her head turned very much to one side, so I put it [the switch] on the opposite side so she has to work at it a little too. So it's got function that way. And it could be used for other things - just doesn't have to be used for music...I think it improved her quality of life that way because she has no other control - that's her one means of controlling something all by herself.

It can be seen from this case example that, although specific interventions may contribute to improvement in one dimension of quality of life, they can also serve to enhance quality of life in other dimensions. In this instance, an intervention which produced a noticeable improvement in a resident's happiness or emotional well-being, also appeared to contribute significantly to the enhancement of social interaction, and the development of cognitive skills. As there were other interventions

interposed between the original one and the evaluation of improved quality of life, however, it was difficult to determine the specific source of this improvement.

It is equally difficult to measure or document some of the changes which are observed. Increased happiness, or an improved ability to exert a measure of control over some aspect of daily life are examples of changes which cannot be measured or recorded objectively. As will be described in the next section, careproviders experience problems in presenting evaluations of improved quality of life to society at large and to outside policy-makers, so that the importance of continuing to provide technologically advanced equipment and quality programming to people who are profoundly impaired will be appreciated.

### **Objective Evaluation of Quality of Life**

The careproviders who were interviewed for this project acknowledged that measuring and documenting improvements in quality of life on behalf of others is often extremely difficult. Frequently, information about the effects of specific interventions on the resident's quality of life is gained indirectly, through observation. In the following segment, one of the occupational therapists discusses an apparent improvement in a resident's quality of life, following her admission to the Adult Program. It was noted, however, that the nature of the improvement was difficult to document, or even to describe.

She just seems like a different person to me - more alert....Now she did have a gastrostomy too, which might have helped her, because she always had that tube up her nose. Maybe she feels better since she doesn't have to have that tube up her nose any more. She just looks like a different person to me and I don't know if that's 'cause she's just healthier or she's now involved in Adult Program - but I think getting her involved in something even though we don't know right away if it's improving her quality of life - ...I can't imagine that it hasn't improved somehow. I think there must be a difference there somewhere. She just seems brighter but I mean I don't know if you can document anything like that.

Similarly, one of the Adult Program staff described changes which were observed to take place with some of the residents in the program, again finding the specific nature of the changes difficult to describe, and referring to attributes which were largely, immeasurable.

...I feel their world has been broadened in that you see them becoming much more gregarious. You see them maturing where there wasn't a lot of potential for maturing before because there was no new information being put in to change a maturity level. There's now some responsibility for decision-making; like you have to decide what work you want to do next and then you have to do it. You can't back out once you've chosen it. So there's choice making, decision-making, those kinds of things, and that's with non-verbal clients....It's hard to describe but you do see people being more alert to what is out there.

Many of the careproviders involved in clinical programs, stated that they relied on expressions of pain and/or pleasure to provide them with feedback about the residents' preferences for particular interventions or programs. One of the physiotherapists described this feedback system.

Some of them can certainly express pleasure very freely, very openly and it seems very obvious whether they're happy or not happy. Certain things and activities that you present them with, they obviously enjoy because they're smiling and they seem eager to do them especially when you present them for a second or third time. Other things definitely cause pain, and you see a painful expression on their face, or a lot of them will cry. A lot of other people - we have one in particular - one resident who just gets so totally uptight and starts perspiring profusely, and we know that he's definitely uncomfortable with what we're doing. So I guess we're reading that type of thing.

Although indicators of pain or discomfort were frequently used as measures of response, the degree of discomfort or pain experienced by the resident was difficult to assess. This problem was described by one of the nurses when she spoke of the difficulty in determining how much discomfort residents might experience from wearing Soft Boston Orthoses.

...I'm sure it adds to their discomfort. Now how much discomfort the residents feel according to their own sort of perspective, again is hard to judge. I can't judge that. They might not feel any discomfort at all. Who knows?

Some of the careproviders noted that, because they were unable to objectively assess the residents' responses to various interventions, the validity of the assumptions upon which treatment decisions were based could be subject to varying interpretations. The process of decision-making based upon attempts to put oneself in the position of another person, has been criticized by opponents of proxy quality of life evaluation because of its inherent subjectivity. One of the physiotherapists described the assumptions used in deciding to re-seat residents who had been confined to bed for several years. This speaker indicated that interventions which might have seemingly obvious benefits to careproviders, might produce quite different reactions in individuals with profound physical and cognitive dysfunction.

The kinds of measures? I think that it's really hard to measure. For example, if you get somebody up who's been lying on the bean bag chair; if you looked at it, and I looked at it and said, how would I feel? Of course, if I was lying in a bean bag chair I'm sure that I would be very happy to be getting up and sitting. It seems an obvious thing, but we don't know. From their point of view, it might be very scary. I'm sure it is to begin with. I'm sure they're quite frightened.

One of the physicians also commented on the assumptions involved in re-seating individuals who have been confined to bed for several years. This speaker noted that, while maintaining people in an upright position has recognized physiological benefits, the effects of those interventions on other aspects of quality of life are often based on assumptions made by careproviders.

...Some of the assumptions that we make I think are well proven- such as you're better off to be upright than you are lying down. But there may be some individuals in whom, if you actually measured it, in whom their quality of life, as they perceive it, may not be better that way. But if you can't measure it, you don't know.

The speaker returned to this subject at a later point in the interview.

... We are assuming that lying down, that person is not having as much quality of life as they would be if they could get up and interact.... We make that assumption, try to get somebody up and around, and then try to assess what happens - try to measure what happens. And in some of the situations, direct or indirect measurements like the person seems to interact with

their environment more, seems to smile or seems to look happier; we assume that we are doing something that is beneficial.

