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Development and Preliminary Validation of a Self-Perceived Burden Scale for Individuals with Chronic Illness

By

Natalie Janine Cousineau

Thesis submitted to the School of Graduate Studies and Research in partial fulfilment of the requirements for the M.Sc. degree in Epidemiology

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Index of Tables.....	vi
Index of Figures.....	vi
ABSTRACT	vii
Chapter 1: BACKGROUND	1
1.1 Self-Perceived Burden.....	2
1.2 Conceptual Framework.....	4
1.2.1 Physical Burden.....	5
1.2.2 Emotional Burden	5
1.2.3 Financial Burden.....	7
1.3 Importance of the Issue of Self-Perceived Burden.....	8
1.3.1 Burden Relating to Helping Relationships.....	9
1.4 Burden and Coping.....	10
1.5 Functional Classification of Measurement Instruments.....	12
1.6 Potential Modifiers of Burden	13
1.6.1 Perceived Control	14
1.6.2 Social Support	14
1.6.3 Help-Seeking Behaviour	16
1.6.4 Gender	16
Chapter 2: OBJECTIVES	18
2.1 Overall Objective:	18
2.2 Objectives for Phase I:.....	18
2.3 Objectives for Phase II:.....	18
Chapter 3: PHASE I	19
3.1 METHODS	19
3.1.1 Overview	19
3.1.2 Phase I Study Participants.....	20
3.1.3 Development of Interview Schedule for Qualitative Study.....	21
3.1.4 Administration of Interview	22
3.1.5 Methods for Scale Development	23
3.1.5.1 Item Extraction	23
3.1.5.2 Face Validity	24
3.1.5.2 Content Validity.....	25
3.1.6 Item Clarity Testing.....	26
3.2 RESULTS.....	29
3.2.1 Scale Development.....	29
3.2.2 Item Clarity Testing.....	33
Chapter 4: PHASE II	35
4.1 METHODS	35
4.1.1 Population	35
4.1.2 Administration of Self-Perceived Burden Scale	37
4.1.3 Selection of Study Instruments.....	38
4.1.3.1 Functional Status Index.....	38

4.1.3.2	Medical Outcomes Study Social Support Survey	39
4.1.3.3	Short-Form-36 Health Survey.....	40
4.1.4	Supplemental Items	40
4.1.5	Examination of Response Patterns	41
4.1.6	Homogeneity of the Items	42
4.1.7	Analytic Procedures.....	43
4.1.7.1	Descriptive Statistics	43
4.1.7.2	Bartlett's Sphericity Test.....	44
4.1.7.3	Factor Analysis	44
4.1.7.4	Principal Component Theory	45
4.1.7.5	Rotation of Factors	46
4.1.7.6	Further Statistical Analysis	47
4.1.7.7	Inter-Group Comparisons	49
4.2	RESULTS.....	50
4.2.1	Factor Analysis.....	54
4.2.2	Item Refinement.....	56
4.2.3	Item Utility Analysis.....	57
4.2.4	Hypothesis Testing	63
4.2.5	Comparison of Burdened vs. Unburdened Patients on Hemodialysis.....	67
Chapter 5:	DISCUSSION	69
5.1	Summary of Findings.....	69
5.2	Correlates of Self-Perceived Burden	71
5.3	How Does This Study Improve Our Understanding of Self-Perceived Burden?	73
5.4	What Determines a Person's Level of Self-Perceived Burden?.....	77
5.5	Do Hemodialysis Patients Believe They Are a Burden to Others?	79
5.6	Purpose of the Self-Perceived Burden Scale.....	80
5.7	Possible Reasons for Negative Results.....	81
5.8	Limitations of the Study	82
5.9	Is Burden Maladaptive Coping?	85
5.10	Future Directions	86
Chapter 6:	CONCLUSION	89
Reference List	90
Appendix I.....		99
Patient Consent Form for Interview		99
Appendix II.....		100
Phase I Patient Interviews-- Semi-Structured Interview Schedule		100
Appendix III.....		101
Phase I-- Health Professional Interviews-- Semi-Structured Interview Schedule		101
Appendix IV		102
Instructions Provided to Respondents for Content Validity Testing		102
Appendix V		103
Patient Consent Form for Item Clarity Testing		103
Appendix VI		104
Item Clarity Testing Questionnaire		104
Appendix VII		115
Patient Consent Form.....		115
Appendix VIII		116
Short Portable Mental Status Questionnaire.....		116

Appendix IX	117
Demographic Information.....	117
Appendix X	121
Functional Status Index	121
Appendix XI	122
MOS Social Support Scale	122
Appendix XII	123
Short-Form 36 Health Survey	123
Appendix XIII	127
Self-Perceived Burden Scale	127
Appendix XIV	129
Supplemental Items	129
Appendix XV	130
Initial List of 80 Items	130
Appendix XVI	133
Factor Loadings-- Principal Components Analysis.....	133
Appendix XVII	134
Rotated Factor Structure (Varimax).....	134
Appendix XVIII	135
Oblimin Oblique Rotation (Δ 0.25).....	135
Appendix XIX	136
Oblimin Oblique Rotation (Δ 0.5).....	136

Index of Tables

Table 1: Semi Structured Interview Schedule Used in Qualitative Phase	27
Table 2: Quotes From Interviews With Patients and Health Professionals	34
Table 3: Themes Included in Conceptual Framework as a Result of Interviews	36
Table 4: 29 Item Scale	37
Table 5: Final List of 24 Items	38
Table 6: Supplemental Items	46
Table 7: Classification of Scale Items Based on Theoretical Framework	52
Table 8: Baseline Characteristics of 100 Participants with End-Stage Renal Disease	56
Table 9: Sources and Nature of Support Available for 100 Patients with End-Stage Renal Disease	58
Table 10: Factor Loadings of Items on Self-Perceived Burden Scale After a Principal Components Analysis With a Varimax Rotation	60
Table 11: Items From Self-Perceived Burden Scale Ranked as Loaded on a Single Underlying Factor Using Principal Components Analysis	62
Table 12: Performance of Individual Items From Self-Perceived Burden Scale as Administered to 100 Individuals	63
Table 13: List of Items Included in the Final Version of the Self-Perceived Burden Scale	66
Table 14: Factor Analysis of 10-Item Self-Perceived Burden Scale Using Principal Components Analysis	68
Table 15: Correlation Testing of Total Self-Perceived Burden Scores Using Independent Samples T-Test	71
Table 16: Correlation Testing of Total Self-Perceived Burden Scores Using Pearson Correlation Coefficient	71
Table 17: Characteristics of Burdened vs. Unburdened Individuals in a Sample of 100 Hemodialysis Patient Using an Independent Sample T-Test	73

Index of Figures

Figure 1: Preliminary Conceptual Framework for Self-Perceived Burden	10
Figure 2: Score Distribution for 24-Item Self-Perceived Burden Scale as Administered to 100 Patients Undergoing Hemodialysis	59
Figure 3: Score Distribution for 10-Item Self-Perceived Burden Scale as Administered to 100 Patients Undergoing Hemodialysis	67
Figure 4: Suggested Structure of Self-Perceived Burden and its Underlying Dimensions	81
Figure 5: Alternate Proposal—Self-Perceived Burden and its Influencing Factors	82

ABSTRACT

i. Statement of the Problem

Caregiver burden has been studied at length in caregivers of many populations of chronically ill people. The other side of the informal caregiving relationship is the recipient's response to aid, especially their perceptions of the burden they pose to their caregiver. This is referred to as self-perceived burden, and has rarely been studied from the patient's point of view. Strong feelings of being a burden may be an important emotional factor influencing adjustment to illness, compliance with physician's orders, utilization of health-care resources and end-of-life decision-making. The current study advances the current understanding of self-perceived burden through the development and preliminary validation of the Self-Perceived Burden Scale.

ii. Methods of Investigation

A thorough review of existing literature provided a starting point for the conceptual framework of self-perceived burden. Following this, semi-structured interviews were conducted with six people currently undergoing regular hemodialysis, as well as four health professionals experienced at counseling patients living with chronic illness. The items generated from this process were subjected to evaluation of face and content validity, resulting in a 24-item scale. This scale underwent item clarity testing with a subset of the study population.

The 24-item Self-Perceived Burden scale was administered to a sample (N=100) of patients currently undergoing hemodialysis. A number of other questionnaires were administered concurrently to allow for hypothesis testing and description of the patient population.

iii. Results

Factor analysis revealed the presence of one main factor. The Self-Perceived Burden Scale showed high inter-item correlations, as well as high internal consistency (Cronbach's $\alpha = 0.92$), indicating a high degree of redundancy. The face validity, content validity, response pattern, loading on the single burden factor and inter-item correlations were examined for each of the 24-items. The Self-Perceived Burden Scale was reduced to 10-items, removing much of the redundancy.

Self-Perceived Burden Scores in our sample of hemodialysis patients were found to correlate with gender ($p < 0.01$), help-seeking behaviour ($p < 0.01$), perceived control ($p < 0.01$), physical functioning ($p < 0.01$), mental health ($p < 0.01$) and many of the subscales of the SF-36 Health Survey. People undergoing hemodialysis who identified their spouse as their primary caregiver had significantly higher feelings of being a burden. Self-Perceived Burden was not found to be significantly correlated with social support, age, education or any co-morbid condition.

iv. Conclusion

Through the course of this study, we have developed a valuable screening instrument for feelings of being a burden. It is brief, easily self-administered, and reliably identifies individuals in emotional distress due to feelings of being a burden on others.

By identifying a more precise source of negative feelings, health care practitioners will be able to devise a more effective intervention aimed at alleviating feelings of being a burden. Possible interventions include altering the caregiving situation by arranging respite care or additional home care resources, or arranging counseling for both the help recipient and the caregiver.

The Collins Dictionary defines burden as “something that is emotionally difficult to bear, or a great source of despair and worry”. In the context of health, the concept of burden refers to the negative feelings experienced as a result of caring for another person (caregiver burden). In this study, we examine burden from another perspective—that of the individual living with a chronic illness. That person’s sense of being a burden to others as a result of their illness is the focus of this study.

This study proposes the development and preliminary validation of a tool intended to measure the degree to which a chronically ill individual feels that they are a burden to their primary caregiver. This proposed measure would predict the patient’s adjustment to their disease or disability—conversely, high feelings of burden would indicate maladjustment to their caregiving situation.

Chapter 1: BACKGROUND

As the population ages and advances are made in medical treatment, people are living with chronic illnesses for increasing periods of time.¹ At a time when hospitals continue to streamline their services, increasing responsibility is placed on the family to care for and assist their loved one with many basic activities of daily living. Often, the burden of care falls to the family, with little to no assistance from paid caregivers.² This responsibility is often a great burden to the unpaid caregiver.³⁻⁶ The other side of the situation, much less researched, is the chronically ill person’s perception of the burden they pose to their caregiver. For the purposes of this study this feeling is referred to as ‘self-perceived burden’. The perception of the burden the person places on their caregiver is

likely to be an important source of negative feelings and distress in the chronically ill individual.

