

UNCERTAINTY, SYMPTOM DISTRESS, AND ANXIETY IN PATIENTS
WAITING FOR CORONARY ARTERY BYPASS SURGERY

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**Uncertainty, Symptom Distress, and Anxiety in Patients
Waiting for Coronary Artery Bypass Surgery**

BY

Kimberley M. McCormick

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

MASTER OF NURSING

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ABSTRACT

The purpose of this descriptive correlational study was to provide an understanding of the experience of waiting for coronary artery bypass graft (CABG) surgery by surveying a cross-section of 42 patients waiting at home for first-time elective CABG surgery. While previous research has been directed toward the process of safely prioritizing patients on waiting lists, the psychological impact of waiting for surgery has been a neglected area of study. To address this gap in the literature, Mishel's Uncertainty in Illness Theory was used to guide the investigation of uncertainty, symptom distress, and anxiety in this waiting population. A triangulated approach to data collection was used. Participants completed a mailed survey of psychometrically sound instruments designed to measure symptom distress as an antecedent to uncertainty, and anxiety as one possible emotional outcome of the uncertainty experience. Comparisons between these study variables, waiting time, and the demographic characteristics of the sample were also made. Qualitative telephone interviews, asking open-ended questions, were conducted with 60% of the total sample ($N = 25$), in order to obtain a patient based perspective of symptom experience, anxiety, and perceptions regarding the ways that life would change following surgery.

The results of this study established that 58% of the waiting patients experienced moderate to severe levels of uncertainty and 72% experienced moderate to severe levels of anxiety. The most frequent symptoms experienced were also the most distressing with fatigue, shortness of breath with activity, and chest discomfort identified as the most significant symptoms. A significant correlation was observed between uncertainty and symptom distress ($p = 0.005$), and symptom distress and anxiety ($p = 0.0002$), but the relationship between uncertainty and anxiety was not significant. A non-significant trend was observed in which anxiety and symptom distress increased, and functional status deteriorated as waiting time increased. Uncertainty scores remained stable despite length of wait. Patient age had an influence on time to surgery with the youngest, (<60), and the oldest patients, (>69), having statistically significant ($p = 0.02$) shorter total waits, regardless of surgical priority and illness severity.

Content analysis of telephone interview data resulted in the emergence of three main categories: i) taking responsibility; ii) getting my life back; and iii) getting it over with. Strategies associated with each of these categories, the consequences of the strategies, and factors that facilitate or constrain their use were also identified. Overall, while this study meets its goal of providing an understanding of the experience of waiting at home for first-time CABG surgery, further research is required to identify effective ways to ease the psychosocial impact associated with long waits for surgery.

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TABLE OF CONTENTS

	Page
ABSTRACT	iii
ACKNOWLEDGEMENTS	iv
TABLE OF CONTENTS	v
LIST OF FIGURES	x
LIST OF TABLES	xi
LIST OF APPENDICES	xiii
LIST OF ABBREVIATIONS	xiv
CHAPTER 1: INTRODUCTION	1
The Waiting List Phenomenon	3
Prioritization for CABG Surgery	8
Cardiac Surgery and Waiting Lists for CABG in Manitoba	11
Purpose of the Study	14
Research Questions	15
Importance of the Study	17
Chapter Summary	18
CHAPTER 2: THEORETICAL FRAMEWORK AND REVIEW	
OF THE LITERATURE	19
Theoretical Framework	19
Uncertainty and the Experience of Waiting for CABG Surgery	23
Review of the Literature	27
Uncertainty	27

	Page
CHAPTER 2: THEORETICAL FRAMEWORK AND REVIEW	
OF THE LITERATURE (continued)	
Symptom Distress and Coronary Disease	31
Psychosocial Aspects of Waiting for Cardiac Surgery	38
Chapter Summary	44
CHAPTER 3: METHODOLOGY	45
Research Design	45
Ethical Approval and Access	47
The Setting	47
Study Design and Procedures	48
The Sample	49
Informed Consent	51
Feedback/Debriefing	52
Risks and Benefits	52
Anonymity and Confidentiality	53
Compensation	54
Data Collection	54
Quantitative Data Collection	54
Qualitative Data Collection	55
Instrumentation	56
The Mishel Uncertainty in Illness Scale	57
The Symptom Frequency and Symptom Distress Scale	57

	Page
CHAPTER 3: METHODOLOGY (continued)	
The Kansas City Cardiomyopathy Subscales	58
Graphical Anxiety Rating Scale	59
Demographic Questionnaire	60
Pilot Testing	61
Data Analysis	61
Quantitative Analysis	61
Qualitative Analysis	62
Limitations	63
Chapter Summary	65
CHAPTER 4: RESULTS	66
Introduction	66
Demographic Characteristics of the Sample	67
Quantitative Data Analysis	73
RESEARCH QUESTION #1: What are patients' levels of uncertainty, symptom distress, and anxiety in relation to how long they have been waiting for CABG surgery?	73
RESEARCH QUESTION #2: Is there a relationship between uncertainty, symptom distress and anxiety in patients on a waiting list for CABG surgery?	79

Page**CHAPTER 4: RESULTS (continued)**

RESEARCH QUESTION #3: Is there a relationship between patients' levels of uncertainty, symptom distress and anxiety, and their functional status (measured by the KCCQ subscales), their personal characteristics (gender, education, age, living situation, work status, area of residence, decision to participate in telephone interview), and their illness severity (baseline CCS angina class, comorbidities, left ventricular function, number of diseased vessels, history of MI).	81
RESEARCH QUESTION #4: Controlling for surgical priority (MRWT in days) and illness severity (baseline CCS angina class, comorbidities, LVF, number of diseased vessels), are there any patient characteristics (age, gender, education, work status, living situation, area of residence) that are associated with a shorter total waiting time for CABG surgery?	88
Additional Analysis: The Symptom Frequency and Symptom Distress Scale	97
Qualitative Analysis of Telephone Interview Data	104
Conceptual Category: Taking Responsibility	109
Conceptual Category: Getting My Life Back	112
Conceptual Category: Getting It Over With	116
Comparison of Quantitative and Qualitative Data for the Variable of Anxiety	123
Chapter Summary	126

	Page
CHAPTER 5: DISCUSSION	127
Introduction	127
Discussion of Findings	127
Applying Mishel's Uncertainty in Illness Theory To the Experience of Waiting for CABG Surgery	127
Uncertainty in illness.	128
The stimuli frame: Symptom pattern.	130
Appraisal of uncertainty: Anxiety or opportunity?	135
Trends in Waiting Times	138
Limitations to Results and Extraneous Variables	143
Nursing Implications	145
Areas For Future Research	147
Conclusion	148
REFERENCES	150
APPENDICES	166

LIST OF FIGURES

	Page
Figure 1: Diagram of the Mishel Uncertainty in Illness Model	20
Figure 2: Modification of the Mishel Uncertainty in Illness Model	26
Figure 3: Survival distribution curve for CABG surgery waiting endpoint N = 42	90
Figure 4: Survival distribution curve for CABG surgery waiting endpoint by age	91
Figure 5: Survival distribution curve for CABG surgery waiting endpoint by gender	92
Figure 6: Survival distribution curve for CABG surgery waiting endpoint by education	93
Figure 7: Survival distribution curve for CABG surgery waiting endpoint by work status	94
Figure 8: Survival distribution curve for CABG surgery waiting endpoint by living situation	95
Figure 9: Survival distribution curve for CABG surgery waiting endpoint by area of residence	96
Figure 10: Histogram of the symptom frequency and symptom distress scale total scores	100
Figure 11: Plot of individual symptom frequency and individual symptom distress for total sample	103

LIST OF TABLES

	Page
Table 1: Urgency Rating Scale	9
Table 2: Definitions and Abbreviations	16
Table 3: Summary of Uncertainty Studies Examining Symptom Distress and/or Anxiety	29
Table 4: New York Heart Association Functional Classification	33
Table 5: Canadian Cardiovascular Society Grading Scale for Angina Pectoris With Modified Class IV	34
Table 6: Summary of Concerns of Patients Waiting for Cardiac Surgery	39
Table 7: Demographic Characteristics of the Sample N = 42	70
Table 8: Health Status Characteristics of Sample N = 42	71
Table 9: Waiting Time Characteristics of Sample N = 42	72
Table 10: Description of Study Variable Scores	73
Table 11: Pearson r Correlation Between Study Variables and Actual and Perceived Waiting Time	77
Table 12: Trends in Variable Means Within Perceived Waiting Times (Categorical)	78
Table 13: Pearson r Correlation Between Uncertainty, Symptom Distress, and Anxiety	80
Table 14: Pearson r Correlation Between Uncertainty, Anxiety and Individual Symptoms	80

LIST OF TABLES (continued)

	Page
Table 15: Pearson r Correlation Between Uncertainty, Symptom Distress, Anxiety and Ratio Subject Data	83
Table 16: Pearson r Correlation Between Functional Status Scores, Age and Individual Symptoms	84
Table 17: A Comparison of Mean Uncertainty, Symptom Distress, Anxiety, Functional Status and Age Scores to Categorical Characteristics of Sample	85
Table 18: Pearson r Item to Total Correlations for the SFSDS	101
Table 19: Ranking of Most to Least: Frequent Symptoms, Distressing Symptoms and Combined Symptom Distress of Individual SFSDS Symptoms	102
Table 20: Conceptual Categories Arising from Qualitative Data Analysis	107
Table 21: Comparison of Quantitative GARS score to Qualitative Data for the Variable of Anxiety	124

LIST OF APPENDICES

	Page
APPENDIX A: Approval Certificate from the University of Manitoba Education/Nursing Research Ethics Board (ENREB)	166
APPENDIX B: Letter of Approval from the Winnipeg Regional Health Authority Re: Research Access	167
APPENDIX C: Letter from the Waitlist Coordinator Introducing the Researcher to the Potential Participants	169
APPENDIX D: Letter from the Researcher Describing the Study and Ethical Considerations for Consent	170
APPENDIX E: Questionnaire Booklet Cover Letter	172
APPENDIX F: Request for Telephone Interview	174
APPENDIX G: Telephone Interview Guidelines	175
APPENDIX H: Illness and Surgery Data Information Form	177
APPENDIX I: Mishel Uncertainty in Illness Questionnaire	179
APPENDIX J: Symptom Frequency and Symptom Distress Scale	183
APPENDIX K: Kansas City Cardiomyopathy Sub Scales	187
APPENDIX L: Graphical Anxiety Rating Scale	188
APPENDIX M: Demographic Questionnaire	189

LIST OF ABBREVIATIONS

CABG:	Coronary Artery Bypass Graft
MI:	Myocardial Infarction
LVF:	Left Ventricular Function
SOB:	Shortness of Breath
COPD:	Chronic Obstructive Pulmonary Disease
CCS:	Canadian Cardiovascular Society
NYHA:	New York Heart Association
MUIS-C:	Mishel Uncertainty in Illness Scale – Community Form
KCCQ:	Kansas City Cardiomyopathy Questionnaire
GARS:	Graphical Anxiety Rating Scale
SFSD:	Symptom Frequency and Symptom Distress Scale

CHAPTER 1

INTRODUCTION

In 1997, ischemic heart disease and other cardiovascular conditions accounted for 36% of all deaths in Canada, making it the leading cause of death in that year (Heart and Stroke Foundation, 1999). Mortality and disability from these diseases has been decreasing steadily since the 1970's primarily due to new technologies and treatments such as coronary artery bypass grafting (CABG). CABG has been advocated as an important treatment for coronary artery disease primarily because of its role in prolonging the lives of the subset of patients with significant left main coronary disease (greater than 50 – 70% stenosis), and those with highly unstable triple vessel disease (Yusuf et al., 1994). It has also been suggested that in patients with these significant coronary anatomical pathologies as well as in patients with severe unstable angina unresponsive to medical therapy, CABG is not only an appropriate treatment option but a necessary one (Roos, Bond, Naylor, Chassin & Morris, 1994).

Nevertheless, despite the success of CABG in prolonging life in a select group of patients with coronary artery disease, the procedure remains a palliative rather than a curative treatment. Coronary artery disease continues to be ongoing in both the native coronary vessels and in the grafted vessels. Therefore other priorities must govern its use in the patient population groups where prolongation of life has not been established. Established goals of CABG include relief of angina (Allen, 1990; CASS Principle Investigators and their Associates, 1983a; Steine, Laerum, Eritsland, & Arnesen, 1996), improved functional status (Allen, 1990; CASS Principle

Investigators and their Associates, 1983b; King, Porter, & Rowe, 1994), and overall improved quality of life (Caine, Harrison, Sharples, & Wallwork, 1991; CASS Principle Investigators and their Associates, 1983b; King, Porter, Norsen, & Reis, 1992; Mayou & Bryant, 1987).

Quality of life in the CABG surgery population is examined primarily to afford treatment justifications especially within the subset of patients where no mortality benefit has been shown over medical therapy (CASS Principle Investigators and Their Associates, 1983a; Rachlis, Olak, & Naylor, 1991). Although the quality of life benefit of CABG over medical treatment in stable low risk coronary patients is significant at a five-year endpoint, this benefit is diminished at 10 years (Rogers et al., 1990). Cohen (1982) proposes that quality of life improvements following CABG surgery may involve a "placebo effect" that causes many patients to feel extra life-enhancement effects over and above those physiological benefits achieved from the surgery itself.

The large numbers of individuals undergoing CABG surgery as treatment for coronary artery disease every year is evidence that patients are choosing the potential future benefits of the operation over the potential risks of having the surgery itself. The reported risk of mortality, (death within 30 days of operation), of CABG surgery was calculated as 3.01% for all patients undergoing CABG at 9 hospitals in Ontario from 1991 to 1993 (Tu & Naylor, 1996). The highest risk is attributed to patients with these specific disease profiles: aged 75 or older (7.2%), grade four left ventricular dysfunction (LVD) (10.4%), emergency surgery (9.6%), history of previous CABG surgery (9.4%), recent myocardial infarction (within 7 days)

(10.8%), and high comorbidity scores (6.1%). Increased risk (greater than 3%) is also reported in patients aged 65-74, women, grade 3 LVD, urgent surgery, and left main disease (Tu & Naylor, 1996). In addition to operative risks, patients are also accepting the hardships and uncertainties of waiting for the scheduled procedure and hoping to achieve future potential benefits in improved quality of life. It is the issues concerned with waiting that will be the primary focus of the remainder of this chapter.

The Waiting List Phenomenon

In 1995, 15, 816 CABG operations were performed in Canada. This number represents a 100% increase in the total CABG operations performed from the approximately 8000 surgeries undertaken in 1982 (Heart and Stroke Foundation, 1997). Despite the obvious increase in the supply of this potentially life-changing operation, the demand for this procedure is increasing at exponential rates. The large increase in demand has led to a severe supply-demand mismatch in CABG surgery availability. The dramatic increase in the numbers of CABG surgeries performed in Canada has occurred despite the widespread use of thrombolytic therapy during myocardial infarction, the advent of Percutaneous Transluminal Coronary Angioplasty (PTCA) as an alternate option for revascularization, and has been noted to be unrelated to an increase in repeat procedures being done on patients who have had previous CABG surgery (Naylor, Ugnat, Weinkauf, Anderson, & Wielgosz, 1992). Mismatches in supply and demand such as those evident in the case of CABG surgery has led to the phenomenon of surgical waiting lists. Waiting lists are a characteristic of a publicly funded health care system such as the one that operates in

Canada. Critics of this system attest that the existence of waiting lists is a form of rationing scarce resources and is, in fact, a failing of universal public health care systems (DeCoster, Carriere, Peterson, Walld & MacWilliam, 1999).

In the last 10 years there has been increasing interest world wide in understanding and systemizing the process of prioritizing patients on a cardiac surgery waiting list. Research in this area has originated in Canada, United Kingdom, New Zealand, Sweden, and The Netherlands where public health care systems are in operation and where supply-demand mismatching for cardiac surgery has elicited public attention. Rachlis et al. (1991) outline several risks inherent in the process of queuing for cardiac surgery. These include: a) the uncertain risk taken in weighing clinical judgment of risk (while establishing a safe length of wait), assuming a potential for needless deaths with miscalculation; b) the harm to other surgical specialties if the occasional death on a cardiac surgery waiting list creates enough public outcry to funnel extra public money into this specialty when it may be better used elsewhere; and, c) the anxiety caused to patients during the wait for their surgery that is often fed by sensationalisms and overstatements of risk presented by the news media.

Overall, in Canada the risk of death on a cardiac surgery waiting list is relatively low. In persons without left main disease or unstable angina the reported risk of death while waiting is 0.33% per month (Rachlis et al., 1991). In a large retrospective study of 8517 patients who left a cardiac surgery queue in Ontario, 0.38% died while on the waiting list and 0.04% suffered a non-fatal MI (Naylor, Sykora, Jaglal, & Jefferson, 1995). Similar results were obtained by Morgan, Sykora,

and Naylor (1998) in 29,293 consecutive patients undergoing CABG and other cardiac surgery in Ontario. These authors found that impaired left ventricular dysfunction, and increasing age were highly significant factors independently associated with waiting list death and that one third of these deaths occurred within 14 days of joining the waiting list. Suttorp et al. (1992) in a sample of 1124 consecutive patients in the Netherlands found that cardiac enlargement on chest x-ray and a positive graded exercise test of short duration were the two strongest predictors of early mortality while waiting for CABG surgery. Smoking, coumadin therapy, unstable angina and left main or triple vessel disease were also lesser predictors of mortality in this study.

In an interesting prospective study by Llewellyn-Thomas, Thiel, Paterson, and Naylor (1999), patients' perception of risk and their beliefs about acceptable waiting lengths were examined. These authors hypothesized that a patient's tolerance for waiting would be influenced by: what patients thought their waiting time would be, their self perceived disease burden, the expectation of improvement following surgery, and how important that improvement was to them in contrast to the perception of risk for an adverse event while waiting. Results of this investigation indicated that patients have severely inflated perceptions of their own risks of myocardial infarction while waiting while they had high expectations for physical improvement following surgery (a mean increase of 12 points on a scale of 27). There was also evidence that patients adjusted their own acceptance of their wait, despite their symptomatic burden, to match what their surgeon indicated would be their approximate waiting time. They also found that 76% of their study population

would choose a higher surgical mortality (2%) with a shorter wait for surgery (one month) over a longer wait (six months) with half the risk (1%). Patients were only willing to “trade-off” the shorter wait for a lower risk when the 1% postoperative mortality wait was reduced to about 2 months. The authors concluded that these patients’ aversion to waiting was strong enough for the patient to discount the risk associated with surgery.

The reality of a publicly funded health care system is that patients have little or no control over how long they wait for surgery. A number of health care issues have had a strong influence on the increase in demand for CABG surgery and the resultant increase in the numbers of patient who are placed on surgical waiting lists. These conditions can be organized into three broad categories: technology related issues, person related issues, and system related issues.

Technology related issues consist primarily of conditions related to advancements in medical techniques and procedures. These advances have created increased confidence in the CABG procedure over time amongst both health care professionals and the patients referred for surgery (Naylor, Ugnat, et al., 1992). Confidence means more referrals from cardiologists and other referring physicians and fewer patients that are likely to refuse surgery when it is offered. Confidence has also resulted in increased use of CABG post MI (Naylor et al., 1991), increases in the numbers of urgent surgeries performed (Naylor, Ugnat, et al., 1992), and a continuing increase in the age of patients that are offered the procedure (Morris & Almond, 1997; Naylor et al., 1991; Naylor, Ugnat, et al., 1992). Other technology related issues that have influenced the increase in demand and the length of waiting lists has

been the increased use and accuracy of non-invasive testing methods as well as increased safety in angiography techniques (Naylor, Ugnat, et al., 1992). These advances may have increased the ability to detect coronary artery disease in patients and also may have increased referrals for angiograms especially in patients who were previously felt to be too high risk.

Person related issues also include age related issues. There are an increasing number of patients aged 65 and over who are no longer willing to accept activity limitations and therefore are more willing to undergo CABG (Naylor, Ugnat, et al., 1992). Other person related issues include patients who defer surgery for personal reasons to a time that is more convenient to them (DeCoster et al., 1999; Maziak et al., 1996). Therefore patients' own decisions and actions may lengthen their own personal waits and, in turn, alter the mean waiting time for the procedure. As well, patients initially assessed as stable may, as they wait overtime, destabilize and "jump the queue" (Doogue, Brett, & Elliott, 1997). This queue jumping may effectively lengthen the waits of other patients previously prioritized ahead of them on the waiting list. Another person related issue is the inevitable perception that certain surgeons are more skilled operators and therefore have lower perceived risks. These particular surgeons may be in higher demand and may individually have longer waiting lists and therefore longer average waiting times for their queued patients (Llewellyn-Thomas et al., 1999). The ultimate effect of these person related factors is that they become disruptive to waiting list management and complicate the ability to successfully prioritize patients in the most fair and equitable manner.

Finally, two system related influences on waiting lists are the ongoing shortage of intensive care nurses and intensive care beds and the fiscal pressures on hospitals to balance the budget within surgical programs (Naylor et al., 1991). The former issue may cause the cancellation of scheduled surgery while the latter may limit the number of surgeries a hospital can afford to perform in any given week. Both conditions cause delays in scheduling elective surgical candidates and may unnecessarily increase the distress of the individual patients on the waiting list affected by these delays.

Prioritization for CABG Surgery

From the above discussion it is evident that organizing a cardiac surgery waiting list is a complicated and daunting task. The “snowball” effect of coronary artery disease progression (Lukkarinen & Hentinen, 1997) necessitates that a patient who was stable when first assigned to the CABG waiting list may easily destabilize and need to be reprioritized over time. The inevitable bumping that occurs when a patient jumps the queue because of a sudden deterioration of disease has psychosocial consequences for the patients on the list who now wait longer or have their scheduled procedure cancelled. Nevertheless, taking into consideration the low death rate of patients on waiting lists, researchers tend to agree that, in general, if it is organized carefully, having a group of patients assigned to “wait” for surgery is essentially safe practice (Carrier, Pineault, Tremblay, & Pelletier, 1993; Cox, Petrie, Pollak, & Johnstone, 1996; Rachlis et al., 1995).

However, physician agreement on the exact criteria and system for prioritizing patients for surgery is low (Naylor, Baigrie, Goldman, & Basinski, 1990; Naylor,

Basinski, Baigrie, Goldman, & Lomas, 1990). In Canada, a panel of cardiologists and cardiac surgeons has attempted to develop a systematic series of criteria to assist with establishing a triage system to prioritize patients established as being in need of CABG surgery (Naylor et al., 1991). Other physicians in other countries have also attempted to develop similar prioritization systems (Agnew, Whitlock, Neutze, & Kerr, 1994; deBono, Ravilious, El-Zoubi, Dyer, & Podinovskaya, 1998; Hadorn & Holmes, 1997). However retrospective investigations of multiple CABG surgery populations has established that even without formal criteria surgeons make a conscious effort to prioritize the patients in the queue for surgery (Naylor, Baigrie, et al., 1990; Naylor, Levinton, & Baigrie, 1992; Naylor, Levinton, Wheeler, & Hunter, 1993).

Table 1

Urgency Rating Scale

LEVEL	TIMING
1 Emergency	Immediate revascularization
2 Extremely urgent	Within 24 hours
3 Urgent	24-72 hours
4 Semi-urgent	72 hours to 14 days (same admission)
5 Short list	2 weeks to 6 weeks
6 Delayed	6 weeks to 3 months
7 Marked delay	3 months to 6 months

Adapted from Naylor, Baigrie, et al., 1990, p. 1071

Current prioritization practices advocate that symptom status and response to medical therapy followed by coronary anatomical pathology are the two top criteria used to prioritize a patient's waiting status. Other prioritization criteria include, left ventricular function and results of non-invasive tests such as graded exercise tests (Naylor et al., 1991; Suttorp et al., 1992). From these criteria patients are then classified on a 7-point scale ranging from emergent to marked delay (see Table 1).

These practices represent objective prioritization processes and do not take into consideration the patient's age, work status or perceived anxiety level and how they may influence a surgeon's decision as to when he/she will operate on a patient. Evidence exists from responses to hypothetical scenarios that physicians will include these characteristics into how they prioritize their patients (Naylor, Levinton, Baigrie, & Goldman, 1992). The latter study described how cardiovascular specialists prioritized a 45-year old disabled labourer who was at risk of losing his job ahead of a 45-year old civil servant. Both patients were prioritized ahead of a 75-year-old retiree whose symptoms interfered with his golf game. All three patients had the same level of symptoms, coronary pathology, and results to non-invasive testing. In addition, each of the patients was ranked into a different waiting classification according to Table 1. The authors concluded that specialists placed considerable weight on age and work status in their prioritization decisions based on hypothetical scenarios. There was also the suggestion that some degree of ageism may be present in specialist's decision-making, however, other researchers have found no evidence of age bias in the urgency ranking of actual patients for CABG (Cox et al., 1996).

Other authors acknowledge that decisions about urgency and priority are often made inconsistently which could potentially increase the levels of uncertainty and anxiety of patients who are waiting for this operation. In addition, anecdotal evidence exists that the phenomenon of “the squeaky wheel gets the grease” is alive and well in cardiac surgery prioritization often to the detriment of uncomplaining patients (Hadorn & Holmes, 1997), however, this phenomenon has not been formally examined. The possibility that a patient’s anxiety level may influence a decision for surgical priority has also not been examined.

Cardiac Surgery and Waiting Lists for CABG in Manitoba

The Winnipeg Regional Health Authority is funded to perform 1000 surgeries per year in Manitoba. This funding provides services to patients in Manitoba, parts of North Western Ontario and parts of Nunavut Territory. The cardiac surgery program in this province operates at two sites both located in Winnipeg, Manitoba: the Health Sciences Centre and the St. Boniface General Hospital. Each hospital performs 500 to 600 operations per year with 7 active cardiac surgeons. Approximately 800 CABG operations were performed between the two sites in 1999. The cardiac surgery waiting list is managed through the Winnipeg Regional Health Authority by a single nursing coordinator.

The process of adding a patient to the centralized waiting list is as follows:

1. The patient has their cardiac catheterization (angiogram) and treatment decisions are made from the results. If it is decided that CABG surgery is the most appropriate treatment, a surgical consult is made. The consult is either made to a specific surgeon or to the cardiac surgeon on call.

2. The surgeon then sees the patient and reviews the need for surgery. If the surgeon offers the patient the option to have surgery and the patient agrees to it, the cardiac surgery waitlist nursing coordinator adds the patient to the centralized database.
3. The coordinator sends a letter to the waiting patient advising him/her of her nursing role as waiting list manager and inviting the patient to telephone her with any concerns that may arise while waiting. It is recommended to the patient that he/she should report any changes in their symptoms or condition to their family physician and their referring cardiologist. If the patient has difficulty contacting either one of these physicians the waiting list coordinator will assist with the necessary communication. A patient's cardiologist or family physician will also contact the coordinator to request information related to the patient's surgical wait. The coordinator's contact with the waiting patient is primarily patient initiated. She also has some contact with patients waiting in hospital.
4. If it is established that a patient's condition has worsened from baseline or if their social situation changes (e.g. disability benefits are coming to an end), the patient's priority status may be altered to reflect these changes. Increasing a patient's priority on the waiting list is made through a decision by the cardiac surgeon based on assessments made by the waitlist coordinator.

Patient priority on this list is managed through a computer program that calculates a maximal recommended waiting time (in days) based on the patients symptom classification according to their baseline Canadian Cardiovascular Society

classification, coronary pathology, left ventricular function, and comorbidity status.

This information is recorded from the patient's medical record and is a combination of information found in the cardiologist's referral, angiography results and the results of other non-invasive tests (e.g. stress testing, echocardiogram, MUGA scan), and the cardiac surgeon's initial assessment.

The waitlist coordinator keeps an extensive database that outlines each patient's cardiac condition and psychosocial characteristics at the time that they were first added to the waiting list. A "patient contact" section on the database is used to record the interactions and discussions between the patient and the waitlist coordinator. It is in this section that the patient's waiting period physical and psychological condition is updated.

The surgical waiting period is said to begin at the time that the surgeon accepts the patient for surgery. Generally patients are accepted for surgery at their first consultation visit. On average, 140 to 220 cardiac surgical patients are waiting for their operation during any given month. Booking for surgery occurs based on priority scores as well as first come first serve basis. Of the total available surgical spots, 50% are reserved for elective surgery while the remaining 50% are used in the event of emergent or urgent cases. For elective patients, the goal is to book surgeries 7 days in advance. With cancellations a patient may be given 24 to 48 hours notice. The waitlist coordinator will phone elective patients to let them know that their name has arrived at the top of the list and to check if they can be ready to come in for surgery when they get the call. If a patient feels that they cannot be ready to come in for surgery at the proposed time, then the coordinator proceeds to the next patient on

the list. This information is also recorded and the patient who delays their surgery for personal reasons does not lose their spot in the list. If a patient is booked for surgery and is subsequently cancelled by the department of surgery, they also do not lose their spot on the list.

Purpose of the Study

While examining the process through which waiting lists for coronary artery bypass patients are organized, it became evident that the difficulties inherent in decision-making and prioritization of patients in need of surgery are further complicated by the cognitive and emotional experiences of the patients on the waiting list. Patients cannot be given an exact date and time for their surgery at the time of their surgical consult. The multiple unpredictable, unknown factors that could affect the patients' surgical date and potentially interfere with that date may lead to uncertainty and anxiety in these waiting patients. In addition, since symptoms are the number one criteria used to prioritize patients on the waiting list, knowledge of how patients' symptoms are affecting their psychological status while waiting has potential significance.

Therefore, the purpose of this study is to describe uncertainty, symptom distress and anxiety in patients waiting for CABG surgery in relation to how long they have waited for surgery at the time of their participation in the study. These variables will be correlated with demographic variables, (e.g. age, education, work status), and coronary artery disease related variables, (e.g. Canadian Cardiovascular Society angina classification, and left ventricular function). In addition, analysis will be undertaken to identify patient characteristics that are

associated with a shorter total waiting time for surgery while controlling for surgical priority and severity of illness. Standardized questionnaires will be used to measure uncertainty, symptom distress, and anxiety. Qualitative questions will be added to help compliment the quantitative data collected for these purposes.

Research Questions

The following research questions will be addressed in the quantitative portion of this study. Please see Table 2 for a list of definitions and abbreviations of related terms.

1. What are patients' levels of uncertainty, symptom distress, and anxiety in relation to how long they have been waiting for CABG surgery?
2. Is there a relationship between uncertainty, symptom distress, and anxiety in patients on a waiting list for CABG surgery?
3. Is there a relationship between patients' levels of uncertainty, symptom distress and anxiety, and their functional status (measured by the KCCQ), their personal characteristics (gender, education, age, living situation, work status, area of residence, decision to participate in telephone interview), and their illness severity (baseline CCS angina class, surgical priority, comorbidities, left ventricular function, left main coronary disease, number of diseased vessels, history of MI)?
4. Controlling for surgical priority (maximum recommended waiting time in days) and illness severity (baseline CCS angina class, comorbidities, LVF, number of diseased vessels), are there any patient characteristics (age, gender, education, work status, living situation, area of residence) that are associated with a shorter total waiting time for CABG surgery?