This physician's narrative was typical of that of careproviders who recognized that objective measures could be valuable indicators of the efficacy of specific treatment interventions, but also recognized that the application of such measures was extremely limited in this particular situation. One of the physiotherapists discussed efforts to objectively measure the results of specific orthopedic surgical procedures in order to determine whether the surgery had contributed to an improved quality of life for the resident.

From the experience that we've had, subjectively we feel that a lot of patients are better off. We have looked at the varus osteotomy study that we did, and we looked at a lot of- I guess a lot of aspects of orthopedic care, in terms of measuring angles and measuring the success of the surgery more than whether or not we actually improved the person's functional capability, which again would determine whether or not their quality of life was better. It's difficult assessing something like pain. We did note that a certain percentage of patients who had pain prior to surgery didn't have the same amount of pain after so many years....

The speaker continued, describing the difficulties experienced in attempting to use objective indicators which would provide a measure of function in a population impaired to the extent of the residents of St. Amant Centre.

...I guess one of the biggest problems that we had with the study was that, at the present time, there is no real objective way at looking at improved function. How do we measure improved seating capability? They may look better, they may subjectively seem to be sitting longer, but a lot of that is related to, not their wish to sit longer, but they're just left sitting longer. You know, they can't tell us that they can only sit for two hours a day or three hours a day. They're just being sat for two hours a day because that's what the scheduling is.... There are patients who do start crying before their time is sort of up, so that's one way we could measure but it's very difficult to do in a study.... We can look at tolerance more closely. Deformity is a very difficult thing to measure.

Thus while there was an appreciation that the use of objective indicators was preferable, there was a recognition that this was not always possible in the case of residents who are profoundly

physically and cognitively impaired. The task was somewhat easier when there was a lesser degree of impairment, but still was not accomplished easily. Another of the physiotherapists indicated that semi-objective indicators were sometimes available in cases where clients were less severely impaired and were able to achieve some degree of independent function, either in terms of mobility, or in activities such as feeding. It was emphasized, however, that most of the information about a resident's progress was obtained indirectly from other careproviders who were involved with them.

Most of the feedback comes through observation. Feedback I get from parents and school teachers, aides in the classroom, ward aides and nurses. Often times you have a nurse who says, "He sits so much better, he feeds himself better. He wasn't eating before, we changed his seating, we put a Soft Boston on; he can feed himself, he isn't falling in his plate. He can move the walker around the ward. He's happier, doesn't get into as much trouble as he did before, doesn't cry as much." That's the type of feedback mostly- most of the residents don't talk. It's hard to get any verbal feedback other than through observations.

In the process of evaluating outcomes, then, careproviders rely heavily on subtle indicators from the residents, from observations made by themselves and others who know the resident well, and in some cases, on semi-objective measures such as improved sitting posture or sitting tolerance. One of the physicians summarized the difficulties of obtaining objective measures, recognizing that these are often considered necessary in today's society, but emphasizing that the use of other methods of evaluation should be acceptable in settings such as St. Amant Centre.

I think that all of our measurements are flawed to some extent because of the fact that you have to define what it is that you're measuring, and make assumptions about what it is that you're measuring. So you could stop right there and say this is all not definable, and everything we do is based on assumptions, but rather than doing that I would say you have to say, "Well, that's fine. We'll do that. We'll make some definitions, whether they're right or wrong and we'll make some assumptions, whether they're right or wrong, so that you can carry on and proceed." And you'll try and measure things as best you can and the measurements can be either direct or indirect measurements, and even though our society tries to be very scientific about measurement and say that it has to be something that you can objectively measure, perhaps the option of semi-objectively measuring a subjective thing is valid in many situations, and particularly in this situation.



### Subjective Evaluation of Quality of Life

As indicated in the previous section, some careproviders felt that it would be preferable to use objective measures, in some instances at least, to evaluate the effects of specific interventions on residents' quality of life. They also recognized, however, that measurement indices which would capture the subtle changes observed in a population such as that at St. Amant Centre were, for the most part, unavailable. For this reason, subjective indicators were acknowledged to be an extremely important, and probably necessary element in the evaluation process.

One of the physicians expressed the opinion that reliance on assessments using standardized measurement tools would be unsatisfactory in this situation, and indicated the importance of subjective evaluation by careproviders.

...I think it would be dangerous to simply base whether you're going to do an assessment or a treatment or not on a number on a numerical scale. I think that is scary. I think that using a scale can maybe aid in the decision-making- but it would be wrong to separate that out from the opinions of caregivers and staff, and the resident if they can participate at all.

This statement succinctly describes proxy decision-making on behalf of those who are incapable of expressing their wishes, as it is practised at St. Amant Centre. The best interests of the individual residents are protected by a process which weighs the benefits of a specific intervention against the burdens, tempered by the subjective evaluations of careproviders regarding the effects of various interventions on all aspects of the resident's quality of life. The experience and expertise of careproviders are important factors in this process. Subjective evaluation of the impact of specific interventions on residents' quality of life, by outside evaluators who are unfamiliar with the residents, might yield significantly different results.

The next sections will describe safeguards which have been incorporated into the proxy decision-making process at St. Amant Centre. These include an emphasis on team assessments, a commitment to advocacy on behalf of the residents, and the personal commitments of careproviders to the residents.

## Safeguards in Proxy Decision-Making

### The Commitment to Team Decision-Making

Although team decision-making was observed by the investigator in a variety of settings (as discussed in Chapter 4), inter-individual narrative is not available for inclusion in this thesis. The observations made by the researcher in team decision-making settings served primarily to validate the information obtained through in-depth interviews with the individual decision-makers.