Caregiver burden has been studied at length in caregivers of various patient populations; for example, people with developmental disabilities,^{7,8} the elderly,⁹ people with mental illnesses,^{10,11} multiple sclerosis,¹² dementia,¹³ stroke,^{3,14,15} and congestive heart failure.¹⁶ Numerous studies have shown that the burden felt by caregivers can lead to physical health problems, social isolation, and emotional distress.^{3,14,17}

Although there is no shortage of literature pertaining to the burden experienced by caregivers of chronically ill people, the concept of burden has rarely been studied from the patient's point of view. If the burden of caring for a chronically ill or disabled individual is likely to impart adverse mental and physical health consequences on the caregiver, it is also likely that the degree to which the patient feels that they are a burden may lead to emotional distress in that patient.

1.1 Self-Perceived Burden

The literature review was accomplished through an extensive search of both MedLine and PsychLit databases. From 1966-1999, MedLine produced 11335 articles using "burden" as a keyword, 3177 articles under the MESH heading "Chronic Disease", and 3189 articles using "Caregiver" as a keyword. A combination of "Burden" and "Chronic Disease" yielded 61 articles, and combining "Burden" and "Caregiver" produced a list of 382 articles. These final 443 articles were reviewed for relevance to patient's feelings towards their

caregivers. Those deemed relevant were critically appraised and the bibliographies reviewed for additional relevant articles. This process resulted in approximately 130 articles relating to coping with chronic illness and recipient's reactions to aid.

This search of the literature revealed only one formal attempt to measure the degree to which a chronically ill patient feels that they are a burden. An Israeli study addressed this idea by examining the perceptions burden of both the elderly cancer patient and his caregiving spouse.¹⁸ Interviewers administered a Caregiver Burden Scale to thirty-two people undergoing treatment for cancer, as well as their spouses. They found that the spouse's scores indicated higher levels of burden than the patient's, indicating that the patient's perceived burden to their caregiver is not an accurate assessment of the actual burden experienced. The explanation offered by the researcher for this difference is that the elderly cancer patient finds it hard to adjust to a situation of dependence, and therefore finds it hard to accept that the illness and treatments are putting a burden on the spouse. With a sample size of thirty-two pairs of cancer patients and their spouses, this study was only a small study. In addition, having the respondents predict their caregiver's responses to a caregiver burden scale is not the same as asking them about their perceived burden directly—the researchers did not test the validity of applying the caregiver burden scale to the patients themselves.

A formal definition of feelings of being a burden is lacking. Even in the literature that refers to this feeling in examining an individual's reaction to chronic

illness, an individual's reaction to needing help and factors (including self-perceived burden) influencing end of life decision-making.¹⁷⁻²⁴ Because none of the studies defined the concept of patient-perceived burden directly, we planned a qualitative study to understand the elements of self-perceived burden as part of the development of the conceptual framework for the scale.

1.2 Conceptual Framework

The amount that an individual feels that they are a burden to their caregiver refers to their perception of the negative effects that they have on the life of that person. Self-perceived burden is a multi-dimensional construct including the patient's feelings of guilt, dependence, frustration and worry, as well as the negative feelings brought on by feelings of responsibility for another's hardship. Although no attempts have been made to examine self-perceived burden, several studies have defined burden as it applies to the caregiver of a chronically ill individual.^{3,13-15,18,25,26} Some of these definitions contain elements which may translate appropriately to the perceived burden of the chronically ill person, either directly or with minor modifications. Three dimensions of perceived burden common in many examinations of caregiver burden are physical burden^{3,12-15,18,26-28}, emotional burden^{3,12-15,18,26-28} and financial burden^{15,22,26,27}. Self-perceived burden is hypothesized to consist of these three main dimensions, seen in Figure 1 below:

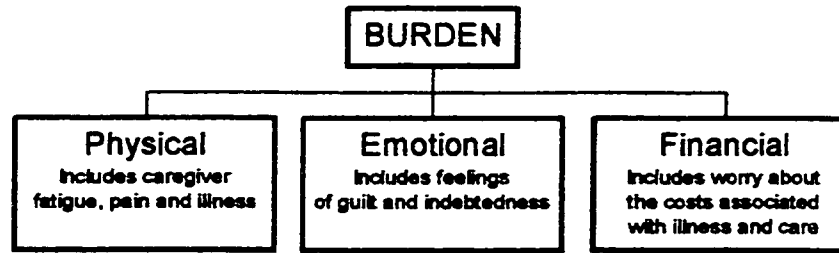


Figure 1: Preliminary Conceptual Framework for Self-Perceived Burden

1.2.1 Physical Burden

Patient-perceived physical burden is the patient's perception of the effects of his/her illness on the physical health of the his/her caregiver. This includes a patient's perceptions of physical exhaustion, as well as deteriorating health of the caregiver as a result of the physical demands of caring for the chronically ill individual. We believe this may be an especially important component of burden when the individual is dependent on the caregiver for transfers and ambulation.

1.2.2 Emotional Burden

Emotional burden encompasses the chronically ill persons worries regarding the emotional and mental health of the caregiver. This includes feelings of indebtedness, guilt, and feelings of responsibility for the stress and emotional exhaustion experienced by the caregiver. Literature has found caregiver burden to encompass feelings of culpability, stress, internal strain, anxiety about the future, and anticipation of future health problems¹⁵. This may also include feelings of anger, impatience, guilt, depression, strain, resentment,

annoyance^{3,14}, emotional exhaustion of caregiver,¹³ and perceived willingness and ability of caregiver to support patient³.

One aspect of patient perceived burden that will be incorporated into the scale is the role of indebtedness. The equity theory of recipients' reactions to aid set forth by Greenberg and Westcott²⁹ states that the exchange of aid often causes a perceived inequity in the eyes of the care recipient. This perceived inequity causes distress for both the overbenefitted and underbenefitted participants in the exchange. This may result in feelings of guilt, burden or indebtedness in the overbenefitted, and anger and resentment in the underbenefitted. As a result, the overbenefitted individual will often do anything in their power to attempt to restore equity to the relationship.

In the case of providing care for an individual with chronic illness, the receipt of aid is often not a choice, but a necessity. In this case, there are two main avenues available to restore the perception of equity. Actual equity may be restored by altering relative gains appropriately. However the quantity of help received by a chronically ill individual cannot be negotiated, as any decrease in the quantity of help received may result in basic needs not being met. Instead, altering perceptions of the situation in either adaptive or maladaptive ways may restore psychological equity. This cognitive distortion may result in feelings of being a burden, subsequently leading to depression, anxiety, or hostility towards the caregiver.

1.2.3 Financial Burden

Patient-perceived financial burden involves the patient's concerns regarding the financial losses experienced by their caregiver as a result of their illness. This refers to the individual's worries over the costs associated with his or her illness, such as loss of wages and expenses associated with medical treatment. In one study exploring stressors, coping mechanisms and quality of life among a sample of 64 Australians on hemodialysis, worry regarding the costs of medical care were a concern cited by 36% of respondents.³⁰ Other studies have also identified decreased financial status and costs associated with illness as stressors and losses that threaten the hemodialysis patient, as well as other people living with chronic illness.³¹⁻³³

These dimensions, while originally applied to caregiver burden, can also be viewed from the perspective of the patient. The greatest difference between the concepts of caregiver burden and patient-perceived burden is the perspective of the respondent. In the case of caregiver burden, the caregiver is responding directly to questions about how he or she feels. This is a direct report of feelings. In the case of patient-perceived burden, it is the chronically ill patient's perceptions of a situation that are being measured. This perception may or may not be an accurate reflection of the situation, and may be influenced by many more factors than those that are objectively integral to the circumstances. For example, it is possible that a person may be oblivious to the burden they impose on their caregiver. This would result in self-perceived burden scores much lower

than caregiver self-reports of burden. Finally, it may be that chronically ill people may see themselves as a much greater burden to their caregivers than is perceived by the caregivers themselves. This last possibility may be influenced by feelings of indebtedness, guilt, or in response to subtle cues from the caregiver.

1.3 Importance of the Issue of Self-Perceived Burden

The degree to which a chronically ill patient feels that they are a burden to their family and/or caregivers may be an important emotional factor interfering with both the delivery of medical care and patient compliance with physician's orders. Repercussions of high feelings of being a burden may include adverse emotional consequences in caregivers as well as negative emotional consequences in patients, such as depression and anxiety. Repercussions of high feelings of being a burden derived from the literature include influences on end of life decision-making^{22,23,34,35}, altered utilization of resources,²² decreased use of life-prolonging measures^{21,22,36} and increased likelihood of requests for euthanasia^{22,36}.

One of the most important reasons to study patient perceived burden is that it may be decreased if modifiable factors are addressed. Possible interventions for a chronically ill patient experiencing emotional distress over feelings of being a burden include counseling for both patient and caregiver, modifying the patient's coping mechanisms for dealing with feelings of emotional distress, and mobilizing additional outside resources, such as the need for respite care.

Consequently, the ability to measure patient burden will better allow researchers to explain the variability in end of life decision-making and utilization of health care resources. This would be accomplished by permitting measurement of a patient's sense of being a burden separately from other factors that may influence their decision whether or not to opt for life-sustaining measures. Also, the ability to measure an individual's self-perceived burden will enable health care providers to optimize the emotional health and well-being of varied populations of chronically ill patients.

1.3.1 Burden Relating to Helping Relationships

Theoretically, the same factors that exert influence on the helper/help recipient relationship will also influence the consequences of that relationship, including feelings of being a burden. Various sources ^{29,37-41} have identified factors exerting influence on the helper/help recipient relationship. These influences have been classified into two broad categories ⁴²: situational characteristics (including helper characteristics, aid characteristics and context characteristics of the aid transaction) and recipient characteristics (including external perceptions, internal perceptions, and behavioral responses). In patients currently undergoing hemodialysis, many of the major elements falling under the heading of situational characteristics have very little variability. In the hemodialysis unit, issues such as the nature of the aid and the nature of the relationship between the helper and the help recipient are, for the most part, constant between individuals. What causes patients to differ in the amount of burden they feel that they present to their caregiver is largely as a result of

recipient characteristics. This includes: their external perceptions of the care, such as whether the aid is offered voluntarily or begrudgingly; internal perceptions, such as the degree to which they feel dependent on the caregiver and the perceived debt to the caregiver created by the caregiving situation; and the patients behavioural responses, such as the impact that feelings of burden may impart on the patient's help seeking behaviour.

1.4 Burden and Coping

A chronically ill patient's feelings of being a burden are also related to the way in which patients appraise and cope with the stress of their illness.^{31,43} For many patients, medical factors alone do not adequately account for the extent of illness-related dysfunction.⁴⁴ If this were so, all patients suffering from similar symptom complaints would experience the same degree of psychological distress. This is not the case, as both the physical and psychosocial functioning of individuals with chronic medical conditions varies widely.⁴⁴

According to the widely cited Lazarus and Folkman (1984) model of stress, adaptation to a stressor is mediated by two factors: appraisal (the personal significance of the stressor and one's resources dealing with it), and coping (the thoughts and behaviors used to manage the demands of the stressor).⁴⁵ Theoretically, coping derives from appraisal processes because one's choice of coping mechanism will be influenced by his judgment and perception of the stressor.⁴⁴ Coping strategies, according to this theory, are divided into two broad functional domains— problem-focused coping which aims

at managing the external environmental aspects of the stressor (i.e. doing something about it), and emotion-focused coping which regulates the internal affective consequences of the stressor (i.e. changing the way you think about it). Prior research has shown that regardless of diagnosis, emotion-focused coping (wishful thinking) had a negative impact on adjustment while problem-focused coping (information seeking) had a positive effect.^{44,46} Other studies have found that the use of problem-focused coping strategies have benefited various patient populations by decreasing symptom complaints^{47,48}.