Table 2

Definitions and AbbreviationsDefinitions

Start of waiting period	The patient's waiting time for surgery will be said to begin at the time of their first consult visit to their cardiac surgeon or when the surgeon officially accepts the patient for surgery whichever date is later.
Waiting time	Start of waiting time for surgery until participation in the study.
Total waiting time	Start of waiting time for surgery until surgical date.
End of waiting period	The date that the patient has their cardiac surgery.
Personal characteristics	Patient characteristics that do not describe his/her heart condition or his/her wait for surgery. Includes age, gender, work status, living situation, and education.
Illness severity	Patient characteristics that describe his/her heart condition at baseline. Includes CCS angina class, surgical priority, comorbidities, left ventricular function, number of diseased vessels and history of MI.
Baseline data	Data recorded on the database based on the patient's initial assessment for surgery.

Abbreviations

CABG: Coronary Artery Bypass Graft

MUIS-C: Mishel Uncertainty in Illness Scale – Community Form

MI: Myocardial Infarction

KCCQ: Kansas City Cardiomyopathy Questionnaire

LVF: Left Ventricular Function

GARS: Graphical Anxiety Rating Scale

CCS: Canadian Cardiovascular Society

SFSD: Symptom Frequency and Symptom Distress Scale

The following questions will be addressed in the qualitative portion of this study:

1. What are patients doing to manage their coronary symptoms while they wait for CABG surgery?
2. How do patients envision that their life will change following CABG surgery?
3. What do patients identify as the causes of their anxiety while they wait for CABG surgery?

Importance of the Study

Little is known about patients' psychological status while waiting for CABG surgery and researchers examining epidemiological issues surrounding CABG waiting lists generally recognize the existence of this gap (Naylor et al., 1995). Knowledge of the patient's psychosocial status during the waiting period is particularly important to nurses because the patient's anxieties, fears, and concerns about their recovery while waiting may influence their behavior during their early recovery. This recovery behavior may, in turn, alter their long-term attitudes towards cardiac lifestyle changes necessary to contribute to prolonging the beneficial effects of surgery and slowing the progression of the ongoing coronary disease.

The research reported in this thesis examines the experience of the patient waiting for CABG surgery from a psychosocial standpoint. The significance of the uncertainties associated with waiting, the frequency and distress related to the intensity of symptoms, and the patient's anxiety will be measured. These components will be compared to several illness-related and social characteristics collected from an existing cardiac surgery database and a demographic questionnaire. The patient's total experience will be analyzed using both quantitative and qualitative methods.

The potential exists that the findings of this research will be influential in finding new directions for the management of patients on a cardiac surgical waiting list in the province of Manitoba.

Chapter Summary

Since coronary disease is the number one killer of both men and women and an aging population dictates that the number of men and women living with this disease will increase, an associated increase in the demand for treating patients with CABG surgery is anticipated. In Canada's public health care system, supply-demand mismatching exists between the number of patients referred for CABG surgery and the number of surgeries that can be performed within current government health care constraints. The result of such a system has been the creation of surgical waiting lists. Waiting lists appear to be a persisting characteristic of Canada's health care system. The experience of living with an illness and waiting for the availability of a treatment is fraught with uncertainties and significant psychosocial consequences may be inevitable. Currently the literature has focused on issues surrounding morbidity and mortality issues of using prioritization systems to assist with deciding which patients should have surgery immediately and which patients are safe to wait. The goal of this research is to examine the neglected psychosocial issues faced by patients on a cardiac surgery waiting list.

CHAPTER 2

THEORETICAL FRAMEWORK AND REVIEW OF THE LITERATURE

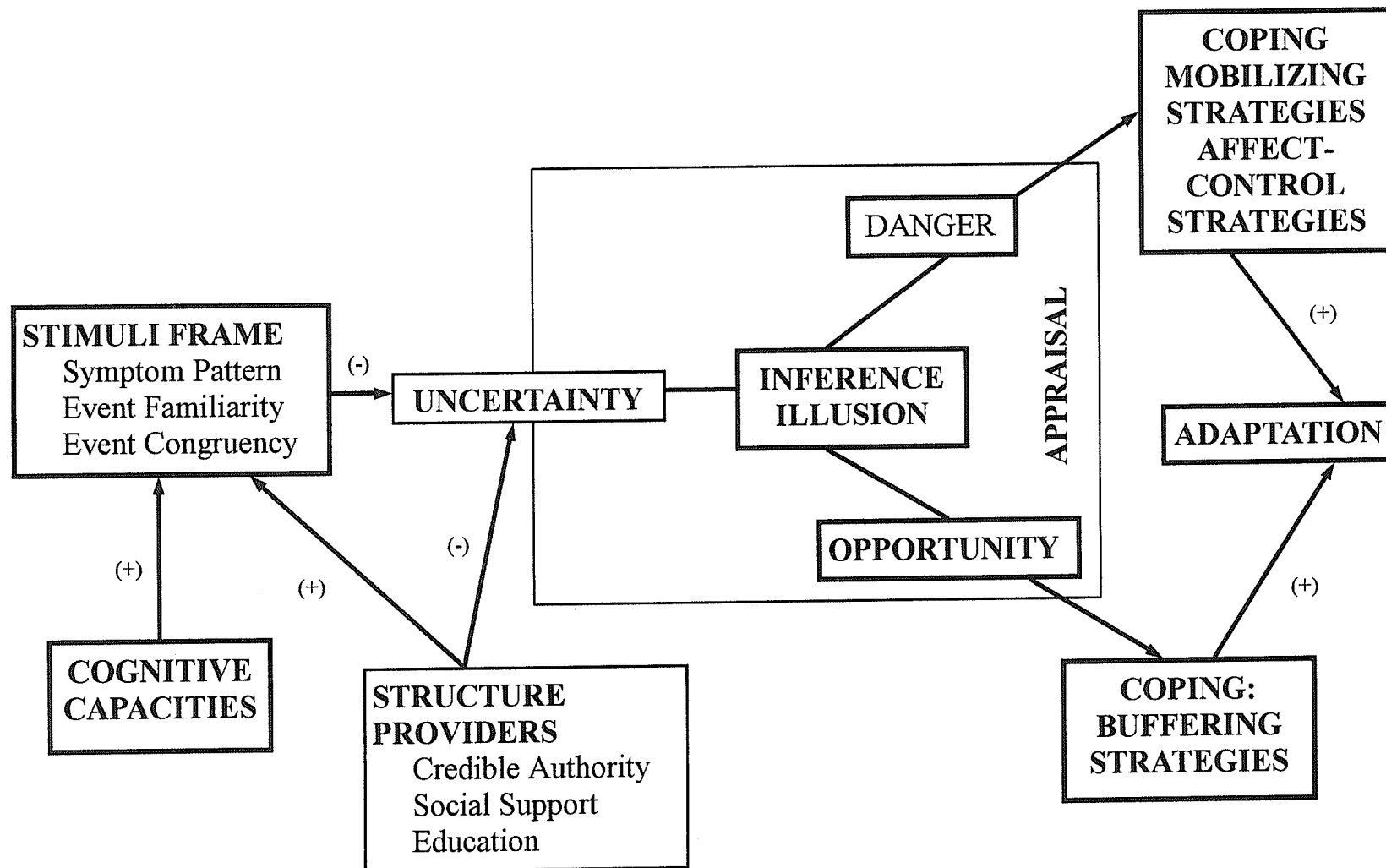
Theoretical Framework

The theoretical framework for this investigation is Mishel's middle-range nursing theory of uncertainty in illness (Figure 1) (Mishel, 1988; 1990). Mishel defines uncertainty as, "the inability to determine the meaning of illness-related events" (Mishel, 1988, p. 225). Mishel also notes that uncertainty is a "cognitive state when the person cannot adequately structure or categorize an event because of a lack of sufficient cues," and it occurs in situations in which, "the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately" (p. 225). Much of Mishel's theoretical work on uncertainty in illness was adapted from the work of Lazarus and Folkman (1984) on stress, appraisal and coping and it was from this adaptation that the Mishel Uncertainty in Illness Scale (MUIS) was developed (Mishel, 1981).

The benefit of the Mishel Uncertainty in Illness Theory is that it helps explain how patients cognitively process illness-related stimuli and construct meaning from these events. The theory describes the "stimuli frame" as the initial antecedent of uncertainty. The stimuli frame refers to the unique characteristics, (composition and structure), of the individual's perception of their illness situation and has three parts: symptom pattern, event familiarity, and event congruence. Symptom pattern refers to the degree to which symptoms present with enough consistency to form a recognizable pattern. Event familiarity refers to the nature of the health care environment and the repetitive nature and structure of this environment. Event

Figure 1

Mishel's Middle-Range Nursing Theory of Uncertainty in Illness



Mishel's model of perceived uncertainty in illness (Mishel, 1988, p. 226)

congruence refers to the consistency between what is expected and what is experienced in the illness situation and is an indication of the stability and the predictability of the event.

These three components of the stimuli frame are influenced by two variables: cognitive capacity and structure providers. Cognitive capacity refers to the patient's ability to process information related to their illness. The model proposes that illness itself seizes the attention of the patient and can act as a distraction. Other miscellaneous cognitive deficits can also influence the patient's cognitive capacity including physiological deficits (e.g. stroke or head injury), psychological disorders, and medications (e.g. sedatives).

Structure providers are individuals or resources that may be available to assist the person in interpreting the stimuli frame. These structure providers may influence uncertainty directly, (through interpreting the stimuli frame events for the patient), or indirectly, (through assisting the patients with the interpretation of the events in the stimuli frame). Structure providers include: education, social support, and credible authority. Credible authority refers to the level of trust and confidence that patients have in their health care providers.

Since Mishel describes the experience of uncertainty as a neutral cognitive event it cannot be considered either a positive or negative event until it is appraised (see boxed in section of Figure 1). Two major processes of appraisal are identified within the uncertainty model: inference and illusion. Inference is derived from the individual's personality and refers to the general beliefs one has about oneself and one's relationship with the environment. For example, learned resourcefulness,

mastery, and locus of control are all components of inference. These beliefs are all put into action in order to appraise uncertainty. Illusions are beliefs that are built out of uncertainty and generally reflect positive outcomes. These types of appraisal processes exist primarily when individuals feel helpless to influence the outcome, or when the outcome has a negative downward trajectory and can include coping mechanisms such as denial and avoidance or can be represented as hope.

Based on how uncertainty is appraised the individual may come to perceive their situation as either a danger or an opportunity. A “danger” outcome is as a result of an inference appraisal and may evoke emotions such as pessimism, anxiety, or depression. An “opportunity” outcome can come from either an inference or an illusion appraisal and results in a preoccupation with the positive such as evaluating the future as a “second chance.” Based on the type of appraisal outcomes that patients experience, specific coping strategies are mobilized and the patient then adapts to the illness situation. The coping and adaptation processes are represented as the final steps in the uncertainty theory.

In 1990, Mishel published her reconceptualization of the uncertainty in illness theory to assist in explaining the experiences of patients suffering from chronic illness who may be living with continual uncertainty. It became clear from this second examination that the present conceptualization of uncertainty reflects a cultural bias of Western society where certainty is valued over uncertainty and the ultimate goal is to eliminate the uncertain state. However it is evident in some situations that uncertainty may be desirable in order for a person to be able to continue to have hope for a positive outcome and view life and the uncertainties within it as an opportunity.

It is this view that is more prevalent in chronic illness. In this paradigm, uncertainty is no longer viewed as an enemy that must be eliminated but, rather, a natural state in which life cannot, and should not, be determined with absolute precision (Mishel, 1990).

Uncertainty and the Experience of Waiting for CABG Surgery

The potential for multiple uncertainties exists within the experience of waiting for heart surgery. The experience of CABG surgery involves both the uncertainty of living with a chronic condition and the stress that accompanies surgery on a significant body organ (Redeker, 1992). Mishel (1984) notes that uncertainty can be generated by events or situations that can be characterized as vague, ambiguous, unpredictable, unfamiliar, inconsistent, or lacking information. The largest uncertainty in the experience of waiting for surgery is not knowing when the surgery date will be set. There is also the unpredictable potential of death or a sudden adverse coronary event, such as myocardial infarction, which may be a part of a patient's uncertainty. Patients may fear dying in the waiting period, during the surgery itself, or following the surgery in the recovery period (Hawley, 1998). Health care professionals often do not have any clear answers for patients about these uncertainties. Research has been inconsistent and unclear regarding matters such as what is an acceptable, safe waiting time and, in addition, there is lack of consensus on what length of surgical delay, if any, is appropriate in order to avoid all adverse events that may occur while waiting (Cox et al., 1996). In addition, individual subtle differences in disease presentation and biophysiology have made it impossible to

predict why, of two patients with very similar disease characteristics, one will die and the other will go on to have successful surgery.

Not being able to plan and living day to day are other uncertainties identified by patients waiting for CABG surgery. Unpredictability of the future is a key component of the waiting experience (Fleury, Kimbrell, & Kruszewski, 1995; King & Jensen, 1994). Vague, ambiguous, unpredictable and inconsistent characteristics to the cardiac symptoms experienced while waiting also create uncertainties. There also may be a lack of familiarity with the CABG surgery procedure and the technology involved with the recovery process (Hawley, 1998). Mishel (1988) has identified four forms of uncertainty within the illness experience: ambiguity concerning the state of illness, complexity regarding treatment and system of care, lack of information about the diagnosis and seriousness of the illness, and unpredictability of the course of the disease and prognosis. It is these four characteristics that are used to operationalize uncertainty within the MUIS.

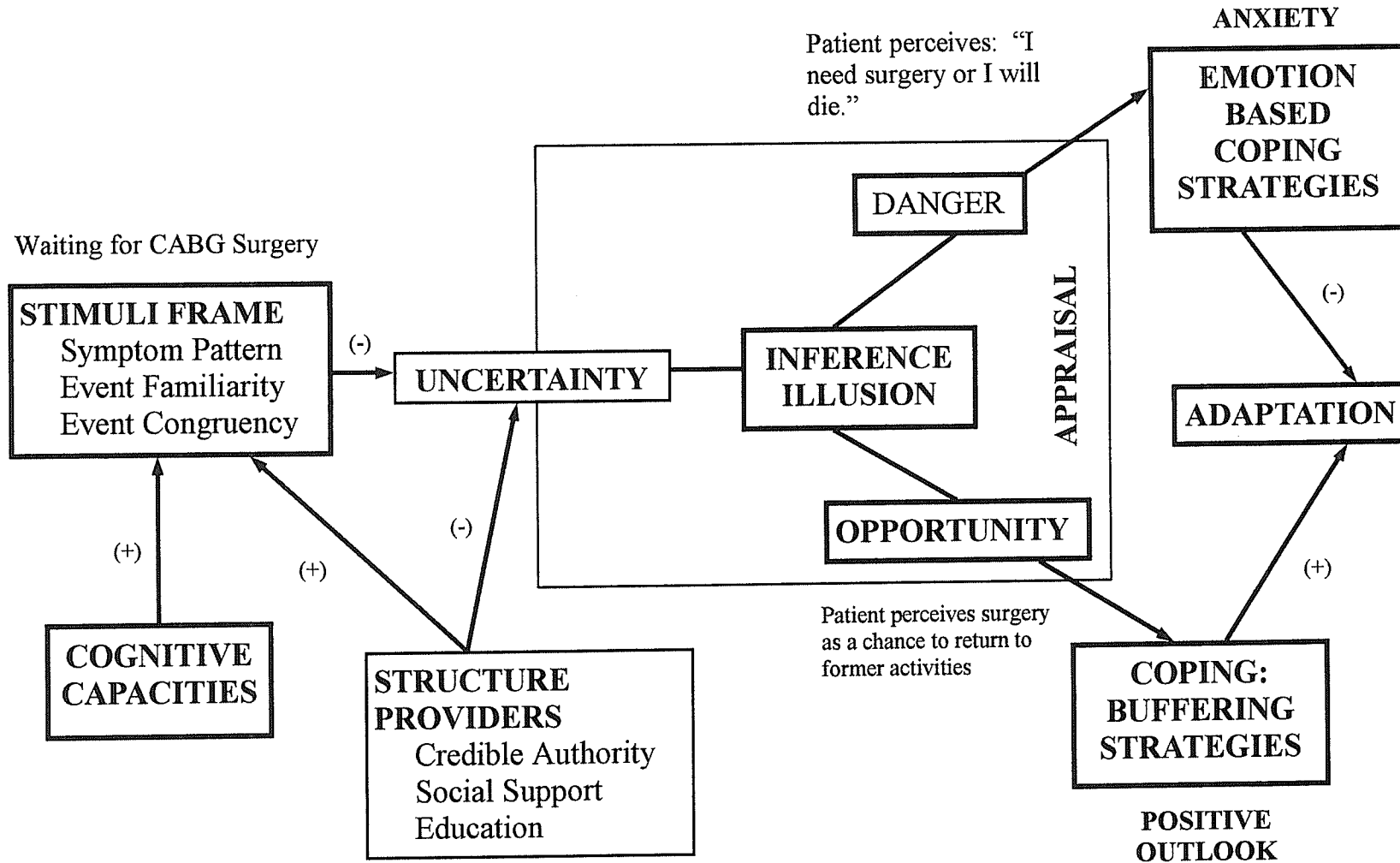
Temporality and probability are other key components of uncertainty (Lazarus & Folkman, 1984) and are important influences on the waiting experience of the CABG patient. Temporality, or temporal uncertainty, refers to not knowing when an event is going to happen. This form of uncertainty is key in the patient waiting for surgery because it is not possible within the queue process to provide patients with an exact date of surgery at their surgical consult. Probability, a component of event uncertainty, examines the likely-hood of something happening. In making the decision to have surgery patients need to weigh the risks of the surgery itself with the potential for benefits. Health care is not an exact science and care decisions are often

made based on probabilities rather than secure, factual information. The way health care providers communicate these probabilities to patients may influence the level of uncertainty that patients experience (Christman et al., 1988).

In using Mishel's middle-range nursing theory of uncertainty in illness to describe the experience of the waiting surgical candidate, the primary focus will be on the symptom pattern component of the stimuli frame and its influence on uncertainty which, in turn, will influence the anxiety level as an emotional adaptation in the waiting patient. Figure 2 is the diagrammatic representation of the uncertainty in illness theory as it will be examined in this investigation. Little is known about the effect of symptoms on the experience of waiting for CABG surgery and, in general, psychosocial components of waiting for surgery have been a neglected area of study. The goal of this investigation is to examine these gaps and clarify the relationships between these complex psychosocial components of waiting for CABG surgery. The variations within the patient's psychological experience of waiting for surgery compared to the length of time they have been waiting will also be identified.

Figure 2

Modification of the Uncertainty in Illness Theory



Adapted from Mishel's model of perceived uncertainty in illness (Mishel, 1988, p. 226)

Review of the Literature

A Medline, CINAHL, and PsychLIT search was conducted using the terms, coronary artery bypass, coronary artery disease, cardiac, symptom (as root), symptom distress, angina, uncertainty, wait (as root), preoperative, anxiety, and psychosocial. Additional references were also identified and collected within the reference lists of key articles identified in the initial literature search. A third source of references for this review came from a reference list on the epidemiology of waiting for CABG surgery provided to the researcher by the Winnipeg Regional Health Authority (WRHA). In examining the literature related to waiting for CABG surgery, literature was found in the general topic areas of medical queuing processes (discussed in Chapter 1), the relationship between symptoms and severity of disease, uncertainty in cardiac illness and other illnesses, preoperative teaching prior to CABG, and psychosocial aspects of waiting for cardiac surgery. Although sufficient information existed on each of these general areas of discussion, little literature existed linking these areas together or describing relationships between these concepts.

Uncertainty

The concept of uncertainty is a generic construct that has been examined in multiple patient populations. A number of variables are described as being related to increased uncertainty. These variables include: recent hospitalization, decreased social support, depressed mood, increased symptom severity, limited financial status or ineligibility for disability benefits, having a specific diagnosis, lower education, decreased physical activity/functional status, increased stress, lower quality of life, pessimism, lack of credible authority, decreased event familiarity, increased anxiety,

loss of purpose in life, and decreased life satisfaction (Mast, 1995). Of the variables of interest to this research, according to the Mishel Uncertainty in Illness Theory, the primary focus will be on one antecedent variable, (symptom distress), and one adaptation variable, (anxiety). A summary of select studies examining these variables with respect to uncertainty in a variety of patient populations can be found in Table 3. The majority of these studies can be classified as descriptive and or correlational. Theory testing research is also represented. No interventional studies were located related to uncertainty and symptom distress or uncertainty and anxiety.

In cardiovascular populations, uncertainty has been examined to a limited extent primarily in patients following myocardial infarction (MI) (Christman et al., 1988; Webster & Christman, 1988) or in patients after CABG surgery or PTCA (Redeker, 1992; White & Frasure-Smith, 1995). Staples and Jeffery (1997), examined uncertainty, hope and quality of life in a cohort of patients and spouses on a waiting list for CABG, however uncertainty was measured with respect to comparing the uncertainty experiences of the patient and his/her spouse and did not examine the patient's uncertainty based on the length of their surgical wait. These authors found that spouses' uncertainty was significantly higher than patients' and that uncertainty had a negative relationship with hope and with the health and functioning domain of quality of life. Winters (1999) examined uncertainty and symptoms in a cohort of patients living with heart failure using both quantitative and qualitative methods. Through a qualitative analysis of the experience of living with heart failure symptoms, these authors concluded that symptom fluctuation was a major determinant of illness uncertainty.

Table 3

Summary of Uncertainty Studies Examining Symptom Distress and/or Anxiety

Author/year	Title of Article	Sample Characteristics	Study Design	Measurement Variables	Findings
Christman et al., 1988	Uncertainty, coping & distress following myocardial infarction	70 post MI patients	Longitudinal exploratory design	MUIS POMS – emotional distress	Uncertainty and emotional distress significantly and positively correlated at all three data collection periods
Deane & Degner, 1998	Information needs, uncertainty and anxiety in women who had a breast biopsy with benign out come	70 women who underwent breast biopsy with benign result	Descriptive Correlational	MUIS STAI – anxiety	Positive relationship between uncertainty and state and trait anxiety
Galloway & Graydon, 1996	Uncertainty, symptom distress and information needs after surgery for cancer of the colon	40 patients post surgery for colon cancer	Prospective nonexperimental correlational	MUIS VAS – symptom distress	Symptom distress scores in low range but when symptoms present they were distressing Uncertainty unrelated to symptom distress at hospital discharge
Mast, 1998	Survivors of breast cancer: Illness uncertainty positive reappraisal and emotional distress	109 women 1-6 years post treatment for stage I-III non metastatic breast cancer	Cross-sectional, descriptive Correlational	MUIS SDS – symptom distress POMS- psychol. distress	MUIS (ambiguity & complexity sub scales) related to SDS and POMS SDS related to POMS
McCain & Cella, 1995	Correlates of stress in HIV disease	53 men with HIV	Correlational	MUIS POMS	Increased uncertainty related to increased psychological distress
Mishel & Braden, 1988	Finding meaning: Antecedents of uncertainty in illness	61 women with gynecological cancer	Correlational Theory testing	MUIS Likert scale – controllability of physical functioning (symptom pattern)	Symptom pattern significantly predicted ambiguity factor on MUIS

Author/year	Title of Article	Sample Characteristics	Study Design	Measurement Variables	Findings
Neville, 1998	The relationships among uncertainty, social support, and psychological distress in adolescents . . .	Adolescents (aged 14-22) diagnosed with various types of cancer	Correlational descriptive	MUIS BSI – psychological symptom states	Ambiguity and complexity scales of MUIS had moderately strong relationship with psychological distress
Small & Graydon, 1992	Perceived uncertainty, physical symptoms and negative mood in hospitalized patients with . . .	26 patients with chronic obstructive pulmonary disease	Descriptive Correlational	MUIS, Emphysema symptom checklist, POMS – 3 scales	Uncertainty related to negative mood, symptoms related to negative mood
Webster & Christman, 1988	Perceived uncertainty and coping post myocardial infarction	20 patients post myocardial infarction	Descriptive survey	MUIS POMS – anxiety and depression	Increased uncertainty significantly related to both anxiety and depression
White & Fraser-Smith, 1995	Uncertainty and psychological stress after coronary angioplasty and coronary bypass surgery	22 angioplasty patients 25 CABG patients	Descriptive Correlational	MUIS GHQ – psychological distress	Uncertainty and psychological distress related at all data collection periods. Angioplasty had greater uncertainty than CABG but equivalent psych. distress
Winters, 1999	Heart Failure: Living with Uncertainty	22 patients living with heart failure	Descriptive and qualitative methods	MUIS Qualitative – symptom distress	Uncertainty present when symptoms first occurred or changed, with treatment changes and when thinking about future health.
Wong & Bramwell, 1992	Uncertainty and anxiety after mastectomy for breast cancer	25 women post mastectomy	Correlational with qualitative methods	MUIS, STAI Semi structured interview	Uncertainty related to state anxiety 1-2 weeks post d/c but not 1-2 days pre d/c. Uncertainty related to trait anxiety at 1-2 days pre d/c

Table Abbreviations:

BSI – Brief Symptom Inventory, POMS – Profile of Mood States, STAI – State-Trait Anxiety Inventory, GHQ – General Health Questionnaire, SDS – Symptom Distress Scale, VAS – Visual Analog Scale, MUIS – Mishel's Uncertainty in Illness Scale

Symptom Distress and Coronary Disease

With the stimuli frame being an important antecedent of uncertainty and the symptom pattern an important component of the stimuli frame, symptom distress is an appropriate construct to measure in conjunction with uncertainty in patients waiting for CABG surgery. Mishel (1988) notes that multiple factors can influence the process of symptom appraisal such as the characteristics of the stimuli, the accuracy of the appraisal, and the saliency or distinguishability of symptoms. Symptoms can be: vague sensations; inconsistent in frequency, duration or precipitating factors; ambiguous as to their cause or ambiguous in that similar symptoms may be indistinguishable from one another; and they may be unpredictable in severity or duration from one day to the next. In her initial work on uncertainty, Mishel (1981) found that patients with diseases characterized by symptom variability, including heart diseases, had higher levels of uncertainty than persons with illnesses characterized by more consistent symptoms.

Benner and Wrubel (1989) described symptoms as being a part of the lived experience of an illness rather than being an exact map of the underlying disease. Nowhere is this truer than with cardiac symptomology. Research into patient delays while seeking treatment for acute MI has shown a large variety of individual differences in how symptoms are perceived and experienced by patients (Dracup & Moser, 1991; Johnson & King, 1995; Lee, 1997; Meischke et al., 1995; Scherck, 1997; Zerwic, 1998; Zerwic, 1999). Even though in the queue for CABG surgery symptom severity is the most highly weighted factor in urgency rankings, there is more and more evidence that symptom presentation – chest pain in particular – is a

very poor predictor of the severity of the anatomical presentation of coronary disease and is a poor predictor of prognosis (Bugiardini et al., 1995; Costa, 1987; Cox, Naylor, & Johnstone, 1994; de Bono et al., 1998; Greene, Schocken, & Spielberger, 1991; Hultgren & Peduzzi, 1984; Warner, 1995). As well, some researchers have suggested that in patients undiagnosed with coronary disease but undergoing angiography for chest pain, the degree of somatic awareness of chest pain by self-report has an inverse relationship to anatomical disease (Green et al., 1991; Warner, 1995).

The primary measure of symptom severity in relation to functional status in research has been either the New York Heart Association (NYHA) Functional Classification (Table 4) or the Canadian Cardiovascular Society (CCS) Grading Scale for Angina Pectoris (Table 5). These scales are remarkably similar to each other and are often considered equivalent, however some authors note that the greater specificity of symptoms in the CCS scale, and recent modifications may make it superior (Cox & Naylor, 1992; Cox et al., 1994).

Cox and Naylor (1992) and Cox et al., (1994), note that there are several limitations to the CCS and NYHA scales. First, they do not show if a patient's symptoms are episodic or variable. Variability may be further confounded if patients use a pre-activity warm up or if they slow down or frequently change activity patterns. These activity characteristics can alter the onset or diminish the severity of symptoms. Second, these scales are unable to account for a patient's perspective or individual tolerance levels of symptoms. Both scales are graded by physicians based on the patient's description of their physical limitations and their symptom status.

Third, these scales do not provide any information on how symptoms progress. Gradual deterioration in physical functioning may go unnoticed by patients until a successful treatment significantly improves their abilities. This is especially significant when examining the use of a scale that is not graded by self-report. Further criticisms of these scales rest with the unproven assumption that there is physiological equivalence among patients at each level of functional/angina status. Related, and perhaps more significant, there are limited relationships found in research between these scales and disease prognosis or quality of life (Cox et al., 1994; Cronin, 1990).

Table 4

New York Heart Association Functional Classification

Class I	Patients with cardiac disease but without resulting limitations of physical activity: Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea, or anginal pain.
Class II	Patients with cardiac disease resulting in slight limitation of physical activity: They are comfortable at rest, but ordinary physical activity results in fatigue, palpitation, dyspnea, or anginal pain.
Class III	Patients with cardiac disease resulting in marked limitation of physical activity: They are comfortable at rest, but less than ordinary physical activity causes fatigue, palpitation, dyspnea, or anginal pain.
Class IV	Patients with cardiac disease resulting in an inability to carry on any physical activity without discomfort: Symptoms of cardiac insufficiency or of the anginal syndrome may be present even at rest, but, if any physical activity is undertaken, discomfort is increased.

Modified from Cox & Naylor, 1992, p. 678.

Table 5

Canadian Cardiovascular Society Grading Scale for Angina Pectoris
With Modified Class IV

Class I	Ordinary physical activity does not cause angina: No angina occurs when walking or climbing stairs; angina does occur with strenuous or rapid or prolonged exertion at work or recreation.
Class II	Slight limitation of ordinary activity: Angina occurs when walking or climbing stairs rapidly; walking uphill; walking or stair-climbing after meals, in the cold, in the wind, under emotional stress, or only during the first few hours after awakening; walking more than two blocks on the level and climbing more than one flight of ordinary stairs at a normal pace and in normal conditions.
Class III	Marked limitation of ordinary physical activity: Angina occurs when walking one or two blocks on the level and climbing one flight of stairs in normal conditions and at a normal pace.
Class IV (general)	Inability to carry on any physical activity without discomfort: Anginal syndrome may be present at rest.
Class IVA	Unstable angina resolved with intensified medical therapy and stabilized on oral medications.
Class IVB	Unstable angina partly resolved on oral therapy, but symptoms return with minimal provocation.
Class IVC	Unstable angina requiring acute care monitoring and parenteral or mechanical (e.g., intraaortic balloon) therapy.

