Symptoms and Distress in Patients Awaiting Coronary Artery Bypass Surgery

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Dans cette étude sur la sévérité des symptômes éprouvés par les patients en attente d'un pontage aortocoronarien, on a joint par le courrier 42 patients inscrits pour la première fois sur une liste d'attente pour cette seule intervention dans le but de constituer un échantillon de commodité, dans le cadre d'un projet de recherche plus vaste portant sur l'attente. On a demandé aux participants de répondre à certaines questions concernant la fréquence des symptômes de maladie coronarienne qu'ils éprouvaient et leur degré de souffrance. Ces données ont été analysées à l'aide d'une version modifiée de l'instrument *Symptom Frequency and Symptom Distress Scale (SFSDS)*. Le score moyen était de 77,7 sur un total possible de 385. On a établi de fortes corrélations entre chacun des éléments sur l'échelle et le score total. Les symptômes les plus fréquents et pénibles qui ont été rapportés sont la fatigue, l'essoufflement pendant l'activité et les douleurs à la poitrine. Les symptômes les plus fréquents étaient également les plus pénibles. Ces résultats soulignent l'importance des symptômes éprouvés par les patients en attente d'un pontage aorto-coronarien et confirment la nécessité de continuer à tester cette version de l'instrument *SFSDS*.

Mots clés : sévérité des symptômes, maladie coronarienne, échelle

In this examination of symptom distress in patients awaiting coronary artery bypass graft (CABG) surgery, a convenience sample of 42 patients on a waiting list for first-time CABG-only surgery were contacted via mail as part of a larger study into the experience of waiting for CABG surgery. They were asked to respond to questions about the frequency and distress of their coronary artery disease symptoms. A modified version of the Symptom Frequency and Symptom Distress Scale (SFSDS) was used. The mean symptom distress score was 77.7 out of a possible 386. Strong correlations were established between each individual item on the scale and the total score. The most frequent and distressing symptoms were fatigue, shortness of breath with activity, and chest pain. The most frequent symptoms were also the most distressing. The findings underscore the significance of symptom experience in patients on a waiting list for CABG surgery and also point to the need for further testing of this version of the SFSDS.

Keywords: coronary artery disease, symptom distress, rating scale

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Coronary artery bypass graft (CABG) surgery has been hailed as a procedure that can save lives as well as improve quality of life. Over 18,000 CABG operations are performed in Canada every year, and trends suggest that these numbers will continue to increase (Heart and Stroke Foundation, 1999). Lengthy waiting lists for CABG surgery indicate that increasing capacity has not kept pace with the demand for treatment. During the waiting period for surgery, patients often remain symptomatic and functionally impaired (Bengtson, Herlitz, Karlsson, & Hjalmarson, 1994, 1996). Symptom status and response to therapy are the main criteria used to prioritize patients on CABG waiting lists (Naylor et al., 1991), but little is known about how patients' symptoms affect their psychological status during the waiting period.

The primary measure of symptom severity in relation to functional status in research is either the New York Heart Association (NYHA) Functional Classification or the Canadian Cardiovascular Society (CCS) Grading Scale for Angina Pectoris. Cox, Naylor, and Johnstone (1994) note that there are several limitations to the NYHA and CCS scales. First, they do not show whether a patient's symptoms are episodic or variable. Second, they are unable to account for a patient's perspective on or individual tolerance level of symptoms. Both scales are graded by physicians based on patients' descriptions of their physical limitations and on patients' symptom status. Third, they 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. Moreover, the assumption that there is physiological equivalence among patients at each level of functional/angina status is unvalidated and no statistical relationships have been found between these scales and disease prognosis, severity of anatomical disease, or quality of life (Cox et al.; Cronin, 1990).

Measuring symptom distress in conjunction with frequency of symptoms may be a more satisfactory means of assessing symptomatology in coronary patients. Symptom distress can be defined 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 but the most intense or frequently occurring symptoms are not always the most distressing (Lough, Lindsey, Shinn, & Stotts, 1987; McClement, Woodgate, & Degner, 1997).

Cardiac symptoms are a continual reminder to patients of their illness. Symptom experience may prompt patients' continuing concern about their health (Cronin, 1990) as well as significantly influencing their psychosocial adaptation to disease as they await CABG surgery. The purpose of this study was to examine symptom distress in patients waiting for CABG surgery. The study was part of a larger, multi-method investigation examining the experience of waiting for CABG surgery.

Theoretical Framework

The theoretical framework for this investigation was Mishel's Middle-Range Nursing Theory of Uncertainty in Illness (Mishel, 1988), according to which the appraisal of symptoms acts as an antecedent to illness uncertainty. The symptom-pattern component of this model refers to the degree to which symptoms present with sufficient consistency to form a clear pattern. Vague, ambiguous, unpredictable, and inconsistent characteristics of the cardiac symptoms experienced may create uncertainty. This model was chosen to guide the larger study, which also examined the relationship between uncertainty and symptom experience. This paper takes an isolated look at the symptom experience of patients awaiting CABG surgery and explores the usefulness of a tool modified to measure this concept.