One possible explanation of the relationship between coping and feelings of burden is that the category of emotion-focused coping strategies includes the patient's perception of being a burden. This class of coping strategies has been associated with depression and anxiety.^{46,49,50}

An alternative explanation of the relationship between burden and coping might be to view feelings of burden as the outcome of attempts to cope with a chronic disease. In this view, feelings of being a burden would be considered a product of coping, analogous to depression. The reason for not classifying burden as an outcome is that it is considered a side effect of the interaction between the chronically ill individual, their disease and their caregiver. Outcomes would be apparent further down the chain, resulting in this case from feelings of being a burden. In this theory, burden is a self-perception and not a disease state, like depression or anxiety. It is a perception that may be realistic or exaggerated, but which in turn influences the development of subsequent disease or disability.

Although the consequences of feelings of being a burden have not been studied directly, it is possible to make assumptions based on studies relating to the consequences of other maladaptive, emotion-focused coping strategies. Generally speaking, avoidance coping (such as self-criticism, self-blame and feelings of being a burden) has been positively correlated with greater symptom complaints.⁴⁴ It has been shown that in specific types of illness, appraisal and coping responses are concurrent predictors of illness-related adaptive functioning and depression.⁴⁴ These responses are independent of the patient's diagnosis, as the same studies found that the patient's adaptation to chronic illness was entirely independent of diagnosis and severity of symptoms.^{32,43,50-52} For this reason, coping thoughts and actions under stress must be measured separately from their outcomes in order to examine, independently, their adaptiveness or maladaptiveness.⁵³

1.5 Functional Classification of Measurement Instruments

Before further work was completed, it was necessary to specify the purpose of the Self-Perceived Burden Scale. The purpose of an instrument refers to the type of research question that it answers. Although there have been slight variations in classification, the three general functional classifications are descriptive, evaluative and predictive.⁵⁴⁻⁵⁶ The distinctions between the three categories are not precise, although there are general guidelines to be followed. A descriptive instrument is used primarily as an assessment— this can then be used to estimate prevalence in a study population, and is often used in surveys. Evaluative instruments serve mainly to detect change in the underlying construct,

such as before and after an intervention. This type of measure is usually more specific than the general descriptive instruments. In the development of an evaluative instrument, the psychometric properties of the scale, especially floor and ceiling effects, are of greater concern. The final category, predictive instruments, are used in screening, diagnosis and risk assessment. These scales go beyond simply measuring the underlying construct by including additional measures intended to predict the likelihood of a future event.

As the current study is the first known attempt to measure the degree to which a person with chronic illness feels that they are a burden to their caregiver, our primary goal is to describe feelings of self-perceived burden in order to gain insight into the patient's well-being. For this reason, the Self-Perceived Burden Scale is intended to be a descriptive instrument. Future work may adapt this measure for evaluative purposes. Using the Self-Perceived Burden Scale, we will be able to describe the prevalence and severity of feelings of being a burden in a population of people with chronic illness.

1.6 Potential Modifiers of Burden

Although a definitive explanation of a persons' perceptions of being a burden has not yet been clearly defined, it is possible to hypothesize the relation between feelings of being a burden and other related factors. These hypotheses are largely drawn from related literature, and will be used subsequent to the development of the scale, in order to perform a preliminary evaluation of validity. It must be noted, however, that in the absence of pre-existing literature pertaining

directly to the concept of self-perceived burden, many of the following hypotheses are based largely on speculation. The rejection of any hypothesis will not necessarily lead to the rejection of the scale, but will lead to further examination of the issue in the exploration of self-perceived burden.

1.6.1 Perceived Control

Generally speaking, greater perceived control is associated with better psychological outcomes for individuals with health problems.⁵⁷⁻⁵⁹ When placed in the context of receiving help, recipients with high levels of perceived control preferred lesser amounts of assistance, whereas recipients with low levels of perceived control are most affected by insufficient help. This may be due to the fact that individuals tend to respond better to social environments that fit with their expectations of the world.⁶⁰

For the purposes of this study, perceived control will be measured through a subscale of the SF-36 and used as a validating hypothesis. The SF-36 includes a 5-item subscale measuring general health perceptions. This subscale has been found to include a valid measure of perceived control.⁶⁰ It is expected that patients with less perceived control over their health would be likely to have greater feelings of being a burden.

Hypothesis: A greater sense of being a burden will be significantly correlated with less perceived control, as measured by the "General Health Perceptions" subscale of the SF-36.

1.6.2 Social Support

Social support has been proven to exert a significant effect on the patient's illness experience, as well as the helper/recipient relationship. It has

been shown that a lack of social support may contribute to deterioration in health and declining physical abilities.^{61,62} Although it is often assumed that all support will result in a positive effect,³⁸ many interactions in which family and friends are attempting to be supportive can be perceived negatively.³⁷ In addition, the experience of serious illness may put strain on a previously supportive relationship.³⁷ This effect may manifest itself in several ways— one study has shown a decrease in patient marital satisfaction after serious illness, and found that a non-supportive marital relationship leads to greater distress among those who received help from a spouse.³⁷ Negative interactions with social network members have been associated with distress and other negative mental health outcomes.⁶³

From the patient's point of view, perceptions of the support available to them may change with decreasing functionality. For example, one study found that perceived social support diminished significantly with poorer health in patients suffering from diabetes.⁵⁰

Social support will also be used in correlations for the purpose of validity testing. The overall perceived social support will be examined, in addition to the subscales tangible support, affection, emotional and informational support, and positive social interaction. These subscales were initially identified by the authors of the scale.⁶⁴ It is expected that those individuals reporting higher levels of social support should also feel a greater sense of being a burden.

Hypothesis: A greater sense of being a burden will be significantly correlated with increased social support as measured by the MOS Social Support Scale.

1.6.3 Help-Seeking Behaviour

There exist many different factors which may modify or influence an individual's help-seeking behavior. These factors may be intrinsic, such as personality traits or self-esteem, or extrinsic, such as the relationship between the helper and the help receiver or the characteristics of the helping situation.⁴² It is hypothesized that feelings of being a burden will exert a strong effect on a chronically ill patient's help-seeking behaviour. Individuals particularly concerned with being a burden on their caregiver will be much less likely to ask for help when they need it, and may do without rather than ask for help.^{29,42} Although help-seeking behaviour is not a dimension of burden itself, these hypotheses will be tested through correlations between perceived burden scores and supplemental questions concerning help-seeking behaviour.

Hypothesis: A greater sense of being a burden will be significantly correlated with a decrease in help-seeking behaviour, as measured by two supplemental questions administered separately.

1.6.4 Gender

Gender of the help-seeker has been identified as an important intrinsic factor in moderating an individual's reactions to receiving help. Women have been documented to seek medically related help more than men, independent of morbidity and physical symptoms.⁴¹ Reasons for this have been widely speculated. Among the suggested hypotheses are sociocultural influences, such as mental stress and female role obligations,⁶⁵ and the possibility that the apparent higher rates of illness in women are more artifactual than real.⁶⁵ Subsequently, it is possible that feelings of being a burden will be more prevalent

among one gender than the other. Interestingly, evidence may support increased burden scores in either gender. In this population of patients, it is hypothesized that men will be expected to have a greater sense of being a burden than women. This is due primarily to the emotional stress associated with a forced deviation from traditional social roles, as well as the higher emotional cost of asking for help in men.^{41,66} Men, having traditionally been the breadwinners of the family, are now faced with not only a loss of that income, but often increasing dependence on a wife, son or daughter. The role of the help recipient is often a difficult one for men to assume, and they are more likely to be aware of the burden that their care places on their caregiver or their family.

Hypothesis: Gender will be likely to be significantly correlated with increasing feelings of being a burden, with men scoring higher on perceived burden than women.

Chapter 2: OBJECTIVES

The overall purpose of this study is to develop a measurement instrument meant to describe the intensity with which a chronically ill patient feels that they are a burden to their caregiver. This will be accomplished in two phases: First, a qualitative study will explore the themes associated with perceptions of being a burden, in order to define the appropriate content for the scale. From this phase, a scale will be constructed and reviewed by experts for face validity and relevance, as well as to eliminate any redundancy. Second, a quantitative study will administer the scale to a sample of 100 patients, and test hypotheses regarding related factors.

2.1 Overall Objective:

1. To develop a measure of self-perceived burden.

2.2 Objectives for Phase I:

1. To identify themes related to self-perceived burden among chronically ill patients.
2. To compile items, drawn from these themes, which capture the concept of burden.

2.3 Objectives for Phase II:

1. To pilot test the items on a population of hemodialysis patients.
2. To perform preliminary validation of the final list of items.

Chapter 3: PHASE I

Phase I of this study involved interviewing patients and health professionals regarding the issues associated with needing help, and the creation of items designed to measure the concept of self-perceived burden.

3.1 METHODS

3.1.1 Overview

A qualitative study was undertaken in order to identify the issues that people with chronic illnesses associated with feelings of being a burden. The concept of self-perceived burden is hypothesized to encompass three major domains—physical burden, such as the physical stress associated with lifting, transfers and assisted ambulation; emotional burden, such as feelings of guilt and indebtedness; and financial burden, such as worries about loss of income and costs associated with illness.

When devising a new measurement instrument in the absence of a clearly defined conceptual framework, one of the best methods available to devise items is through key informant interviews, where people who have had the disorder in question can tell you how they felt.⁶⁷ This can also be accomplished through interviews with clinicians who have had extensive experience counseling people with the disorder.⁶⁷ In this study, an experienced interviewer conducted one-on-one interviews with six patients and four health professionals following a semi-structured interview schedule (Table 1). This interviewer was chosen based on her extensive experience interviewing people living with chronic illness, specifically those dealing with end-of-life issues.

3.1.2 Phase I Study Participants

Six patients currently undergoing hemodialysis and four health professionals at the Ottawa Hospital, General Campus were selected for participation in semi-structured interviews. The hemodialysis population was chosen mainly due to their widely varied levels of disability.^{30,68,69} This particular patient population may range from needing no help at all to being very dependent on others for their activities of daily living. People requiring dialysis have been shown to be limited in their physical activity,⁶⁹ and therefore likely to depend on a family member or friend in some aspects of their lives. This may cause them to experience feelings of being a burden to those from whom they receive help. The four health professionals were identified through their involvement with the Ambulatory Kidney Unit at the General Campus of the Ottawa Hospital. This group included one clinical psychologist, two social workers and one nursing unit manager, all of whom had extensive experience working with chronically ill individuals on hemodialysis.