Modified from Cox & Naylor, 1992, p. 679; Cox et al., 1994, p. 277.

The potential exists that measuring symptom distress in conjunction with frequency of symptoms may be a more specific measure of symptomology in coronary patients. Symptom distress, defined and described most frequently in cancer patient populations can be represented as, "the degree of discomfort reported by the patient in relation to their perception of the symptoms being experienced" (McCorkle & Young, 1978, p. 374). It has been observed that frequency or intensity of symptoms is often equated with symptom distress, however the most intense or frequently occurring symptoms are not always the most distressing (Lough, Lindsey, Shinn, & Stotts, 1987; McClement, Woodgate, & Degner, 1997).

The impact of symptoms and how distressing or upsetting they may be for patients is little examined within the literature with respect to coronary artery disease symptoms. Three studies (Grady, Jalowiec, Grusk, White-Williams, & Robinson, 1992; Grady, Jalowiec, & White-Williams, 1998; Lough et al., 1987), examining cardiac transplant patients, were found to be related. Grady et al. (1992) examined symptom distress in 175 cardiac patients waiting for heart transplant using a heart transplant symptom checklist designed specifically for their study. These researchers found that the most distressing symptoms for patients were tiredness, difficulty breathing during activity, difficulty sleeping, and whole body weakness. High symptom distress was also correlated significantly with higher stress, decreased life satisfaction, lower quality of life and more functional disability. In this study the symptoms that were the most frequent were also the most distressing. In a later study (Grady et al., 1998) using the same symptom checklist and examining quality of life in 219 transplant recipients six months following their operation, no significant

differences in symptom distress were found amongst patients at different levels of the NYHA functional status classification or UNOS (United Network for Organ Sharing) priority status.

Lough et al. (1987), examined symptom distress in 75 patients after cardiac transplantation particularly related to immunosuppressive drugs and their side effects. The Symptom Frequency and Symptom Distress Scale (SFSD) was developed specifically for this investigation. In this study the most frequently occurring symptoms were not necessarily the most distressing. The patient's present quality of life was negatively associated with both symptom frequency and symptom distress but the impact was reportedly small, suggesting that adaptation to symptoms may occur over time. The SFSD scale has also been adapted for use in examining gastrointestinal symptoms in patients post CABG surgery (Ball & Grap, 1992; Grap, Savage, & Ball, 1996).

One pilot study examining symptom distress and weighing behavior in 30 clinic patients with congestive heart failure (CHF) was also located (Sulzbach-Hoke, Kagan, & Craig, 1997). The McCorkle and Young (1978) Symptom Distress Scale (SDS) was used to measure symptom distress in this population. The symptom of swelling was added to make this scale more CHF specific. Results showed fatigue, insomnia, breathing, pain and cough were the most distressing symptoms experienced by CHF patients. Swelling was the seventh most distressing symptom. The purpose of this study was to compare symptom distress in patients who weighed themselves daily and patients who did not weigh themselves, however only a small number of

patients reported that they did not weigh themselves making this comparison statistically impossible.

The examination of symptoms experienced by patients waiting for CABG surgery is minimally represented in the literature. One study (Bengtson, Herlitz, Karlsson, & Hjalmarson, 1994) examined symptoms and complaints amongst patients referred for either coronary angiography or revascularization (PTCA or CABG) in comparison to a control group in the general population not waiting for any procedure. The study found that more than half the patients had daily attacks of chest pain, while only 16% reported less than one attack per week or no pain at all. A longer waiting time for a procedure, (greater than 6 months), was not associated with more pain but there was a significant parallel increase in nervous symptoms such as restlessness and insomnia and a moderately significant greater use of sedatives and cigarettes. Patients also reported that their symptoms influenced activities such as work, hobbies and their social life. In an extension of the same study these researchers (Bengtson, Herlitz, Karlsson, & Hjalmarson, 1996) also described non-pain symptoms in relation to patients reporting mild, moderate or severe chest pain (based on frequency of attacks). Eighty percent of patients indicated that their chest pain limited their daily activities to a greater or lesser degree (seldom to all the time). Dyspnea, psychosomatic symptoms, sleeping disorders, and psychological symptoms were significantly associated with the severity of chest pain.

Teo et al. (1998) reported that 57% of their patient population (N = 102) felt that their symptoms were getting worse while they waited for surgery and 87.5% perceived deterioration in their quality of life. Jonsdottir and Baldursdottir (1998)

observed a non-significant trend in their sample ($N = 72$) where patient's conditions got worse as their waiting time increased. Patients' most frequently experienced symptoms in this study were fatigue, shortness of breath and chest pain.

As described above, while the measurement of symptoms in coronary artery disease and the relationship of those symptoms to anatomical disease severity is limited, it is recognized that symptoms serve as a continual reminder of the patient's cardiac illness and, therefore, contributes to the patient's continuing concern or uncertainty about their health (Cronin, 1990). This may have a significant influence on a patient's psychosocial adaptation to coronary disease as a patient waits for CABG surgery and monitors his/her symptoms as part of the process.

Psychosocial Aspects of Waiting for Cardiac Surgery

Research on the experience of waiting for cardiac surgery is limited and has been conducted using a variety of methodologies. Researchers have identified, through open-ended questioning of patients waiting for cardiac surgery, numerous surgery related and waiting related concerns of these patients. These concerns are summarized in Table 6.

Table 6

Summary of Concerns of Patients Waiting for Cardiac Surgery

Summary of Concerns of Patients Waiting for Cardiac Surgery	Bradley & Williams, 1990	Bresser et al., 1993	Carr & Powers, 1986	King, 1985	Lamarche et al., 1998	Lindsay et al., 1997	Radley et al., 1987	Shih et al., 1998
Surviving the surgery or surviving Until the surgery	X	X		X	X	X	X	X
Returning to former activities/ Recovery Process	X	X	X				X	X
Pain	X		X		X	X		X
Improving Heart Condition/ Operative Success	X					X	X	
Loss of control/Being Dependent On Others	X	X				X		X
Understanding the surgical procedure	X					X		
Emotional responses to surgery And waiting	X					X		
Affects on relationships with others	X					X		
Unfamiliarity with the ICU	X							X
Financial Concerns	X							X
How family would manage if Patient died		X						X
Actual date of surgery					X	X		
Nature of patient care to be received						X		X
Developing complications	X							
Lifestyle changes following surgery	X							
Absence from home or business			X					
Inability to make future plans				X				
Leaving unfinished business								X
Being able to speak with a Spiritual advisor	X							
Sharing a room with another patient			X					

Patients' preoperative expectations of the surgical process have also been clearly examined and include: return to "normal", relief of symptoms, improved functional status, increase in sexual activity, new activities made possible, find new hobbies, reduction of medications taken, improve relationships with family, lengthen/prolong life, prevent MI, improve quality of life, become a "new person", return to work, travel, and relaxation (Engblom et al., 1992; Gortner, Gilliss, Moran, Sparacino, & Kenneth, 1985; Gortner et al., 1989; Gortner, Jaeger, Harr, & Miller, 1994; Radley & Green, 1985; Radley, Green, & Radley, 1987). It has been shown that these preoperative expectations, if realized, have a direct link to improved life satisfaction post-operatively (Engblom et al., 1992; Flynn & Frantz, 1987). If preoperative expectations as well as other thoughts and feelings have an influence on post-operative outcome, the importance of examining the psychosocial status of patients waiting for surgery is affirmed.

Rakoczy (1977), in a qualitative examination of the waiting period for cardiac surgery, identified four phases patients' thoughts progressed through as they anticipated surgery. The phases are confrontation, self-reflection, resolution, and countdown.

Confrontation is the period of time when the patient comes face to face with the reality of surgery. This is a period of heightened emotions: disbelief, anxiety, shock, and fear. Confidence in the surgeon and close relationships with family were important during this phase in aiding the patient to justify the necessity of the surgery.

Self-reflection refers to patient attempts to justify or explain the cause of their heart problems. In this phase patients mourn losses, especially loss of control and loss of health. Self-pity, grieving, and guilt are key emotions in this phase.

Resolution is the period where patients internalize the meaning of the surgery and incorporate this into their self-concept. Here patients have high hopes for recovery and work towards rebuilding their self-esteem.

The last phase, the countdown, occurs the day before surgery. Patients “countdown” the time remaining before the surgery in fixed units of preparation based on routine tasks. Patients and families tend to keep to themselves during this phase and patients, once again, speak more about their confidence in their doctors.

The 11 patients who participated in this study were admitted to hospital and interviewed twice during the three days before their surgery; therefore, this patient population was examined after their surgical date had been determined. Although this model is limited in its ability to describe the experience of the patient waiting at home for his/her surgery with an undetermined surgical date, it is a valuable early examination of the waiting period for cardiac surgery because it emphasizes the patient’s psychological status during this time period – in particular the emotional turmoil of waiting for surgery. It has been hypothesized that the emotional anxiety experienced by patients waiting for CABG surgery may be a more troublesome symptom than angina (Bengtson et al., 1996; Kee, McDonald, Kirwan, Patterson, & Love, 1997). Bengtson et al., (1996) noted that 56% of their study population reported that uncertainty, fear, or other unspecified problems were more disturbing than pain. Pain was reported as most disturbing by 44% of this cohort.

The existence of anxiety in a patient waiting for cardiac surgery seems almost self evident and the causes of this anxiety are exhibited in many of the patients' concerns previously described in Table 6. However the measurement of anxiety in patients waiting for CABG surgery has been infrequent and rarely has it been a primary focus of the study in question. Cox et al. (1996) reported that 64% of their study population (N = 100) registered at least moderate anxiety related to their surgical waiting time with anxiety being greater in patients less than 60 years of age. Underwood, Firmin and Jehu (1993), found that 28% of their sample (N = 68) had clinically significant anxiety while 41% were borderline. This group of patients also had significant (47%) or borderline (26%) depression. Both anxiety and depression were significantly related to time on the waiting list. Jonsdottir and Baldursdottir (1998) noted a trend that patients in their study (N = 72) who had waited an intermediate amount of time (3-4 months) were emotionally worse off than patients who had waited either a shorter or longer period of time. These researchers also found younger patients (< 63) to be more emotionally distressed than older ones.

The effects of surgical cancellation have also been examined by researchers (Bresser, Sexton & Foell, 1993; Kennedy, 1966). Bresser et al. (1993) noted that postponement of surgery shifted patients' worries from the surgery itself to when the surgery would take place. The resultant uncertainty manifested itself in anger, frustration, loss of control, and physical symptoms. Anger, frustration, disappointment, and stress were also emotions experienced by the patients cancelled in the small qualitative study conducted by Kennedy (1966). Both studies noted the lack of nursing involvement in counseling patients through the period of cancellation.

Waiting for surgery has been reported to have a negative effect on multiple areas of patients' lives including work, social activities, leisure activities, home management, family relationships, sexual relationships, and financial status (Jonsdottir & Baldursdottir, 1998; Pieper, Lepczyk, & Caldwell, 1985; Radley, Green & Radley, 1987; Underwood et al., 1993). Patients have also reported having to give-up one to two of their regular activities (hobbies or obligations) specifically as a result of the surgical wait (Radley & Green, 1985).

Several interventions have been suggested in order to ease patients' transition to cardiac surgery during the waiting period. Educational interventions are the most frequent suggestion and have been assessed in two interventional studies (Lamarche, Taddeo, & Pepler, 1998; Nelson, 1996). Nelson (1996) provided a pre-admission education session for the experimental group of cardiac surgery patients, while the control group received information from the ward staff on admission. Sixty-seven percent of patients in the experimental group felt their anxieties had been relieved by the education session and 100% felt they had benefited from the experience. Few comparisons were made between the experimental and control groups in this research report making it difficult to assess the success of this intervention. Lamarche et al. (1998) used a telephone intervention with cardiac surgery patients to help assess the emotional status of this patient population as well as alleviate any knowledge deficits. No significant differences were found between the experimental or control groups in anxiety or knowledge levels.

The use of a cardiac surgery management system nursing coordinator has also been discussed in the literature (Wright & Arthur, 1996). These authors found that as

patient anxiety increased, they were more likely to discuss this with the coordinator of the management system, and 75% of patients who choose to call the coordinator reported a decrease in their anxiety level as a direct result of that contact. However the longer patients waited the more likely they were to call their doctor rather than call the coordinator. Patients were also more likely to contact their doctors about changes or deteriorations in physical status. Knudtson (1997) states that a full time coordinator should be assigned to waiting list patients in order to maintain contact and screen for changes in symptom status. No studies have been conducted using proven, reliable and valid measurement tools to assess the success of such a program.

Chapter Summary

The above review of the literature reveals that uncertainty, psychosocial responses such as anxiety, and symptoms are all significant to the experience of patients waiting for CABG surgery. However, research examining these concepts has been limited and has used a wide variety of study methods and measurement tools to examine variables. This has caused results to be inconsistent and difficult to compare. In addition, to date, no research has been done to succinctly examine the relationship between all three concepts in a single study. A description of the relationship between psychosocial variables and patient characteristics to length of time on the waiting list has also been limited. In countries with publicly funded health care systems and surgical waiting lists, there is a need to examine the influence of waiting for a surgical procedure on the patient's psychosocial state. Since preoperative psychological status is the best predictor of post-operative psychological status (Strauss et al., 1992), research undertaking these examinations is well justified.

CHAPTER 3

METHODOLOGY

Uncertainty, symptom distress and anxiety in patients waiting for coronary artery bypass surgery was explored using a cross-sectional survey to collect quantitative data and open-ended questions to collect qualitative data. Data was analyzed to evaluate the significance of these variables in patients who had waited various lengths of time for surgery. As well, the relationships between the study variables, sociodemographic and illness related constructs were also identified. Qualitative data was used to complement the quantitative study data and contribute to the understanding of the patients' psychosocial status and experience while waiting for CABG surgery.

Research Design

The research design used in this study was a descriptive, correlational, cross-sectional survey. Polit and Hungler's (1999) nursing research text was used to provide the descriptions of each methodological component summarized in the following paragraphs.

The purpose of descriptive research is to "observe, describe, and document aspects of a situation as it naturally occurs" (pp. 195-196). It is particularly valuable if the goal of the research is to generate hypotheses or develop theory.

Correlational research or *ex post facto* (after-the-fact) research is research that is conducted "after the variations in the independent variable have occurred in the natural setting" (p. 194). A correlation is an "interrelationship or association between

two variables,” or, the “tendency for variation in one variable to be related to variation in another” (p. 194).

Descriptive correlational research generally has no experimental or random assignment to groups and, therefore, no control over the independent variables. The aim of this kind of research is to “describe the relationship among variables rather than to infer cause-and-effect relationships” (p. 196).

A cross-sectional design involves the collection of data at one point in time. The responses of the study subjects are then compared in order to have greater understanding of the experience of subjects who are at different phases in the process under study. The purpose of this design is to infer trends over time. The main advantage in this type of study design is practicality, economical feasibility, and ease of management.

Survey research is “designed to obtain information from populations regarding the prevalence, distribution, and interrelations of variables within those populations” (p. 200). Surveys obtain information of a sample of people by self-report methods and are limited only by the extent to which respondents are able and willing to report honestly and accurately on the topic at hand. Survey data can be collected via personal interviews, telephone interviews, and questionnaires. This type of research is both flexible and broad in scope and can be used in multiple research situations with multiple populations.

Polit and Hungler (1999) describe multiple advantages to implementing multimethod research designs, primarily those that combine quantitative and qualitative methods. The weaknesses of a single approach can be overcome by the

addition of an alternate method. The quantitative (number) data can be complemented by the qualitative (word) data and new insights may be found in the study results that would not have been possible with only one method. In addition, study findings may have enhanced validity with use of multiple methods. Qualitative data may also help to illustrate the meaning of the quantitative results or explain why various relationships exist.

Ethical Approval and Access

Ethical approval from the University of Manitoba (Appendix A) and access approval to the Winnipeg Regional Health Authority database through their Research Review Committee (Appendix B) was obtained prior to the start of this study. The coordinator of the cardiac surgery waitlist was provided with the inclusion and exclusion criteria for the study and was instrumental in the data collection process

The Setting

The setting for this study is the cardiac surgical program, consisting of four cardiac surgeons, of one university affiliated teaching hospital located in Winnipeg, Manitoba, Canada. This cardiac surgical program covers surgical consults for the entire province of Manitoba, part of the Nunavut Territory, as well as accepting selected referrals from North Western Ontario. Although two cardiac surgical programs exist within this region, only the Health Sciences Centre patients will be surveyed because of logistical difficulties in adding the referred surgical patients from the second site to the central waiting list in a timely and efficient manner. The waiting list is located in a central database that is managed by the Winnipeg Regional

Health Authority (WRHA) under the direction of the Medical Director of Surgery, the Nursing Director of Surgery, and a single Cardiac Surgery Waitlist Coordinator.

Study Design and Procedures

This project was conducted in two-parts. In part one, subjects were identified from an existing cardiac surgery waitlist database that is managed by the Winnipeg Regional Health Authority. All subjects booked for surgery at the Health Sciences Centre site that met the criteria for participation in this study were mailed a letter introducing the researcher and signed by the coordinator of the cardiac surgery waiting list (Appendix C). The researcher's description of the study and the ethical considerations for consent accompanied this introductory letter (Appendix D). In these letters, potential participants were asked to phone and leave a message with the waiting list coordinator (by a specific date) if they were not interested in receiving the study survey. Once the indicated date had passed the waitlist coordinator mailed the questionnaire package to participants who did not object to receiving the study survey. This package included a self-addressed stamped envelope, a cover letter (Appendix E), an invitation to participate in a telephone interview, and all study instruments including a demographic questionnaire.

Part two of this study consisted of a qualitative telephone interview. The offer to participate in the qualitative telephone interview, including a copy of the proposed questions, was included in the questionnaire booklet (Appendix F). Participants in the telephone interview were self-selected. Subjects who completed the survey booklet were asked to indicate in a yes/no box their willingness to receive a telephone call from the researcher to answer the qualitative questions. The participants who

indicated their willingness to receive this phone call were telephoned within one week of receiving their returned survey booklet. The telephone interview guidelines presented in Appendix G were followed to provide informed consent to these participants. Handwritten notes were used to record the participant's responses to the open ended questions. No audiotaping was used to collect data.

Data on participants was also collected from the paper form of the cardiac surgery database files and used in the descriptive and correlational analysis. Participants were informed in the initial consent form and in the cover letter to accompany the survey booklet that participation in this study included examination of these records. They were asked to sign a separate consent form that would allow the researcher to examine these records (Appendix E).

The Sample

A convenience sample of subjects was recruited from the patients on the cardiac surgery waitlist database who were waiting for surgery at the Health Sciences Centre. The description of how participants were recruited is found in the "Study Design and Procedures" section above. The population of interest for this study was patients waiting for elective coronary artery bypass surgery. The sample was restricted to patients waiting for first time CABG surgery and therefore did not include patients waiting for repeat procedures, for valve replacement procedures, for combined valve and CABG procedures or for other cardiac or thoracic vessel procedures requiring median sternotomy or thoracotomy. Criteria for study inclusion were:

- Eighteen years of age or older

- Ability to read and write English
- A working telephone connection (for qualitative component)
- Absence of significant psychological or neurological deficits
- Waiting at home or out of hospital for surgery
- Willing to participate in the study following informed consent

All patients on the waiting list who met the above criteria were approached via mail to participate in this research. Since recruitment was taking place within a fixed population of subjects, (all CABG patients on a given day at the start of the data collection period), preliminary statistical consultation established that all of the qualified patients would be sampled. Data was analyzed for the entire responding sample and select aggregate database information was analyzed for the non-responding sample.

During any given month approximately 100 cardiac surgical patients, (including surgeries other than first time CABG patients), are waiting for surgery on the Health Sciences Centre waiting list. At the initial sampling (January 11, 2001), 41 patients were identified that met the study criteria. Although a high response rate was achieved from this group of participants, in order to increase the total sample size, a second sampling of the waitlist took place approximately three and a half months after the initial sample (April 26, 2001). Two separate recruitment processes were undertaken in order to maintain a population that had a wide range of wait lengths. Continuous weekly sampling following the first sample was considered but this method would have biased the study population with participants who had waited a short period of time at the time of responding to the questionnaire.

Informed Consent

Two separate procedures for obtaining informed consent were used in this study: one for the quantitative survey booklet and the other for the qualitative telephone interview. A full description of the ethical considerations for consent were included in the initial mailing describing the study (Appendix D). A variation of this information was also included in the letter introducing the survey booklet (Appendix E). Subjects were also given the opportunity to refuse participation in the study, before receiving the survey booklet, by calling the cardiac surgery waitlist coordinator (Appendix C). For the quantitative portion of the study, return of the questionnaire booklet was considered consent to participate in the study. Therefore, in this study, subjects had two opportunities to refuse participation. First, they could refuse to participate by calling the waitlist coordinator before they received the questionnaires. Second, they could refuse to participate by not mailing back the completed study booklet. Using this type of recruitment technique allowed individuals the control to decide whether or not they will be contacted, as opposed to receiving unsolicited contact from the researcher.

For the qualitative telephone interview, participants gave verbal consent over the phone following a description of the ethical considerations (see Appendix G). A consent form requesting permission to examine the participant's individual cardiac surgery database was included with the study booklet. General access to the aggregate data within the cardiac surgical database was requested and granted from the WRHA. No essential information was deliberately withheld or presented in a misleading way to the participants in this study.

Feedback/Debriefing

Participants were given the opportunity to receive a summary of the study results at the conclusion of this research. This summary was mailed to participants who indicate an interest in receiving this information by checking a “yes-no” box. The option to receive the summary is presented on the demographic questionnaire that was included in the survey booklet (Appendix M).

Risks and Benefits

There were no significant risks associated with the study process however there was the slight possibility that participants may have experienced some uncomfortable feelings when answering the study questions while they reflected on their waiting experience. The telephone interview was discontinued and the participant was allowed to discuss their feelings or end the interview if he/she indicated any sign of physical or emotional discomfort.

It was recognized that the researcher, in the process of collecting data, had the opportunity to identify a patient who indicated in their study questionnaire or during their telephone interview that he/she had more severe symptoms, or was in a more severe state of anxiety than what had been recorded in that patient’s cardiac surgical database. In the event of such an occurrence, with the participant’s permission, the researcher contacted the cardiac surgery waitlist coordinator to express her concerns about the patient so that appropriate follow-up could be initiated with the patient and, if necessary, the patient’s physicians. The researcher contacted the waitlist coordinator on behalf of one telephone interview participant. The researcher also suggested to several other telephone interview participants that he/she should initiate

contact with the waitlist coordinator to discuss their symptom status or other waiting issues.

The opportunity to express their feelings about waiting for CABG surgery was identified as a potential benefit to participants. Participants, however, will likely not directly benefit from any final conclusions made from this study except in knowing that they may have had an influence on the nursing care of future patients waiting for CABG surgery.

Anonymity and Confidentiality

The voluntary nature of the study was made clear to participants within all communications and participants were informed that they had the freedom to withdraw, or choose not to participate without influencing their current or future medical or nursing care. They were made aware that physicians and other health care professionals would not know if they chose to participate. Participants were also informed that participation in this research would neither lengthen nor shorten their surgical waiting period.

Anonymity of participants was assured by using only code numbers on the mailed questionnaires. A master log of patients' names, addresses, and phone numbers, (where applicable), with participant numbers was kept separate from the returned questionnaires and open-ended interview transcripts/notes. Participants were informed that the results of the study would not be reported or published in a manner that would identify individual respondents.

Only the researcher and her thesis advisor had direct access to the raw data. The master log of patients' names, addresses, and phone numbers was kept in a

locked drawer. All anonymous, completed surveys will be kept by the researcher for a period of seven years then shredded.

Compensation

No costs to the participants were anticipated for participating in this research project. The participants did not need to travel to meet with the researcher during the data collection process. Where applicable, participants that made long distance phone calls related to their participation in this project were allowed to call collect to avoid any personal costs. A 1-800 number was available to participants who were calling from outside the city of Winnipeg to the Cardiac Surgery office.

Data Collection

Quantitative Data Collection

The primary method of data collection was through mailed questionnaire. Methods for administering mail surveys are described in detail in Bourque and Fielder (1995) and these guidelines served as the procedural basis of conducting this study.

A second form of data collection was used to amalgamate illness related data from the cardiac surgery database. This data was recorded on The Illness and Surgery Information Data Form, (Appendix H), which was developed for this research. This form allowed the researcher to record information for use in this study on: past history of myocardial infarction, CCS angina classification, presence of comorbid diseases such as diabetes, renal failure/insufficiency, chronic obstructive pulmonary disease (COPD), and smoking, left ventricular function, number of diseased vessels, left main disease, maximal allowable waiting time, cancellations,

patient contact and reason, and final date of surgery. The date of the patient's first visit to their cardiac surgeon or the date that the patient was accepted for surgery (whichever was later) was also recorded. This date was considered the start of the patients' waiting period.

Qualitative Data Collection

Participants who returned the mailed questionnaires and indicated an interest in continuing on in the study and answering the open-ended questions were telephoned within a week of receiving their mailed response. The interview was conducted either at that initial phone call or an alternate time was arranged based on participant availability. Chapple (1999) has noted that it is possible to obtain rich, useful data through qualitative telephone interviewing. Telephone interviewing is particularly helpful when collecting data from geographically dispersed populations.

The following questions were asked of participants agreeing to participate in the telephone interview:

1. Some patients who wait for heart surgery need to manage symptoms such as chest pain/pressure, shortness of breath or fatigue. Are you doing anything specific to manage your heart related symptoms while you have been waiting for your surgery? What have you been doing? If you have not been having symptoms why do you think that is? (Purpose of question: to clarify the symptom pattern of illness. Also examines how patients are coping with their symptoms.)
2. Why do you think that having bypass surgery will be a beneficial or a worthwhile undertaking? What do you expect will be different for you as a

result having the surgery? (Purpose of question: Examines patient's expectations of surgery, which is a component of the event congruence variable of the stimuli frame in Mishel's Uncertainty in Illness Theory. These questions also examine the possible "opportunities" that the patient may see within their illness uncertainty experience.)

3. Some people who are waiting for heart surgery have indicated that they feel anxious. Do you feel that way? What would you say has caused you the most anxiety during the waiting period for surgery? If you do not feel that you have been anxious, what things help you not to be anxious? (Purpose of question: To clarify causes of anxiety while waiting for surgery and relate them to patient's individual anxiety scores.)

Responses to the above questions were recorded by taking notes in the form of key phrases during the telephone conversation. Key phrases and content were repeated back to the participants during the interview to confirm that the participant's meaning was being understood. The handwritten notes taken by the researcher were summarized and elaborated on immediately after the interview was completed. If participants made significant statements related to their waiting time but unrelated to the interview questions these were also recorded.

Instrumentation

Four standardized instruments were included in the mailed questionnaire booklet used in this study: The Mishel Uncertainty in Illness Scale, a modified version of the Symptom Frequency and Symptom Distress Scale, two subscales of the Kansas City Cardiomyopathy Questionnaire (physical limitation and social

limitation), and a graphical anxiety rating scale. A demographic questionnaire was also included in the package. A description of these scales and their reliability and validity measures is included in the following paragraphs.

The Mishel Uncertainty in Illness Scale (Appendix I)

The Mishel Uncertainty in Illness Scale (MUIS) was first developed in 1980 and the results of initial testing were first published in 1981 (Mishel, 1981). Since this time, the scale has been used to examine uncertainty in multiple patient populations including post MI patients and patients who had coronary artery bypass surgery. The items on the MUIS are graded on five point Likert scales ranging from strongly disagree to strongly agree. The process of scoring and administering this scale as well as reliability and validity data is described in the Uncertainty in Illness Scales Manual (Mishel, 1997). The MUIS Community (MUIS-C) version was used in this research. On this version of the scale only a total scale score can be obtained by adding the responses given on the 23 items of the scale. Total scores can range from 23 to 115. Higher scores indicate higher levels of uncertainty. Co-efficient alpha scores of reliability range from moderate to high (.74 to .92). Construct validity has been determined through the scale's ability to differentiate between medical, surgical and diagnostic patients (Mishel, 1981).

The Symptom Frequency and Symptom Distress Scale (Appendix J)

The Symptom Frequency and Symptom Distress Scale (SFSDS) was first developed for use in heart transplant patients by Lough, Lindsey, Shinn and Stotts (1987). This self-administered scale is described as being suitable for distribution by mail and assesses physical symptoms experienced and emotional distress caused by

symptoms. A five point Likert scale from 0 to 4 (never to always) is used to measure subjectively assessed symptom frequency while a parallel scale of 0 to 4 (not at all upsetting to extremely upsetting) is used to measure the perceived level of associated distress. The transplant symptom frequency scale demonstrated a co-efficient alpha of .70 while the corresponding distress scale demonstrated an alpha of .87.

Because this scale was developed to measure the frequency and distress of immunosuppressant drug therapy for the purposes of this study it has been modified to represent symptoms of coronary artery disease and heart failure. These symptoms were identified from the medical and nursing literature and from the researcher's extensive experience with individuals with coronary disease symptoms. Due to the nature of the modifications of this scale, before its use in this research it was piloted among experienced cardiac clinicians to assure face validity. No changes to this scale were required based on feedback from these groups.

The modified SFSD scale was scored by multiplying the symptom frequency score with the symptom distress score for each item and adding the total score. This scoring method was a modification of the scoring described by Lough et al. (1987) Using this method, total scores can range from 0 to 368 with higher scores indicating higher symptom distress. Each symptom can also be used as a separate subscale of the SFSD.

The Kansas City Cardiomyopathy Questionnaire Subscales (Appendix K)

The Kansas City Cardiomyopathy Questionnaire (KCCQ) is a newly developed scale to measure health status in patients with heart failure (Green, Porter, Bresnahan, & Spertus, 2000). For the purposes of this study the physical limitation

scale and the social limitation scale were used to assess functional status in the patients waiting for CABG surgery. Each physical or social activity is rated on a five-point scale ranging from extremely limited to not at all limited. The patient is also able to indicate if they were limited from the activity for reasons other than their heart condition or if they did not do the activity. After fitting participant responses into a formula (mean score of scale items, minus one, divided by four, and multiplied by 100), scores for each scale can range from 0 to 100 with a lower score indicating greater limitation. Cronbach's alpha scores for the physical limitation domain and the social limitation domain are 0.90 and 0.86 respectively. The physical limitation domain was validated by comparing this subscale of the KCCQ with NYHA functional status, the Minnesota Living with Heart Failure, the Short Form-36 (SF-36) functional status scales and the 6-minute walk test. Each comparison demonstrated high correlations with p -values < 0.001 . The social limitation domain was significantly correlated ($p < 0.001$) with the NYHA and the SF-36. The KCCQ was also sensitive to changes in condition over time.