Method

Procedure

After approval had been obtained from the University of Manitoba Nursing-Education Research Ethics Board and access to the study population had been granted by the Winnipeg Regional Health Authority, potential participants were identified from a cardiac surgery waitlist database. Individuals waiting for first-time, CABG-only surgery at a tertiary-care teaching hospital were invited by mail to participate in the study. After allowing a period of time sufficient for potential participants to decline, a questionnaire package was mailed to the remaining individuals. Those who returned the completed questionnaire were asked to sign a consent form permitting the researchers to examine their personal cardiac surgery database and to contact them by telephone.

Sample

The sample was restricted to patients waiting for first-time, CABG-only surgery. Criteria for inclusion were: 18 years of age or older, ability to

read and write English, and waiting at home or out of hospital for surgery.

Data collection took place over a 5-month period from January 2001 to May 2001 inclusive, with recruitment conducted in two separate convenience samplings (January 11 and April 26) to obtain a variety of patients who had waited varying lengths of time for CABG surgery. A total of 66 patients (41 from the January sampling and 25 from the April sampling) met the criteria and were mailed the introductory letter. Six patients (9%) indicated that they were not interested in participating. Six others (9%) were not mailed the package because they had surgery or were taken off the list in the interim between the mailing of the introductory letter and the time allotted for refusal. Of the remaining 54 potential subjects, 45 returned the questionnaire (for a response rate of 83.3%). Three of the returned questionnaires were eliminated from the analysis when close examination revealed that they did not meet the study criteria ($N = 42$).

The Symptom Frequency and Symptom Distress Scale

The Symptom Frequency and Symptom Distress Scale (SFSDS) was first developed for use in heart-transplant patients by Lough et al. (1987) in relation to immunosuppressive therapy. This self-administered scale is described as being suitable for distribution by mail and assesses physical symptoms experienced and emotional distress caused by the symptoms. A five-point Likert scale (0 = never; 4 = always) is used to measure subjectively assessed frequency of symptoms, while a parallel scale (0 = not at all upsetting; 4 = extremely upsetting) is used to measure the perceived level of associated distress. Cronbach's alpha was found to be .70 for the transplant-symptom frequency scale and .87 for the corresponding distress scale.

For the purposes of this study, the SFSDS was modified to represent symptoms of coronary artery disease and heart failure as identified in the medical and nursing literature and from the principal researcher's extensive experience with individuals with coronary disease symptoms. Experienced cardiac clinicians assessed the modified scale as having face validity.

The modified SFSDS was scored by multiplying the symptom frequency score with the symptom distress score for each item and adding the total score. This is a modification of the scoring method described by Lough et al. (1987). With this method, total scores can range from 0

to 368, with higher scores indicating greater distress. Each symptom can also be used as a separate subscale of the SFSDS.

Results

An evaluation of the demographic characteristics of the sample revealed that the mean age of participants was 64 years (*SD* = 8.5) and that the majority of participants were male (90.5%) and lived at home with a partner (71%). Ninety-five percent had at least one myocardial infarction (57% had two or more), 73% suffered from Class III angina or worse according to the CCS, 95% had a left ventricular ejection fraction (EF) of less than 50% (22% had EFs of less than 35%), and 77% were waiting for CABG on three or more vessels. The average wait, from the date placed on the waiting list to the date of questionnaire completion, was 97 days (*SD* = 61; *range* = 23–260 days).

Figure 1 shows a histogram of the total scale scores for the sample, with score distribution heavily skewed to the left or lower one third of the possible total scale scores. The mean symptom distress score in this sample was 77.7 (*SD* = 60; *range* = 7–286) out of a possible 368. Eighty-two percent of the scores clustered in the lower one third of the range of scores identified for this scale.