Patients participating in the study were informally screened for mental competence and English language ability by the nursing unit manager of the hemodialysis clinic. Any patient who reported requiring help from an unpaid caregiver (i.e., family member, spouse, friend or neighbour) was considered eligible for participation. Patients identified as eligible for participation were subsequently approached during their routine dialysis treatment for completion of the interview. Health professionals were interviewed at their convenience in a private office setting.

3.1.3 Development of Interview Schedule for Qualitative Study

The interview schedule was developed by combining questions regarding burden derived from the literature with questions exploring the hypothesized conceptual framework of patient self-perceived burden. The questions were developed in conjunction with a clinical psychologist, and were designed to encourage the patient to speak openly about their relationship with their caregiver. For the health professionals, questions were identified based on existing literature relating to caregiver burden and the need to rely on others for help. All questions were reviewed with a clinician and a clinical psychologist to ensure relevance to the conceptual framework. Questions were worded in such a way as to allow the interviewer flexibility to pursue other relevant themes as they arise.

Table 1: Semi Structured Interview Schedule Used in Qualitative Phase**For Patients:**

- 1) Who helps you with your day-to-day activities?
 - a) What kind of help do they give you?
 - b) How does it feel to need their help?
- 2) When someone helps you, how does it make you feel?
 - a) What do you think makes you have these feelings?
- 3) Whom do you expect to offer you help?
 - a) When they don't offer, how do you feel about asking?
- 4) Do you feel that you are getting enough help?
 - a) How often do you feel that you need more help?
 - b) What could be done to ensure that you get the help that you need?
- 5) What concerns do you have about your caregiver's ability to handle the physical demands of helping you?
- 6) How has needing help changed your relationship with your caregiver?
 - a) In what ways has it changed?
- 7) How has your illness affected your other relationships/friendships?

For Health Professionals:

- 1) What kind of patients do you counsel?
- 2) How disabled are these patients?
- 3) When patients can no longer care for themselves, what is done to ensure that they get the help that they need?
- 4) What issues have you noticed come up regularly when talking to patients about their caregiving arrangements?
- 5) How are your patients experiencing increasing levels of dependence on their family and friends?
- 6) Are feelings of being a burden a common occurrence among patients that you have dealt with?
- 7) Do negative feelings about receiving care influence the relationship between the patient and their caregivers? If so, why?
- 8) What sorts of issues and situations have you found to increase the sense of burden found in your patients?
- 9) What other feelings have you observed to be associated with feelings of being a burden?

3.1.4 Administration of Interview

Interviews were performed during the respondents regular dialysis session. Initial contact was made by a member of the patient's health care team, and informed consent was obtained prior to the interview.(Appendix I) Before commencing the interview, anyone accompanying the respondent to dialysis was asked to leave the room in order to encourage the individual to speak freely

regarding their caregiver and their need to rely on others. These interviews, which were recorded on audiocassette, were intended to explore the patient's feelings regarding relying on others for help. All health professional interviews were conducted in a private office, recorded by the investigator. Recordings were transcribed verbatim within 24 hours of each interview. Transcripts of each interview were examined carefully, and all quotes regarding relying on others for help and perceptions of being a burden were identified and recorded.

3.1.5 Methods for Scale Development

3.1.5.1 Item Extraction

Using the preliminary conceptual framework (Figure 1) as well as the information from interviews with dialysis patients and health professionals, the conceptual framework was further expanded and refined. Based on the resulting framework elaborated from Phase I, a master list of themes relating to patient perceived burden identified by patients, health professionals, and the literature were transformed into item format. These items based on patient and health professional interviews were combined with those items based on the literature, resulting in a list of 80 items concerning issues relating to (and including) a patient's self-perceived burden. The list of 80 items is included in Appendix XV. This list was reviewed by a clinical psychologist, a physician and myself for relevance to the conceptual framework of patient perceived burden. Subsequently, the same researchers identified obvious redundancies and removed redundant items from the scale, as well as items with no evident bearing on the burden construct (e.g. items relating to depression, perceived social support, hopelessness, anger). In addition, items deemed redundant,

jargon-filled or double-barreled were removed as per guidelines set out in Streiner and Norman⁷⁰. These items were written in the first person singular (e.g. I feel..., I worry..., I am concerned...) designed for responses following a Likert-type five point scaling system. Response possibilities ranged from "none of the time" to "all of the time". This resulted in a 29 item scale.

3.1.5.2 Face Validity

The concept of face validity examines whether or not the items appear to be assessing the desired qualities.⁷¹ A high degree of face validity increases the acceptance of the instrument by those who will ultimately use it. If the item appears to the respondent to be irrelevant, they may object to it or omit it entirely, regardless of its possibly superb psychometric properties.⁷² By developing the measurement instrument based on proven qualitative methods, face validity was maximized. This was done in three ways: First, themes were identified from caregiver burden literature. These themes were hypothesized to apply to self-perceived burden as well. Second, additional themes were identified through semi-structured interviews with key informants, a process which also served to confirm the relevance of the themes derived from the caregiver burden literature. These themes were carefully transformed into items by the members of the research team. Third, to verify the face validity of each item, the individual items were tested through consensus of the members of the research team. Each item was examined for clarity and relevance to the proposed conceptual framework, those items not meeting the approval of all members of the research team were

subsequently eliminated. These steps maximized face validity of the items in the scale.

3.1.5.2 Content Validity

The concept of content validity is closely related to that of face validity in that it helps to determine whether the scale appears to be appropriate for the intended purpose. In addition to this judgement, content validity ensures that the scale has enough items and adequately covers the domains under investigation.⁷¹ As a result, the higher the content validity of a measure, the broader are the inferences that we can draw about the result under a variety of conditions and situations.⁷² For the purpose of this study, content validity was established in the development of the scale by having a panel of health professionals rate each item on a scale of one to ten for relevance to the conceptual framework.

The 29-item scale (Table 7) was given to a psychologist and two social workers for review. The three clinicians were supplied with a printed copy of the conceptual framework, and were asked to rank each item on a scale of one to ten for relevance to the proposed conceptual framework. A copy of the instructions provided to respondents for this process is provided in Appendix IV. All items scored lower than five by any reviewer were subsequently reviewed by the researchers, until a consensus judgement was made. Some of the items deemed questionable were retained in a separate section entitled 'Supplemental Items' for the purpose of validity testing and comparison of item performance.

3.1.6 Item Clarity Testing

The next step of scale development was to test its clarity with its target population. Standard item clarity testing was performed with a convenience sample of five patients from the patient population of the hemodialysis unit at the Ottawa Hospital, General Campus. All patients participating in the Phase I item clarity testing were identified through the dialysis unit at the Ottawa Hospital, General Campus. Patients were informally screened for mental competence and English language ability by the nursing unit manager of the hemodialysis clinic. Any patient who reported requiring a significant amount of help from an unpaid caregiver (i.e., family member, spouse, friend or neighbour) was considered eligible for participation. Informed consent was obtained from each participation prior to commencement of the interview.(Appendix V)

The technique of item clarity testing was originally introduced by Nuckols⁷³ to ensure that items are understood, unambiguous and jargon-free. The goal of this testing is to ensure that the final scale is understandable to a wide range of patients. The technique used in this study was proposed by Foddy,⁷⁴ and involved patients explaining to the interviewer the thought process that led to their response to each item. If this thought process indicated that the respondent had correctly interpreted the item, the item is deemed clear. Item clarity testing was performed in a structured interview format, with notes being recorded by the interviewer. The complete item clarity testing interview is provided in Appendix VI.

First, the patient read the introduction to the Self-Perceived Burden Scale. This introduction explains the study definition of a caregiver, and gives examples of some activities with which the respondents may need help though the course of their day. The instructions conclude by requesting that the patient rate each statement on the Likert-type scale, being as honest as possible. After reading the introductory paragraph, each patient was asked a series of questions. The first question asked if the respondent understood what the instructions were asking him to do. The second question explored his understanding of what kind of relationship the questionnaire was asking about. The third simply asked if there was any aspect of the instructions that was not clear to the respondent.

Following the assessment of the introduction, each patient was presented with a full-page copy of the five point Likert scale as shown below:

None of the time	A little of the time	Some of the time	Most of the time	All of the time
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This scale was evaluated for ease of understanding and discrimination by each patient. This was accomplished by testing each interval of the response scale in order to ensure that respondents could differentiate between categories. For example, in order to test the first interval on the scale, respondents were asked if they were able to see a difference between “none of the time” and “a little of the time”. This process was repeated for each interval on the response scale.

In the last portion of item clarity testing, each patient was presented with the items on the burden scale in sequence, and asked a series of questions designed to rate the acceptability and ease of understanding of each item. The questions are shown below.

1. Do you understand this statement?
2. What is this statement talking about?
3. What specific things do you think of when you try to rate this statement on the scale?
4. Is there any part of this statement that you find unclear?

This process was repeated for each of the twenty-four items.

3.2 RESULTS

3.2.1 Scale Development

Individual semi-structured interviews were successful in identifying many themes and issues associated with feelings of being a burden, as well as other feelings and concerns associated with increasing dependence on others. A sample of the transcripts of the semi-structured interviews are displayed in Table 2 below.

Table 2: Quotes From Interviews With Patients and Health Professionals

Verbatim Quotes from Patients

- "...because since my daughter has been helping me a lot, it made her sick. She had a burnout, so her doctor suggested that she stay away, because I was dragging her down with all my sickness." (Mrs. A)
- "Well, at first I didn't like it (*asking for help*). I was the kind of person who wanted to be independent, so it was hard to ask 'will you help me with this, will you help me with that?.'" (Mrs. A)
- "You just think 'God I have to ask (*for help*) again and I don't feel like asking. You're a pest.'" (Mrs. A)
- "Oh God, that's the worst thing in the world (*to rely on others for help*). She has to help me, and I don't like it." (Mr. B)
- "I don't want to interfere (*in my children's lives*)..." (Mr. B)
- "Very sad. A bit of anger. You have to start answering for yourself." (*describing his reaction to family member's refusal to help*) (Mr. B)
- "I don't like to say 'will you do this for me, will you do that.' I don't like to do that, even with my wife." (Mr. C)
- "I used to not want people to help at all. My daughter would try to help, and I wouldn't let her. Until she just said 'don't be so damn stubborn!'" (Mr. D)
- "I've learned to accept it. I just said one day 'I can't go on living this way without any help' and so I got some." (Mr. D)
- "I've got 3 son-in-laws, and a son, all helpful. But I say away from them, frankly, when it comes to needing help, they frustrate the hell out of me. They sort of take over the job and I feel left out of it. I don't like that. So we've stopped asking them for help unless it's really something that I can't handle." (Mr. E)
- "... it makes you feel beholden to them (*when friends and neighbours help me out*), and you wish that you could do something for them... you're in debt to them and I don't like to be." (Mr. E)
- *How does it make you feel to have to ask others for help?* "Well, rather like a burden... I just am so used to being the one who helps." (Mrs. F)