Recognizing the subjectivity which is inherent in the proxy decision-making process, some of the respondents emphasized that team assessments and decisions were more important in this situation than in others. One of the physicians stressed that a number of different viewpoints should be obtained.

...I think that one of the things that has to be done in decision-making for people who can't decide for themselves is that it has to be a team approach. And I think that physicians making these decision in isolation will be wrong as often as they are right. I think that the primary caregivers- nurses' aides, nurses - everybody should be pulled into a major decision.

A member of the psychology department also emphasized the importance of team evaluation in the proxy decision-making process.

Most issues revolving around quality of life here anyway, in my experience, are rarely decided by one person. It's usually a team that decides this is okay. I think that's really good because if a person is unable to tell you what they want out of their life, it's important that you get as many people as possible involved so that you can get a number of different viewpoints, and so it's not just one person making a decision for another person.

One of the nurses discussed some of the concerns which might be raised during the process of deciding for or against an invasive intervention such as a surgical procedure. She stressed the importance of discussing all the potential effects of the surgery.

What we actually do here is have a team, discuss. This includes the parents. Just talk about the person, what seems to be the best for him. If the person has had orthopedic surgery and it wasn't successful in changing the quality of life and surgery is recommended again, we would question it....How routine in the problem? What's the potential with the surgery? What are the possibilities of a good result?

As indicated in the preceding narrative, some careproviders perceived the emphasis on team decision-making to serve as a system of checks and balances. It ensured that decisions were not made on the basis of one person's evaluation of the potential for improving quality of life, but on the basis of a consensus among careproviders.

As the various teams involved in decision-making were inter-disciplinary in their composition, an emphasis on team decision-making also helped to ensure that specific professional agendas did not receive disproportionate weighting in the decision-making process. An example is the decision-making which takes place at Orthopedic Clinics. The orthopedic surgeon, physiotherapists, occupational therapists and an orthotist attend these clinics regularly. Some of the nurses, however, make a point of attending when residents on their living units are presented for review. One of these nurses indicated that, although she was not directly involved in decisions regarding orthopedic surgery, she would not hesitate to express her concerns regarding various procedures in the decision-making forum.

The orthopedic surgery- I would have to say I'm not really involved in the decision making. It really comes from the physician and the physiotherapist....I don't feel I'm knowledgeable enough in that specialty to have an opinion. But I certainly question it. If I have a question I certainly would say, "Are you really convinced? Can you explain to me why?"

Other careproviders described instances where they felt that decisions had been made without adequate representation from all concerned. One of the members of the feeding assessment team expressed frustration at what was perceived to be a failure to adhere to assessment protocols prior to making decisions to perform gastrostomy surgery.

... My biggest beef, I guess, with everything that's happening now is the decision-making process when it comes to somebody having a gastrostomy. Right now it's sort of, well so-and-so needs a gastrostomy, they don't eat very well. They may have a feeding assessment, although there have been a few who just all of a sudden went off for surgery and we didn't hear about them. That really upset me. I felt it should go through a process....They should have to go for feeding assessment by the multi-disciplinary team....

Despite the emphasis on the importance of team decision-making, however, careproviders recognized that parents or legal guardians have the final say in decisions concerning major interventions such as surgery. One of the physicians expressed the following viewpoint.

...If the parents feel very strongly about something, I think their decision-making should be honoured. It would be in all other cases. ...If the child were at home, the parents would have the ultimate say.

One of the physiotherapists described the role of the parents in decision-making, noting that, even though the medical team may feel that a procedure is indicated, it is not difficult to understand why a parent might refuse the procedure on their child's behalf.

You can see why a Mom would say, "No, don't put them through it," but you hope that they will go for it, because obviously the people that are working with her are pretty sure that she would be able to sit better and more comfortably when it's all over with. But the parents do get the final say on that.

Parents who were interviewed were in agreement that the final decision in such matters rests with them. The following excerpts were extracted from interviews with parents of two residents.

#### **Excerpt #1**

They wouldn't have done it [the surgery] if I wouldn't have agreed. They can't. I'm her mother so even though she lives at St. Amant, unless it's an emergency and they can't get me, they really wouldn't okay any surgery of any kind.

**Excerpt #2**

When something like that [gastrostomy surgery] is going on, I don't think of it as their [the careproviders'] decision to make.

Although parents were adamant that they reserved the right to make decisions on behalf of their children, however, several of them indicated that, in most cases, they would base their decisions on the recommendations of the medical team.

I'm not a doctor or a nurse, and I don't look after her every day. So if they tell me that this is going to be better for her and better for them, then chances are I'm not going to say, "No, I don't want it done."

Both careproviders and parents also indicated that, if they disagreed with a recommendation or decision put forth by the others, they would not hesitate to question it. One of the psychologists made the following observations concerning parental involvement in decision-making.

We definitely have some families who have questioned the efforts of staff, like why is physio getting involved? It was clear that our expectations of their children in terms of what they need to experience a good quality of life were higher or greater than the family's expectations and aspirations for their child. So in those cases we resisted family's efforts to limit involvement. We met with them and repeated as basically part of our education process to explain to them why it is important.

Similarly, one of the parents described her reaction to not being consulted on matters related to her daughter's care.

...At the beginning they would- not do as they pleased but- maybe try this and if I didn't say anything, they would think it's fine. But then I made it clear that I would like to know exactly what's going on before they do it. Even if it's a minor thing, please come and ask me first.

The emphasis on team assessments helps to ensure that balanced decisions are made. Another safeguard which serves to promote fair and just decision-making on behalf of residents, is a strong commitment to advocacy. Some careproviders were adamant that residents of residential care

facilities such as St. Amant Centre should not be denied equitable access to health care resources on the basis of a severe, permanent impairment.