Graphical Anxiety Rating Scale (Appendix L)

Graphical Rating Scales are an alternate version of visual analogue scales. Visual analogue scales (VAS) are represented as a straight line, most often 100 millimeters in length, with the end anchors of that line labeled as the extreme boundaries of the response being measured. It may be either horizontal in orientation or vertical, however a horizontal VAS has been shown to produce more uniform distribution of scores. When descriptors are placed at intervals along the horizontal

line, the scale is then described as a Graphical Rating Scale (GRS) (Wewers & Lowe, 1990).

Reliability and Validity of the GRS varies for the construct being measured and is described in detail in McCormack, Horne, and Sheather (1988) and Wewers and Lowe (1990). These authors advise careful examination of the population being studied with specific attention to their ability to understand and respond to the VAS. They also caution the selection of variable to be measured by the VAS. According to these authors, anxiety is a variable that is frequently measured by a form of a VAS often with successful results. Vogelsang (1988) identified that the VAS is an accurate and sensitive method of self-reporting preoperative anxiety.

The Graphical Anxiety Rating Scale (GARS) used for this study asks participants to place a cross on the line at the place that best reflects their anxiety level. The scale is a horizontal 100-millimeter line anchored with "not anxious" on the left end and "as anxious as I could be" on the right end. The words "mild", "moderate", and "severe" are the descriptive terms that are evenly spaced along the horizontal line. The scale was scored by measuring, in millimeters, from the left end of the scale to the participants mark. The responses were placed in three groupings: mild (0-30 mm), moderate (31-69 mm), and severe (70-100 mm).

Demographic questionnaire. (Appendix M)

Also included in the mail questionnaire booklet was a personal information survey used to collect demographic information from the participants. Demographic information collected included gender, age, level of education, work status, living arrangements, and patient identified length of wait for surgery

Pilot Testing

Three nurses with experience looking after cardiac surgery patients were asked to review and comment on the contents of the questionnaire booklet (including all instruments), the Illness and Surgery Data Information Form, and the qualitative interview questions. Suggestions were considered and appropriate changes were made.

Data Analysis

Quantitative Analysis

Numerical data was entered into a computer for analysis with the SAS program for statistical analysis. Tables were used to summarize the data and correlational matrixes were used to present the relationships between the study variables. A description of the quantitative data analysis techniques is presented for each research question below.

1. What are patients' levels of uncertainty, symptom distress, and anxiety in relation to how long they have been waiting for CABG surgery? (Pearson's r and ANOVA)
2. How do waiting CABG patients' levels of uncertainty, symptom distress and anxiety correlate to each other? (Pearson's r)
3. How are uncertainty, symptom distress and anxiety related to the patients' functional status, personal characteristics (gender, education, age, living situation, work status), and illness severity (CCS angina class, surgical priority, comorbidities, left ventricular function, number of diseased vessels)? (Pearson's r , unpaired two tailed t-tests for independent groups, ANOVA)

4. Controlling for surgical priority and illness severity, what patient characteristics are associated with a shorter total waiting time for CABG surgery? (Multiple linear regression)

Qualitative Analysis

Content analysis was undertaken to analyze the transcribed notes taken during and following the telephone interviews. Patient responses were categorized question-by-question and compared for fittingness with the theoretical framework. General themes emerging from the interview transcripts were also examined. The findings were then reorganized to present the data within conceptual categories. The qualitative categories were then used to help explain the quantitative relationships between variables in the discussion portion of this thesis.

While reflecting on the trustworthiness of this data, qualitative reliability and validity, (or qualitative rigor), was maintained by attending to the credibility, fittingness, auditability, and confirmability of the interview data (Sandelowski, 1986). One motive for including a qualitative component was to bring the researcher closer to at least some of the waiting CABG patients in order to hear their waiting experiences in their own words. Specific hypotheses were made about the experience of waiting for CABG surgery, which were based on the Mishel Uncertainty in Illness Theory. The qualitative research questions and interview questions were designed based on the modification of this theory and were kept direct and simple in keeping with the premise that the qualitative portion of this study was only included to complement the quantitative results. Confirmability was achieved through consistently maintaining this perspective throughout the data collection and data

analysis phase of the project. In meeting the criteria for auditability, a clear decision making trail was recorded during the analysis of the interview transcripts, outlining how the data was transformed from the transcripts, and how themes were chosen. Credibility and fittingness were achieved through both triangulation with quantitative data, and through questioning the fit of the data with the real world. The initial draft of the content analysis of this data was shared with two experienced researchers, the first an expert on cardiac care and the second an expert in qualitative methods and cancer research. Both researchers identified with the initial themes identified from the transcript and suggestions were made regarding the organization of the conceptual categories. Both researchers felt there was a credible fit of this data to their own experiences with patients and pointed to the transferability of these results to other patient populations, (e.g. cancer patients), who also experience uncertainty, anxiety, and symptoms, and are forced to wait at some point during their medical care.

Limitations

Some limitations are present in the methodology of this study. The descriptive correlational design limits the ability to find causal relationships among the research variables, however, Polit and Hungler (1999) identify that with a strong well-tested theoretical framework, approaching causal relationships may be possible. In addition, correlational findings are complicated by complex relationships in the real world, as there is no guarantee that the subjects waiting for surgery were similar to each other before the waiting period began.

Polit and Hungler (1999) also identify limitations in cross-sectional designs. The primary limitation in this type of research is that it assumes that participants at a

later stage in the study process would have responded in a similar manner as the participants in an early stage of the study process if they had been answering the survey questions at that time. Making this assumption allows the researcher to make comparisons between groups at different stages and draw conclusions from these comparisons. However, this type of design does not account for confounding variables such as individual differences in personality, coping styles, or emotional responses of the participants that may influence their responses to the study questions.

Self-selection was used as a sampling method for the qualitative portion of the study. The difficulty with self-selection is that the participants that chose to participate may have characteristics extraneous to the research problem that influenced their responses to the questions (Polit & Hungler, 1999).

Use of a non-randomized convenience sample imposes limitations related to the generalizability of the research findings. Unfortunately inconsistencies in the way in which the two cardiac surgery centers in Manitoba referred patients for CABG surgery made it difficult to collect data from one of the surgical centers and limited the population base of eligible participants for this study.

Conducting the qualitative interviews over the telephone poses limitations to this portion of the data collection. Telephone contact is less personal than face-to-face contact and may have influenced the responses provided by the participants. Chapple (1999) also identified that telephone interviewing is limited by the participants' comfort level with speaking on the telephone or their hearing ability. Telephone interviewing also does not allow the researcher to see the participant's facial expressions or body language, which are pertinent components of

communication. The researcher is also not able to assess the participant's social or cultural context, which may be important to the research question.

The telephone interviews were not tape-recorded or transcribed verbatim, which may have inadvertently altered the meaning of some of the participant's statements. Care was taken to be as accurate as possible when hand recording the participants responses to the questions.

Chapter Summary

The methodology for this study was a descriptive, correlational, cross-sectional survey to examine uncertainty, symptom distress and anxiety in patients waiting for coronary artery bypass surgery. Qualitative interviewing was also utilized to complement the responses to the quantitative survey. Ethical standards were adhered to throughout the subject recruitment and data collection process. Four proven reliable and valid instruments were included in the mail questionnaire (MUIS-C, SFSD, KCCQ physical and social limitation subscales, and GARS) as well as a demographic questionnaire. Patients who completed and returned the mail questionnaire self-selected themselves to participate in the telephone interview. Data was analyzed to assess the levels of uncertainty, symptom distress, and anxiety in patients waiting for CABG surgery. Correlates of these variables were also analyzed. Differences in responses between subgroups of patients such as men and women and those who had been waiting a short, intermediate or longer period of time were also calculated. Controlling for severity of illness and surgical priority, variables associated with shorter waiting times were also identified.

CHAPTER 4

RESULTS

Introduction

Data collection for this research project took place over a 5 month period from January 2001 to May 2001 with subject recruitment being done in two separate samplings to obtain a variety of participants who had waited varying lengths of time for CABG surgery. A total of 41 patients at the January sampling and 25 patients at the April sampling were identified as meeting the study criteria for a total of 66 patients who were mailed the introductory letter. This number was lower than anticipated for total CABG-only patients on the Health Sciences Centre site waiting list. Two reasons were identified as contributing to these low numbers: two surgeons primarily operated on valve and combined procedure patients, and a third surgeon was in the process of leaving the centre and stopped adding patients to the list during the data collection period for this project. Because this latter surgeon's patients were being reassigned to other surgeons and occasionally other hospitals, it was clear that this process would have a potential influence on the study variables for this project. The researcher made a decision in consultation with a statistician and her thesis chair to halt data collection at this time.

Of the initial 66 patients, a total of 6 patients (9%) called the waitlist coordinator's office and indicated that they were not interested in receiving the survey. Eligible subjects who refused participation were not asked to provide an explanation for their decision. An additional 6 patients (9%) were never mailed the survey package because they had their surgery or were taken off list in the period of

time between the mailing of the introductory letter and the time allotted to allowing the participants to phone in and refuse the survey. Therefore, 82% of eligible patients were mailed the survey package for a total of 54 potential subjects. Nine of these packages were never returned leaving a total of 45 returned questionnaires and a response rate of 83.3% from the pool of mailed questionnaires. Three of the returned questionnaires were eventually eliminated from the analysis: one because the participant was taken off the waiting list prior to filling in the survey, and two additional participants were waiting for procedures other than first time CABG and were mistakenly included in the initial sample resulting in a final total of 42 eligible questionnaires.

Demographic Characteristics of the Sample

Table 7 provides a summary of the demographic characteristics of the study sample. The mean age of participants was 64 years (S.D. 8.5) with ages ranging from 46 to 82 years. The majority of participants were male, older than 60 years of age, lived at home with a spouse or equivalent, had at least some high school education, were retired, had no change to their work status while waiting, resided in Winnipeg and had chosen to also participate in the telephone interview portion of this study.

Table 8 provides a summary of the study variables related to health status of the participants. The majority of participants had had two previous MIs, were currently living with Class III angina according to the CCS, had a left ventricular ejection fraction between 35 and 49%, had no concurrent comorbidities (e.g. diabetes, renal disease, history of stroke or transient ischemic attacks, current smokers), had three or more diseased coronary vessels, and left main coronary artery occlusion of

less than 50%. All of the study participants had been classified as "elective" surgery candidates.

Table 9 provides a summary of the characteristics of the participants' waiting times. The mean actual waiting time from the time placed on the list to the time of participation in the study was 97 days (S.D. 61) with a range from 23 to 260 days. In comparing this data with the participants' stated perceived wait up to interview participation, 27 (64%) identified their wait as the same as what was stated in their health record, 8 (19%) thought their wait had been longer, and 5 (12%) thought their wait had been shorter. If the participants' perceived wait was within 10 days of the actual wait, the participants' perceived wait was classified as "the same" as their actual wait. The typical waiting patient at the time of participation in this study had waited between two and four months and perceived their wait to be the same as what was listed on their health record.

By the beginning of the data analysis period, 33 (79%) of the study sample had had their surgery, 5 (12%) had gone off list because they felt better (patient choice) (3), perceived their own risk to be too high because of their comorbidity status (1), or because they were re-evaluated by the surgery team as ineligible for surgery (1), and 4 (10%) were still waiting for their surgery at the conclusion of this study. The average total waiting time for this sample was 172.3 days (S.D. 83.7) with the minimum wait of 64 days and maximum wait of 419 days. When comparing this data to the maximum recommended waiting time (MRWT), which is calculated within the waiting list database for each patient and represents surgical priority, the mean MRWT was 64.9 days (S.D. 26.7). After removing the 9 participants who did

not have surgery as their waiting endpoint, a correlation was performed on the variables of total waiting time and MRWT and found that they were significantly correlated ($p = 0.01$). This correlation indicates that, for this sample, participants with shorter MRWT had their surgeries earlier than participants with longer MRWT, however only one (2%) study participant had his surgery within his calculated MRWT.

Table 7

Demographic Characteristics of the Sample N = 42

Demographic Characteristics		Mean (SD)
Age (years)		64 (8.5)
		N (%)
Age (categorical):	45-60	18 (43%)
	61-70	14 (33%)
	>71	10 (24%)
Gender:	Male	38 (90.5%)
	Female	4 (9.5%)
Living Situation:	Alone	4 (10%)
	With Spouse or Equivalent	30 (71%)
	With Spouse and Children	6 (14%)
	With Other Family/Friends	2 (5%)
Education:	High School or Less	28 (66%)
	Some College/University or More	14 (33%)
Work Status:	Working Part Time	3 (7%)
	Working Full Time	5 (12%)
	Stopped Working Because of Their Health	11 (26%)
	Retired	19 (45%)
	Other	1 (2%)
	Not Answered (N/A)	3 (7%)
Change in Work Status Since Waiting for Surgery:		
Yes		11 (28%)
No		28 (72%)
Residence:	City of Winnipeg	22 (52%)
	Rural Community/Outside Winnipeg	20 (48%)
Agreed to Participation in Telephone Interview:		
Yes		26 (62%)
No		16 (38%)

Due to rounding items may not add up to 100%

Table 8

Health Status Characteristics of Sample N = 42

Health Status Characteristics	N (%)
History of Myocardial Infarction: None One Two >Two	2 (5%) 16 (38%) 23 (55%) 1 (2%)
Angina Classification: Class II Class III Class IVa	11 (26%) 22 (52%) 9 (21%)
Left Ventricular Ejection Fraction: >50% 35-49% 20-34% <20%	2 (5%) 30 (73%) 7 (17%) 2 (5%)
Comorbidities (diabetes, stroke, TIA, renal disease, smoking): Present Absent	15 (36%) 27 (65%)
Number of Diseased Vessels: One Two Three >Three	2 (5%) 7 (17%) 11 (26%) 22 (52%)
Left Main Disease >50%: Yes No	5 (12%) 37 (88%)

Due to rounding items may not add up to 100%

Table 9

Waiting Time Characteristics of Sample N = 42

Waiting Time Characteristics	Mean (SD)	Range
Actual Wait (days) from time added to list to interview date	97 (61)	23-260
Perceived Wait (days) from perceived time added to list to interview date	102 (55)	24 -241
	N (%)	
Comparison of perceived wait (days) and actual wait (days) up to interview date:		
Perceived Wait Same as Actual Wait	27 (64%)	
Perceived Wait Longer than Actual Wait	8 (19%)	
Perceived Wait Shorter than Actual Wait	5 (12%)	
N/A	2 (5%)	
Waiting Outcome at conclusion of study:		
Had Surgery	33 (79%)	
Off List	5 (12%)	
Still Waiting	4 (10%)	
Perceived Wait at interview date in months (Categorical):		
0-2 months	8 (19%)	
2-4 months	17 (40%)	
>4 months	13 (31%)	
Did not know	4 (10%)	
	Mean (SD)	Range
Total Wait from time added to list to date of surgery*	172 (84)	64-419
Maximum Recommended Waiting Time (MRWT)*	64 (27)	18-171
	N (%)	
Total Wait in months (Categorical):		
0-2 months	0 (0%)	
2-4 months	11 (26%)	
4-6 months	17 (40%)	
>6 months	14 (33%)	
Surgery within Maximum Recommended Waiting Time		
Yes	1 (2%)	
No	41 (98%)	

Due to rounding items may not add up to 100%

* Comparison of Total Wait to MRWT elicited $p = .01$ after removing the 9 participants who did not have surgery as their waiting outcome.

Quantitative Data Analysis

The researcher scored the quantitative data collected for this study and a third party was hired to transfer the data to computer. The SAS system was used to complete the data analysis. Data analysis was conducted using a variety of statistical tests including descriptive statistics, Pearson r to test for correlation, two-tailed t -tests for independent groups to compare group means, analysis of variance (ANOVA) to compare group means of more than two groups, and regression analysis.

RESEARCH QUESTION #1: What are patients' levels of uncertainty, symptom distress, and anxiety in relation to how long they have been waiting for CABG surgery?

Both the participants' actual waiting time and their perceived waiting time up to the date of their interview were compared to the results of the following three instruments:

1. The Mishel Uncertainty in Illness Scale – Community Form (MUIS-C)
2. The Symptom Frequency and Symptom Distress Scale (SFSDS) (both total score and the scores from each individual symptom)
3. Graphical Anxiety Rating Scale (GARS)

In additional analysis, actual and perceived waiting time were also compared to the two subscales of the Kansas City Cardiomyopathy Questionnaire (KCCQPL, physical limitation, and KCCQSL, social limitation) as well as the age of the participants.

Table 10 presents a description of the scores from the MUIS-C, SFSDS, GARS, KCCQPL, and KCCQSL scales. If scores for the MUIS-C are grouped into mild (23-53), moderate (54-84) and severe (85-115), a mean score of 58.4 for this

scale would indicate that, for this sample, the average participants' uncertainty level could be described as moderate. Similarly, the mean scores from the GARS (50.6), KCCQPL (52.7), and the KCCQSL (52.2) also fall into the moderate range. All three of these scales have possible scores in the range of 0 to 100 with 100 being the most severe score for the anxiety scale and zero being the most severe score for the KCCQ subscales.

The mean sample score for the SFSDS was 77.7 out of a possible 368 maximum. Due to the newness of this scale it is not possible to classify this score as mild, moderate, or severe because the presence or absence of symptoms is unique to each patient and not every patient will have every symptom represented on this scale. The majority scores for this sample (82%) cluster in the lower one third of the range of scores identified for this scale, however it would not be accurate to say that this sample had mild symptom distress. Specific symptoms, however, were more distressing than others (See page 97, Additional Analysis: The Symptom Frequency and Symptom Distress Scale, for further discussion).

Table 10

Description of Study Variable Scores

Study Instrument	Mean (SD)	Range
Mishel Uncertainty in Illness Scale – Community Form (MUIS-C) (23-115)	58.4 (13.5)	31-92
Mild Uncertainty (23-53)	N (%)*	
Moderate Uncertainty (54-84)	18 (43%)	
Severe Uncertainty (85-115)	20 (48%)	
	4 (10%)	
Symptom Frequency and Symptom Distress Scale (SFSDS)** (0-368)	77.7 (60.0)	7-286
(0-25)	N (%)*	
(26-50)	8 (21%)	
(51-75)	3 (8%)	
(76-100)	11 (28%)	
(101-125)	7 (18%)	
(126-150)	3 (8%)	
(151-175)	4 (10%)	
(176-368)	1 (3%)	
	2 (5%)	
Graphical Anxiety Rating Scale (GARS) (0-100)	50.6 (29.1)	0-100
Mild Anxiety (0-30)	N (%)*	
Moderate Anxiety (31-69)	12 (29%)	
Severe Anxiety (70-100)	18 (43%)	
	12 (29%)	
Kansas City Cardiomyopathy Questionnaire – Physical Limitation Scale (KCCQPL) (100-0)	52.7 (22.2)	15-95
Mild Physical Limitation (70-100)	N (%)	
Moderate Physical Limitation (31-69)	13 (31%)	
Severe Physical Limitation (0-30)	20 (48%)	
	9 (21%)	
Kansas City Cardiomyopathy Questionnaire – Social Limitation Scale (KCCQSL) (100-0)	52.2 (28.8)	0-100
Mild Social Limitation (70-100)	N (%)*	
Moderate Social Limitation (31-69)	13 (31%)	
Severe Social Limitation (0-30)	19 (45%)	
	10 (24%)	

*Due to rounding totals may not add up to 100%

**N = 39 for the SFSDS due to missing values

The study variables were correlated with both the participant's actual waiting time and their perceived waiting time. Actual waiting time was calculated in days based on the date added to list found in each participants cardiac surgery database, up until the date participants answered the mailed survey. Perceived waiting time was calculated in days based on the date the participant remembered first seeing their cardiac surgeon and making a decision to have surgery, up until the date the participant answered the mailed survey. Table 9 discussed the mean results of actual and perceived waiting time for this sample. Table 11 describes the Pearson r correlation coefficients for the study variables and these two waiting times. The SFSDS has been compared both as a total score and as individual symptom scores, which were obtained by multiplying together the frequency score and the distress score for each symptom. A significant correlation was found between actual waiting time and the symptom of loss of appetite ($p = 0.02$). The symptom of indigestion approaches a significant relationship with both perceived and actual waiting time ($p = 0.07$). As positive correlations, there is an indication that these symptoms are more severe in patients who have had a longer wait. A p -value of <0.0001 was found between actual and perceived waiting time.

Table 11

Pearson r Correlation Between Study Variables and Actual and Perceived Waiting

Time

Variable	Actual Waiting Time	Perceived Waiting Time
Actual Wait	1.0	0.74225*
Perceived Wait	0.74225*	1.0
Age	-0.06076	-0.09852
MUIS-C	.21295	.04856
GARS	.04668	-0.03241
KCCQPL	-0.03978	-0.05264
KCCQSL	-0.13623	-0.10171
SFSDS (total)	0.05564	-0.01623
Chest discomfort	-0.15849	-0.20849
Arm/shoulder pain	0.13499	-0.01203
Back/neck pain	0.23560	0.19623
Jaw/throat/tooth pain	-0.15181	-0.18612
Indigestion	0.28330	0.29259
Generalized discomfort	0.05085	0.02737
SOB with activity	-0.07814	-0.09706
SOB lying flat	-0.02988	0.01817
Nocturnal SOB	-0.02500	-0.11660
Dizziness/Lightheadedness	0.29022	0.15769
Palpitations	0.08116	0.11088
Irregular heart rate	0.12061	0.14480
Fatigue	0.25025	0.13071
Edema	0.24678	0.21054
Difficulty Sleeping	0.03834	-0.01017
Nausea	-0.03093	-0.04726
Loss of Appetite	0.36278**	0.03319
Depressed Mood	0.05549	-0.09052
Nervousness/Shakiness	0.02274	0.00915
Feeling Fearful	-0.05334	-0.10604
Feeling Tense	0.01137	-0.08548
Panic Spells	-0.02544	-0.01488
Restlessness	-0.10506	-0.14535

* p=<0.0001 **p=0.02

To assist with additional analysis and look for trends in the data, participants responded to a categorical version of their perceived waiting time. These waiting categories were compared to the study variables to look for significant differences between groups. An analysis of variance (ANOVA) was performed on the study variable means of the following perceived waiting time, (up to date of survey), categories: less than two months, two to four months, and greater than four months. A description of this data is represented in Table 12.

Table 12

Trends in Variable Means Within Perceived Waiting Times (Categorical)

Perceived Waiting Time at Interview (Categorical)		MUIS-C***	SFSDS**	GARS	KCCQPL	KCCQSL
	N (%)*	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
<2 months	8 (19%)	58.5 (10.8)	57.9 (46.7)	37.5 (27.8)	60.6 (26.2)	65.6 (29.0)
2-4 months	17 (40%)	54.2 (13.7)	73.8 (52.9)	50.2 (25.6)	52.9 (21.8)	52.8 (27.7)
>4 months	13 (31%)	62.2 (14.0)	102.8 (75.6)	61.7 (32.3)	49.8 (23.3)	45.2 (32.2)

* 4 (10%) of sample did not provide a response

** SFSDS N = 39 (<2mons = 7; 2-4 mons = 17; >4mons = 12; N/A = 3)

*** See Table 10 for full names of study instruments

Although no statistically significant differences were observed between groups, several trends were observed. Uncertainty scores remained relatively stable across waiting time categories with a slight increase in mean uncertainty levels in participants who had waited greater than four months. Symptom distress and Anxiety mean scores trended toward increasing as waiting time increased, as well as the two

subscales of the KCCQ for which the scores decreased as waiting time lengthened. These findings indicate a potential for clinically significant deterioration of social and physical functional status as waiting time increases.

RESEARCH QUESTION #2: Is there a relationship between uncertainty, symptom distress and anxiety in patients on a waiting list for CABG surgery?

Table 13 is a correlation matrix of the Pearson r coefficients describing the relationship between uncertainty, symptom distress, and anxiety for this study sample. Significant relationships are noted between uncertainty and symptom distress ($p = 0.005$) and between symptom distress and anxiety ($p = 0.0002$). The relationship between uncertainty and anxiety approaches but does not quite achieve statistical significance with $p = .08$. Table 14 describes the correlation between the individual symptoms of the SFSDS, (frequency score multiplied by the distress score), to anxiety and uncertainty, which provides a more in-depth analysis of the relationship between uncertainty, anxiety and symptom distress. As the table indicates, numerous individual symptoms also have strong correlations with uncertainty and anxiety.

Table 13

Pearson r Correlation Between Uncertainty, Symptom Distress, and Anxiety

	MUIS-C	GARS	SFSDS
MUIS-C	1.0		
GARS	0.27611 p =.08	1.0	
SFSDS	0.43945 p =.005*	0.56149 p =.0002*	1.0

*Highlights statistically significant values to $p < 0.05$

Table 14

Pearson r Correlation Between Uncertainty, Anxiety and Individual Symptoms

Symptoms	MUIS-C	GARS
Chest discomfort	0.48078****	0.48656****
Arm/shoulder pain	0.45747***	0.40469***
Back/neck pain	0.51877****	0.52901****
Jaw/throat/tooth pain	0.42336***	0.25134
Indigestion	0.23675	0.43121***
Generalized discomfort	0.37360**	0.41695***
SOB with activity	0.28173	0.42570***
SOB lying flat	0.24928	0.34573**
Nocturnal SOB	0.31201*	0.33026*
Dizziness/Lightheadedness	0.29429	0.34690**
Palpitations	0.25334	0.29252
Irregular heart rate	0.25405	0.31742*
Fatigue	0.33662*	0.45738***
Edema	0.28593	0.22240
Difficulty Sleeping	0.52888****	0.38977***
Nausea	0.47133****	0.38566***
Loss of Appetite	0.54332****	0.20003
Depressed Mood	0.37452**	0.51015****
Nervousness/Shakiness	0.32400*	0.43843***
Feeling Fearful	0.27556	0.36482**
Feeling Tense	0.30952*	0.42596***
Panic Spells	0.28720	0.41399***
Restlessness	0.30354*	0.47142****

* $p = 0.05$, ** $p = 0.02$, *** $p = 0.01$, **** $p = < 0.001$

RESEARCH QUESTION #3: Is there a relationship between patients' levels of uncertainty, symptom distress and anxiety, and their functional status (measured by the KCCQ subscales), their personal characteristics (gender, education, age, living situation, work status, area of residence, decision to participate in telephone interview), and their illness severity (baseline CCS angina class, comorbidities, left ventricular function, number of diseased vessels, history of MI)?

Table 15 provides a summary of the relationships between uncertainty symptom distress, and anxiety and the ratio data (KCCQ and age) collected on this sample. Highly significant correlations were found between the KCCQ social limitation scale (SL) and anxiety, symptom distress and physical limitation (KCCQPL). Physical Limitation also strongly correlated with uncertainty, anxiety and symptom distress. The participant's age had no correlation with any of the study variables. Table 16 presents an additional analysis comparing the functional status scores (KCCQ) and age with the individual symptoms of the SFSDS. The table highlights numerous strong correlations for this sample between the individual symptoms and the functional status scores represented by the KCCQPL and SL scales. There were no correlations between the individual symptoms and the age of the participants with the exception of the symptom "palpitations". Older patients in this sample were significantly more likely to report this symptom as distressing.

Table 17 presents the data of the mean scores for uncertainty, symptom distress and anxiety for the categorical characteristics of the study sample (gender, education, living situation work status, area of residence, telephone interview participation, CCS Angina Class, comorbidities, LVF, number of diseased vessels,

and history of MI). Additional analysis performed on the categorically grouped data examined the mean functional status and age scores for each grouping. Unpaired two-tailed t-tests for independent groups were performed to look for significant differences between subject groups.

No significant differences were found between groups with respect to uncertainty in all categories, and uncertainty scores, in general, appear to have remained stable. Although no significant differences were found, participants had higher mean symptom distress scores if they were male, quit work because of their health, had changed their work status while waiting, lived in an urban area, had decided not to participate in the telephone interview, had CCS angina classification of at least Class III, reported one or more comorbidities, had an ejection fraction of less than 35% and had three or more occluded coronary vessels requiring bypass.

Participants had higher mean anxiety scores if they were male, had quit work because of their health, had changed their work status while waiting, had at least Class III angina and reported one or more comorbidities, however no statistically significant differences were noted for this variable.

Significant differences were found within the category of living situation in that participants who lived alone were more likely to report a worse functional status both physically ($p = .01$) and socially ($p = .05$), however, the low number of patients in the "living alone" group require these results to be viewed cautiously.

Participant age was not significantly related to any of the health status related categories, however, demographically the four female participants in this study on average were older than the male participants (N.S.), older participants were

significantly more likely to have less education ($p = .04$), and retired participants were significantly older ($p < .0001$) than participants who were still working or who had stopped working because of their health.