Verbatim Quotes from Health Professionals

- "There are some people who have said that they don't want to rely, don't want to be a burden on their families, they put it that way, 'I don't want to bother them, I don't want to burden them.'" (Nursing Unit Manager)
- "They don't want to bother people. 'I feel useless. They have better things to do than take care of me. They have their own life.'" (Nursing Unit Manager)
- "...one of the things that comes up is the guilt that they feel that they can't do things around the house." (Psychologist)
- "...but the thing that will make them cry, is when you talk about the emotional burden." (Psychologist)
- "...I have to take some responsibility for this extra stress on the house, because it's my disability that caused this extra stress" (Psychologist)
- "...with *(the patient's)* reduced ability to take care of themselves, they become concerned with how much of a burden it is for themselves, for their family..." (Psychologist)
- "They don't want to impose on the caregiver, so they've pushed themselves to the maximum." (Social Worker A)
- "They see their needs as interfering with their children being able to get on with their own life." (Social Worker A)
- "I think there's a sense of loss as people become a burden, and I think it's very much related to end-of-life issues... since it was associated with death, dying, loss of health, they just blocked it out and went on their merry way, which was a way of coping." (Social Worker A)
- "There's a little bit of a contradiction when I talk to people where they want to live for the family, and at the same time there is that feeling of being a burden on the caregiver." (Social Worker B)
- "There's this vulnerability of the patient in having to depend yet again on both finances and the caregiver. They're completely dependent. And I think that's where you'll see more of that element of depression. And that becomes like a debt, in need of repayment." (Social Worker B)
- *(other feelings associated with a patient's perception of being a burden are)* "...loss of will to live, depression, fear of what would happen if something happens to caregiver... fear of the possibility of placement, fear of the caregiver not wanting to care for them anymore..." (Social Worker B)

The amendments and additions to the conceptual framework as a result of the semi-structured interviews are illustrated in Table 3 below. These themes fall under the headings of physical, emotional and financial burden, and were later transformed into item format for inclusion in the Self-Perceived Burden Scale.

Table 3: Themes Included in Conceptual Framework as a Result of Interviews

- Worry that health of caregiver may suffer
- Reluctance to ask for help
- Worry about needing to be placed in a long-term care facility
- Not wanting to be a bother
- Difficulty in accepting need to rely on others
- Afraid to interfere in other's lives by asking for help
- Caregiver helping begrudgingly
- Frustration with being dependent
- Feelings of indebtedness
- Anger, often directed at people who are trying to help
- Eventual acceptance—relying on others becomes easier with time
- Willing to accept help if it's offered, but not if they have to ask for it
- Feeling like they're a burden
- Would rather go without than have to ask for help
- Guilt over not being able to function
- Feelings of being useless
- Feeling responsible for extra stress in household
- Torn between asking more of caregiver and resisting having to be placed in a residence or nursing home
- Anger related to inability to manage own care
- Sense of loss associated with end-of-life issues
- Results in loss of will to live

These issues were drawn directly from transcripts of patient interviews, and were subsequently re-written into items. This process resulted in the construction of 80 items.(Appendix XV) Further examination of the scale following methods outlined previously resulted in the creation of a 29-item scale, shown below.

Table 4: 29 Item Scale

1. I am concerned that my caregiver will "wear out" because of the demands of helping me.
2. I worry that the health of my caregiver could suffer as a result of caring for me.
3. I worry that my caregiver is overextending him/herself in helping me out.
4. I am concerned that it costs my caregiver a lot of money to care for me.
5. I worry that my caregiver has to take time away from other things to help me.
6. I feel guilty about the demands that I make on my caregiver.
7. I feel guilty that my caregiver has to change their plans in order to help me.
8. I worry about my caregiver because they have to take on too much responsibility for me.
9. I worry that my caregiver has lost control of their life due to caring for me.
10. I'm concerned that my needs are so great that my caregiver can't handle them.
11. It troubles me to ask my caregiver for help so I overextend myself.
12. I am concerned that if I ask for help it will put too much pressure on my caregiver.
13. I often find myself doing without some things rather than having to ask for help.
14. I often feel dependent on others to get by.
15. I am concerned that because of all they do for me, the person caring for me may not be able to do so much longer.
16. I am concerned that my caregiver is helping me beyond their capacity.
17. I am concerned that I won't be able to "repay" my caregiver for all they've done for me.
18. I find it easier to ask for help when I feel that I can give something in return.
19. I am concerned that the demands of my care have strained my relationship with my caregiver.
20. I am concerned that if I asked for outside help, my caregiver would resent it.
21. I am concerned that I am "too much trouble" to those around me.
22. Receiving help from others makes me feel loved.
23. I am concerned that because of my illness, my caregiver is trying to do too many things at once.
24. I am concerned that because of caring for me, my caregiver is being pulled in too many directions.
25. I am concerned about the negative effects of my illness on those around me.
26. I am confident that my caregiver can handle the demands of caring for me.
27. I am concerned that if my caregiver had a choice, they wouldn't be caring for me.
28. I find it easier to accept help when it's offered, rather than when I have to ask.
29. I think that I make things hard on my caregiver.

The process of assessing for content validity by health professionals resulted in the removal of items 11,13,14,20,27. This resulted in a list of 24 items, which were subsequently re-numbered for simplicity.

The final scale contained 24 items and is illustrated below.

Table 5: Final List of 24 Items

- | |
|---|
| <ol style="list-style-type: none"> 1. I am concerned that my caregiver will “wear out” because of the demands of caring for me 2. I worry that the health of my caregiver could suffer as a result of caring for me 3. I worry that my caregiver is overextending him/herself in helping me out 4. I am concerned that it costs my caregiver a lot of money to care for me 5. I worry that my caregiver has to take time away from other things in order to help me 6. I am concerned that I won’t be able to “repay” my caregiver for all they’ve done for me 7. I feel guilty about the demands that I make on my caregiver 8. I worry about my caregiver because they have to take on too much responsibility for me 9. I feel guilty that my caregiver has to change their plans in order to help me 10. I worry that my caregiver has lost control of their life due to caring for me 11. I’m concerned that my needs are so great that my caregiver can’t handle them 12. I am concerned that if I ask for help it will put too much pressure on my caregiver 13. I am concerned that because of all they do for me, the person caring for me may not be able to do so much longer 14. I am concerned that my caregiver is helping me beyond their capacity 15. I find it easier to ask my caregiver for help when I feel that I can give something in return 16. I am concerned that the demands of my care have strained my relationship with my caregiver 17. I am concerned that I am “too much trouble” to my caregiver 18. Receiving help from others makes me feel that they care for me 19. I am concerned that because of my illness, my caregiver is trying to do too many things at once 20. I am concerned about the negative effects of my illness on those around me 21. I am confident that my caregiver can handle the demands of caring for me 22. I find it easier to accept help when it’s offered, rather than when I have to ask 23. I am concerned that because of caring for me, my caregiver is being pulled in too many directions 24. I think that I make things hard on my caregiver |
|---|

3.2.2 Item Clarity Testing

The process of item clarity testing revealed no inconsistencies or ambiguities relating to the instructions, the scoring method or the scale items themselves. All items were understood by all five patients, and no problems with format or language were identified. None of the items were removed as a result

of item clarity testing with a subset of the target population. The Self-Perceived Burden Scale was deemed ready for validity testing on a patient population.

Chapter 4: PHASE II

Phase II of this study involved the administration of the 24-item burden questionnaire to a larger patient population, in order to complete preliminary validity testing.

4.1 METHODS

4.1.1 Population

All patients participating in the Phase II testing of the Patient-Perceived Burden Scale were identified through the hemodialysis unit at the Ottawa Hospital, General and Civic Campuses. Inclusion criteria included a score of 8 or greater on the Short Portable Mental Status Questionnaire, English language fluency, and reports of requiring a significant amount of help from an unpaid caregiver (i.e., family member, spouse, friend or neighbour). Language and helping criteria were informally determined by the nursing unit manager of each hemodialysis unit.

Using a master list of hemodialysis patients from the General Campus, patients were excluded if considered mentally incompetent, deaf, or unable to speak or understand the English language. Eligible patients remaining on the list were approached within the first two hours of their dialysis treatment. Once approximately 70 patients had been enrolled at the General Campus, the study expanded to include the Ottawa Hospital's Civic Campus, where this process was repeated.

Once a patient had been identified, they were introduced to the researcher who informed them of the goals of the study. If the patient agreed to participate, the researcher obtained informed consent (Appendix VII) and assessed the caregiving situation by asking a brief series of questions designed to determine characteristics of the care situation, with the goal of assessing suitability for inclusion in the study. I administered three general screening questions regarding the respondent's living arrangements, the person whom usually helps them with day-to-day activities and whether they have any friends or family in the area that they could call for help if it was needed. If the patient indicated through their responses to these questions that they relied on a friend or family member for help, they were enrolled in the study. The screening continued with the Short Portable Mental Status Questionnaire,⁵⁴ administered in order to assess mental competency. (Appendix VIII) The Short Portable Mental Status Questionnaire has been developed as a screening tool for cognitive deficit. The SPMS consists of ten questions, covering short- and long-term memory, orientation to surroundings, knowledge of current events and ability to perform mathematical tasks. For respondents with some high school education, 3 to 4 errors is considered to represent an impaired state.⁷⁵ This screening instrument has been proven reliable in numerous studies with reported alpha and test-retest reliability ranging from 0.82 to 0.85⁷⁵⁻⁷⁷. This particular screening instrument was chosen for its brevity, simplicity, and ease in scoring. A score of 8 or higher (total score possible was 10) indicated mental competency, and a score of 7 was accepted for those patients with less than a seventh grade education.⁷⁸

Patients with end stage renal failure requiring hemodialysis were chosen mainly due to their widely varied levels of disability.^{30,68,69} Patients undergoing regular hemodialysis may range from needing no help at all to being very dependent on others for all of their activities of daily living. People on hemodialysis were chosen because they have been shown to be limited in their physical activity,⁶⁹ and therefore likely to depend on a family member or friend in some aspects of their lives. This could cause them to experience feelings of being a burden to those from whom they receive help.

Approval for the study was obtained from the Research Ethics Committee of the Ottawa Hospital, and each patient gave informed consent prior to participation on the study.(Appendix VII)

4.1.2 Administration of Self-Perceived Burden Scale

Demographic information was obtained either from the patient record or through direct inquiries with the patient. I also assessed the quantity and nature of paid and unpaid help available to the patient, as well as the identity of the individual identified by the patient as being their primary caregiver. Patients were then asked to complete four questionnaires on their own—a draft version of the Self-Perceived Burden Scale, and three measures for use in validity testing (Functional Status Index,⁷⁹ MOS Social Support Scale⁶⁴ and the SF-36⁸⁰). Each patient was offered the option of completing the questionnaires independently; however, visual handicaps, illiteracy, extreme fatigue, or having the dialysis access line impeding their writing arm often required administration of the questionnaires by a researcher. For those choosing to have the questionnaires

administered verbally, each item was read verbatim and answers were recorded on the questionnaire. For those patients choosing to complete the study independently, I returned in 30–45 minutes to collect the completed questionnaires. The completed questionnaires were reviewed with the respondent to ensure that no items had been omitted. Demographic information was obtained through review of the medical record at a later date.