### **The Commitment to Advocacy**

In describing his/her commitment to an advocacy role on behalf of the residents, one of the careproviders recognized that decisions for profoundly disabled people could, potentially, be based upon a different set of standards.

I'm constantly on the look out for double standards. Do we make decisions differently for disabled people than we would for other segments of the population?

This speaker continued, indicating that if careproviders believed that the decisions of parents/guardians ignored or contradicted treatment which was perceived to be in the best interests of the resident, they would intervene on the resident's behalf. Once again, reference was made to the conflict between the moral philosophy of St. Amant Centre, and what was perceived to be the viewpoint of the wider external society.

Parents do have a lot of influence. At the same time, though, I think that we have to always remind ourselves that parents are not the person and they again have their own needs....I generally feel that families are more likely to make good decisions than anyone else for the person....But again, families and parents are part of our general culture in society, different parts of society, different stages in terms of how they view people with disabilities....

One of the physicians described the steps which would be taken in the event that parents/guardians refused treatment which was considered to be in the resident's best interests.

...If it ever came to a situation where I thought that it was urgent that the surgical procedure should be done and the parents said, "Absolutely not," then I think I would want to pull in another advocate for the resident....

It's never happened....but I think if I thought that the parents were not acting in the best interests of the child, I would certainly ask for another physician's opinion. I would bring that opinion back to the parents. If it [consent] again wasn't forthcoming, I would talk to the social service agency under which the child was admitted...

One of the social workers described the process of advocating on the resident's behalf, and the role of the Department of Social Services in that process.

For instance, if there was a child that was in pain, and surgery was required, and the parents were not signing, my role would be to contact the Child and Family Services Agency to make them aware of the concern, and request that they follow-up with meetings with the parents to discuss. First of all doing the advocating role of getting the people together, but if that's not successful, then I would go to the agency that was responsible; the agency that could take action.

Some careproviders believed that they had a larger role to play in terms of advocating on the resident's behalf; that of negotiating to ensure that institutionalized individuals who are permanently and profoundly impaired are guaranteed access to the best possible care. One of the respondents described this commitment to advocacy, in regards to informing policy-makers of the benefits which were afforded through specific treatment programs and interventions.

A lot of the policy-makers, I think, take their cues from us, and if we are very assertive and confident when we say that, now at this Centre, a certain percentage of the population require this type of feeding for comfort and quality of life, etc., and that's our expert opinion - that people will take that cue. It may be hard to come up with the monies, but they're not going to argue with the point that it's important- the average policy-maker won't.

If we come across a lot softer and say, "Well, we know it's expensive, and we're not really sure if it's the best thing but it just seems to be," then we won't get as far. So it has a lot to do with confidence.

This speaker continued, expressing the frustration which results from the perception that not all careproviders at the Centre are equally committed to this advocacy role.

I'm frustrated sometimes with, internally, what I see as the limited commitment to advocacy in that way within the Centre by some staff. People are saying, as a staff member, "I'm a taxpayer, and I don't want to-."

Our job is 100% to advocate on behalf of the resident; to push the limits and see what we can do to make life better, and not to think of ourselves as taxpayers when we're doing it. That's what we're supposed to do....I think the message comes through too often to policy-makers that we're not 100% committed to it either; and if we're going to waffle, they're not going to go through with it.

This commitment to advocacy was also reflected in comments regarding the applications of the principles of distributive justice. The respondent quoted below was adamant that there should be equitable access to resources.

...I don't feel restricted at all in that way and if I did, I think I'd fight for it 'cause I think it's not fair that somebody has to go without something.... I would be pretty up in arms if there was a time when I couldn't get somebody something that I knew would improve their life.

### **Personal Commitment**

Careproviders' personal commitments to the residents were also reflected in the narrative. Some careproviders emphasized that, if evaluations of quality of life based on social worth were applied to this particular population, they would consider the contributions of the residents of the Centre as equal, or perhaps greater than those of other members of society.

...[Y]ou see people out in society who have it all; they have money, families, and yet they're still... complaining that they're not happy. Some of these little kids in here with the big smiles, they seem to be basically happy and satisfied with life. Who's life is worth more? Their's or the complainers of society? They're drinking and driving and they're causing a heck of a lot of damage, too. They're beating up on their families. Like those people, I would say I wouldn't want to save them. I'd rather save one of our little residents, or even one of our adults who's happy, and who is contributing to other people's happiness, maybe just by responding to them, and by being friends with other individuals in here.

This viewpoint was shared by other respondents who expressed a genuine commitment to improving quality of life for the residents, and indicated that the responses of these children and adults made their work very rewarding.



...If their life is very restricted and what they can do is very restricted- you try and make that as nice as possible. Whereas out in society, if you're working with people who have all kinds of potential to do things on their own and maybe they have a sore back or something, you don't really feel that you're making that much difference to that sort of individual [by providing treatment], or as much difference as you would to maybe somebody in here by giving them just a little tender loving care.

A lot of people say, "I can't understand how you can work in a place like that. You don't make any progress, nothing really happens." They obviously don't understand.

## CHAPTER 10

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### SUMMARY AND IMPLICATIONS

This thesis has described how health careproviders make proxy decisions involving quality of life considerations, on behalf of institutionalized individuals who are profoundly cognitively and physically impaired. The body of descriptive data and analysis represents a contribution to a rapidly expanding body of literature pertaining to the assessment and evaluation of health-related quality of life. As little research has been published on proxy assessment of quality of life in preparation for decision-making, it is hoped that the research produced will narrow a gap in the published literature, and enhance understanding of this process among researchers, clinicians and policy-makers.