Table 15

Pearson r Correlation Between Uncertainty, Symptom Distress, Anxiety and Ratio

Subject Data

	MUIS-C	GARS	SFSDS	KCCQPL	KCCQSL	AGE
KCCQPL	-0.31887 $p = .04^*$	-0.47255 $p = .002^*$	-0.54567 $p = .0003^*$	1.0		
KCCQSL	-0.25485 $p = .10$	-0.60132 $p < .0001^*$	-0.57842 $p = .0001^*$	0.80926 $p < .0001^*$	1.0	
AGE	0.17839 $p = .26$	0.03933 $p = .80$	0.03928 $p = .81$	-0.24157 $p = .12$	-0.14802 $p = .35$	1.0

*Highlights statistically significant values to $p < 0.05$

Table 16

Pearson r Correlation Between Functional Status Scores, Age and IndividualSymptoms

Symptoms	KCCQPL	KCCQSL	AGE
Chest discomfort	-0.58480****	-0.54818****	0.23055
Arm/shoulder pain	-0.51750****	-0.45721***	0.08892
Back/neck pain	-0.42658***	-0.35024**	0.04542
Jaw/throat/tooth pain	-0.26259	-0.24057	0.03675
Indigestion	-0.38496***	-0.45405***	-0.03083
Generalized discomfort	-0.44355***	-0.38872***	0.00374
SOB with activity	-0.62886****	-0.49253****	-0.01961
SOB lying flat	-0.53657****	-0.50551****	0.14184
Nocturnal SOB	-0.35763**	-0.27139	0.17147
Dizziness/Lightheadedness	-0.39826***	-0.44572***	0.01504
Palpitations	-0.44173***	-0.42265***	0.32967*
Irregular heart rate	-0.50941****	-0.49646****	0.16654
Fatigue	-0.51576****	-0.56764****	0.09857
Edema	-0.40586***	-0.42000***	-0.00307
Difficulty Sleeping	-0.10439	-0.20820	-0.02251
Nausea	-0.39901***	-0.40306***	0.24241
Loss of Appetite	-0.33055*	-0.40740***	0.21017
Depressed Mood	-0.10314	-0.16160	-0.08507
Nervousness/Shakiness	-0.38596***	-0.48283****	-0.04348
Feeling Fearful	-0.22821	-0.26582	-0.21003
Feeling Tense	-0.35069**	-0.50641****	-0.12523
Panic Spells	-0.24905	-0.25797	0.03417
Restlessness	-0.22055	-0.31461*	0.04261

* p = 0.05, ** p = 0.02, *** p = 0.01, **** p = <0.001

Table 17

A Comparison of Mean Uncertainty, Symptom Distress, Anxiety, Functional Status and Age Scores to Categorical Characteristics of Sample

		SFSDS		MUIS-C	GARS	KCCQPL	KCCQSL	AGE
	N (%)	Mean (SD) p value	N (%)	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value
Gender:								
Male	36 (92%)	80.3 (60.8)	38 (90%)	58.9 (14.1)	52.4 (29.1)	52.7 (21.8)	51.9 (27.4)	63.4 (8.5)
Female	3 (8%)	46.7 (47.6)	4 (10%)	53.8 (6.4)	33.5 (26.8)	52.1 (29.8)	55.2 (45.3)	71.0 (5.5)
		.358		.477	.221	.956	.829	.089
Education:								
Up to High School	27 (69%)	76.0 (66.6)	28 (67%)	56.1 (13.2)	48.8 (30.7)	53.8 (21.7)	53.0 (31.6)	66.1 (8.9)
More than High School	12 (31%)	81.4 (44.1)	14 (33%)	63.0 (13.5)	54.1 (26.3)	50.3 (23.7)	50.6 (22.9)	60.3 (6.2)
		.800		.121	.583	.632	.804	.04*
Living Situation:								
Lives Alone	4 (10%)	82.5 (19.3)	4 (10%)	53.8 (16.9)	58.0 (9.1)	27.1 (7.9)	25.0 (8.8)	64.8 (7.5)
Lives With Others	35 (90%)	77.1 (63.2)	38 (90%)	58.9 (13.3)	49.8 (30.4)	55.3 (21.5)	55.1 (28.7)	64.1 (8.7)
		.868		.477	.599	.01*	.05*	.882
Work Status:								
Working Part time or full time	8 (21%)	65.8 (41.6)	8 (19%)	60.5 (14.7)	44.9 (28.6)	50.5 (24.5)	58.4 (23.6)	58.5 (7.7)
Quit work because of health	11 (28%)	107.7(70.6)	11 (26%)	55.5 (11.4)	67.1 (24.7)	53.9 (21.0)	44.9 (34.1)	59.3 (4.7)
Retired	17 (44%)	72.5 (58.1)	19 (45%)	59.2 (15.6)	46.1 (29.7)	51.4 (22.5)	53.4 (27.9)	69.6 (6.6)
Other/missing	3 (8%)	29.0 (33.9)	4 (10%)	58.8 (7.1)	38.0 (30.4)	59.4 (27.1)	53.7 (33.9)	62.8 (11.9)
		.226		.712	.119	.940	.578	<.0001*

*Highlights statistically significant values to $p < 0.05$

Table 17 (continued)		SFSDS		MUIS-C	GARS	KCCQPL	KCCQSL	AGE
	N (%)	Mean (SD) p value	N (%)	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value
Change in Work Status:								
Yes	10 (26%)	85.1 (75.0)	11 (26%)	59.5 (12.8)	63.5 (28.0)	50.0 (22.0)	41.7 (27.0)	63.5 (10.0)
No	29 (74%)	75.1 (55.2) .743	31 (74%)	58.0 (14.0) .860	46.0 (28.5) .137	53.6 (22.6) .634	55.9 (28.8) .157	64.4 (8.0) .898
Residence:								
Urban (Winnipeg)	19 (49%)	84.2 (45.2)	22 (52%)	60.1 (15.9)	49.0 (23.5)	48.6 (23.8)	49.6 (28.8)	62.6 (9.0)
Rural/Outside Winnipeg	20 (51%)	71.6 (72.0) .515	20 (48%)	56.6 (10.5) .404	52.4 (34.8) .707	57.1 (19.9) .219	55.0 (29.1) .550	65.8 (7.7) .231
Telephone Interview:								
Agreed to Participate	23 (59%)	68.4 (60.0)	26 (62%)	58.0 (15.1)	51.3 (28.8)	50.6 (22.5)	50.6 (29.0)	65.0 (8.3)
Did not Participate	16 (41%)	91.0 (59.4) .253	16 (38%)	59.1 (11.1) .791	49.4 (30.5) .843	56.0 (22.0) .444	54.8 (29.2) .648	62.7 (8.8) .389
CCS Angina Class:								
Class II	10 (26%)	54.9 (49.7)	11 (26%)	56.4 (12.4)	37.9 (30.6)	57.9 (27.8)	60.2 (31.7)	61.5 (5.2)
Class III or IV	29 (74%)	85.6 (62.0) .167	31 (74%)	59.1 (14.0) .567	55.1 (27.6) .093	50.8 (20.1) .370	49.3 (27.6) .286	65.1 (9.3) .133
Comorbidities:								
Absent	25 (64%)	65.4 (44.4)	27 (64%)	56.9 (11.1)	44.6 (28.9)	55.2 (20.0)	57.9 (26.6)	63.8 (7.9)
Present	14 (36%)	99.7 (78.0) .147	15 (36%)	61.2 (17.2) .388	61.3 (27.2) .074	48.1 (25.8) .324	42.0 (30.6) .086	64.8 (9.7) .713
Left Ventricular Function:								
Ejection Fraction >35%	31 (79%)	68.5 (44.6)	33 (79%)	58.1 (12.1)	47.7 (28.5)	53.4 (22.4)	54.3 (27.2)	63.4 (8.9)
Ejection Fraction <35%	8 (21%)	113.1(96.0) .238	9 (21%)	59.7 (18.7) .691	61.3 (30.5) .173	49.9 (22.7) .573	44.5 (34.6) .292	66.9 (6.4) .260

Table 17 (continued)		SFSDS		MUIS-C	GARS	KCCQPL	KCCQSL	AGE
	N (%)	Mean (SD) p value	N (%)	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value	Mean (SD) p value
Number of Occluded Vessels:								
One or Two	8 (21%)	67.1 (34.1)	9 (21%)	63.3 (17.2)	53.2 (36.0)	50.7 (27.8)	55.1 (28.8)	62.0 (9.5)
Three or More	31 (79%)	80.4 (65.2) .438	33 (79%)	57.1 (12.4) .223	49.9 (27.5) .764	53.2 (20.9) .775	51.4 (29.2) .737	64.7 (8.2) .399
History of MI:								
None or One	16 (41%)	76.1 (64.6)	18 (43%)	62.1 (15.3)	52.2 (28.9)	45.1 (21.6)	45.9 (29.2)	64.4 (8.2)
Two or Three	23 (59%)	78.8 (58.1) .890	24 (57%)	55.6 (11.6) .126	49.4 (29.8) .758	58.3 (21.3) .056	57.0 (28.1) .220	63.9 (8.8) .845
Left Main Coronary Disease:								
Greater than 50% Occlusion	5 (13%)	68.2 (34.8)	5 (12%)	55.2 (6.5)	47.6 (26.3)	58.6 (19.2)	52.5 (20.1)	64.4 (8.8)
Less than 50% Occlusion	34 (87%)	79.1 (63.1) .710	37 (88%)	58.8 (14.2) .579	51.0 (29.8) .809	51.8 (22.7) .530	52.2 (30.0) .979	62.4 (6.5) .630

RESEARCH QUESTION #4: Controlling for surgical priority (MRWT in days) and illness severity (baseline CCS angina class, comorbidities, LVEF, number of diseased vessels), are there any patient characteristics (age, gender, education, work status, living situation, area of residence) that are associated with a shorter total waiting time for CABG surgery?

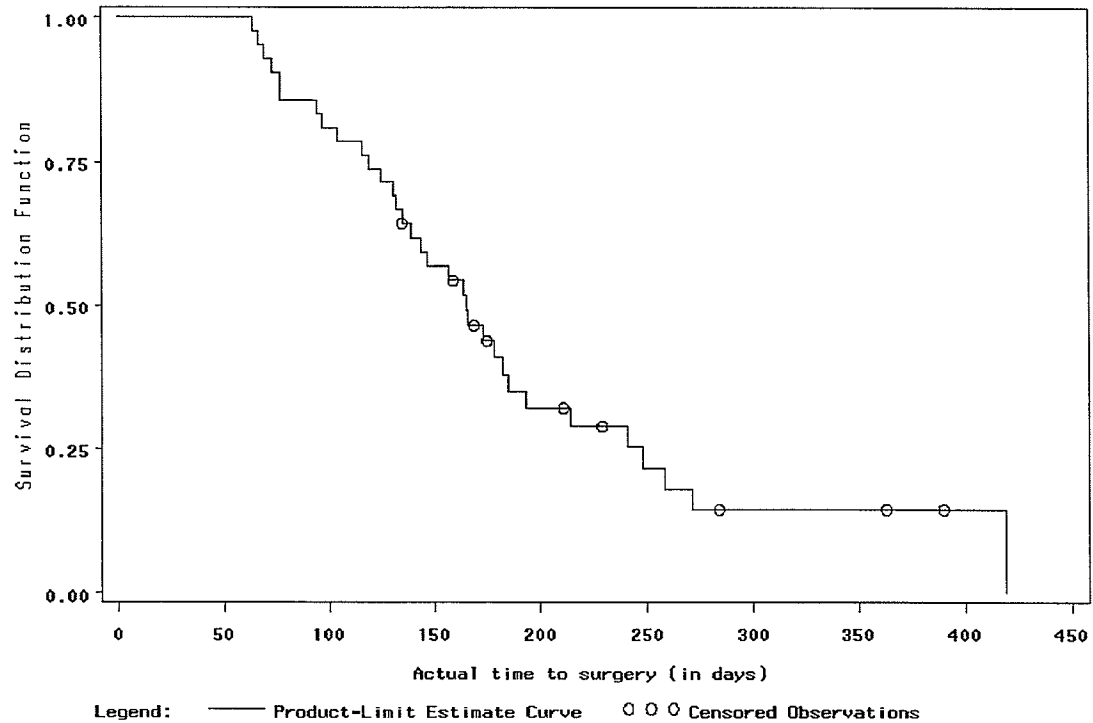
In analyzing the data with respect to total waiting time, (time placed on waiting list up to date of surgery), survival distribution curves were drawn for the patient characteristics, (non illness related), which had the potential to influence total waiting time. Figure 3 depicts the survival distribution curve for the total sample and censors out the 9 individuals who did not have surgery as their waiting endpoint. The vertical axis represents the survival distribution factor, or percentage of surgeries completed, while the horizontal axis depicts time measured in days. Figure 3 shows that approximately 50% of the participants in this sample had their surgery by 150 days of waiting.

Figures 4 through 9 represent the survival distribution curves for the participants by age, gender, education, work status, living situation, and area of residence. A Cox proportional hazard regression analysis performed on these categories found no significant differences in time to surgery based on gender, education level, work status, living situation or area of residence.

When examining the influence of age on total waiting time (Figure 4), a significant difference was found ($p = 0.02$) between age categories. Individuals who were less than 60 years of age had their surgery 2.8 times faster than participants aged 60 to 69, and participants aged 70 and older were operated on 2.1 times more quickly

than the same middle age range group. Participants were more likely to have a shorter total wait for surgery if they were less than 60 years of age or older than 69 years of age. This age discrepancy in time to surgery remained even when surgical priority (MRWT) and illness severity were taken into consideration.

Figure 3. Survival distribution curve for CABG surgery waiting endpoint N = 42.



* Censored Observations indicate patients who went off list or who were still waiting at conclusion of study.

Figure 4. Survival distribution curve for CABG surgery waiting endpoint by age.

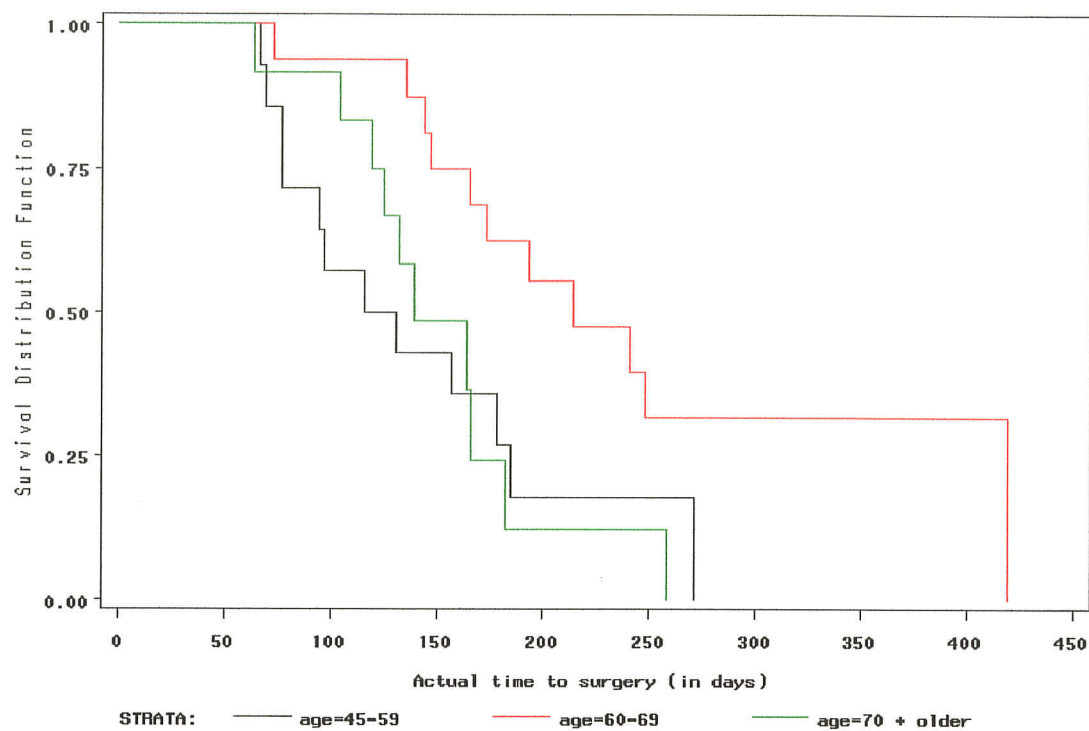


Figure 5. Survival distribution curve for CABG surgery waiting endpoint by gender.

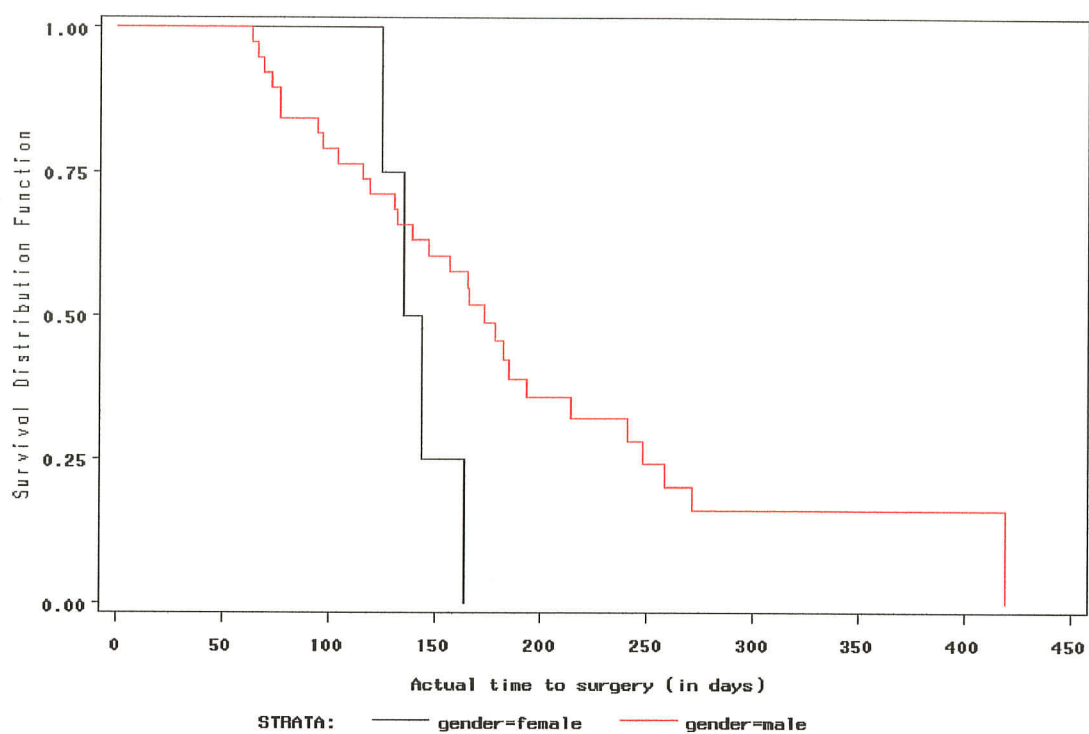


Figure 6. Survival distribution curve for CABG surgery waiting endpoint by education.

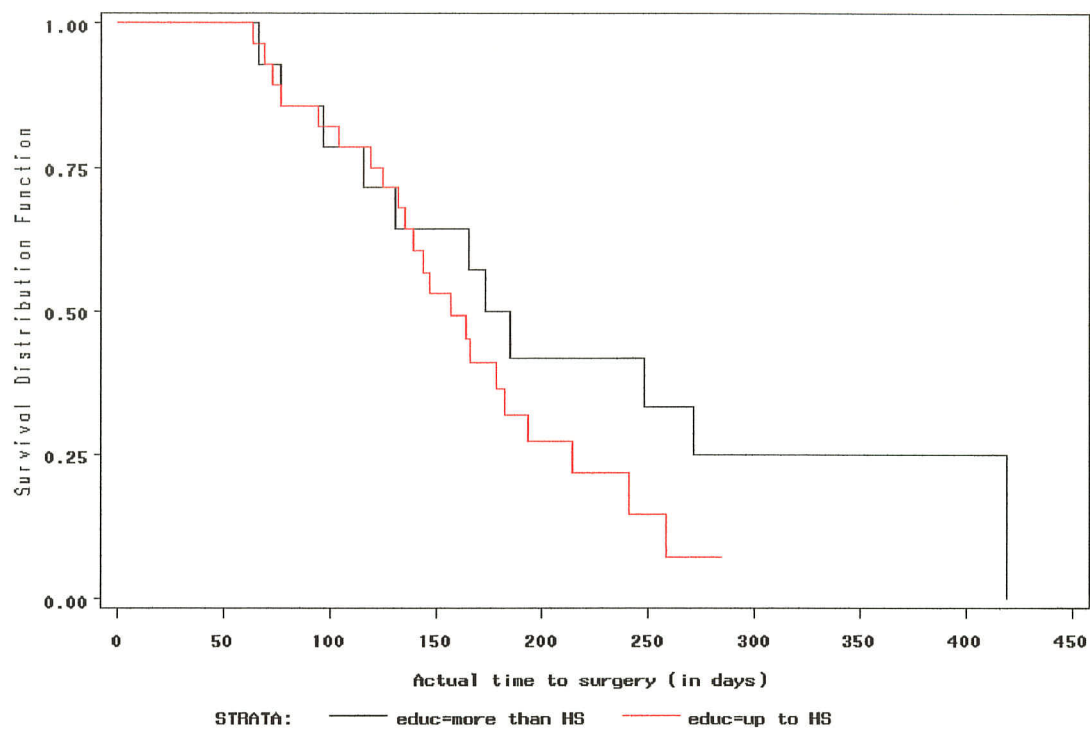


Figure 7. Survival distribution curve for CABG surgery waiting endpoint by work status.

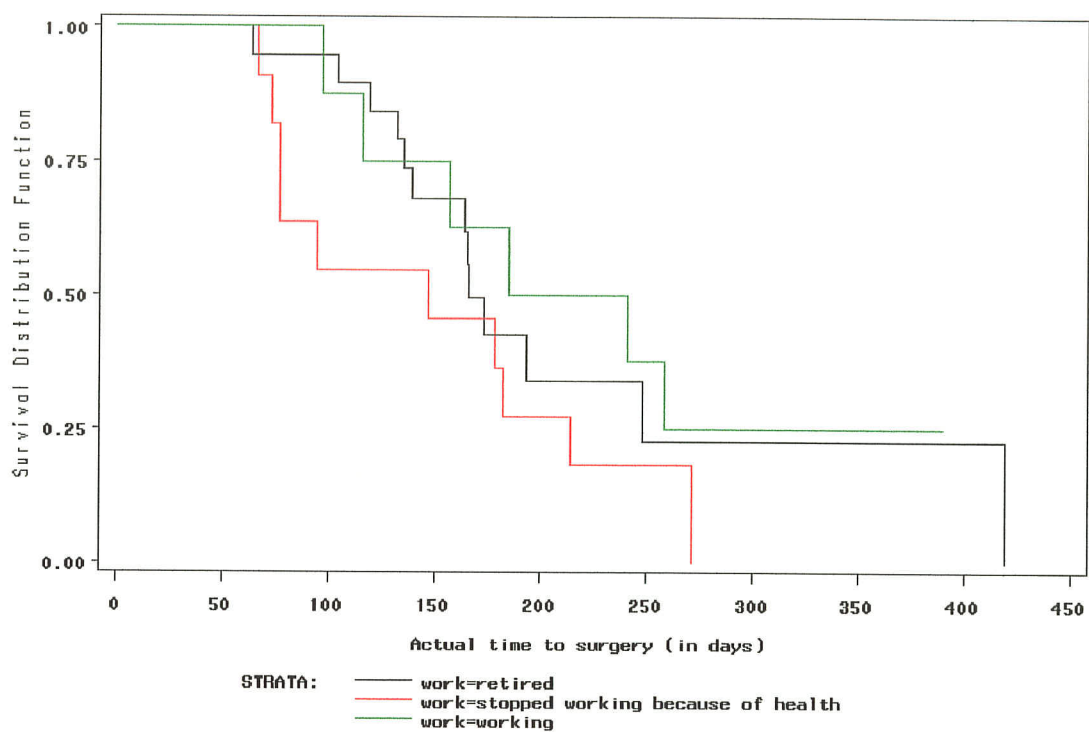


Figure 8. Survival distribution curve for CABG surgery waiting endpoint by living situation.

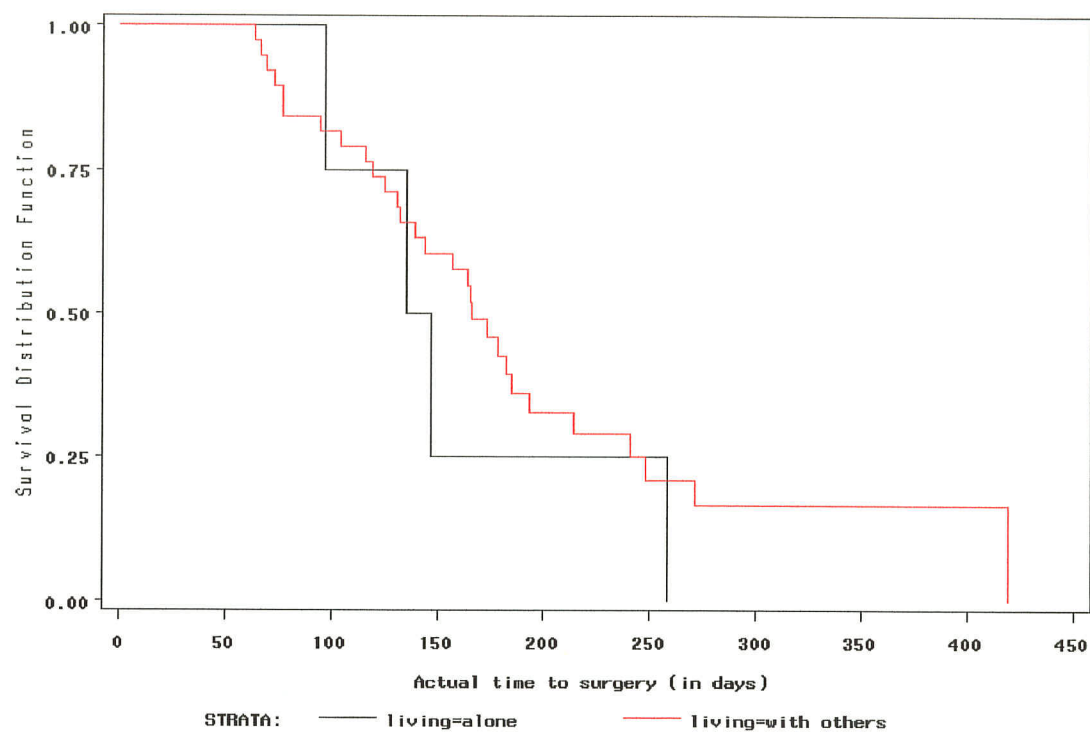
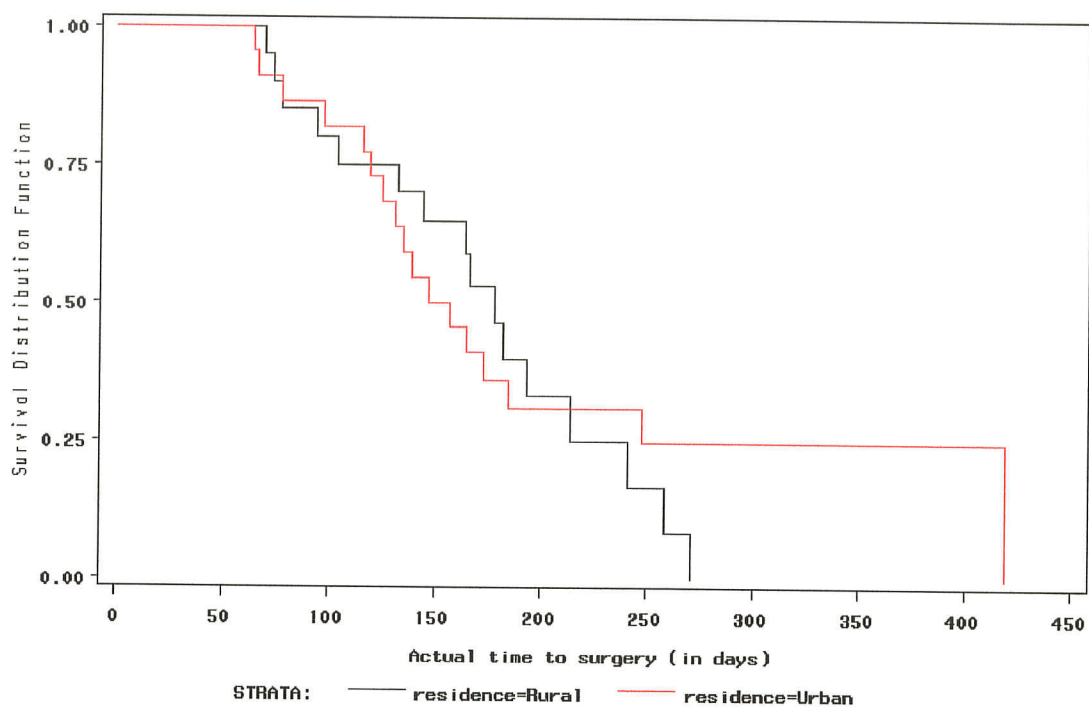


Figure 9. Survival distribution curve for CABG surgery waiting endpoint by area of residence.



Additional Analysis: The Symptom Frequency and Symptom Distress Scale

The Symptom Frequency and Symptom Distress Scale used for this project was adapted from the scale of the same name developed by Lough, Lindsey, Shinn, and Stotts (1987) to measure symptom frequency and distress related to immunosuppressive drug therapy in heart transplant recipients. Although the format of the present SFSDS is identical to the Lough et al. scale, virtually all the symptoms have been altered to reflect the experience of patients with coronary artery disease or congestive heart failure. In addition, a decision was made to assess an alternate scoring method for this scale. Therefore further examination of the results of this scale is necessary to assess its reliability as a measurement tool.

Lough et al.'s (1987) examination of symptom frequency and symptom distress did not produce a total scale score for the SFSDS but instead examined each symptom individually for most frequent symptoms and most distressing symptoms and then compared two groups of heart transplant recipients, (those on Azathioprine immunosuppressive therapy versus those on Cyclosporine), for significant differences in symptom frequency and distress. For the coronary artery disease version of the SFSDS, multiplying the symptom frequency score with the symptom distress score for each symptom, and then adding the total obtained a total scale score. Using this method scores could range from 0 to 368. Figure 10 shows a histogram of the total scale scores for this sample with a score distribution that is heavily skewed to the left or lower one third of the possible total scale scores. As noted earlier, because the scores do not distribute normally over the range of the scale, it is difficult to assess what sub-ranges would constitute mild, moderate, or severe symptom distress. The

scores of the scale do distribute relatively normally over the lower one third of the scale's total range.

Individual symptoms can also be used as individual subscales of the SFSDS, and multiplying the symptom frequency score with the symptom distress score can attain a combined symptom distress score for a specific symptom. Tables 11, 14, and 16 show how individual symptom distress scores were used in this analysis. Table 18 presents an item to total correlation as a test of reliability for this version of the SFSDS. All symptoms had very significant item to total correlations with the majority having p-values of .0001 or less with the exception of feeling fearful and panic spells which correlated at $p = .002$. In addition, Table 14 also looks at the correlation of the GARS to the individual symptoms. The psychosomatic symptoms of depressed mood, nervousness/shakiness, feeling fearful, feeling tense, panic spells, and restlessness are likely psychological and physical manifestations of anxiety and all six of these symptoms correlated significantly with the GARS.

Ranking of the most to least frequent symptoms, the most to least distressing symptoms and the most to least combined symptom distress scores for each symptom was also possible. This analysis is represented in Table 19 and includes the rank score for each symptom in each category. Three comparable lists of symptom rankings are exhibited here. This table illustrates that the most frequent symptoms were also the most distressing symptoms in this sample. The relationship between individual-symptom frequency and individual-symptom distress is further clarified in Figure 11 where individual-symptom frequency for the total sample, (on the vertical axis), is plotted against individual-symptom distress for the total sample, (on the

horizontal axis). This figure shows a very linear relationship between the frequency and distress of a particular symptom further confirming that the most frequent symptoms are also the most distressing.

Although most symptoms that were present had some associated distress, it was possible to have a symptom occur frequently but to be scored as “never” distressing. This possibility numerically translated into a combined symptom distress score of zero even though the symptom was present. The reverse was also possible where some participants noted that they “never” experienced a symptom but had marked a distress score for that symptom of more than zero because, maybe, the thought of potentially having that symptom was distressing. However, numerically the combined symptom distress score would also be zero. Having a symptom that had zero frequency, but some level of distress also occurred in this sample. There was an initial concern that such “zero” scores would alter the overall symptom distress score for a participant, however, the similar rank orders for frequency of individual symptoms, distress of individual symptoms, and overall symptom distress of individual symptoms is an indication that these “zeros” had little influence on relative importance of a particular symptom.