4.1.3 Selection of Study Instruments

Additional measurement instruments were selected with the goal of describing the patient population and providing data for hypothesis testing in order to assess validity. Patients completed the Self-Perceived Burden Scale, the Functional Status Index, the Medical Outcomes Study Social Support Survey, and the Short-Form 36 Health Survey.

4.1.3.1 Functional Status Index

The Functional Status Index (FSI)^{79,81-83} was used as a means of assessing each patient's limitations with basic activities of daily living. The FSI focuses on self-reported functional performance, that is the level of function of the person whose health status is being assessed. This scale was originally derived from the Quality of Well-Being Scale⁵⁴, which uses self-reports in order to assess performance across three dimensions of confinement: mobility, physical activity and social activity. The FSI consists of a list of 12 tasks of varying difficulty, and the respondent rates their difficulty on a scale of one to four. Higher scores indicate more disability, with a total score range from 12 to 48.

This shortened, self-reported version of the FSI has been validated on older elective surgery patients⁸⁴, orthopedic patients^{79,85} and patients with atrial fibrillation⁸¹. All found the modified Functional Status Index to be valid and reliable with various clinical populations. This scale was chosen as a brief, succinct measure of physical ability that was able to be both self-administered and interviewer-administered without difficulty.

4.1.3.2 Medical Outcomes Study Social Support Survey

The MOS Social Support Survey was developed by the Rand Medical Outcomes Study team to assess the ability to develop and maintain major social relationships. Preliminary studies have shown this scale to be both valid and reliable^{61,64,86} with reports of internal consistency as high as $\alpha=0.97$ and test-retest reliability at 0.78. This survey has been specifically recommended for use in surveys and epidemiological studies of chronic disease etiology.⁸⁷ Four subscales are incorporated into this scale, including tangible support, affection, positive social interaction, and emotional or informational support. The subscale scores may be combined in order to illustrate total social support reliably. Each item is scored on a Likert-type scale with responses ranging from 1 to 5, corresponding to how often the respondent feels that each type of support is available to him. Higher scores indicate better perceived social support, and the total reported score may range from 20 to 100. This measure of social support was chosen because it is easily self-administered, and measures not only the quantity of social support available to the respondent, but its perceived quality as well.

4.1.3.3 Short-Form-36 Health Survey

The Medical Outcomes Study Short-Form-36 Health Survey is a multi-item scale measuring each of eight health concepts: (1) physical functioning, (2) role limitation due to physical health problems, (3) bodily pain, (4) general health, (5) vitality (energy/fatigue), (6) social functioning, (7) role limitations due to emotional problems, and (8) mental health (psychological distress and psychological well-being). The SF-36 was chosen primarily due to its ease of administration and reputation for being the "Gold Standard" of general health measures. Using the Rand approach, answers are recoded onto a weighted 0-to-100 score, oriented so that high values represent more favorable health states.⁵⁴ Research to date offers good support for the assumption of a linear relationship between item scores and the underlying health concept defined by their scales, if all prescribed scoring assumptions are satisfied.⁶⁰ The SF-36 has been proven valid and reliable, with reported alpha reliability exceeding 0.80 in a number of studies.⁶⁸⁻⁹¹ It is widely accepted, and has been shown to be effective in a wide variety of patient populations, including the chronically ill and patients undergoing hemodialysis.^{69,92,93}

4.1.4 Supplemental Items

Items not considered to fall under the hypothesized burden construct but still of interest to the researchers were administered to respondents as a separate group of items, labelled 'Supplemental Items' shown below (Table 6).

These additional items include questions identical to those retained in the burden scale only worded positively, as well as questions pertaining to help-seeking behaviour, dependence on caregiver and an item directly assessing perceived burden. These items will be compared to the properties of those retained in the Self-Perceived Burden Scale. Other supplemental items will be used for the purpose of testing the hypothesis regarding the effect of burden on help-seeking behaviour. Each supplemental item was in statement format. Response alternatives followed a Likert-type format identical to that used for the items of the Self-Perceived Burden Scale, with options ranging from 'none of the time' to 'all of the time'.

Table 6: Supplemental Items

- | |
|--|
| <ol style="list-style-type: none"> 1. I feel certain that I do not make too many demands on my caregiver 2. I am not worried that my caregiver is overextending him/herself in taking care of me 3. I don't think that I ask too much of my caregiver 4. I am concerned that I am a burden to my caregiver 5. I am concerned that my caregiver really doesn't want to help me 6. I am concerned that if I asked for outside help, my caregiver would resent it 7. I am concerned that my caregiver doesn't "let" me do things for myself that I can do 8. It troubles me to ask for help so I overextend myself 9. I often find myself doing without some things rather than having to ask for help 10. I often feel dependent on others to get by 11. I am concerned that if my caregiver had a choice, they wouldn't be caring for me |
|--|

4.1.5 Examination of Response Patterns

The first step was to examine the distribution of responses to each item in the 24-item scale (Table 8).⁷⁰ Items with extreme response patterns (either very high or very low) were eliminated. If p is over 0.95 or under 0.05, we would be able to predict the response to the item before it is administered with greater than 95% accuracy. We therefore learn very little by knowing how an individual actually responded.⁷⁰ Skewed distribution may result in ceiling effects, where

most of the responses are clustered at the high extreme.⁹⁴ This effect makes it difficult to detect improvement, or distinguish among positive responses. Skewed distribution towards the negative end of the response scale results in floor effects, making it difficult to discriminate between respondents at the lower end of the underlying construct.

A general guideline offered by Streiner and Norman⁶⁷ is to retain all items with endorsement rates between 0.20 and 0.80. The endorsement rate refers to the proportion of people who give each response alternative to an item. With a 5-point Likert-type scale such as the one used to score the Self-Perceived Burden Scale, each item has 5 'frequencies of endorsement': the proportion choosing option A, the proportion choosing option B, and so forth. For the purpose of this analysis, the highest proportion of response in any one category was recorded. Results showing greater than 80% of respondents in the same response category were regarded as suspect, as this illustrates a highly skewed response distribution.

4.1.6 Homogeneity of the Items

In the case of self-perceived burden, we were attempting to measure feelings and emotions—therefore, it was assumed that we would like the scale to be relatively homogeneous. As a result, all of the items should tap different aspects of the same attribute rather than different parts of different traits.⁹⁵ One method of calculating this correlation is through the Cronbach's α coefficient of internal consistency.

Cronbach's α is a measure of reliability through correlation—it reflects the average correlation among items of a scale, taking into account the total number of items in the scale.⁹⁶ This is done through comparison of the sum of variance of individual items with the total variance of the scale. This formula is a measure of how homogeneous the scale items are, and must be calculated separately for each subscale in the measurement instrument. A low α may indicate that either the scale is unreliable, or that it actually measures several different things.⁹⁶ This measure is not without shortcomings— α is highly dependent on the number of items in the scale, and the inferences made from α are highly variable depending on the purpose of the scale. The goal of internal reliability is that the items should be moderately correlated with each other, and that each item should correlate with the total scale. “Moderate” correlation is specified to avoid redundancy and the sacrifice of content validity.⁹⁷ If α is too high, this may suggest a high level of item redundancy. Thus, α should be above 0.70 to reassure that the scale does measure a cogent theme,⁹⁸ but not higher than 0.90, which suggests redundancy and needless length.⁹⁵

4.1.7 Analytic Procedures

4.1.7.1 *Descriptive Statistics*

Demographic information was obtained through examination of frequency tables, means, standard deviation (interquartile ranges) and histograms using SPSS 9.0 statistical package for Windows. Preliminary investigation into the performance of the Self-Perceived Burden Scale was accomplished through assessment of response histograms for each of the 24 items. This allowed for

determination of the highest endorsement rate for each item, as well as the identification of items with highly skewed response patterns. The mean, standard deviation and frequency distribution of each item were examined for anomalies and outliers, as well as any suspect distribution.

4.1.7.2 Bartlett's Sphericity Test

When performing a factor analysis with a sample size of 100 or smaller, it is important to apply Bartlett's sphericity test. This procedure tests the null hypothesis that the variables in the population correlation matrix are uncorrelated.⁹⁹ If the null hypothesis is not rejected there is no reason to do the components analysis as the variables themselves are already uncorrelated. As the sample size in the current study is $n=100$, Bartlett's test for sphericity was run.

4.1.7.3 Factor Analysis

Using the statistical software package SPSS 9.0 for Windows, a factor analysis was performed using the original 24-item scale. The purpose of the factor analysis is primarily to interpret the correlations among a number of intercorrelated quantitative variables and group variables into a few 'factors', such that variables within each factor are more highly correlated with variables in their factor than with variables in other factors.¹⁰⁰ Factor analysis assumes that each item is a measure of an abstract—and not directly measurable—underlying theme. Once these correlations are calculated, the factor analysis manipulates the correlations among the items to produce linear combinations of the items.¹⁰¹

Each linear combination is called a factor. There are two methods of obtaining the best estimates of factors: the method of maximum likelihood and the method of least squares. The factor analysis using the method of maximum likelihood was performed with data collected from the administration of the Self-Perceived Burden Scale. The maximum likelihood solution is a method of statistical estimation which seeks to identify the population parameters with a maximum likelihood of generating the observed sample distribution.

4.1.7.4 Principal Component Theory

For the purpose of this study if the hypothesized conceptual framework is correct, we should expect to observe the extraction of three principal components, identifiable as physical, emotional and financial burden. Principal component analysis is an analytic method distinct from common factor analysis, although they often yield similar results.^{99,102} Both principal component analysis and factor analysis derive linear combinations of the original variables, and often a small number of these account for most of the variation.⁹⁹ Principal component analysis is mathematically simpler than factor analysis. This process partitions the total variance by first finding the linear combination of the variables which accounts for the maximum account of variance. The first component accounts for the largest amount of variance, the second component accounts for the next largest amount of variance after the variance attributable to the first component has been removed in the system, and so on until no variance remains unaccounted for in the system.⁹⁹ Each component is constructed as to be uncorrelated with the others.

In deciding which components should be retained, the most widely used criterion is that of Kaiser, which states that all eigenvalues greater than one should be retained. The size of the eigenvalues reflects the dispersion of the data in a multivariate space that has one axis for each component.¹⁰⁰ This criterion has been shown to be quite accurate, especially when there less than 30 variables⁹⁹. For this reason, we will employ the default Kaiser criterion and retain all variables with eigenvalues greater than one.

4.1.7.5 *Rotation of Factors*

Rotating the factors obtained through factor analysis or principal components analysis will generally increase their interpretability, making interpretation of the resulting factors easier. This may be accomplished through two major classes of rotations: orthogonal rotations, where the new factors remain uncorrelated, and oblique rotations, where the new factors will be correlated.⁹⁹ With the current data, we decided to perform one orthogonal rotation and one oblique rotation with various delta settings. The orthogonal rotation was a Varimax, designed by Kaiser to rotate each factor so that it loads higher on a smaller number of variables.⁹⁹ This will make interpretation of the resulting factors easier, although the maximum variance property of the original components is destroyed. We chose Oblimin rotation as our oblique rotation, although it has been argued that no rotation is better than any other, as all rotations are simply different ways of looking at the same thing, and are statistically equivalent.