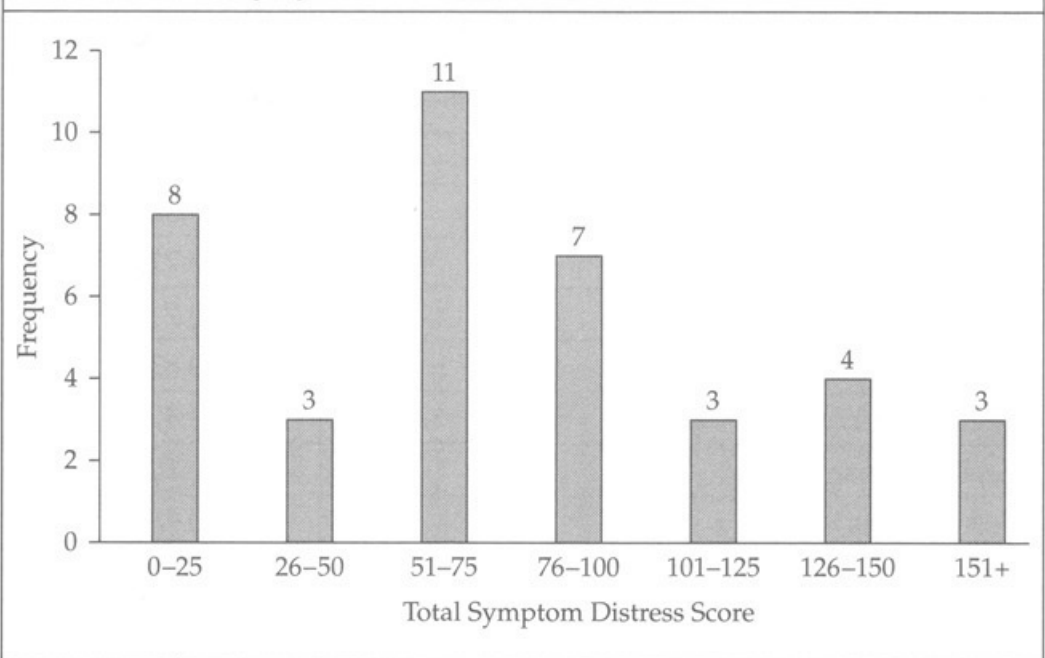**Figure 1** *Distribution of Scores on the Symptom Frequency and Symptom Distress Scale*

Table 1 presents the Pearson's *r* item-to-total correlation as a test of reliability for this version of the SFSDS. All symptoms had significant item-to-total correlations, with the majority having *p* values of .0001 or less. The exceptions were feeling fearful and panic spells, which correlated at .002.

Table 1 *Pearson's r Item-to-Total Correlation for the SFSDS*

| Symptoms	SFSDS Total Score Correlation
Chest discomfort	0.69**
Arm/shoulder discomfort	0.68**
Back/neck discomfort	0.68**
Jaw/throat/tooth discomfort	0.68**
Indigestion	0.68**
Generalized discomfort	0.76**
SOB with activity	0.69**
SOB lying flat	0.75**
Nocturnal SOB	0.64**
Dizziness/lightheadedness	0.60**
Palpitations	0.61**
Irregular heart rate	0.75**
Fatigue	0.68**
Edema	0.57**
Difficulty sleeping	0.64**
Nausea	0.58**
Loss of appetite	0.71**
Depressed mood	0.73**
Nervousness/shakiness	0.82**
Feeling fearful	0.47*
Feeling tense	0.70**
Panic spells	0.48*
Restlessness	0.78**
* *p* = .002, ** *p* = < .0001.	

Table 2 *Rank Order of Scores Related to Frequency of Symptoms, Level of Distress, and Combined Symptom Distress of Individual SFSDS Symptoms for the Total Sample*

	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 discomfort (100)	3	Chest discomfort (93)	3	Chest discomfort (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)

Ranking was also possible for the most to least frequent symptoms, the most to least distressing symptoms, and the most to least combined symptom distress scores for each symptom. This analysis is represented in Table 2 and includes the rank score for each symptom in each category. Three comparable lists of symptom rankings are exhibited here. Table 2 shows that the most frequent symptoms were also the most distressing symptoms in the sample. The relationship between individual-symptom frequency and individual-symptom distress is clarified in Figure 2, where individual-symptom frequency for the total sample

Figure 2 *Frequency and Distress Scores for 23 Symptoms*
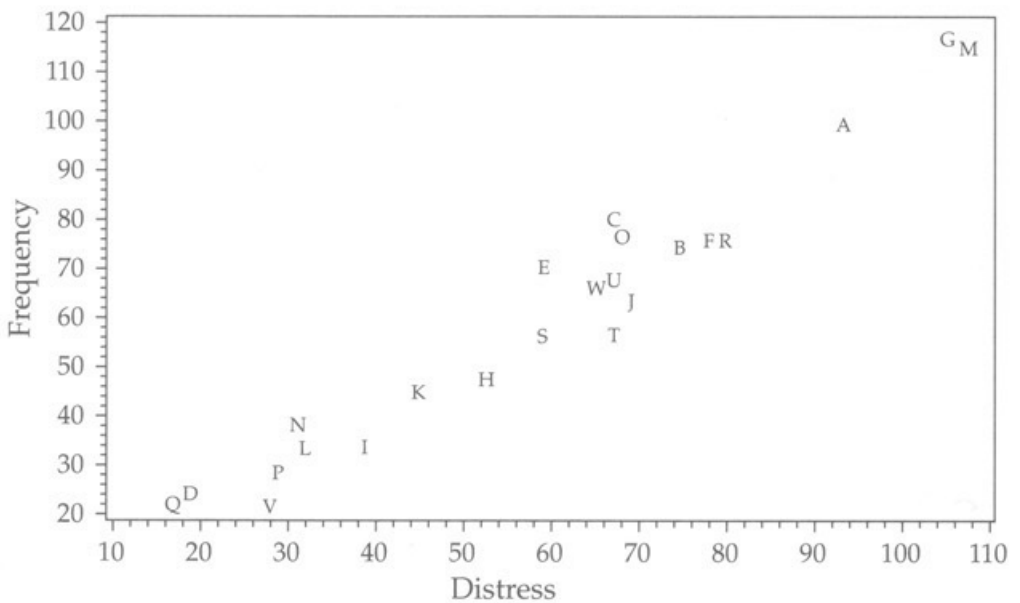
Legend: Plot of individual symptom frequency and individual symptom distress for total sample