Distribution of Symptom Frequency and Symptom Distress Scale Scores

Figure 10. Histogram of the symptom frequency and symptom distress scale total scores.

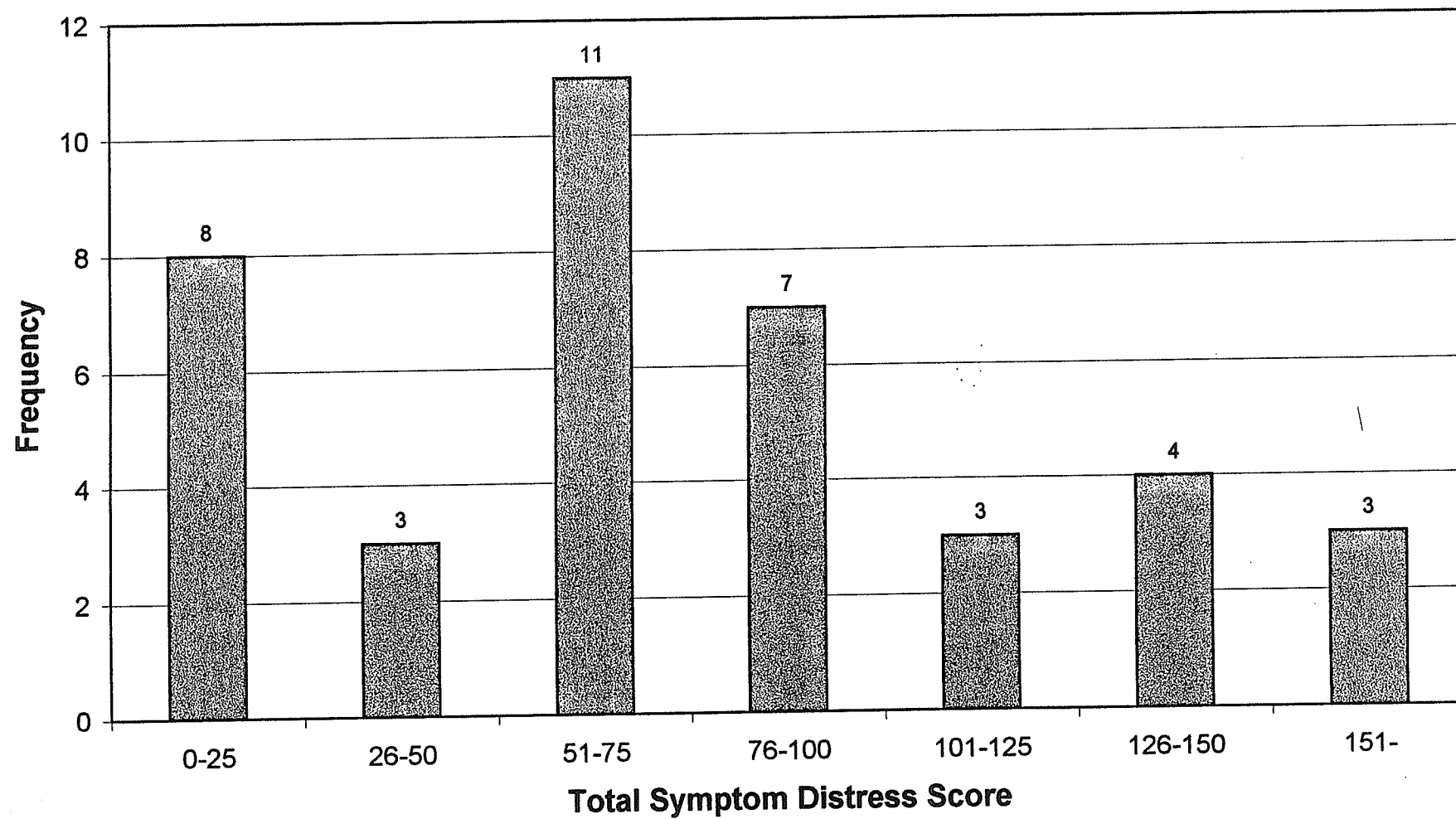


Table 18

Pearson r Item to Total Correlations for the SFSDS

Symptoms	SFSDS Total Score Correlation
Chest discomfort	0.69110**
Arm/shoulder pain	0.68282**
Back/neck pain	0.68079**
Jaw/throat/tooth pain	0.67683**
Indigestion	0.68451**
Generalized discomfort	0.75733**
SOB with activity	0.69125**
SOB lying flat	0.75473**
Nocturnal SOB	0.63567**
Dizziness/Lightheadedness	0.59707**
Palpitations	0.60547**
Irregular heart rate	0.75265**
Fatigue	0.67897**
Edema	0.57174**
Difficulty Sleeping	0.63939**
Nausea	0.57704**
Loss of Appetite	0.71471**
Depressed Mood	0.73213**
Nervousness/Shakiness	0.82061**
Feeling Fearful	0.47338*
Feeling Tense	0.70339**
Panic Spells	0.47513*
Restlessness	0.78214**

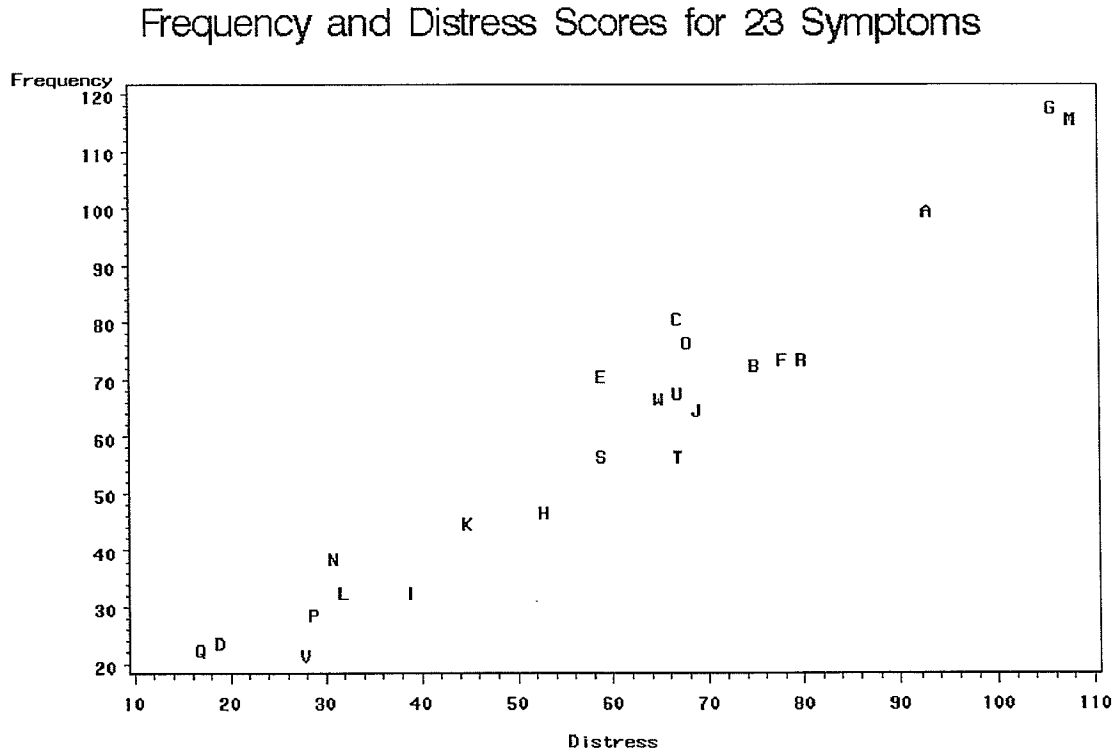
* p = .002, ** p = <.0001

Table 19

Ranking of Most to Least: Frequent Symptoms, Distressing Symptoms and Combined Symptom Distress of Individual SFSDS Symptoms

	Frequency (rank score)		Distress (rank score)		Combined Symptom Distress (rank score)
1	SOB with activity (118)	1	Fatigue (108)	1	Fatigue (350)
2	Fatigue (116)	2	SOB with activity (106)	2	SOB with activity (345)
3	Chest pain (100)	3	Chest pain (93)	3	Chest pain (249)
4	Back/Neck discomfort (81)	4	Depressed Mood (80)	4	Depressed Mood (205)
5	Sleeping problems (77)	5	Generalized discomfort (78)	5	Sleeping Problems (191)
6	Generalized discomfort (74)	6	Arm/Shoulder discomfort (75)	6	Generalized Discomfort (175)
6	Depressed Mood (74)	7	Dizziness/Lightheadedness (69)	7	Back/Neck discomfort (171)
8	Arm/Shoulder discomfort (73)	8	Sleeping problems (68)	8	Arm/Shoulder Discomfort (168)
9	Indigestion (71)	9	Back/Neck discomfort (67)	9	Indigestion (167)
10	Feeling tense (68)	9	Feeling fearful (67)	10	Dizziness/Lightheadedness (165)
11	Restlessness (67)	9	Feeling tense (67)	11	Feeling Tense (155)
12	Dizziness/Lightheadedness (65)	12	Restlessness (65)	12	Nervousness/Shakiness (150)
13	Nervousness/Shakiness (57)	13	Indigestion (59)	13	Restlessness (148)
13	Feeling fearful (57)	13	Nervousness/Shakiness (59)	13	Feeling fearful (148)
15	SOB lying flat (47)	15	SOB lying flat (53)	15	SOB lying flat (116)
16	Palpitations (45)	16	Palpitations (45)	16	Palpitations (95)
17	Edema (39)	17	Nocturnal SOB (39)	17	Edema (86)
18	Irregular heart rate (33)	18	Irregular Heart Rate (32)	18	Irregular Heart rate (82)
18	Nocturnal SOB (33)	19	Edema (31)	19	Nocturnal SOB (80)
20	Nausea (29)	20	Nausea (29)	20	Nausea (52)
21	Jaw/Throat/Tooth discomfort (24)	21	Panic spells (28)	21	Panic spells (49)
22	Loss of Appetite (23)	22	Jaw/Throat/Tooth discomfort (19)	22	Loss of Appetite (42)
23	Panic spells (22)	23	Loss of Appetite (17)	23	Jaw/Throat/Tooth discomfort (33)

Figure 11. Plot of individual symptom frequency and individual symptom distress for total sample.



Legend

A	Chest Pain	L	Irregular Heart Rate
B	Arm/Shoulder Discomfort	M	Fatigue
C	Back/Neck Discomfort	N	Edema
D	Jaw/Throat/Tooth Pain	O	Sleeping Problems
E	Indigestion	P	Nausea
F	Generalized Discomfort	Q	Loss of Appetite
G	Shortness of Breath (SOB) with Activity	R	Depressed Mood
H	Shortness of Breath Lying Flat	S	Nervousness/Shakiness
I	Nocturnal SOB	T	Feeling Fearful
J	Dizziness/Lightheadedness	U	Feeling Tense
K	Palpitations	V	Panic Spells
		W	Restlessness

Qualitative Analysis of Telephone Interview Data

Of the 45 returned questionnaires, 28 participants consented to participate in the telephone interview (62.2%). Three participants who consented to the interview could not be included in the qualitative analysis: two participants were waiting for procedures other than first time CABG and had been accidentally included in the initial sample, and the third participant who consented for the telephone interview had gone in for surgery in the time between returning the questionnaire and the attempt at telephone contact.

Therefore, out of the 42 eligible study participants, a total of 25 telephone interviews (59.5%) were included in the qualitative analysis. The 25 interviews analyzed represent the waiting experiences of 21 male (84%) and 4 female (16%) participants. In addition, it is interesting to note that 100% of the female participants in this study agreed to participate in, and completed, the telephone interview. An analysis of the difference between participants who consented to participate in the telephone interview and those who did not, found no significant differences between these groups in levels of uncertainty, symptom distress, anxiety, functional status or patient age (see Table 17). The length of time spent for each telephone interview ranged from approximately 8 minutes to 55 minutes and had a mean approximate interview time of 16.24 minutes.

The questions asked in the telephone interview were based on three research questions that were identified from the literature and based on the theoretical framework (see Chapters 1 and 2). The research questions guiding the interview were as follows:

1. What are patients doing to manage their coronary symptoms while they wait for CABG surgery?
2. How do patients envision that their life will change following CABG surgery?
3. What do patients identify as the causes of their anxiety while they wait for CABG surgery?

The above research questions then translated into the following open-ended interview questions:

1. Some patients who wait for heart surgery need to manage symptoms such as chest pain/pressure, shortness of breath or fatigue. Are you doing anything specific to manage your heart related symptoms while you have been waiting for surgery? What have you been doing? If you have not been having symptoms why do you think that is?
2. Why do you think that having bypass surgery will be a beneficial or a worthwhile undertaking? And, What do you expect will be different for you as a result of having the surgery?
3. Some people who are waiting for heart surgery have indicated that they feel anxious. Do you feel that way? What would you say has caused you the most anxiety during the waiting period for surgery? What things help you to not be anxious?

Content analysis was used to evaluate the qualitative data. Coding of the interview data was completed manually by writing key words and phrases in the margins of the interview transcripts and underlining corresponding text. Multiple readings of the transcripts were done to ensure a thorough review of the data. The

text of the interviews was analyzed for recurrent categories for each interview question as well as for general themes that emerged from the total interview. The categories and general themes were then reorganized into a more meaningful framework of conceptual categories, which are presented in Table 21 and discussed below.

Three conceptual categories emerged from the data: taking responsibility, getting my life back, and getting it over with. Each of these conceptual categories had specific strategies associated with it as well as factors that existed to facilitate or constrain the use of the strategies. In addition, there were also consequences to taking specific actions associated with the conceptual category.

Table 20

Conceptual Categories Arising from Qualitative Data Analysis

Conceptual Category	Strategies Associated with Conceptual Category	Factors that exist to facilitate or constrain the use of these strategies	Consequences of taking actions
Taking Responsibility	<ol style="list-style-type: none"> Using medications Changes in activity pattern Changes in work status Risk factor management Embracing alternative therapies 	<ul style="list-style-type: none"> * Physician recommended * Self initiated 	<ul style="list-style-type: none"> * Limiting cardiac symptoms * Increased awareness of their bodies
Getting My Life Back	<ol style="list-style-type: none"> Envisioning physical improvements: <ul style="list-style-type: none"> * Increasing activity tolerance/ return to prior activities * Returning to work * Relieving symptoms/ return to health * Prevention of death/MI Envisioning psychosocial improvements: <ul style="list-style-type: none"> * Enjoyment of life - forgetting about problems - freedom from worry - feeling safe - not having to take medications 	<ul style="list-style-type: none"> * Information received from physician * Fear 	<ul style="list-style-type: none"> * A sense of normalcy or control over their situation

TABLE 20 (continued): Conceptual Categories Arising from Qualitative Data Analysis

Conceptual Category	Strategies Associated with Conceptual Category	Factors that exist to facilitate or constrain the use of these strategies	Consequences of taking actions
Getting it over with	1. Cognitive strategies: * avoidance (trying not to think about it) * realization and acceptance of the need for surgery * faith in God * trust in doctors * comparisons with others 2. Behavioral Strategies: * keeping busy 3. Affective Strategies: * Participating in research	* Support of family (positive and negative) * Word of mouth stories of the experiences of others (both positive and negative) * Presence of symptoms * Systemic factors within the medical system that cause increased waiting times * Uncertainty of the impact of the waiting period on possible disease progression * Fear of dying	* Peace of Mind * Protecting family members

Conceptual Category: Taking Responsibility

The category of “taking responsibility” relates to actions that the participants took to take care of themselves while they waited for their surgery, specifically in the management of coronary symptoms. Five strategies associated with “taking responsibility” were identified from patient responses: using medications, changes in activity pattern, changes in work status, risk factor management and embracing alternative therapies.

With the strategy of “using medications”, patients described taking daily oral medications, wearing a nitroglycerine patch, as well as using nitroglycerine pills or spray as necessary to relieve chest pain. For most participants the use of medications was a successful way to manage their heart related symptoms. As one participant noted:

Since I have started wearing the patch and taking the heart pills, I have noticed that I haven't been having as much pains.

Taking medications is a standard way of controlling the symptoms of coronary artery disease. By discussing their need to take medications, the participants of this study recognized the importance of these medications in limiting cardiac symptoms and maintaining comfort while waiting for surgery.

The second strategy, “changes in activity pattern,” was implemented as a recommendation from his/her physician, a purposeful self-limitation to prevent symptoms, or as a way of slowing down to stay below the pain threshold. A common statement from participants was: “I just don't do much that is all.” Other comments

participants made illustrating this strategy included, "take it easy", "slow down", "do what I feel is most comfortable", and "pace myself."

"Change in work status," was also discussed as a way to avoid symptoms.

Similar to change in activity pattern, changing the nature of their work involved the need to slow down to avoid symptoms. Several participants mentioned quitting work, either on the advice of their physician or as a self imposed change. Other participants changed the nature of their job to something that was less strenuous, such as one participant who converted his active job into more of a desk job.

"Risk factor management" was the fourth strategy of active efforts participants made to manage their symptoms. The risk factors that participants mentioned consciously modifying during their wait were: reducing or avoiding stress, continuing, where possible, to maintain a light walking program, quitting smoking, and changing their diets, in particular, to reduce cholesterol.

Two participants actively mentioned the use of "alternative therapies" as a way of managing their heart related symptoms. Both participants used a herbal remedy known as Strauss' herbal drops which claim to help improve circulation and open blood vessels. One of the two participants using the herbs claimed a resounding success to the extent that he had made a decision to delay his surgery.

Last summer I couldn't do anything without getting chest pain. I haven't had to use nitro since September when I started using the drops. I can walk two to three kilometers and use an exercise bike. I have been able to shovel snow and carry in wood. I was told not to vacuum, mow the lawn, carry loads but I have been doing a lot of this stuff.

The second participant did not have the same success:

It has given me better blood circulation. I had problems with cold feet at night and now I have no tingles in the legs. But I have been needing more nitro more often and I know I am getting worse. I have had two stress tests since starting [the drops] and they have not made a bit of difference to the results.

A third patient mentioned that he looked into other therapies such as these herbal drops and Chelation therapy, but made a conscious decision not to pursue this avenue because of lack of medical support:

I have decided not to follow any of that and my doctors, of course, are against it anyway because they say that it doesn't reverse the disease.

For these participants, alternative medicines, proved to be an adjunct therapy to attempt to relieve symptoms during the wait for surgery. The different responses of the individual participants to the success of these therapies emphasizes the need to use caution and inform a physician when choosing to use herbal remedies or other alternative therapies.

As factors that existed to facilitate or constrain the use of strategies of "taking responsibility," it is clear from the above discussion that many took the medications and the actions that they did, or avoided specific actions on the advice of physicians. As well many of the choices that participants made to change their work status, modify risk factors, take a specific herbal remedy, or change their activity pattern were self initiated actions.

Consequences of the actions participants took to avoid their cardiac symptoms were also clear from the interview data. Many patients during the course of their interview commented on the success or lack of success of the methods they were using to help limit their cardiac symptoms. "I feel I have been successful in slowing

attacks.” The quotations above from the two participants using the herbal remedies are more specific examples of these observations.

Participants also reported a self-awareness of their bodies when asked about controlling their cardiac symptoms, and were clear about what activities or situations caused them to develop symptoms and what they needed to do to make their symptoms go away. As one participant noted:

When I get carried away I end up having to sit down and take big breaths to get away from the tightness.

For other participants, bodily awareness was a heightened sensation:

Since this diagnosis [I] have become more aware of my own feelings. I start to notice things that might be indigestion – “Is this indigestion, or is this an event?” – [I have] heightened awareness now of what this is.

These statements reinforce that patients waiting for heart surgery are becoming more in touch, with their bodies, the nature of their pain and other symptoms, and what activities are successful in preventing and limiting these symptoms.

Conceptual Category: Getting My Life Back

The conceptual category of “getting my life back” represents the expressed desire by many participants to get back to normal. Participants commonly responded, “I just want to be back to normal,” or, “give me my life back again.” Waiting to get their life back, involved the strategy of envisioning how they hoped life would be in the future after they had recovered from surgery. Within this conceptual category, participants used the strategy of envisioning improvements that were either physical and psychological. Physically, participants hoped to increase their activity tolerance

and return to prior activities, return to work, relieve symptoms and return to health, and prevent death/MI. Psychologically enjoyment of life was a primary goal.

As a part of envisioning physical improvements, "increasing activity tolerance" included returning to leisure activities, increasing the strenuousness of what they were able to do, making activities of daily living easier, improving sexual activity, exercising, working on hobbies, and taking vacations. As one participant responded:

I want to be able to do all the things I am not doing now. I feel that I could do them but I am limiting myself.

Another participant was more specific on how activity limitations had changed his life:

My lifestyle is doing things, it is being active and able to move as opposed to sitting on the internet and reading.

Interestingly there were a few participants who commented that, although they expected life to go back to normal, they did not expect to be able to do anything new. For example: "I don't expect to be doing things that at my age would be out of place," and, "I don't think too much will change. I don't do active sports."

"Return to work", included both work outside the home, and work inside, (housework or homemaking), and around the home, (yard work and home maintenance). Many participants continued to do as many of these duties as possible while they waited but were often limited in their speed and efficiency due to symptoms. One female participant noted that when she cleaned her house she did it, "one room at a time." A male participant described that his "biggest job" was going downstairs to throw a couple of logs on the furnace.

A third identifiable envisioning strategy was “relief of symptoms”. “Relief of symptoms” encompassed a general wish to “feel better” or “return to health” as well as the more specific desire to decrease pain. Relieving symptoms was a primary reason why patients chose to consent to surgery and was described as an important way that these waiting participants could feel they had their life back.

“Prevention of death or myocardial infarction (MI)” was also a common benefit that participants discussed during their interviews. As the participants stated:

I'm hoping it will do me better and I can do work and survive longer.

Not get an attack in something I am doing maybe.

I want to prevent damage to the heart muscle.

It's the right thing to do. I don't want to have another heart attack.

“Prevention of death or MI” introduces a fear factor into the experience of waiting as well as acts as an indication of the participants’ confidence in the CABG procedure itself. Participants who made these statements believe that having surgery will reduce the potential for adverse events.

Psychologically, enjoyment of life was the primary goal in getting their life back to normal. Enjoyment of life included: forgetting about problems, peace of mind, freedom from worry, having a “new lease on life”, and the general desire for life enjoyment. As the participants noted: “it’s just the idea of feeling safer,” and, “I need to have surgery to free me from worrying.”

As part of envisioning the future, not having to take medications was another strategy that would help achieve the goal of enjoying life. As one male participant described:

It plays havoc on me that I have to take all these pills and I don't like it. I will do anything to get off these pills.

Taking medications was yet another burden these participants faced that kept them from "getting back to normal." Having surgery, as these patients believed, was a way to ease their mind and lift the weight of their health problems off their shoulders so that they could "enjoy life" once again.

One factor that facilitated the envisioning process was that participants believed that they could "get their life back" because their surgeon, cardiologist or other physician had told them that CABG surgery would be beneficial. As one participant stated:

I was told [by a doctor] that I may have a stroke or die if I continued without having surgery.

A female participant's said:

The [surgeon] told me I am 78 years old and it is worth it.

The information received from physicians about the potential success of CABG surgery in assisting these participants to "get their life back" was a powerful facilitator of the envisioning process. Their physician's word gave these participants permission to envision the future benefits afforded by having surgery.

Simultaneously, as is evident in the above discussion, physicians also had the power to constrain the envisioning process by opening the patient up to fear of death or other adverse consequences if they did not have this operation.

As a consequence of envisioning strategies of "getting my life back," participants were able to gain a sense of normalcy and control over the future. As one participant stated: "I try to carry on with how life was before I knew I had to have

surgery.” Feeling “normal” gave the participants the power to have some relief over their waiting anxiety. Avoidance of anxiety is also key in the third conceptual category of “Getting it over with.”

Conceptual Category: Getting It Over With

For the majority of participants there was an overwhelming sense that having surgery would create a great sense of relief. As one participant stated:

I would like to get it done and over with. I would like to get my life back to the way it was rather than sitting around and doing nothing.

In the conceptual category of “getting it over with” strategies which helped the participants work through the need to “get their surgery over and done with”, or in other words, relieve their anxiety, fall within the cognitive, behavioral and affective domains. Cognitive strategies included: trying not to think about the surgery, realization and acceptance of the need for surgery, faith in God, looking forward to the future, trusting their physicians, and comparing themselves with others. Behaviorally participants tried to keep busy and affectively they participated in research which allowed them a release of the emotions they were experiencing while waiting.

When the participants were asked about the things that helped them to feel less anxious many simply stated: “I try not to think about it”. Psychological avoidance of the inevitable shows a “realization and acceptance of the need for surgery”. As one participant stated:

I have a realization that it needs to be done. I am not in physical distress. If I was getting chest pain and couldn't do anything then I would be more anxious. . . . What my subconscious is doing with all

this I don't know. I don't dream or have nightmares or anything like that.

In a similar fashion many patients used their "faith in God" as a strategy to relieve the anxiety associated with wanting to get their surgery over with. Others put their faith and "trust in the doctors" that would be involved in the surgery:

The [surgeon] I have been talking to has made me feel so confident about things.

The big turning point for me was the pre-op when I found I was dealing with professionals.

Other strategies associated with relief of anxiety included "making comparisons with other waiting candidates" as an altruistic way of rationalizing a long wait over which they had little or no control. In the participants words:

I am an impatient person and I like to get things done. But then I realize that there are cases much more serious than mine.

So many people have waited so long. I have only waited four months so I don't feel that is that long yet.

While the above cognitive strategies provided significant relief of anxiety, behavioral strategies were also employed. A key behavioral strategy associated with relieving the anxiety was keeping busy:

I try to keep busy with something you are still capable of doing. You are limited physically but you can still keep busy with your mind.

By keeping busy, participants were able to distract themselves from thoughts of the surgery itself and from thinking about the long uncertain wait.

Participating in this research project proved to be an affective strategy for relieving the anxiety of some participants:

Doing your survey reinforced that I wasn't as bad as I thought because I don't have all the symptoms that you listed. That made me feel better.

Not only did they have the opportunity to share their thoughts and feelings about waiting for surgery but for this participant it was reassurance that he wasn't as sick as he thought he was.

The factors that facilitated and constrained the relief of anxiety were primarily outside influences or people in the participant's lives who supported them during their wait. Family and friends played a large role in the participants' psychological well-being while waiting for surgery in both a positive and negative fashion. While some participants saw family as easing the waiting process, ("My wife is the best part of it all and has made things 100% easier"), others described their awareness of their family's own anxieties and, at times, family anxiety influenced the participant's anxiety.

I feel anxious when I see my family members are uptight about the situation. Get more phone calls of concern and it kind of reverts back to me

My family and wife are more worried about it than I am.

While family support and impressions about the waiting period were important factors in influencing these participants' anxiety levels, there were consequences to the inevitable involvement of family. Often the participant made a conscious effort to hide their anxiety from their family members or protect their family members from parts of their experience that the participant knew would increase the family member's anxiety:

My strongest asset is self-discipline. Just between you and me, I don't like to show [how anxious and distressed] I am to my family and friends.

I try to be quiet when I get my [nitro] pills [in the middle of the night] but sometimes I disturb my wife and worry her. Once she heard me and got up and got dressed saying, "I know what comes next."

The anxiety and worry of family members was a primary concern to many of the interview participants. They spoke of how family and friends were always asking about them and their situation. These examples clearly illustrate how the concern of family members is an important component of the waiting experience.

Word of mouth stories that the participants had heard during their waiting period about others who had also had the surgery also acted as both a facilitating and a constraining factor in the experience of waiting anxiety. Many of the facilitating stories related positive experiences of surgical success and provided hope and relief to the waiting patient:

Knowing people who have gone through it they seem to forget about their problems.

My brother seemed to get along better after it.

There are fears – "I will survive" – then you hear all the positives of people who have had it.

By all reports I should be as good as new – anyone who has had it says that.

Although many participants took comfort from the success stories of others not all stories were ones of success and these stories were more constraining on participants' ability to relieve their anxiety:

The longer you wait you get more nervous. Then you start hearing stories – lots of success but some not.

I know people who have had it and feel good after and I know people who have blocked up very quickly afterward.

One male participant found that the stories he heard, though well intentioned, were something that forced him to think about his situation and the upcoming operation when he would have rather been thinking of something else:

I try to keep this quiet [telling others that I am having this operation], because I don't know how long I will be waiting. I hear stories – my mother, cousin, my nephew, will be getting it. I would rather be talking about something on TV or sports.

With the increasing occurrence of CABG surgery, waiting participants are more and more likely to have friends, relatives, and acquaintances who have also had the surgery. Their stories become featured in the waiting candidate's experience and influence the anxiety level of the patient both in a positive and negative fashion.

Other constraining factors on the participants wish to "get their surgery over with" and relieve their waiting turmoil include the things that the participants identified as their chief sources of waiting anxiety: presence of cardiac symptoms, the experience of waiting itself including the systemic factors within the medical system which increase waiting times, the impact of waiting on possible disease progression, and the fear of dying.

The discussion of symptoms as a chief source of anxiety for the waiting CABG candidate is not a surprising one given that symptom management is the primary reason that patients are offered CABG surgery. As the participants stated:

When I am awake I can deal with the attacks. As long as I am awake I have a fighting chance.

If I forgot my nitro I would become quite scared I think. When the pain goes away it helps relieve anxiety.

As long as I sit around and don't have any chest pain that part relaxes me. I know everything is OK as long as I don't exert myself.

It is one of the best feelings when the pain goes away.

For the participants who mentioned their "symptoms" as the chief source of waiting period anxiety, the presence of "symptoms" brought on the anxiety and the absence of "symptoms" was equivalent to being anxiety free. Participants recognize the seriousness of their symptoms and therefore symptoms become an important factor influencing waiting period anxiety.

The wait itself was also a frequently mentioned cause of these participants' anxiety because of the frustration present in having little control over the health care system factors which often work to increase waiting times rather than decrease them. Several participants commented on these systemic influences:

I was told one to three months and it is already past my three months. I don't blame anybody about it. Our system is just not able to cope with it all.

I wish they shortened the waiting. Shortage of nursing I can't do nothing about but the government can.

It is really bad now because you don't know what is going on. . . . I have had the whole situation explained to me and you don't know who to be mad at – the minister of health? I don't know -- there is nothing that you can really do. . . I am quite sure there are a lot of frustrated people.

While participants know how to prevent and control their symptoms and they know what helped them distract themselves from the stress of waiting, one piece of information would remain elusive: the date of surgery. As one participant stated:

"[It's] just the waiting and not knowing what or when it is going to happen."