There are a number of points which must be emphasized in summarizing this material:

- 1) Careproviders were able to provide a multi-dimensional description of quality of life, as they applied the concept in interpreting the experience of people with profound impairment.
- 2) Some systematic similarities were present in the narrative of members of the same professional group, when they described those dimensions of quality of life which were considered most important.
- 3) Some systematic differences were present in inter-disciplinary descriptions of quality of life.

- 4) Careproviders described a hierarchial arrangement of the dimensions of quality of life, which was considered either directly or indirectly in decision-making. In this arrangement, the dimensions of physical and emotional well-being were considered to be fundamental to maintaining a good quality of life. Achieving improvement in these two dimensions was often perceived to be the immediate, and most easily attainable goal of specific treatment programs.
- 5) The achievement of physical and emotional well-being was often considered to be an inadequate criterion, taken by itself, in defining a good quality of life. Increased social interaction, improved intellectual and cognitive development, and enhanced self-esteem and social status, were considered to be the ultimate goals of many interventions.
- 6) The consensus of opinion about which dimensions of quality of life are most important in the final analysis, enabled careproviders with different agendas to agree that either intervention, or non-intervention was in the resident's best interests.
- 7) Participants recognized that considerations related to the impact of alternate interventions on careprovider workload were acknowledged in making decisions about interventions such as orthopedic surgery. They emphasized that it is often difficult to sort out the contributory effects of specific interventions on the careprovider, and on the resident. Careproviders felt, however, that considerations pertaining to the impact of specific interventions on their own workload should not be the primary motivating factors in proxy decision-making.
- 8) Careproviders acknowledged that the influence of more general societal ideas about the valuation of disabled people, may affect resource allocation decision-making, particularly when decisions are made by health careproviders and policy-makers outside the Centre. They were adamant that considerations pertaining to social worth should not be allowed to play a significant role in decision-making.

- 9) Careproviders outlined the requisites for proxy quality of life assessment in their unique situation. These included the need for long-standing, intimate relationships with the residents, the need for long-term evaluation, the need for intuitive evaluation in some cases, and the need for agreed-upon baseline assumptions about the definition of quality of life and the dimensions of quality of life which are most important in decision-making.
- 10) Careproviders described the ways in which both subjective and semi-objective measures are used in determining the effects of specific interventions on residents' quality of life.
- 11) Careproviders expressed firm commitments to ensuring that fair and just decisions are made on behalf of the residents. These included a commitment to team decision-making, a commitment to advocacy, and a personal commitment to provide the best possible quality of life for the residents.

### **Clinical Application of Research Findings**

Although careproviders will be unable to apply the findings of this particular project directly to proxy decision-making situations, it is anticipated that the description of the process of making decisions on behalf of others will be of special interest to those who participated in this research project. The finding that there is agreement among careproviders with different agendas about which considerations contribute most significantly to overall quality of life, is an important one, both in terms of quality of life assessment, and in terms of the recognition among careproviders that their ultimate goals for the residents are very similar. Although there were systematic differences in the dimensions of quality of life judged to be of immediate importance by careproviders depending on their professional ideologies and scopes of practice, the existence of systematic similarities in the dimensions of quality of life which were perceived to be of ultimate importance facilitated the formation of consensus, in most instances.

The documentation of the complexity of proxy evaluation of quality of life in this situation, and the various ways in which careproviders attempt to deal with this complexity, may also be of interest to those who work at St. Amant Centre. The descriptions of the ways in which different staff members attempt to assess both the potential and the actual impact of specific interventions on residents' quality of life, may serve to clarify the evaluation process for some careproviders.

Finally, the commitment of the careproviders at St. Amant Centre to fair and just decisions which are based on the best interests of the residents, may also be a source of comfort to the parents who participated in this project. The shared definitions and assumptions which were apparent from the narrative of careproviders from different disciplines, provide a solid basis for proxy decision-making. There was no evidence to suggest that decisions made on behalf of the residents are based on a different set of standards, than similar decisions made for other members of society.

### **Implications for Future Research**

Future research could take a number of different directions. A project designed to provide external validation of the respondents' observations regarding the attitudes of careproviders in other health care facilities towards active intervention in situations involving people who are profoundly handicapped, would provide an important contribution to the literature. Similarly, a study which involved interviews with less cognitively impaired residents at St. Amant Centre might provide important insights into the concept of quality of life as it is applied to the experience of disabled people. Finally, an objectively-based research project could be designed to examine methods of measuring and documenting the impact of specific interventions on overall quality of life, to assist health care professionals and policy-makers outside the Centre to understand and appreciate the value of quality care and programming to the residents of St. Amant Centre.

## Postlogue

In closing, a final excerpt from the narrative of one of the careproviders at St. Amant Centre serves to summarize the objectives of careproviders at the Centre, in terms of improving quality of life for the residents.

There's generally a tendency for people to view the greater the disability, the less the quality of life; so that someone who is profoundly handicapped just automatically doesn't have a high quality of life.... Maybe if I saw myself in that situation, I would think of what a lousy life I have, but a lot of these people, this is all they've ever known. They're the only ones that can really judge their own quality of life.

I think that's what you have to do when you're making decisions about their quality of life. This is what they know, they don't know any different.... To them the most enjoyable, the best part of their life is this. This is what we should be working towards.

\* \* \* \* \*

## APPENDICES

## APPENDIX A

### GLOSSARY OF TERMS AND PROCEDURES

**CEREBRAL PALSY**- This diagnosis encompasses a group of non-progressive disorders occurring in young children as a result of lesions which interfere with the maturation of the central nervous system. Clinically, there is impairment of muscle co-ordination, the result of which is the inability to perform normal movements or to maintain normal postures. The disorder is characterized by abnormal muscle tone and involuntary movements. In addition to motor and sensory deficits, some individuals may experience blindness, deafness, speech disorders, mental retardation, behaviour disturbances and/or seizures.