A Chest discomfort
B Arm/shoulder discomfort
C Back/neck discomfort
D Jaw/throat/tooth discomfort
E Indigestion
F Generalized discomfort
G SOB with activity
H SOB lying flat
I Nocturnal SOB
J Dizziness/lightheadedness
K Palpitations

L Irregular heart rate
M Fatigue
N Edema
O Sleeping problems
P Nausea
Q Loss of appetite
R Depressed mood
S Nervousness/shakiness
T Feeling fearful
U Feeling tense
V Panic spells
W Restlessness

(on the vertical axis) is plotted against individual-symptom distress for the total sample (on the horizontal axis). Figure 2 shows a linear relationship between the frequency and distress of a particular symptom, providing confirmation that the most frequent symptoms are also the most distressing.

Although most symptoms were associated with some distress, it was possible for a symptom to occur frequently yet be rated as *never* distressing, resulting in a combined symptom distress score of zero even though the symptom was present. The reverse also occurred in that some participants indicated that they *never* experienced a given symptom yet rated the distress for that symptom higher than zero. Because multiplying a value by zero elicits a score of zero, there was initial concern that assigning an overall distress score of zero to a symptom that a patient identified as significant would alter the total SFSDS score. The similar ranking of symptoms in three categories (frequency, distress, and total), as shown in Table 2, indicates that this was not the case.

Discussion

Although the majority of scores clustered in the bottom third of the scale (82%), 62% of the subjects also participated in a qualitative telephone interview during which symptoms were identified as a key source of anxiety in the waiting period. The relief of symptoms was identified as important to the relief of anxiety, thus establishing a link between the presence of symptoms and psychological distress (McCormick, 2002).

There are several possible explanations for the low distress scores as measured by the SFSDS. First, this 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 will be rated zero (in both frequency and distress) for each patient. Second, true symptom distress may realistically be low due to proper medical and patient self-management during the waiting period. As well, the chronic nature of cardiac symptoms may have influenced the distress scores. Many patients would have been living with cardiac symptoms for many years prior to being placed on the 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 they have adjusted to a life that includes cardiac symptoms. A few of

the telephone interviewees, when asked about their symptoms during the waiting period, indicated that their symptoms had been present for a long time prior to the waiting period and they dealt with them as a part of daily living (McCormick, 2002). The phenomenon of accommodation to cardiac symptoms has been identified in prior research (Radley, Green, & Radley, 1987). This scale may be useful in detecting subtle but serious deterioration in a patient's condition that, because of accommodation, would ordinarily go unrecognized by the patient and would not be reported to the health-care team.

Although it has been observed with cancer patients (McClement et al., 1997) and heart-transplant recipients (Lough et al., 1987) that the most frequent symptoms are not necessarily the most distressing, such was not the case in this study. The SFSDS results show that individual symptoms rated for frequency, distress, and combined-symptom distress produced similar lists. The three most frequent and distressing symptoms experienced by the sample were fatigue, shortness of breath with activity, and chest discomfort. This finding is consistent with that of Jonsdottir and Baldursdottir (1998). Because the most frequent symptoms were also the most distressing, it is possible that measuring frequency alone might be equivalent to measuring an overall symptom-distress level. However, more research is needed before it can be confidently suggested that the frequency or distress level of a symptom alone is equivalent to overall symptom distress for coronary artery disease populations.

The present results are limited by the untested nature of the Symptom Frequency and Symptom Distress Scale as modified for this project. Further information about and revisions to the scale will be necessary to evaluate its usefulness in this population of patients, as well as to identify what constitutes mild, moderate, and severe symptom distress. Scoring of the scale also requires re-examination, and a factor analysis using a large sample of patients with a variety of cardiac conditions would be a useful way of statistically assessing this instrument. Because many of the symptoms included in the scale could be non-cardiac in origin (e.g., indigestion, back/neck discomfort), it is essential to identify which symptoms most clearly represent the patient's total cardiac symptom distress.

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Authors' Note