Frustration with the system is part of what made participants feel powerless to overcome those issues over which they had no control.

Another frustrating issue related to the wait that was discussed by participants was the potential risk of disease progression that might occur while waiting. As one participant said:

Not doing anything, just sitting in the house and wondering when they are going to call. I have no idea if my arteries are getting plugged worse or what.

Waiting represents uncertainty and not knowing what kind of effect the wait, (are my arteries becoming more blocked?), and the surgery will have on both their present and future well-being.

The possibility of dying while waiting or dying during the surgery was an additional fear expressed by the participants:

I am afraid of it in a way because something could go wrong.

The thoughts – I never really realized what depression was but it is really easy to get down and slip into negative thinking. What if something happens to me while I am waiting here?

Thoughts of potentially dying were claimed by several participants and most indicated that these thoughts contributed to waiting period anxiety. Some patients used these thoughts to try and analyze their own risk:

You do address questions of mortality and what happens after you die. . . . Most people who die have a lot more wrong with them than a bad heart.

The fear of dying while waiting or during the surgery is a reality faced by all patients awaiting CABG surgery. Anxiety from this source is a realistic burden to waiting patients.

As a consequence of wanting to get the surgery “over with” yet maintain a sense of normalcy, patients achieved a sense of peace of mind by being able to actively participate, cognitively, behaviorally, and affectively, in limiting their own waiting anxiety despite their lack of control over their situation.

Comparison of Quantitative and Qualitative Data for the Variable of Anxiety

Table 21 lists participants’ responses to the first portion of interview question number 3, (“Some people who are waiting for heart surgery have indicated that they feel anxious. Do you feel that way?”), by descending order of their graphical rating for anxiety. Comparing the qualitative response to the quantitative number that participants assigned to their anxiety shows that there is an association between participants’ telephone interview statements and their graphical anxiety score. The table indicates that the majority of participants who scored their anxiety above 50 on the graphical anxiety rating scale (GARS) confirmed the presence of anxiety during their telephone interview, and the majority of participants who scored below 50 on the GARS denied anxiety during their interview.

Table 21

Comparison of Quantitative GARS score to Qualitative Data for the Variable ofAnxiety

GARS Anxiety Score	Participant Responses to Question: "Some people who are waiting for heart surgery have indicated that they feel anxious. Do you feel that way?"
100	I want it done and over with if that is what I need.
88	To a certain extent I am anxious. It is really bad now because you don't know what is going on.
84	Yes. Just the waiting and not knowing what or when it is going to happen.
82	I would like to get it done and over with. I am afraid of it in a way because something could go wrong.
79	I don't think about it. I keep waiting. I just want to get this thing over with.
77	In October I had an attack. They say it wasn't a heart attack and I have been waiting ever since.
70	Yes, but trying not to be. Worried that one morning I won't wake up.
67	I do feel anxious and would like to get it over with. The longer you wait you get more nervous.
60	Once and a while I feel anxious.
60	Yes. Not a lot of good news out there these days about the available resources to do these things.
59	At times. Like to get on with it and on with my life because it is put on hold right now, big time. I would say very very anxious because I think about it all the time.
55	At first I did but now I really don't.
52	Yes. I want this surgery. I am not anxious from fear.

Table 21 (continued)

GARS Anxiety Score	Participant Responses to Question: "Some people who are waiting for heart surgery have indicated that they feel anxious. Do you feel that way?"
51	Yes. I try not to think about it too much.
50	Not really anxious because I know it is coming.
50	Yes. I am on an anti-depressant to try to relieve anxiety symptoms.
49	No. Anxious to get it done and a little restless to get it over with.
49	I may have been anxious in the beginning.
48	Not yet. I just don't think about it.
18	No. I wish that I would get a phone call and get it over with.
11	No. Maybe sometimes if I think about it.
4	I don't know. I don't think so. I don't get myself worked up to that state.
4	No, not anxious. I accept things as they are.
0	No, not anxious at this point.
0	Do not have anxiety now which I attribute to lack of symptoms.

Chapter Summary

This study identified that uncertainty, symptom distress and anxiety are present in what are likely clinically significant levels in these patients waiting for coronary artery bypass surgery, however, while the data trended towards a deterioration in psychosocial status as waiting time increased, the relationships were not statistically significant. With respect to total waiting time, the youngest and the oldest participants in this study were more likely to have faster surgery, and this effect remained even when surgical priority and illness severity were taken into account.

Uncertainty, symptom distress, and anxiety were significantly related to measures of social and physical functional status. There were no significant differences in uncertainty, symptom distress, and anxiety with respect to the participants' age, gender, education, living situation, work status, area of residence, CCS angina class, comorbidity presence, left ventricular function, number of occluded vessels, history of previous MI, and presence of left main coronary disease greater than 50%.

The qualitative analysis of the telephone interview data found that participants were "taking responsibility" for their cardiac symptoms while they waited, they were able to envision benefits from CABG surgery that would assist them in "getting their life back", and they were anxious to "get their surgery over with" and, as a result, they employed various strategies to distract themselves from the turmoil of waiting. Collectively the findings of this study indicate that the wait for cardiac surgery has a significant influence on all aspects of waiting patients' lives.

CHAPTER 5

DISCUSSION

Introduction

The purpose of this descriptive correlational study was to provide an understanding of the experience of waiting for coronary artery bypass surgery in a small group of patients waiting at home for first time elective CABG surgery. The literature identified that uncertainty, symptom distress, and anxiety could realistically be expected in a population of patients on a waiting list for cardiac surgery. Patients' length of time spent on the waiting list could also potentially influence these three key study variables. Both the quantitative and qualitative results of this study have assisted in providing a clearer description of the waiting experience.

Discussion of Findings

Applying Mishel's Uncertainty in Illness Theory To the Experience of Waiting for CABG Surgery

The conceptual framework used to guide this study was Mishel's Uncertainty in Illness Theory (Mishel, 1988). Chapter 2 presented this theoretical framework and its fit with the experience of waiting for cardiac surgery (See also Figure 2 found in Chapter 2 for a diagram of the modified framework). The purpose of this investigation with respect to the uncertainty model was to examine the symptom pattern component of the stimuli frame using symptom distress as an antecedent to uncertainty. Uncertainty is then appraised and the appraisal of uncertainty leads to emotion based outcomes such as anxiety. The qualitative interviews provided further analysis of the experience of symptoms, the experience of anxiety, and the appraisal

of uncertainty as either a danger or an opportunity. The results of this interview process have been used to clarify the results from the questionnaires for a complete picture of the psychosocial experience of waiting for heart surgery.

Uncertainty in illness.

Moderate to severe uncertainty levels were reported by 57% of this study population indicating that clinically significant levels of uncertainty were present in these waiting patients. The mean uncertainty score for these waiting patients (58.4) is slightly higher than the uncertainty scores using the same scale (MUIS-C) in similar populations of patients living with cardiac disease, including patients living with heart failure (54.9) (Winters, 1999), and one other population of waiting cardiac surgery patients (50.2) (Staples & Jefferey, 1997).

The Mishel Uncertainty in Illness Theory proposes that the presence of a symptom pattern is an antecedent to uncertainty and the process of appraising uncertainty as a danger could lead to anxiety. Thus, one would expect a correlation between uncertainty and symptom distress and uncertainty and anxiety. Uncertainty significantly correlated with symptom distress ($p = .005$) but not with anxiety in this study. This lack of identified relationship between uncertainty and anxiety is unusual when compared to other studies, including samples of cardiac patients and patients living with cancer, in which these variables were also measured (Deane & Degner, 1998; Webster & Christman, 1988; Wong & Bramwell, 1992). One possible explanation for this discrepancy is that none of these other studies used a graphical anxiety rating scale to measure anxiety. Perhaps patient difficulty in responding to the GARS on a mailed questionnaire contributed to this finding.

The results of this current study show that uncertainty is a highly prevalent experience amongst patients waiting for CABG surgery and the experience of uncertainty is independent of most demographic and illness characteristics of the sample except for physical limitation ($p = .04$). No significant differences or clear trends were observed in uncertainty levels with respect to age, gender, social limitation, education, living situation, work status, area of residence, CCS angina class, comorbidity status, left ventricular function, number of occluded vessels, number of previous MIs, or presence of significant left main disease, but mean uncertainty levels in these groups were consistently in the moderate range.

Mishel (1984) stated that uncertainty can be generated by events or situations that can be characterized as vague, ambiguous, unpredictable, unfamiliar, inconsistent, or lacking information. Many of these characteristics of uncertainty were seen in the conceptual categories identified within the qualitative analysis. Participants described vague or ambiguous symptoms, discussed their fears of dying or having a heart attack while waiting, agonized over not knowing when their surgery would be, and envisioned an unpredictable future. Several other qualitative studies examining cardiac populations have also identified evidence of uncertainty as a component of their participants' experience (Fitzsimons, Parahoo, Stringer, 2000; Hawley, 1998; Lindsay, Smith, Hanlon, Wheatley, 2000; Winters, 1999). The recurrent qualitative finding of uncertainty as a central experience of cardiac patients is evidence of both the universality of uncertainty and the transferability of these results (Fitzsimons et al., 2000).

The stimuli frame: Symptom pattern.

Prior to this investigation, little was known about the symptom experience of patients on a waiting list for coronary artery surgery. The Mishel Uncertainty in Illness Theory (1988) discusses the symptom pattern of illness as an antecedent to experiencing uncertainty because symptoms form an important component of the patient's perception of illness. In the current study, symptom pattern was measured using a modification of the Symptom Frequency and Symptom Distress Scale (SFSDS) designed by Lough et al. (1987).

While it is difficult to separate the symptom distress scale into severity levels, (mild, moderate, severe), at the early stage of development of this tool, and the majority of scores cluster at the bottom one third of the scale (82%), low symptom distress has not been confirmed in this population. Qualitative analysis for this project suggested that the participants were experiencing symptoms and that these symptoms were a source of distress during the waiting period. In participant interviews, symptoms were a key source of anxiety, and the relief of symptoms was identified as an important way that anxiety was relieved, thus establishing a link between the presence of symptoms and psychological distress.

Several explanations for the low scores for symptom distress as measured by the SFSDS have been identified. First, the coronary artery disease version of the SFSDS was designed to include all possible symptoms of coronary artery disease and their various manifestations. Not all symptoms on the scale will be relevant for all patients, and it is inevitable that several symptoms may be scored as "zero" for each patient. Second, true symptom distress may be realistically low due to proper

medical and patient self-management while waiting. As well, the chronic nature of cardiac symptoms may have influenced symptom distress scores. Many patients would have been living with cardiac symptoms for many years prior to being added to a CABG waiting list and may have adapted to living with the somatic effects of cardiac disease. As a result, adaptation to symptoms may have influenced the levels of distress that patients associated with each individual symptom because these participants have accepted a life that includes cardiac symptoms. A few of the telephone interview participants, when asked about their symptoms during waiting, indicated that their symptoms had been present for a long time prior to waiting. The phenomenon of accommodation to cardiac symptoms has been identified in prior research. Radley, Green, and Radley (1987) observed that the male cardiac surgery patients in their study who were not able to accommodate their illness into their lifestyle were the ones that "most wished for its removal" (p. 158).

Although it has been observed with cancer patients (McClement, Woodgate, & Degner, 1997), and heart transplant recipient populations (Lough, Lindsey, Shinn, & Stotts, 1987), that the most frequent symptoms are not necessarily the most distressing ones, such was not the case in this study. The SFSDS identified (See Table 19, Chapter 4) that the most frequent, distressing, and combined symptom distress ranking of individual symptoms produced similar lists. The top three most frequent and distressing symptoms experienced by this sample were fatigue, shortness of breath with activity and chest discomfort, which were consistent with the findings of Jonsdottir and Baldursdottir (1998). The analysis of symptoms completed for this study suggests that the overall experience of symptom distress is similar to the

frequency rate or distress level of a symptom alone. However, more research is needed before it can be confidently suggested that the frequency rate of a symptom or the distress level of a symptom alone is equivalent to overall "symptom distress" for coronary artery disease populations.

Symptom distress correlated significantly and positively with both uncertainty ($p = .005$) and anxiety ($p = .0002$). In addition, the overall symptom distress scores for several individual symptoms correlated significantly with uncertainty and anxiety (see also Table 14, Chapter 4). The individual symptoms that correlated highly with uncertainty included angina pain symptoms (chest discomfort, arm/shoulder pain, back/neck pain, jaw/throat/tooth pain, generalized discomfort), and gastrointestinal symptoms (nausea, loss of appetite), psychological distress symptoms (depressed mood, nervousness/shakiness, feeling tense, restlessness), as well as the symptoms of difficulty sleeping, fatigue, and nocturnal shortness of breath (SOB). Winters (1999) found in a group of heart failure patients that symptom fluctuation was a major determinant of illness uncertainty and concluded that uncertainty was present when symptoms first occurred or changed. Mishel and Braden (1988) while studying a group of 61 women with gynecological cancers found that symptom pattern significantly predicted the ambiguity factor on the MUIS but that symptoms were not significantly related to general uncertainty. Contrary to the results of this investigation, other cancer studies have failed to show a relationship between uncertainty and symptom distress (Galloway & Graydon, 1996). This research is the first cardiac patient study to examine uncertainty and symptom distress both as a total score and as an individual symptom score. The findings indicate that symptom

distress as measured in this study has a strong relationship to the experience of uncertainty in illness.

Individual symptom scores that correlated highly with anxiety scores included angina pain symptoms (chest discomfort, arm/shoulder pain, back/neck pain, indigestion, generalized discomfort), gastrointestinal symptoms (nausea), respiratory symptoms (SOB with activity, SOB lying flat, nocturnal SOB), other cardiac symptoms (dizziness/ lightheadedness, irregular heart rate), all the psychological distress symptoms (depressed mood, nervousness/shakiness, feeling fearful, feeling tense, panic spells, restlessness), and symptoms such as fatigue, and difficulty sleeping. It is not surprising that such a large number of symptoms would correlate strongly with anxiety when many of the symptoms of cardiac disease are initially mistaken for anxiety symptoms. Other symptoms on the symptom distress scale, (symptoms of psychological distress), were included primarily to capture the anxiety component of experiencing cardiac symptoms and their correlation with anxiety was expected.

Based on the individual symptoms correlations with uncertainty and anxiety, it is proposed that the symptoms that correlated with anxiety were symptoms that were the most anxiety provoking, or were physical manifestations of anxiety as well as symptoms of cardiac disease. Individual symptoms that correlated with uncertainty may be perceived by the patient as having the largest bearing on future health and well being, or are symptoms which are experienced as vague, ambiguous, or unpredictable. Symptoms that correlated with both uncertainty and anxiety have a combined effect on the patient's experience.

Additional analysis compared the overall symptom distress of individual symptoms to functional status (KCCQPL and SL) (Table 16, Chapter 4). The symptoms that were most likely to cause a disruption to patient function had the highest correlations with the physical and social limitation scales. Total symptom distress also correlated with deteriorated physical and social functioning ($p = .0003$, $p = .0001$). This correlation between symptoms and functional status was confirmed in the qualitative analysis. Participants expressed disruption in their functional pattern caused by symptoms as a need to “get my life back.” Return to physical and social activities, as well as symptom relief, were discussed as benefits that participants hoped would help them get their lives back to normal.

Despite acknowledgement by several authors that symptom status is a poor predictor of underlying anatomical disease (Bugiardini et al., 1995; Costa, 1987; Cox, Naylor, & Johnstone, 1994; de Bono et al., 1998; Greene, Schocken, & Spielberger, 1991; Hultgren & Peduzzi, 1984; Warner, 1995), participants with the most severe baseline coronary artery disease status, (history of previous MI, angina class, number of diseased vessels, presence of comorbidities, left ventricular function, left main disease), also reported the highest mean symptom distress, however, none of these findings were statistically significant. Participants who had quit work because of their health, as expected, reported higher mean symptom distress as these participants likely left their jobs because of symptom limitation, however, this relationship was not significant. Participants who were male or lived in an urban area also reported higher mean symptom distress scores, however, there were no clear explanations for these non-significant trends.

Qualitatively symptoms emerged as a primary theme in the waiting experience. Participants identified ways in which they were “taking responsibility” to manage their symptoms while on the waiting list and described how they self-evaluated the success of both the medications and treatments prescribed to them by physicians, and their self-initiated choices in symptom management. Participants were also familiar with the activities they could and could not do, how their bodies would respond if they “over did it,” and knew what to do to alleviate their personal pain if they did develop symptoms. An interesting finding was that some patients discussed a “heightened awareness” of their bodily sensations. The ambiguousness of symptoms caused patients to question any abnormal sensation within their body: “Is this indigestion or is this an event?” Mishel (1984) discusses such ambiguity as a component of illness uncertainty. Participants’ attentiveness to their symptoms and the resultant heightened bodily awareness is a perception of their illness and further strengthens the stated relationship of the symptom pattern acting as an antecedent to uncertainty.

Appraisal of uncertainty: Anxiety or opportunity?

The appraisal process of the uncertainty experience involves the patients’ accommodation of uncertainty into their environment as either a danger or an opportunity (Mishel, 1988). The Mishel Uncertainty in Illness Scale focuses primarily on examining uncertainty when it is perceived as a danger and, thus, using this quantitative method, uncertainty as an opportunity cannot be evaluated with any confidence. The inability to quantitatively measure the power of uncertainty when it is viewed as an opportunity may be an explanation for some of the unusual findings

of this project such as the lack of significant correlation between uncertainty and anxiety, and the lack of significant differences between groupings of patients with respect to their uncertainty scores. Patients, who viewed their uncertainty experiences positively, for example as a second chance at life, may have muted the relationship of uncertainty to anxiety. The view of uncertainty as an opportunity is particularly significant in patients who are living with a chronic condition such as coronary artery disease (Mishel, 1990).

The mean anxiety score for this population was in the moderate range (50.6) and 71% of participants rated their anxiety at a moderate to severe level. These levels of anxiety are similar to the moderate to severe anxiety results reported by Cox et al. (1996) (64%) and Underwood et al., (1992) (69%). Although, in this study, anxiety did not correlate with uncertainty, anxiety did positively correlate with symptom distress further clarifying what previous research has alluded to as the presence of a psychosocial component to all symptom experience (Jenkins, Stanton, & Jono, 1994). Anxiety also positively correlated with both the physical and social limitations of functional status ($p = .002$, $p < .0001$). No significant differences were found with respect to any of the demographic or illness related variables but trends were observed where higher mean anxiety scores were present in participants who were male, had quit work because of their health, had at least Class III angina and reported the presence of comorbidities. It is unclear why male patients may report higher anxiety than female patients but participants who had quit work because of their health, had Class III or IV angina, or comorbidities may have increased anxiety related to the severity of their condition.

Qualitatively, anxiety emerged as a strong desire to “get the surgery over with.” A comparison of graphical anxiety rating scale scores and the qualitative statements made by participants during their telephone interview about the presence of anxiety illustrated that there was congruence between the two methods of assessing anxiety. Key sources of anxiety for these patients were, symptoms, the waiting itself, fear of death or myocardial infarction, as well as uncertainty about the possibility of disease progression while waiting. These results parallel those discussed by Bradley and Williams (1990) and Carr and Powers (1986) who examined stressors and concerns of cardiac surgery patients. Fitzsimons et al. (2000) also identified anxiety as an important theme associated with waiting for CABG surgery. Participants in this study also described employing various strategies to help relieve their anxiety including avoiding thoughts about the surgery and keeping busy. To date, the literature review showed that the present study is the only study that has asked patients to discuss what they were actively trying to do to alleviate anxiety while waiting for surgery.

The modification of the uncertainty in illness model suggests that patients who appraise uncertainty as a danger will focus primarily on the possibility of dying if they do not have surgery, and patients who appraise uncertainty as an opportunity will focus on surgery as a chance to return to former activities. This perspective of illness appraisal was first proposed by King, Porter, Norsen, and Reis (1992) who asked post-operative CABG patients, “Was it worth it?” These authors found that those patients that believed that CABG was worth it because it saved them from death scored lower in life satisfaction and mood than those patients who believed that

surgery was worth it because it improved their functional status. The qualitative results of this study confirm that King et al.'s findings have been appropriately applied to the modified theoretical model of uncertainty in illness. The conceptual category of "getting my life back" best illustrates this finding. The interview question that preceded the development of this conceptual category asked participants to envision why they felt that CABG surgery would be a beneficial or worthwhile undertaking. While some participants discussed the "danger" aspect of CABG benefit, (prevention of death or MI), others described the "opportunity" component of CABG benefit, (improved functional and symptom status, enjoyment of life, and psychological uplifting). Some participants discussed both the danger and the opportunity component of CABG benefit and indicated that while they perceived anxieties and "dangers" in their wait they also hoped for life improvements. The possibility that uncertainty could be appraised as both a danger and an opportunity simultaneously has been suggested but not investigated (Babrow, Kasch, & Ford, 1998). The basic benefits that patients described in the current study parallel those found by Gortner et al., (1985), Gortner et al., (1989), and Gortner et al. (1994), in their studies with CABG and cardiac surgery patients examining expected and realized benefits.

Trends in Waiting Times

The average total waiting time for participants in this study from the date they were added to the list to the date they had their surgery (or went off list) was 172 days, or approximately five and one half months. This mean length of wait was consistent with the estimated 4 to 6 month wait that patients are told to expect at their

surgical consult. Nevertheless, 14 participants (33%) in this study waited 6 months or longer and 3 of these participants (7%) waited a year or longer. It is unknown if any of the prolonged waits were related to a patient's personal delays. The long waits experienced by this sample were longer than the 2.8 months average wait reported for elective patients in a Canadian study by Carrier et al. (1993), however it is difficult to make this comparison due to the numerous changes to both the health care environment and to the management of cardiac surgery delivery that have occurred in the 9 to 10 years between the studies. Most other studies that report average waits have included the waiting times of emergent and urgent patients in their results and cannot be used as a comparison here (Morgan et al., 1998; Naylor et al., 1995).

The Winnipeg Regional Health Authority reported that the mean total waiting time for all patients who had elective CABG-only surgery during the period of this study, (January to June 2001), at the Health Sciences Centre (HSC) site was 115.32 days and was 89.15 days at the second surgical site. These reported averages were approximately two (2) months shorter than the total waiting times for the participants of this investigation. The discrepancy is likely due to the short waits of patients on the waiting list who missed being included in this study because they had their surgery during the period of time between the introductory letter and the mailing of the questionnaires. In addition, other elective patients with short waits may have been missed during the three and one half (3 ½) months between the two samplings of the waiting list. The shorter reported waiting time at the second site was likely do to systemic factors such as nursing shortages, which were not as severe at the second site during the period of this study.

One primary goal of this study was to describe how uncertainty, symptom distress and anxiety as well as functional status, compared with participants' time on the waiting list. Surprisingly, there was no relationship between these study variables and either perceived or actual waiting time, (expressed in days), up to the date of participation in this study. When individual symptoms were compared to perceived and actual waiting time (in days) only the symptom of loss of appetite became significantly more distressing as waiting time lengthened. Loss of appetite was included in the symptom frequency and symptom distress scale because diminished appetite could be a consequence of a worsening heart condition or it may be a symptom of anxiety. In this sample, loss of appetite did not have a significant correlation with anxiety. Despite the statistically significant relationship with waiting time, loss of appetite was not identified as a clinically important symptom by participants with only 14 (36%) of participants claiming any level of frequency to their loss of appetite (ranking 22nd on the frequency of symptom scale, 23rd on the distress scale, and 22nd on the combined symptom distress scale). As a secondary symptom of the cardiac disease experience, the observed correlation between loss of appetite and waiting time cannot be easily explained as a stand-alone result and further investigation would be needed to confirm this relationship and understand its clinical significance.

The study variables of uncertainty, symptom distress, anxiety and functional status were also compared with a measure of perceived waiting time in categorical format (Table 12 in Chapter 4). Again no statistically significant differences were observed between group means in the uncertainty, symptom distress, anxiety or

functional status categories. Non-significant trends were observed where symptom distress and anxiety became more severe as waiting time increased, and functionally, both socially and physically, participants deteriorated as waiting times lengthened. No trends were observed in uncertainty scores based on waiting time. Jonsdottir and Baldursdottir (1998) in an Icelandic study ($N = 72$) of waiting CABG patients also observed a non-significant trend of subject deterioration as waiting time increased. However, a UK study ($N = 68$) (Underwood, Firmin, & Jehu, 1992) did observe statistically significant relationships between time spent on waiting list and anxiety ($p = .05$), depression ($p = .005$), impairment of work ($p = < .0001$), family relationships ($p = < .0001$), private leisure activities ($p = < .0001$), and social activities ($p = .004$). Although the changes in symptom distress, anxiety and functional status related to waiting time did not reach a level of statistical significance, this may have been due to the small sample size. Since the trended relationship to waiting time may be clinically significant, it may be worth increasing the sample size to see if statistical significance is achieved.

Surprisingly, patient age emerged as a potential predictor of having earlier surgery. This finding suggests that, for this sample of CABG candidates, there was an age bias as to which patients had surgery first with the youngest patients, (age under 60), and the oldest patients, (age greater than 69), being more likely to have a shorter total waiting time ($p = 0.02$). Rate of surgery was 2.8 times earlier for patients less than 60 years of age and 2.1 times earlier for patients aged 70 or older. The age disparity remained even when surgical priority and baseline severity of illness were taken into consideration.

It is unlikely that the youngest patients and the oldest patients received surgery earlier solely because of their age. One of the goals of CABG surgery is to help patients return to work (Allen, 1990), and perhaps, patients' issues with their work status, if shared with the cardiac surgery team, encouraged earlier surgery. Work status issues may have affected the youngest patients in this sample as this investigation also found that working participants were significantly younger than retired participants ($p = .0001$), however the survival distribution curve for work status, (Figure 7, Chapter 4), found no significant differences in time to surgery based on work status categories. A second possible factor that may have contributed to the age disparity is that although severity of illness was taken into consideration when examining the differences in time to surgery based on age, a baseline measurement for illness severity was used. The patients' measures of severity of illness may have deteriorated from baseline during the waiting period. Deterioration in condition while waiting in the youngest and oldest patient groups may have influenced a faster rate of surgery for these participants. A third hypothesized explanation for the age disparity is patient contact with the cardiac surgery team while waiting. Hadorn and Holmes (1997) suggested that certain populations of waiting cardiac surgery patients may receive earlier surgery because they "complain" more about their condition and the experience of waiting. Perhaps patients in this sample, (or their families), in the oldest and youngest age groups were more vigilant in updating their condition with the waitlist coordinator or were more likely to stay in contact with the cardiac surgery team and thus, influenced their own waiting times.

While the exact cause of the age disparity found in this investigation is unknown, the presence of a potential age bias is contrary to what has been observed by other authors when investigating surgical waiting lists (Cox et al., 1996). However, a research project examining prioritization using hypothetical scenarios, (Naylor, Levinton, Baigrie, & Goldman, 1992), found that practitioners would take age and work status into consideration when prioritizing patients with the same illness severity. While efforts are made to keep the prioritization process as equitable as possible, managing people is a human experience and necessarily human emotions, opinion, and intuition will have an inevitable influence on the process.

Limitations to Results and Extraneous Variables

The primary limitations to the results of this study were lack of randomization and sample size. As discussed in previous chapters, in order to keep the population of waiting CABG patients as stable as possible, a decision was made early on in the planning of this project to only sample CABG patients at one surgical site, the Health Sciences Centre. This decision was made due to inconsistencies in the way that patients are added to the CABG waiting list at the second surgical site. Other extraneous variables also influenced the final sample size in this project. The CABG-only population at the site of data collection was surprisingly low in number and random selection from this small population would have further cut the final sample size. Two of the four operating surgeons at the Health Sciences Centre site primarily performed valve surgeries or combined procedures limiting the number of first time CABG-only patients on the waiting list. In addition, a third surgeon, who primarily operated on CABG-only patients, was in the process of leaving the hospital during the

data collection period and therefore stopped adding patients to the waiting list. This surgeon's remaining waiting patients were eventually shuffled to other surgeons and occasionally other hospitals. Because of these potential extraneous influences on the CABG-only population, the researcher made a decision, in consultation with a statistician and her thesis chair, to halt data collection at the 42 participants.

Another extraneous variable that may have potentially had both a positive and a negative influence on the results of this study was media coverage. In January 2001, just as data collection began, there were frequent media reports discussing the waits of cardiac surgery patients based on the nursing shortage ongoing in the province of Manitoba. ("HSC cuts heart surgeries, may have to send some patients out of province: Nurse shortage chokes cardiac care.") (O'Connor, 2001, January 25). Manitoba was facing a severe nursing shortage during the period of this study and there is no doubt that this nursing shortage negatively influenced the waiting times of these participants. In the qualitative interviews, several participants discussed the nursing shortage and indicated an awareness of its influence on their wait. As a positive influence, the media's coverage of the nursing shortage and its relationship to the cardiac surgery waiting list may have influenced subjects' decision to participate in this study and share their waiting experience. The media may also have had a negative influence on the anxiety and uncertainty levels of the participants in this research and altered the results that are presented here.

Because of these limitations and extraneous variables, the results of this study cannot be generalized beyond the participants of this study, and can only remotely represent the experiences of other cardiac surgery patients waiting in similar health

care environments. A larger sample size may help to clarify the observed trend that symptom distress and anxiety increased as waiting times increased. This investigation, however, provides a framework for the study of the psychosocial effects of waiting for coronary artery bypass graft surgery.

Nursing Implications

At present, the cardiac surgery waiting list is managed by one nursing coordinator in conjunction with the medical director of surgery, the nursing director of surgery, and a team of cardiac surgeons. Because at any given time there may be over 200 patients on the waiting list, it is impossible for this coordinator to initiate contact with the waiting patients on a regular basis. Although many telephone participants mentioned that they had spoken with the waitlist coordinator and were complimentary about her and her role, none of the participants discussed the coordinator as a specific resource for anxiety relief during their waiting period. Physicians, however, were mentioned as a resource for anxiety relief and enhanced patient confidence. Education about the nursing role may be necessary to increase the extent to which patients recognize nurses as a resource in coping with the effect of waiting for surgery.

An early hypothesis for this project was that patients who initiated contact with the waitlist coordinator more frequently would have different levels of anxiety and uncertainty, and perhaps a shorter time to surgery than patients who chose not to contact the coordinator. This hypothesis was impossible to test during this project due to the difficulty in assessing from the patients' databases what contacts were patient initiated and what contacts were coordinator initiated. A interventional study

where half the sample is contacted at regular intervals by a nurse experienced with cardiac surgery patients and the other half receives usual care could help to assess if regular patient contact and assessment during the wait for surgery would decrease the anxiety, symptom distress or uncertainty of these patients.