To interpret the factor structure of the Self-Perceived Burden Scale, it is necessary to begin by distinguishing those factors relating to emotional burden, physical burden and financial burden. It was found during this process, that several of the items could be interpreted as reflecting both physical and emotional burden. These items were grouped together as 'General Burden' as shown in Table 7. Each factor structure was examined with these categories in mind in order to aid in the identification of factors.

Table 7: Classification of Scale Items Based on Theoretical Framework

<p>Emotional Burden</p> <p>5. I worry that my caregiver has to take time away from other things...</p> <p>6. I am concerned that I won't be able to repay my caregiver...</p> <p>8. I worry about my caregiver because they have to take on too much responsibility...</p> <p>9. I feel guilty that my caregiver has to change their plans...</p> <p>10. I worry that my caregiver has lost control of their life...</p> <p>12. I am concerned that if I ask for help it will put too much pressure on my caregiver...</p> <p>15. I find it easier to ask for help when I feel I can give something in return...</p> <p>16. I am concerned that the demands of my care have strained my relationship...</p> <p>17. I am concerned that I am 'too much trouble'...</p> <p>18. Receiving help from others makes me feel that they care for me...</p> <p>20. I am concerned about the negative effects of my illness...</p> <p>22. I find it easier to ask for help when it's offered...</p> <p>23. I am concerned that because of caring for me, my caregiver is being pulled...</p> <p>Physical Burden</p> <p>1. I am concerned that my caregiver will 'wear out'...</p> <p>2. I worry that the health of my caregiver will suffer...</p> <p>3. I worry that my caregiver is overextending themselves in helping me out...</p> <p>11. I'm concerned that my needs are so great that my caregiver can't handle...</p> <p>19. I am concerned that because of my illness, my caregiver is trying to do too many things...</p> <p>21. I am confident that my caregiver can handle the demands of caring for me...</p> <p>Financial Burden</p> <p>4. I am concerned that it costs my caregiver a lot of money to care for me.</p> <p>General Burden</p> <p>7. I feel guilty about the demands that I make on my caregiver.</p> <p>13. I am concerned that the person caring for me may not be able to do so...</p> <p>14. I am concerned that my caregiver is helping me beyond their capacity..</p> <p>24. I think that I make things hard on my caregiver.</p>
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4.1.7.6 *Further Statistical Analysis*

In order to test the hypotheses previously stated, the total score on the Self-Perceived Burden Scale will be compared to the variable of interest. For

dichotomous variables, these analyses are reported as a comparison between the average burden scores of respondents with each of the conditions of interest present or absent. Comparison between the two means was performed using the student's independent samples t-test. This is a common test used to determine if there exists a statistically significant difference between the means of two independent samples. The null hypothesis for this statistical test is $H_0: \mu_1 = \mu_2$. If the p value is less than 0.05, the null hypothesis is rejected and we may conclude that the source population outcome means are not equal.¹⁰³ Variance may be assumed equal if the sample population is sufficiently large,¹⁰³ and this study satisfies this assumption.

Categorical variables, such as "Identity of Primary Caregiver", "Education" and "Etiology of Renal Failure" were also analyzed using the t-test by transforming each variable into one that was dichotomous. This was accomplished by identifying a cut-point for each variable. This method was determined by the researchers to provide more meaningful results than an ANOVA or similar test comparing all categories of the categorical variable.

To measure the correlation between two continuous variables, we examined the Pearson Correlation Coefficient. This value may range from -1 to $+1$, depending on the extent of linear correlation between the two variables of interest.¹⁰³ The r^2 for each continuous variable was reported to illustrate the percentage of variance in burden score total accounted for by each variable.

4.1.7.7 *Inter-Group Comparisons*

In order to investigate the characteristics of respondents experiencing significant feelings of being a burden, the respondents in the highest quartile of burden scores (deemed 'burdened' individuals) were compared to the remainder of the sample ('unburdened' individuals). The percentage of burdened respondents with the trait in question was compared to the percentage of unburdened respondents with the trait for all dichotomous variables (gender, high school education, presence of a comorbid condition). This comparison was analyzed for significance using the chi square test for a 2x2 contingency table. This test compares the observed and the expected counts in a contingency table problem.¹⁰⁴ For continuous variables, the average score of the measure in question was compared between the burdened and unburdened groups. These two average scores were compared through application of the Student's t-Test.

4.2 RESULTS

One hundred and eleven individuals undergoing hemodialysis agreed to participate in the current study. Seven of these individuals were excluded from the study because scores on the Short Portable Mental Status Questionnaire or their proficiency in English were below the acceptable limit. One hundred and four individuals scored greater than 8 out of a possible 10 on the SPMSQ and gave informed consent. Subsequently, four of these patients did not complete the study. Three respondents changed their minds regarding participation. The fourth respondent was judged to not have the mental capacity necessary to provide meaningful and consistent responses, in spite of passing the SPMSQ. The Self-Perceived Burden Scale and other study instruments were administered to the remaining 100 patients. The demographic information obtained from the respondents is listed in Table 8 below.

Table 8: Baseline Characteristics of 100 Participants with End-Stage Renal Disease

Demographic Characteristic	Proportion
Gender (% male)	55%
Age (in years)	64.7 years (s.d. 14.1)
Education	
Less than Grade 7	7%
Junior High School (Gr.7-9)	22%
Partial High School (Gr.10-12)	18%
High School Graduate	22%
Partial College (1 year min)	11%
College or University Graduate	17%
Postgraduate (Masters, PhD)	3%
Professional Degree	1%
Months on Hemodialysis	30.3 months (s.d. 32.6)
Past Experience on CAPD (Continuous Ambulatory Peritoneal Dialysis)	23%
Co-morbid conditions (any)	71%
Angina	33%
Congestive heart failure	26%
Diabetes	24%
Arthritis	14%
Respiratory illness	12%
Neurologic Disease	5%
Liver Disease	2%
Other co-morbid conditions	19%
Previous Kidney Transplant	18%
Etiology of Renal Failure	
Hypertension	21%
Diabetes	23%
Glomerulonephritis	11%
Polycystic kidney disease	9%
Idiopathic	18%
Other	19%
How long before beginning hemodialysis were you aware that you would need it?	
Immediately before dialysis	30%
Less than 6 months	8%
More than 6 months	61%

The respondents in this study were slightly more likely to be male (55%) with an average age of 64.7 (S.D. \pm 14.1) years. The majority of the participants had extensive experience on hemodialysis, averaging 30.3 months (S.D. \pm 32.6) of regular hemodialysis. The great majority of the patients enrolled had at least one co-morbid condition (71%), the most commonly cited being angina (33%) and congestive heart failure (26%).

All participants reported obtaining some kind of support with their daily activities. Most respondents reported that they required help to cook meals (70%) and clean the house (67%), with a lesser number reported needing help for laundry, driving and shopping. Help was overwhelmingly provided by the spouse (61%). Although many respondents identified a son or daughter as a significant source of unpaid help, few of them identified these family members as primary caregivers (6% and 16%, respectively). A significant number of respondents perceived a barrier to their caregiver's ability to care for them, the most commonly named being the health of the caregiver (named by 20% of hemodialysis patients) and the career demands of the caregiver (named by 11% of patients). Nearly a third of patients also obtained paid help from an outside source, most commonly with housekeeping duties (29%) and driving (26%). Detailed responses are outlined in Table 9.

Table 9: Sources and Nature of Support Available for 100 Patients with End Stage Renal Disease

Sources of Unpaid Help	
Spouse	61%
Daughter	41%
Son	36%
Other Family	22%
Friend	13%
Neighbour	9%
Other Sources	3%
Type of Unpaid Help	
Cooking	70%
Cleaning	67%
Laundry	42%
Driving	41%
Shopping	34%
Lawn/Snow	9%
Other	37%
Primary Caregiver	
Spouse	61%
Daughter	16%
Son	6%
Other Family	11%
Friend	3%
Other	3%
Barriers to Helping*	
Health of caregiver	20%
Work of caregiver	11%
Family	3%
Other	3%
Professional Help	
Housekeeping	29%
Driving Service	26%
Nursing Care	13%
Landscaping	13%
Snow Removal	11%
Other Paid Help	2%

* In response to the question: "Are there any factors that you believe interfere with your caregiver's ability to care for you?"

The 24-item Self-Perceived Burden Scale produced total scores ranging from 24 to 120. The distribution of scores is provided below in Figure 2:

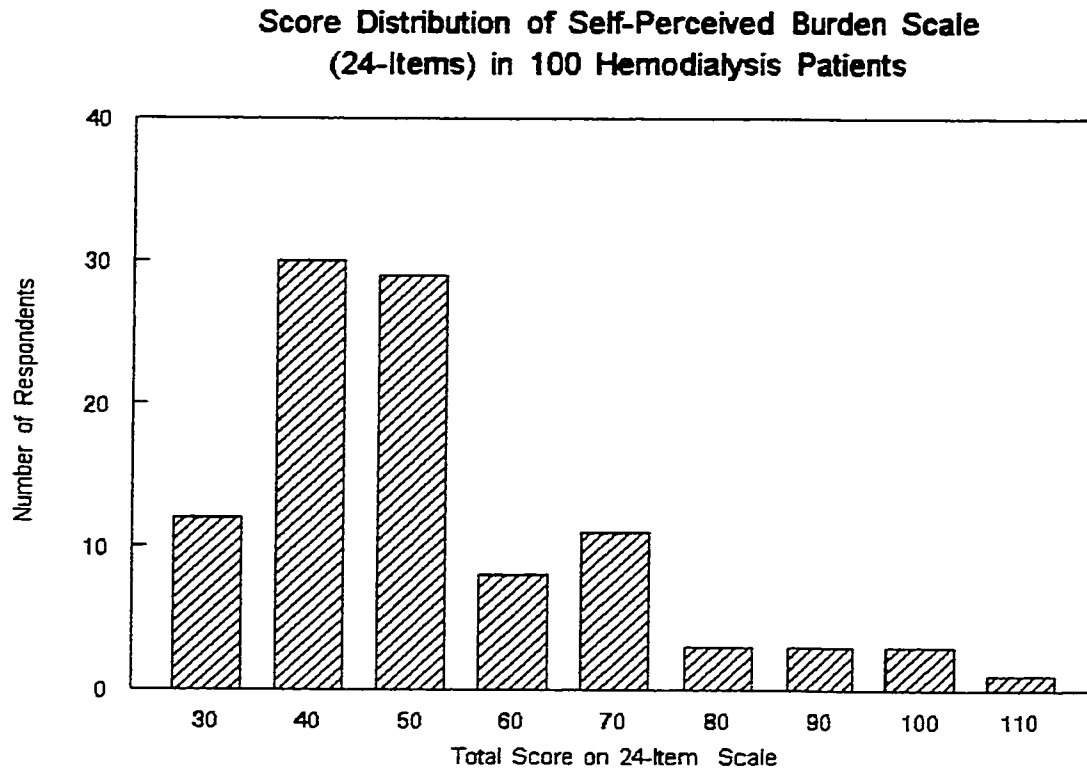


Figure 2: Score Distribution of 24-Item Self-Perceived Burden Scales Administered to 100 Individuals on Hemodialysis

4.2.1 Factor Analysis

Bartlett's test produced an approximate chi-square of 1490.58 with 276 degrees of freedom, which corresponds to a p value of <0.001. This test is highly significant, indicating that the items are significantly correlated.