**DIAPERING**- References to diapering occur throughout the text in discussing the care of residents who have bladder and bowel incontinence. The procedure becomes somewhat difficult in cases where the residents are heavy adults, and also in the presence of skeletal deformities and/or spasticity of the lower extremities.

**GASTROSTOMY**- A surgical procedure whereby a feeding tube is inserted directly into the stomach. The tube is clamped between feedings and, because it is hidden by clothing, is relatively unobtrusive. At mealtimes, the tube is hooked to a longer tube which is attached to a bottle suspended from a pole.

**PELVIC OBLIQUITY**- A deformity in which one side of the pelvis is tilted upwards. Pelvic obliquity is a common sequelae to an uncorrected dislocation of one hip.

**SCOLIOSIS**- A lateral curvature of the spine. Scoliosis is frequently associated with an pre-existing dislocation of one hip and pelvic obliquity.

**SEATING**- The term "seating" refers to the process of positioning an individual in a wheelchair or other type of mobility system. This is an area of expanding technology in which the available options, in terms of accessories and customized inserts which are designed to provide total body support, are rapidly proliferating.

**SOFT BOSTON ORTHOSIS**- A light-weight body jacket extending from the upper chest to the pelvis, and providing non-rigid support for the spine. The orthosis is applied with the resident lying down and is secured by means of front-fastening velcro straps.

**SPASTICITY**- A pathological increase in muscle tone, commonly occurring in individuals with cerebral palsy and other neurological disorders.

**SPINAL STABILIZATION**- Any surgical procedure resulting in bony fusion or mechanical stabilization of all or part of the vertebral column.

**VARUS OSTEOTOMY**- Removal of a wedge of bone from the upper end of the femur, resulting in re-alignment of the femur away from the midline of the body. This procedure may be performed in the presence of a pre-existing hip dislocation, in which case the leg tends to be adducted or pulled in towards the other leg. Care procedures such as bathing and diapering become difficult in the event that one or both legs cannot be moved to the side.



## APPENDIX B

### HISTORY OF ST. AMANT CENTRE, INC.

#### Historical Roots

St. Amant Centre derives its name from Mrs. Beatrice St. Amant who, having a son with epilepsy, elected in 1939 to convert a Transcona farmhouse into a hospital for handicapped children (St. Amant Centre MISSION Booklet). Although the idea for this facility originated with Mrs. St. Amant, however, the Centre is, and has always been owned and operated by the Sisters of Charity of Montreal (the "Grey Nuns"). During the time in which Mrs. St. Amant was taking handicapped children into her home, the Grey Nuns assisted her with equipment, food and moral support. When her health failed in 1956, they assumed responsibility for the care of the children, first at Hospice Tache and later at the St. Boniface Sanatorium. In 1974, the Sanatorium was renamed the St. Amant Centre for Children.

As its previous name suggests, the Centre was originally established in 1931 as a Sanatorium for persons with tuberculosis. In 1959, when the decline in tuberculosis rendered such a facility unnecessary, the Centre began to admit young children with physical and mental handicaps. During the period 1959-1974 it also served as an extended care facility for elderly persons. After the Extended Care Wing was completed at St. Boniface Hospital in 1974, all elderly residents requiring such services were transferred there. The St. Amant Centre then became a facility dedicated solely to the care of severely mentally and physically handicapped children.

The Centre has undergone a number of changes since that time. A major expansion in 1974 provided space for recreation, physical medicine and educational facilities, as well as the addition of two cottages for 24 children, most of whom were ambulant. By 1976, the West Wing had been renovated to accommodate the severely retarded, non-ambulatory residents. In 1983, three additional units housing 24 ambulatory, severely handicapped teenagers were added. St. Amant Centre has also opened group homes and apartments to accommodate residents who are candidates for community living.

#### The Roman Catholic Tradition Continues

The St. Amant Centre is presently "a corporation owned by the Grey Nuns and established by the Legislature of Manitoba for the purpose of carrying out works of charity and mercy" (St. Amant Centre MISSION Booklet: 4). The Sisters of Charity of the Council of the St. Boniface Province are the members of the corporation and ensure that the Centre fulfils its corporate purposes. They appoint a Board of Directors which, acting through an Executive Director, is responsible for the operation and direction of the Centre. The Sisters serve in various capacities in the Centre, providing a central force of Christian leadership. While they retain the moral and legal responsibility for the Centre, they work with lay people in its administration and direction.

The philosophy of the Centre reflects the mandate of the Roman Catholic Church by providing "a visible example of Christ's love and concern for the sick and disabled" (St. Amant Centre MISSION Booklet: 4). The dignity of the person and respect for life as a gift from God are guiding principles in providing quality care for the residents. St. Amant Centre strives, therefore, to meet not only the physical and medical needs of the individuals who live there, but also to fulfil their spiritual, educational, recreational, social and emotional needs.