The qualitative analysis for this project found that the patient's experience of symptoms was an important source of anxiety and uncertainty for patients waiting for surgery. Regular assessment of symptoms during the waiting period would help to ensure that the patients' cardiac status remained stable during their wait. Although the patients in this sample provided evidence that they were "taking responsibility" for their symptom management, assessments at intervals may help the patients to recognize a gradual deterioration of condition that may otherwise go unnoticed. These assessments would be especially important in cases where patients are expected to be on the waiting list for 4 to 6 months or longer.

The presence of waiting period anxiety and uncertainty has been confirmed in several studies undertaken with this population of patients including the current study. Only recently have studies also examined the effect of pre-operative anxiety on post-operative psychosocial status of patients (Duits et al., 1999). Nurses must recognize that what happens to their patients while they wait for surgery, including length of wait, symptom status, and levels of anxiety and uncertainty, may influence their attitude towards recovery, both short and long term. An awareness of these factors is essential for complete, holistic care of the cardiac surgery patient.

Areas For Future Research

Although waiting lists for cardiac surgery and other procedures are a pervasive characteristic of publicly funded health care systems, it has only been recently that much needed attention has been given to the psychosocial status of the waiting patient. In particular, the trend of increasing anxiety and symptom distress with increased waiting time needs to be clarified with larger sample sizes. Time series surveys and semi-structured interviews, which bypass the limitations afforded by a cross-sectional approach, may also clarify the nature of the psychological status of patients waiting for cardiac surgery. Comparison of results with post-operative outcome may also be instrumental in understanding the effects of long waits for surgery on short and long-term recovery.

The qualitative analysis highlighted three areas of future research. First, simultaneous examination of the experience of the family members' of waiting patients is an area for future study. This project showed that family played a large role in influencing the patient's waiting experience. Second, the qualitative experience of symptoms requires further evaluation. In particular, the role of cardiac symptoms on bodily awareness emerged as an interesting component of the qualitative analysis. Third, word of mouth stories about others who have also experienced CABG may have a specific influence on anxiety and uncertainty levels in the waiting patient. The relationships between these experiences should be examined to further the understanding of the experience of waiting for cardiac surgery.

This study examined a new concept in the experience of cardiac patients, that of symptom distress. The untested nature of the Symptom Frequency and Symptom

Distress Scale modified for this project was a limitation to the results of this study. Further information about this scale and revisions to the scale will be necessary to evaluate its usefulness in this population of patients, as well as identify what constitutes mild, moderate and severe symptom distress. Scoring of the scale also needs to be re-examined and a factor analysis using a large sample size of a variety of cardiac patients would be a useful method of statistically assessing this instrument. Because many of the symptoms included in the scale may also have a non-cardiac origin, (e.g. indigestion, back/neck discomfort), it is essential to identify which symptoms most clearly evaluate the total cardiac symptom distress of the patient.

This study used both quantitative and qualitative methods in evaluating the experience of uncertainty, symptom distress and anxiety in patients waiting for coronary artery bypass surgery. The triangulation of these two methods proved to be a useful way to clarify the concepts under study and explain patterns in the data. Further research combining these two methods may enhance the understanding of the experience of waiting for cardiac surgery.

Conclusion

This study has been a useful elucidation of the experience of waiting for coronary artery bypass surgery. The majority of patients waiting for CABG surgery in this sample experienced moderate levels of uncertainty and anxiety and experienced fatigue, shortness of breath with activity, and chest discomfort as their most significant symptoms. While no statistically significant relationships were observed, anxiety, symptom distress, and functional status trended toward deteriorating as waiting time increased. Patient age appears to have had an influence

on time to surgery with the youngest and oldest patients in this sample having statistically significant shorter total waits.

In comparing both the quantitative and the qualitative results of this study to the Mishel Uncertainty in Illness Theory, it was concluded that the symptom experience, including symptom distress, provided a perceptual framework that acted as an antecedent to uncertainty. Uncertainty was prevalent in this group of waiting patients but the appraisal of uncertainty as either a danger or an opportunity influenced uncertainty's relationship with anxiety. Qualitatively, the appraisal of uncertainty as a danger or opportunity was confirmed with patients discussing benefits of surgery both as a way to save themselves from death or MI and as a way to improve functional status and return to former activities. In the interviews, symptom experience also presented itself with a clear relationship to anxiety because the presence of symptoms was equivalent to the presence of anxiety, and the absence of symptoms was equivalent to the relief of anxiety. This relationship was confirmed quantitatively with a significant correlation between symptom distress and anxiety.

Overall, while this study meets its goal of providing an understanding of the experience of waiting at home for first-time CABG surgery, further research is required to identify effective ways to ease the psychosocial impact associated with long waits for surgery. Areas for future research with waiting patients have been discussed and interventions, such as frequent health care provider contact with the patients while waiting, may be an effective way to lessen the psychosocial impact of waiting for cardiac surgery.

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APPENDIX A

THE UNIVERSITY OF MANITOBA

OFFICE OF THE PRESIDENT
Office of Research Services

244 Engineering Building
Winnipeg, Manitoba
Canada R3T 5V6

Tel: (204) 474-8418
Fax: (204) 261-0325

APPROVAL CERTIFICATE

13 October 2000

TO: Kimberley McCormick
Principal Investigator

FROM: Lorna Guse, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2000:003
"Uncertainty Symptom Distress and Anxiety in Patients Waiting for
Coronary Artery Bypass Surgery"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.



Winnipeg Regional
Health Authority

Office régional de la
santé de Winnipeg

APPENDIX B

1800-155 Carlton St.
Winnipeg, Manitoba
R3C 4Y1 CANADA

TEL: 204 / 926.7000
FAX: 204 / 926.7007
www.wrha.mb.ca

155, rue Carlton, suite 1800
Winnipeg, Manitoba
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www.wrha.mb.ca

Nov 1, 2000

Ms. Kimberlev McCormick

R

Dear Ms. McCormick:

**Re: Uncertainty, Symptom Distress and Anxiety in Patients
Waiting for Coronary Artery Bypass Surgery**

On behalf of the Winnipeg Regional Health Authority (WRHA) Research Review Committee, I am pleased to inform you that your research access request for the above-named study has been approved on the condition you clarify and address the following issues:

- Ethics approval –We will require a copy of the letter from the Research Ethics Board at the University of Manitoba granting ethics approval for this current time period;
- For the following concerns please contact Katherine Choptain should you have any questions at 926-7049.
 - Sample Letter of Approval:
 - Bullet #1 – The researcher and all of the Master Thesis Research Committee members are mandated under PHIA to sign a PHIA Pledge of Confidentiality. The researcher needs to confirm that the pledges have been signed versus sending the policy and pledge to them, and we can assist with this task. Please contact Katherine Choptain should you require assistance.
 - Bullet #4 – In accordance with PHIA S.24(d)(ii), you will need to advise as to when you intend to remove identifying information and the procedures to destroy the identifying information; to the satisfaction of the Katherine Chop, Director, Access and Privacy.
 - Study Design and Procedures
 - Who will monitor the wait list to ensure reminder notices?

- Asking potential participants to phone or leave a message to advise whether or not they are interested in receiving the study survey constitutes informed consent in accordance with Section 24(5) of PHIA. There may be a need to include written consent to participate in the telephone interview (Part 2) and Part 3 needs to be revised to obtain written consent to access PHI from the data base and from medical records.
- It is not clear as to whether or not the researcher will be accessing the entire database. The Researcher cannot access the database to obtain personal health information about wait list patients who have not consented to participate. How will the researcher be provided with PHI from the database for those individuals who have consented and be restricted from access to PHI for those individuals who have not consented.

You agree to the following terms:

- You agree not to report or publish personal health information in a form that could reasonably be expected to identify the individuals concerned;
- You agree to use any personal health information solely for the purposes of the approved research project;
- You inform us when your data collection is complete;
- You submit a summary of the final results of the study to the WRHA Research Review Committee and provide us with a copy of any publications arising from the study;
- You agree to submit any article or report that names the WRHA to the Research Review Committee for review prior to submitting for publication; and
- You sign this letter on the line indicated below and on the copy, and return one of the signed letters to the Chair, WRHA Research Review Committee.

Please proceed with this project once you have addressed the above concerns. Your responses to the above items should be provided in writing.

Our best wishes are extended for the successful completion of your study. For further information please contact me at

Sincerely,

Dr. Jan Trumble Waddell
Acting Chair,
WRHA Research Review Committee



Winnipeg Regional Health Authority
Office régional de la santé de Winnipeg

APPENDIX C

April 26, 2001

Dear Patient,

The Winnipeg Regional Health Authority has received a request from Kim McCormick R.N., a student in the Masters of Nursing Program at the University of Manitoba to conduct a survey of patients currently waiting for heart bypass surgery. Kim is interested in learning about how people have been feeling while they wait for surgery and how they have been managing with their heart related symptoms.

I am writing to ask your permission to mail you a questionnaire booklet that will ask you several questions about your experience while waiting for heart surgery. **If you have any objections to this request please let me know by calling the cardiac surgery waitlist coordinator's office, at 204-787-3943 or 1-800-667-7070. If you do not call by May 7, 2001 I shall assume it is acceptable for me to mail out the survey booklet.** The booklet will only be mailed to patients who do not object to this request.

Should you decide to participate, no information about you will be shared with the health care professionals caring for you. Physicians and other health care providers will not know if you have decided to participate in this study. All information will be strictly confidential. Whether or not you decide to participate in this study neither your current, nor your future medical or nursing care will be affected in any way. Your decision to participate will also not lengthen or shorten your wait for surgery.

Thank you for considering this request. A more detailed description of the study and what your participation will entail is enclosed for your consideration. If you have questions about this study you can reach Kim collect at _____ or Dr. Barbara Naimark R.N., her thesis advisor collect at 204-474-7467.

Yours truly,

Peggy Holt R.N.
Winnipeg Regional Health Authority
Waitlist Coordinator, Cardiac Surgery

APPENDIX D

Dear Patient:

Hello, my name is Kim McCormick R.N. I am a student in the Masters of Nursing Program at the University of Manitoba. I am conducting a study as part of my Masters thesis titled Uncertainty, Symptom Distress and Anxiety in Patients Waiting for Coronary Artery Bypass Surgery. My study will look at some of the thoughts and feelings you may be having while you are waiting for surgery as well as your heart symptoms and certain personal characteristics. This study has the approval of the Education Nursing Research Ethics Board at the University of Manitoba and the Winnipeg Regional Health Authority Research Review Committee.

The Coordinator of the Winnipeg Regional Health Authority Cardiac Surgery Waitlist Program's letter has introduced the nature of my study, and asked that you consider participating in this research study. Should you decide to participate, I have outlined in detail below what your participation would involve. Only contact the coordinator if you **do not** wish to participate in the study.

You will notice that there are three components to this study. The first part involves your answering a questionnaire and the second part consists of a short telephone interview that will ask you questions about your experience with waiting for heart surgery. You will be asked to indicate if you wish to participate in the telephone interview at the end of the questionnaire. The third part consists of my accessing your health records.

Your participation in this study means:

Part one:

- 1) You will be asked to complete a survey booklet that contains 5 short questionnaires. This booklet will take approximately 30 to 50 minutes of your time to complete. There are no right or wrong answers to the questions on the survey. It is important to answer each question based on your personal experience. If you do not feel comfortable answering specific questions you can leave them out.
- 2) I will also include a personal information form that will ask you questions such as your age, your education, and whether or not you are working.
- 3) When you have completed the survey, please mail it back in the enclosed self addressed stamped envelope and indicate by checking the appropriate box if you wish to participate in the telephone interview (part 2) of the study. **You are not obligated to participate in the telephone interview and you can end your participation by mailing back the questionnaires.**

Part two:

- 4) The telephone interview includes 3 questions which will further explore some of your feelings about waiting for surgery. It is expected that the telephone interview will take approximately 30-45 minutes of your time.

Part three:

- 5) The Winnipeg Regional Health Authority has given me access to the general cardiac surgery waitlist database. The information that I will receive about this database will not include the names of the patients who are waiting for heart surgery.

- 6) As part of the study I will need to collect information from your individual heart surgery database about your heart condition. Some of this record is on computer and some of it is filed on paper. This information is collected by the cardiac surgery waitlist coordinator and is based on your medical records. Some of the information that is a part of this record includes: how many arteries in your heart are affected, whether or not you have other medical conditions such as diabetes, or whether or not you have had a heart attack in the past. Collecting this type of information will tell me more about the general characteristics of patients, like yourself, who are waiting for heart surgery. You will be asked if you are willing to let me view your individual record when you receive the study booklet.

There will be no monetary expense to you if you choose to participate in this study. Participation is completely voluntary and you may decide to withdraw from the study at any time. Any information that you provide to me will be kept in strict confidence and your name will not be connected in any way to the results of this study. Whether or not you decide to participate in this study, neither your current, nor your future medical or nursing care will be affected in any way. Physicians and other health care providers will not know if you decide to take part in my study. Your decision to participate will also not lengthen or shorten your wait for surgery. Although it is not expected that there will be any immediate benefits to you if you choose to participate, a study such as this will help nurses and other health professionals to better understand the effects of the waiting period on the life of the patient.

The results of this study will be presented in summary form and may in the future be published. On the study questionnaire you will be asked if you are interested in receiving a summary of the study results. If you indicate that you are interested in receiving a copy of the results they will be mailed to you at the end of the study.

If you do not call the Cardiac Surgery Waitlist Coordinator by (date) then you can expect to receive the study survey in the mail in approximately 2-3 weeks. If you have questions about this study I would be happy to hear from you. You can call me collect at - or you may contact Dr. Barbara Naimark R.N., my thesis advisor collect, at 204-474-7467.

Sincerely,

Kim McCormick R.N.
Graduate Student
University of Manitoba
Faculty of Nursing

APPENDIX E

Questionnaire Booklet Cover Letter

Dear Patient,

Thank you for considering participation in this research study about patients waiting for heart bypass surgery. This study is being conducted by Kim McCormick, a student in the Masters of Nursing Program at the University of Manitoba. This is an independent project not connected with the Health Sciences Centre. A summary of the results will be shared with the cardiac surgery team.

Your participation in this study is important. It will help health care professionals to better understand what it is like to wait for heart surgery.

Little is known about how patients feel about waiting for heart surgery. In this booklet you will find 5 short questionnaires. Answering this survey will take approximately 30 to 50 minutes of your time. In many of the questions you will be asked to rate how you feel about many health related situations. Other questions will ask you about some of the heart symptoms you have been experiencing or how you have been managing with your daily activities since you have been waiting for surgery. There are also a series of questions that ask you to provide some personal information. There are no right or wrong answers to any of the questions. Please answer the questions based on your personal experience with waiting for heart surgery. If you do not feel comfortable answering specific questions you may leave them blank. . Returning this booklet will be considered consent to participate in this study.

The Winnipeg Regional Health Authority has given me access to the general cardiac surgery waitlist database. The information that I will receive about this database will not include the names of the patients who are waiting for heart surgery. As part of the study I will need to collect information from your individual heart surgery database about your heart condition. Some of this record is on computer and some of it is filed on paper. This information is collected by the cardiac surgery waitlist coordinator and is based on your medical records. Some of the information that is a part of this record includes: how many arteries in your heart are affected, whether or not you have other medical conditions such as diabetes, or whether or not you have had a heart attack. Collecting this type of information will tell me more about the general characteristics of patients, like yourself, who are waiting for heart surgery. To give me permission to view your database record, you need to sign the consent form below.

When you have answered all the questions, place the questionnaire in the enclosed self-addressed stamped envelope and mail to:

Kim McCormick

MB R

Please remember that your answers to these questions are completely confidential and will only be seen by Kim McCormick and her thesis advisor Dr. Barbara Naimark. If you have any questions about the contents of this survey do not hesitate to call Kim McCormick collect at - or Dr. Barbara Naimark collect at 204-474-7467.

Please complete and mail back this survey as soon as possible! Thank you for your participation. If you have any concerns with the manner in which this research has been conducted you may contact the Human Ethics Secretariat at 204-474-7122.

Sincerely,

Kim McCormick R.N.
Graduate Student
University of Manitoba
Faculty of Nursing

Participant # _____

I give permission for Kim McCormick R.N. to view my individual cardiac surgery database. I understand that this information will be used for research purposes only and that my name will never be associated with any of the information collected from this record.

Name (Please Print): _____

Signature: _____

Date: _____

APPENDIX F

Request for Telephone Interview

Thank you for your time in completing this survey and participating in this study. If you are interested you may also participate in the second part of this study which involves a short telephone interview to further explore your feelings about waiting for heart surgery. It is estimated that the telephone interview will take 30 to 45 minutes of your time. You are not obligated to participate in the telephone interview and you can end your participation by mailing back this questionnaire in the enclosed self-addressed stamped envelope and checking "No" at the options presented below. If you decide to participate you will receive a telephone call from the researcher (Kim McCormick) within 1 to 2 weeks of mailing back this questionnaire.

To help you make your decision, a list of the questions that will be asked in the telephone interview are included below. If you choose to participate in the telephone interview, please check "Yes" at the options presented below. You can change your mind later and end your participation at anytime.

QUESTIONS:

1. Some patients who wait for heart surgery need to manage symptoms such as chest pain/pressure, shortness of breath or fatigue. Are you doing anything specific to manage your heart related symptoms while you have been waiting for your surgery? What have you been doing? If you have not been having symptoms why do you think that is?
2. Why do you think that having bypass surgery will be a beneficial or a worthwhile undertaking? What do you expect will be different for you as a result having the surgery?
3. Some people who are waiting for heart surgery have indicated that they feel anxious. Do you feel that way? What would you say has caused you the most anxiety during the waiting period for surgery? If you do not feel that you have been anxious, what things help you not to be anxious?

A copy of these questions has been included on a separate sheet for your records.

☐ Yes I am interested in participating in the telephone interview and answering the questions listed above.

The best time to call me is
(weekdays)

- ☐ Morning 9am to 12 pm
☐ Afternoon 12pm to 4pm
☐ Evening 6pm to 9pm

Name: (Please Print) _____ Telephone #: _____

☐ No I am not interested in participating in the telephone interview.

APPENDIX G

Telephone Interview Guidelines

Hello my name is Kim McCormick. I am a graduate student in nursing from the University of Manitoba. I received your returned survey in the mail recently and noted that you were interested in participating in the telephone interview portion of my study. I thank you for your interest.

Is this a convenient time for you to talk to me about this project? If no, arrange for a mutually convenient time. If yes, proceed:

Do you have any questions about the telephone interview? Answer any and all questions. Then proceed:

You understand that you are by no means obligated to participate in this study. If you decide that you would like to participate in this interview, you can withdraw at any time. Whether you agree to participate or not, neither your medical nor nursing care will be affected in any way. Physicians and other health professionals will not know if you have decided to answer my questions. Participating will also not lengthen or shorten your wait for surgery. There are no anticipated benefits to you if you choose to participate. You understand that any information that you give me during this interview will be kept in strict confidence and that answering my questions will be considered consenting to be included in this portion of the study? Please also be aware that all your answers will be recorded by hand and no tape recording of this conversation will occur. Do you understand? No (clarify), Yes (proceed).

Are you still interested in participating in the telephone interview?

Yes – Arrange a mutually suitable interview time and proceed with interview.

No – Thank you for your time, if you would like to participate in the interview at a later time you may contact me free of charge at () .

The Interview

Interview Time (start) _____ (finish) _____

Questions

1. Some patients who wait for heart surgery need to manage symptoms such as chest pain/pressure, shortness of breath or fatigue. Are you doing anything specific to manage your heart related symptoms while you have been waiting for your surgery? What have you been doing? If you have not been having symptoms why do you think that is?
2. Why do you think that having bypass surgery will be a beneficial or a worthwhile undertaking? What do you expect will be different for you as a result having the surgery?

3. Some people who are waiting for heart surgery have indicated that they feel anxious. Do you feel that way? What would you say has caused you the most anxiety during the waiting period for surgery? If you do not feel that you have been anxious, what things help you not to be anxious?

APPENDIX H

Illness and Surgery Data Information Form

Participant # _____

Date of surgical consult: _____

Date of surgery: _____

Past History of MI:

- (1) No history of MI
- (2) one MI
- (3) two MI
- (4) more than two MI

CCS Angina Classification:

- (1) Class I
- (2) Class II
- (3) Class III
- (4) Class IVA

LVF: _____ %

- (1) greater than 50%
- (2) 35-50%
- (3) 20-34%
- (4) less than 20%

Presence of Comorbid Diseases:

- (1) Diabetes
- (2) Renal failure
- (3) Renal insufficiency
- (4) COPD
- (5) Smoker

Number of Diseased Vessels:

- (1) 1
- (2) 2
- (3) 3
- (4) more than 3

LM disease greater than 50%:

- (1) Yes
- (2) No

Urgency Rating: Score _____

- (1) Emergent
- (2) Urgent (1-14 days)
- (3) Semi-Urgent (15 – 42 days)
- (4) Elective (43 – 180 days)

Surgical Cancellations: Reason: _____ (see below)

- (1) one cancellation
- (2) two or more cancellations
- (3) patient unavailable for surgery at first offered time
- (4) patient had surgery at first available time

Cancellation Reasons

- | | |
|--|---|
| 1. Bumped by more urgent/emergent case | 6. Patient refused surgery/changed mind |
| 2. Patient not NPO | 7. Patient did not come in – day of surgery |
| 3. Unfit for surgery | 8. Deferred/rescheduled |
| 4. Superimposed illness | 9. Pre-booked emergency |
| 5. Indications for surgery disappeared | 10. Other _____ |

Patient Contacts: # _____

Anxiety code marked:

(1) Yes

(2) No

Reasons for patient contacts:

Maximum calculated waiting time (as calculated by database variables): _____(days)

Actual Waiting time: _____(days)

(1) less than one month (2) 1-2 months (3) greater than 2 months

APPENDIX I

No. _____

MISHEL UNCERTAINTY IN ILLNESS SCALE - COMMUNITY FORM**INSTRUCTIONS:**

Please read each statement. Take your time and think about what each statement says. Then place an "X" under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree." If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree." If you are undecided about how you feel, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

2. I have a lot of questions without answers.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

3. I am unsure if my illness is getting better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

4. It is unclear how bad my pain will be.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

5. The explanations they give about my condition seem hazy to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

6. The purpose of each treatment is clear to me.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

7. My symptoms continue to change unpredictably.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

8. I understand everything explained to me.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

9. The doctors say things to me that could have many meanings.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

10. My treatment is too complex to figure out.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

11. It is difficult to know if the treatments or medications I am getting are helping.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

12. Because of the unpredictability of my illness, I cannot plan for the future.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

13. The course of my illness keeps changing. I have good and bad days.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

14. I have been given many differing opinions about what is wrong with me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

15. It is not clear what is going to happen to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

16. The results of my tests are inconsistent.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

17. The effectiveness of the treatment is undetermined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

18. Because of the treatment, what I can do and cannot do keeps changing.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

19. I'm certain they will not find anything else wrong with me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

20. The treatment I am receiving has a known probability of success.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

21. They have not given me a specific diagnosis.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

22. The seriousness of my illness has been determined.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

23. The doctors and nurses use everyday language so I can understand what they are saying

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
-----------------------	--------------	------------------	-----------------	--------------------------

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

APPENDIX J

Symptom Frequency and Symptom Distress Scale

Please think about the symptoms and conditions that affect you as a result of your **heart condition**.

Beginning at the scale on the left side of the page, rate if you have a particular symptom and how **frequently** it causes you problems. In the second scale rate how **emotionally upsetting** the symptoms are to you.

Frequency

0 = Never have symptom

1 = Rarely have symptom

2 = Sometimes have symptoms

3 = Often have symptoms

4 = Always have symptom

Emotional Upset

0 = not at all upsetting

1 = A little upsetting

2 = Moderately upsetting

3 = Quite a bit upsetting

4 = Extremely upsetting

Note: It is possible to be distressed or upset about a symptom if it worries you a lot even if you do not suffer from that symptom at this time

Examples are given below.

Example:

Do you have this symptom?

If yes, how frequently?

How Upsetting is this symptom to you?

	Never	Rarely	Sometimes	Often	Always		Not at all	A little	Moderately	Quite a bit	Extremely
Do you have problems with varicose veins?	0	1	2	3	4	How upsetting are varicose veins to you?	0	1	2	3	4
Do you have problems with bad breath?	0	1	2	3	4	How upsetting is bad breath to you?	0	1	2	3	4

Do you have this heart symptom?
If yes how frequently?

How upsetting is this symptom
to you?

	Never	Rarely	Sometimes	Often	Always		Not at all	A little	Moderately	Quite a bit	Extremely
Do you have problems with chest pain, pressure or discomfort?	0	1	2	3	4	How upsetting is chest pain, pressure or discomfort?	0	1	2	3	4
Do you have problems with left or right arm pain or numbness?	0	1	2	3	4	How upsetting is left or right arm pain or numbness?	0	1	2	3	4
Do you have problems with back or neck pain?	0	1	2	3	4	How upsetting is back or neck pain?	0	1	2	3	4
Do you have problems with jaw or throat pain or toothache?	0	1	2	3	4	How upsetting is jaw or throat pain or toothache?	0	1	2	3	4
Do you have problems with indigestion or heartburn?	0	1	2	3	4	How upsetting is indigestion or heartburn?	0	1	2	3	4
Do you have problems with feeling generalized discomfort?	0	1	2	3	4	How upsetting is feeling generalized discomfort?	0	1	2	3	4
Do you have problems with shortness of breath with activity?	0	1	2	3	4	How upsetting is shortness of breath with activity?	0	1	2	3	4
Do you have problems with shortness of breath when lying flat?	0	1	2	3	4	How upsetting is shortness of breath when lying flat?	0	1	2	3	4

	Never	Rarely	Sometimes	Often	Always		Not at all	A little	Moderately	Quite a bit	Extremely
Do you have problems with waking up in the middle of the night unable to catch your breath?	0	1	2	3	4	How upsetting is waking up in the middle of the night unable to catch your breath?	0	1	2	3	4
Do you have problems with dizziness or light-headedness?	0	1	2	3	4	How upsetting is dizziness or light-headedness?	0	1	2	3	4
Do you have problems with heart palpitations or fast heart beat?	0	1	2	3	4	How upsetting are heart palpitations or fast heart beat?	0	1	2	3	4
Do you have problems with irregular heartbeats?	0	1	2	3	4	How upsetting are irregular heartbeats?	0	1	2	3	4
Do you have problems with fatigue?	0	1	2	3	4	How upsetting is fatigue?	0	1	2	3	4
Do you have problems with swelling to the feet, ankles or hands?	0	1	2	3	4	How upsetting is swelling to the feet, ankles or hands?	0	1	2	3	4
Do you have problems sleeping?	0	1	2	3	4	How upsetting are sleeping problems?	0	1	2	3	4
Do you have problems with nausea?	0	1	2	3	4	How upsetting is nausea?	0	1	2	3	4
Do you have problems with loss of appetite?	0	1	2	3	4	How upsetting is loss of appetite?	0	1	2	3	4

	Never	Rarely	Sometimes	Often	Always		Not at all	A little	Moderately	Quite a bit	Extremely
Do you have problems with depressed mood?	0	1	2	3	4	How upsetting is having a depressed mood?	0	1	2	3	4
Do you have problems with nervousness or shakiness inside?	0	1	2	3	4	How upsetting is nervousness or shakiness inside?	0	1	2	3	4
Do you have problems with feeling fearful?	0	1	2	3	4	How upsetting is feeling fearful?	0	1	2	3	4
Do you have problems with feeling tense?	0	1	2	3	4	How upsetting is feeling tense?	0	1	2	3	4
Do you have problems with panic spells?	0	1	2	3	4	How upsetting are panic spells?	0	1	2	3	4
Do you have problems with restlessness?	0	1	2	3	4	How upsetting is restlessness?	0	1	2	3	4

APPENDIX K

Kansas City Cardiomyopathy Sub Scales

Heart Disease affects different people in different ways. Some may experience chest discomfort while others feel short of breath or fatigue. Please indicate how much you are limited by your heart condition (chest discomfort, shortness of breath or fatigue) in your ability to do the following activities over the past 2 weeks.

Place an X in one box on each line

[illegible]

How much does your heart condition affect your lifestyle? Please indicate how your heart condition may have limited your participation in the following activities over the past 2 weeks.

Please place an X in one box on each line

[illegible]

APPENDIX L

GRAPHICAL ANXIETY RATING SCALE

What has been your level of anxiety during the past two weeks? Place a mark on the line below which indicates how anxious you have been while waiting for your heart operation.

Not Anxious		_____		As Anxious as I could be
		M I L D MODERATE S E V E R E		

Example: How do I mark this scale?

How would you describe Canada's winter climate?

Canada has good winters		_____		Canada has the worst winters imaginable
		M I L D MODERATE S E V E R E		

APPENDIX M

Demographic Questionnaire

Personal Information

Please complete the following questions. Any information that you give is completely confidential. At no time will your name be used in connection with this questionnaire. Please make an "X" on the line beside the answer of each item that is appropriate for you.

Today's Date: Month _____ Day _____ Year _____

Gender: Male _____ (1) Female _____ (2)

Age (in years): _____

How long have you been waiting for your heart surgery?

- | | |
|--------------------------|---|
| _____ 0-2 weeks (1) | _____ 2-3 months (5) |
| _____ 2-4 weeks (2) | _____ 3-4 months (6) |
| _____ 4-6 weeks (3) | _____ more than 4 months (7) |
| _____ 6-8 weeks (4) | _____ I don't know how long I have been waiting (8) |

In your recollection what was the date that you saw your cardiac surgeon and a decision was made to have surgery?

Month _____ Day _____ Year _____

Living Situation:

With whom do you live with now?

- _____ live alone (1)
- _____ live with spouse or equivalent (2)
- _____ live with spouse and other family (e.g. children) (3)
- _____ live with other family or friends (4)
- _____ other (please specify) _____ (5)

Level of Education:

What is the highest grade of school you have completed?

- ☐ Grade 6 or less (Elementary School) (1)
☐ Grade 7 or higher (High School) (2)
☐ Some College or University (3)
☐ College or University Degree (4)
☐ Graduate Degree (5)

Work Status:

What is your current work situation?

- ☐ Working full-time (1)
☐ Working part-time (2)
☐ Stopped working because of my health (receiving illness/disability benefits) (3)
☐ Stopped working because of my health (benefits have run out) (4)
☐ Stopped working because of my health (other, specify _____) (5)
☐ Retired or not working for other reasons (6)
☐ Homemaker (7)
☐ Other (please specify) _____ (8)

Has your work status changed since the decision was made for you to have surgery?

Yes _____ No _____

Your cooperation in completing these items is very much appreciated. Thank you!

If you would like a summary of the findings from this study please check below.

☐ No, I do not want a summary of the findings.

☐ Yes, I would like a summary of the findings.

Name: (please print) _____

Address: _____ City: _____ Postal Code: _____