## APPENDIX C

### DETAILED CHRONOLOGY OF ACCESS AND FIELDWORK

- March 5, 1991- Letter requesting access to St. Amant Centre for specified research program sent to Executive Director.
- March 15- Reply received from Assistant Executive Director of Clinical Services with Research Review Form enclosed.
- April 15- Completed Research Review Form sent to members of Research Review Committee.
- May 14- Letter indicating approval for project received from St. Amant Research Review Committee. Committee members requested copy of approval of Human Subjects Committee of Faculty of Medicine, University of Manitoba, and preparation of separate explanatory letter and consent agreement for parents and guardians of residents of St. Amant Centre.
- May 15- Submission sent to Human Subjects Committee, Faculty of Medicine, University of Manitoba.
- June 3- Reply received from Human Subjects Committee requesting additional information.
- June 14- Additional information submitted to Human Subjects Committee as requested.
- June 25- Approval of Human Subjects Committee received.
- July 8- Copy of Human Subjects Committee approval and parental forms of explanatory letter and consent agreement forwarded to Research Review Committee at St. Amant Centre.
- September 15- Preliminary meetings with Assistant Executive Director (Clinical Services) and Medical Director of St. Amant Centre. IPP schedules obtained.
- September 17- Meeting with Director of Physiotherapy at St. Amant Centre re participant-observation at Orthopedic Clinics.
- September 25- Letter to Assistant Executive Director (Clinical Services) and Medical Director documenting arrangements re participant-observation at Orthopedic Clinics, and procedure for obtaining parental consent agreements.
- October 8- Application submitted for research funding from Friends of St. Amant Centre.
- October 15- Commenced participant-observation at Orthopedic Clinics on a bi-weekly basis.

November 12- First explanatory letters and consent agreements sent to parents of residents whose cases were reviewed at Orthopedic Clinics. First explanatory letters and consent agreements distributed to staff members who participated in decision-making at Orthopedic Clinics. Letters also sent to some parents whose children were being reviewed at up-coming IPP's. Copies of all material mailed out to parents was sent to acting head of Social Services at St. Amant Centre, in case any queries regarding this particular project were received by the Centre from parents.

November 18-27- First signed consent agreements received from parents/guardians.

December 3- First signed consent agreements received from staff members of St. Amant Centre.

December 13- Semi-structured, in-depth interviews commenced with staff members.

December 16- Notice received that funding would be forthcoming from Friends of St. Amant Centre, Inc..

January 29, 1992- Semi-structured, in-depth interviews commenced with parents.

January-May- Continued to distribute letters of information to parents and staff, to attend Orthopedic Clinics and IPP's, to carry out in-depth interviews, and collect information on case studies. Attended a Resident's Rights Council Meeting, a Restraint Committee meeting, and observed several sensory stimulation classes for profoundly impaired adults who were not involved in any other programming in the Centre at that time.

February 18- Presentation to Research Interest Group at St. Amant Centre.

February-September- Conducted literature search and completed formal research proposal.

October- Proposal accepted by the members of Thesis Committee.

October 23- Paper presented outlining preliminary results of study on quality of life decision-making at conference on severe developmental disabilities, sponsored by St. Amant Centre, Inc..

October-June 1993 - Analysis and preparation of final research report.

## APPENDIX D

### INFORMATION FOR POTENTIAL PARTICIPANTS IN THE RESEARCH PROJECT ENTITLED:

#### **Decision-Making by Health Careproviders on Behalf of Profoundly Impaired Persons: Quality of Life Considerations**

I am a physiotherapist who is presently a graduate student in the Department of Community Health Sciences, University of Manitoba. In the process of completing the research project identified above, I am interviewing, and in some cases observing, health care professionals and adult family members who are involved in treatment intervention decision-making on behalf of other individuals who are unable to participate in the decision-making process. The primary objective is to describe how the various dimensions of quality of life are defined, weighted and attributed in such situations.

If you decide to participate in this study, you will be one of a group composed of at least 20 health careproviders and adult family members of residents at this Centre. Participation is totally voluntary and will not affect your relationship with this institution in any way.

As a participant, you may be asked to do any or all of the following:

- 1) You may be asked to participate in an in-depth, semi-structured interview approximately 1-2 hours in length, in which you will be given an opportunity to express your views on the various ways in which you define and attribute quality of life for those who are incapable of making their own viewpoints known.
- 2) You may be asked to discuss with me, and possibly to allow me to observe, your assessment of one or more individuals for whom various treatment interventions are being considered, and to describe how and why you feel quality of life may or may not be improved by the proposed treatment intervention. Interventions of concern will be those which assist or enable individuals to attain or maintain an upright position, eg. various types of orthopedic surgery, aggressive physiotherapy, the provision of orthoses and specialized seating devices, etc..
- 3) You may be a participant at rounds or clinics at which I am an observer.

The data obtained from in-depth interviews with health care professionals and adult family members, observation and discussion of assessments concerning specific treatment interventions, and observations made at rounds/clinics, will be coded thematically, indexed, and any common themes will then be extracted. All data will be treated confidentially, and anonymity will be preserved at all times. Although as a participant, you will be requested to allow audiotaping of in-depth interviews, any information which could identify you or any other individual will be removed or masked prior to using any of the material, especially any that is used verbatim.

Thank you for your interest in this project. It is hoped that the results will enable all of us to better understand the factors which we take into account when making proxy decisions regarding treatment interventions designed to improve quality of life. If you have questions or concerns, please contact me. Should you decide to participate, I will ask that you read and sign an appropriate consent form.

**CONSENT TO PARTICIPATE IN THE PROJECT ENTITLED:****Decision-Making by Health Careproviders on Behalf of  
Profoundly Impaired Persons: Quality of Life Considerations**

In consenting to participate in the study as outlined in the accompanying letter of information, I agree to the following:

I understand that I may be requested to participate in observation/discussion sessions as described in the letter of explanation and/or to participate in an in-depth interview dealing with my views on quality of life as it is attributed by health careproviders on behalf of profoundly impaired persons. Rounds at which I am a participant may also be observed. During individual assessments or discussions of assessment results, and also during rounds/clinics, notes will be taken. In-depth interviews will be audiotaped and transcribed later by the researcher. No one else will have access to this information. I understand that the sole intent of this project is to provide information concerning the various dimensions of quality of life in severe impairment and that there is no evaluative component.

I also understand that, in addition to using this material in the preparation of a thesis, the researcher may use it in journal articles, oral presentations to interested groups, or for instructional purposes in an educational setting. In the event that material from the in-depth interview is presented verbatim, at no time would my name, or the names of any other persons who may be mentioned in the course of the interview be used. All efforts will be taken when using verbatim quotations to remove or mask any information which might serve as personal identifiers. I will be requested, however, to indicate my professional or personal affiliation (i.e. whether I am a nurse, physiotherapist, etc.).

I understand that I am free to withdraw at any time from the study. I may also withdraw my consent to have specific excerpts of the interview used, if I notify the researcher at the end of the interview. In the event that there should arise an instance in which the researcher would wish to use any of this material for purposes other than those stated above, I will be contacted for additional written consent. I am invited to read applicable portions or all of various drafts of the thesis, if I so desire.

I \_\_\_\_\_, have read the above statements and agree to be a participant in this study under the conditions stated above.

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Signature of witness

\_\_\_\_\_  
Signature of researcher

\_\_\_\_\_  
Date

## INFORMATION FOR PARENTS AND GUARDIANS CONCERNING THE RESEARCH PROJECT ENTITLED:

### **Decision-Making by Health Careproviders on Behalf of Profoundly Impaired Persons: Quality of Life Considerations**

I am a physiotherapist and a graduate student in the Department of Community Health Sciences, University of Manitoba. In the next few months, I will be working on a project looking at decision-making by health careproviders on behalf of profoundly impaired persons. In doing so, I will be interviewing some of the staff members at St. Amant Centre, as well as some of the parents and guardians whose children are residents at this Centre. I will also be observing rounds or clinics at St. Amant.

The purpose of this study is to find out how health professionals and parents decide what kind of treatment is best for individuals under their care when these individuals are unable to speak for themselves. I am particularly interested in how the decision is made as to whether or not quality of life will be improved by a particular treatment.

As well as talking to parents and staff members, I will be observing rounds or clinics where team decisions are made about equipment (such as new seating systems or wheelchairs), and treatments (such as surgery and physiotherapy), which might improve somebody's ability to sit. This will be done to determine what kind of criteria are used when decisions which are often aimed at improving an individual's quality of life are made. I will then look at the information which is obtained during the discussion and observation sessions to see if the participants express common ideas about quality of life, or if each person has his/her own ideas about what that concept means.

At least 20 health professionals and parents/guardians will be interviewed for this study. I will be discussing treatments which are being considered for at least 12 residents at St. Amant Centre, and will be observing rounds or clinics at which the decisions concerning these treatments are made. Participation in this study is totally voluntary and will not affect your relationship with St. Amant Centre in any way. In carrying out the discussions and observations which I have described, I will not be participating in, or attempting to influence, the decision-making process in any way.

As a parent or legal guardian, you may be asked to do one or both of the following:

- 1) You may be asked to participate in an in-depth interview which may last 1-2 hours. I am interested in the ways in which you define quality of life for those who cannot express their own views. I will be asking to tape these interviews.
- 2) You may be asked to allow me to observe rounds or clinics at which your son, daughter, or other person for whom you are legally responsible is discussed.

All information will be confidential and names of participants or residents at St. Amant Centre will not be used. Any information which could identify you or any other individual will be removed or disguised before the material is used in any way.

If you have any questions or concerns, please contact me. If you decide to participate in an interview, or if you are willing to allow me to observe rounds or clinics at which a person for whom you are responsible is being presented, I will ask that you read and sign the attached consent form.

Thank you for your interest in this project. It is hoped that the results will contribute towards a better understanding of the kinds of considerations which are taken into account when decision are made on behalf of others.

**PARENTAL CONSENT FORM for project entitled:**  
**DECISION-MAKING BY HEALTH CARE PROVIDERS ON BEHALF OF**  
**PROFOUNDLY IMPAIRED PERSONS: QUALITY OF LIFE**  
**CONSIDERATIONS**

I understand that the researcher may be observing rounds, clinics and/or meetings at which my son, daughter, or other person for whom I am legally responsible is presented. Notes will be taken during these rounds, clinics or meetings, about the way quality of life issues enter into the decision-making process. No one but the researcher will have access to this information. The information will not be used to evaluate any of the decisions made, but only to describe the meaning of quality of life in these cases.

I understand that I may consent to participate in an in-depth interview dealing with my views on the ways in which quality of life considerations are taken into account when making decisions on behalf of others. The researcher will ask to tape this interview.

I also understand that, in addition to using the information collected in the preparation of a thesis, the researcher may use it in journal articles, or for other educational purposes. At no time would my name or the name of any other person be used. If direct quotations are used, all efforts will be taken to remove or disguise any information which might serve to identify myself or any other person. I will be asked, however, to allow the researcher to state that I am a parent or guardian of a resident of St. Amant Centre.

I understand that I am free to withdraw at any time from the study. I may also withdraw my consent to have some of the taped material used, if I notify the researcher at the end of the interview. Should the researcher want to use the information for any purpose other than what was stated above, I will be contacted again for my consent. I am invited to read part or all of the thesis if I wish.

I \_\_\_\_\_, have read the above statements and agree to:

- 1) have the researcher observe rounds, clinics or meetings at which the child or other person  
for whom I am legally responsible is presented yes\_\_\_\_\_ no\_\_\_\_\_
- 2) an interview with the researcher yes\_\_\_\_\_ no\_\_\_\_\_

Signature of parent, guardian or public trustee

Date \_\_\_\_\_

Signature of witness

Signature of researcher



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