Principal components analysis set to extract eigenvalues greater than one resulted in the extraction of 4 factors. The resulting factor loadings showed no

identifiable factors. The Varimax rotation extracted four factors, with a better distribution of items than that of the initial solution. Once again, however, although distinct factors were evident in the item loadings, the items in each factor did not combine to form meaningful and identifiable subscales. The results of the principal components analysis after a Varimax rotation are shown in Table 10 below.

Table 10: Factor Loadings of Items on Self-Perceived Burden Scale After a Principal Components Analysis with a Varimax Rotation

Number	Item	Factor			
		I	II	III	IV
2	Health of caregiver could suffer	.78	.36	.02	.03
1	Caregiver will wear out	.73	.19	-.03	.14
3	Overextending caregiver	.73	.30	.16	.23
8	Take on too much responsibility	.72	.20	.23	.20
10	Caregiver lost control of life	.69	.35	.31	-.04
9	Guilt that caregiver has to change plans	.69	.25	.25	-.14
5	Takes time away from other things	.66	.21	.27	-.04
7	Guilty about demands	.64	.36	.16	.25
4	Costs caregiver a lot of money to care	.51	.25	.50	.01
12	Asking for help puts pressure on caregiver	.48	.43	.32	-.04
13	May not be able to care much longer	.20	.78	.15	-.01
16	Strained relationship with caregiver	.27	.69	.25	.05
23	Caregiver pulled in too many directions	.40	.67	.15	.10
17	I am 'too much trouble' to caregiver	.50	.64	.16	.19
24	Make things hard on caregiver	.40	.63	.14	.12
14	Helping beyond their capacity	.30	.60	.56	.08
20	Negative effects of illness	.44	.58	.12	.03
11	Needs too great for caregiver to handle	.36	.37	.67	.04
6	Won't be able to repay caregiver	.32	.24	.59	.22
19	Trying to do too much at once	.45	.34	.55	.27
18	Makes me feel that they care for me	.31	.05	-.45	.41
21	Confident that caregiver can handle demand	-.11	.28	-.19	-.75
22	Easier to accept help that's offered	-.01	.28	-.07	.74
15	Giving something in return	.01	.38	.37	.48

Following this, various Oblimin rotations were attempted, with delta ranging from -1 to +1. The maximum iterations for convergence were set at 25, and most attempts were unable to converge at less than 25 iterations. Two rotations were completed, at deltas of 0.25 and 0.5.(Appendices XVIII and XIX) Both factor

analyses extracted four factors, none of which produced any meaningful subscales after careful analysis by the investigator and advisors. Factor analysis by means of maximum likelihood showed nearly identical results, with no identifiable factors beyond the first general burden factor. Based on this portion of the analysis, it seemed increasingly appropriate to restrict further analysis to one general factor.

4.2.2 Item Refinement

Principal Components Analysis was again performed, restricting extraction to 1 main factor, as opposed to the four factors which were obtained using the Kaiser criterion. After the first run, the item loading the least on the principal factor was eliminated from analysis. This left twenty-three items included in the analysis. With the number of items reduced by one, the analysis was run again. Again, the item loading the least on the common factor was rejected from analysis, reducing the pool of items to twenty-two. This analysis was repeated until one sole item was left in the factor analysis, resulting in a ranked list of items. This ranking is presented in Table 11, from the item loading the strongest on this single factor to that which loaded the least.

Table 11: Items from Self-Perceived Burden Scale Ranked as Loaded on a Single Underlying Factor Using Principal Components Analysis

3. I worry that my caregiver is overextending themselves in helping me.
2. I worry that the health of my caregiver could suffer as a result of caring for me.
17. I am concerned that I am "too much trouble" to my caregiver.
7. I feel guilty about the demands that I make on my caregiver.
8. I worry about my caregiver because they have to take on too much responsibility for me.
10. I worry that my caregiver has lost control of their life due to caring for me.
19. I am concerned that because of my illness, my caregiver is trying to do too many things at once.
23. I am concerned that because of caring for me, my caregiver is being pulled in too many directions.
24. I think that I make things hard on my caregiver.
11. I'm concerned that my needs are so great that my caregiver can't handle them.
14. I am concerned that my caregiver is helping me beyond their capacity.
16. I am concerned that the demands of my care have strained my relationship with my caregiver.
4. I am concerned that it costs my caregiver a lot of money to care for me.
9. I feel guilty that my caregiver has to change their plans in order to help me.
12. I am concerned that if I ask for help it will put too much pressure on my caregiver.
20. I am concerned about the negative effects of my illness on those around me.
5. I worry that my caregiver has to take time away from other things in order to help me.
13. I am concerned that the person caring for me may not be able to do so much longer.
1. I am concerned that my caregiver will "wear out" as a result of caring for me.
6. I am concerned that I won't be able to 'repay' my caregiver for all they've done for me.
15. I find it easier to ask for help when I feel that I can give something in return.
22. I find it easier to accept help when it's offered, rather than when I have to ask.
18. Receiving help from others makes me feel that they care for me.
21. I am confident that my caregiver can handle the demands of caring for me.

4.2.3 Item Utility Analysis

The final step in determining which of the items will be retained in the final scale is an examination of all data available to date. By combining information on face validity, content validity, response pattern, split-half reliability, and the items' proximity to a general burden factor, each item was examined and a decision made on whether or not the item should be retained in the final version of the self-perceived burden scale. Details of this process are displayed in Table 12.

Table 12: Performance of Individual Items from Self-Perceived Burden Scale as Administered to 100 Individuals

ITEMS	FACE	CONTENT	RESPONSE PATTERN	CHANGE IN α IF ITEM REMOVED	RANK OF LOADING ON SINGLE FACTOR
1. I am concerned that my caregiver will "wear out" as a result of caring for me.	✓	✓	51%	-0.0040	19
2. I worry that the health of caregiver could suffer as a result of caring for me	✓	✓	56%	-0.0062	2
3. I worry that my caregiver is overextending themselves in helping me out.	✓	✓	48%	-0.0065	1
4. I am concerned that it costs my caregiver a lot of money to care for me	✓	✓	80%	-0.0039	13
5. I worry that my caregiver has to take time away from other things in order to help me.	✓	✓	52%	-0.0043	17
6. I am concerned that I won't be able to repay my caregiver for all they've done for me.	✓	✓	63%	-0.0033	20
7. I feel guilty about the demands I make on my caregiver.	✓	✓	49%	-0.0058	4
8. I worry about my caregiver because they have to take on too much responsibility for me.	✓	✓	59%	-0.0053	5
9. I feel guilty that my caregiver has to change their plans in order to help me.	✓	✓	58%	-0.0047	14
10. I worry that my caregiver has lost control of their life due to caring for me	✓	✓	80%	-0.0059	6
11. I'm concerned that my needs are so great that my caregiver can't handle them.	✓	✓	78%	-0.0038	10
12. I am concerned that if I ask for help it will put too much pressure on my caregiver.	✓	✓	73%	-0.0040	15
13. I am concerned that the person caring may not be able to do so much longer.	✓	✓	77%	-0.0033	18
14. I am concerned that my caregiver is helping me beyond their capacity...	✓	✓	75%	-0.0053	11
15. I find it easier to ask for help when I feel I can give something in return.	✓	✓	43%	0.0003	21
16. I am concerned that the demands of care have strained my relationship with my caregiver.	✓	✓	78%	-0.0043	12

ITEMS	FACE	CONTENT	RESPONSE PATTERN	CHANGE IN α IF ITEM REMOVED	RANK OF LOADING ON SINGLE FACTOR
17. I am concerned that I am "too much trouble" to caregiver.	✓	✓	68%	-0.0068	3
18. Receiving help from other makes me feel that they care for me.	✓	✓	37%	0.0061	23
19. I am concerned that because of my illness, my caregiver is trying to do too many things at once.	✓	✓	57%	-0.0066	7
20. I am concerned about the negative effects of my illness on those around me.	✓	✓	64%	-0.0053	16
21. I am confident that my caregiver can handle the demands of caring for me.	✓	✓	41%	0.0129	24
22. I find it easier to accept help when it's offered, rather than when I have to ask.	✓	✓	38%	0.0039	22
23. I am concerned that because of caring for me, my caregiver is being pulled in too many directions.	✓	✓	55%	-0.0057	8
24. I think that I make things hard on my caregiver.	✓	✓	66%	-0.0046	9

In order to determine which items were eliminated from further analysis and which would be retained in the final draft of the Self-Perceived Burden Scale, we examined the correlation matrix, degree of loading on the general factor, response patterns and content of each item individually. Based on this examination, a judgement was made. Most items in the scale were highly correlated, and the degree of correlation factored highly into the decision to keep or reject each items. Items 5,18,20,22 and 23 were rejected primarily due to their high degrees of correlation with other items, making them redundant. Items 1,9,11,13 and 16 were rejected primarily based on their low loadings on the general burden factor, indicating that they may not correlate well with the underlying burden construct. Items 8,10,11,12 and 16 were rejected primarily due to their poor response patterns—no item was rejected due solely to a skewed response pattern, but were often also highly correlated with other items. Finally, items 6 and 15 were also excluded from further analysis. These items were known to be measuring the concept of indebtedness, which was hypothesized to be a dimension of burden. As these items evidently fall outside of the general burden factor, it is likely that although feelings of indebtedness may be closely related to feelings of being a burden, they are a separate dimension from burden itself. For this reason, it was not seen as necessary to include these items in the final instrument.

Nine of the original 24 items were retained in the final patient perceived burden screening instrument. These are identified in Table 13:

Table 13: List of Items Included in the Final Version of the Self-Perceived Burden Scale

- | |
|--|
| <p>2. I worry that the health of my caregiver could suffer as a result of caring for me</p> <p>3. I worry that my caregiver is overextending themselves in helping me</p> <p>4. I am concerned that it costs my caregiver a lot of money to care for me</p> <p>7. I feel guilty about the demands that I make on my caregiver</p> <p>14. I am concerned that my caregiver is helping me beyond their capacity</p> <p>17. I am concerned that I am 'too much trouble' to my caregiver</p> <p>19. I am concerned that because of my illness, my caregiver is trying to do too many things at once</p> <p>21. I am confident that my caregiver can handle the demands of caring for me</p> <p>24. I think that I make things hard on my caregiver</p> |
|--|

In addition to the nine items outlined above, another item was considered for inclusion. Supplemental item #4 (I feel that I am a burden to my caregiver) was tested along with the burden scale. This item loaded adequately on the general factor when included in the scale, and correlated highly with each individual's total score on the original 24-item burden scale. With the inclusion of this item, internal consistency remained high.

Cronbach's alpha for internal consistency of the entire scale fell from 0.92 to 0.85, indicating that the new scale retained a high degree of internal consistency, while eliminating much of the redundancy. The Pearson Product-Moment Correlation between the total scores of the 24-item version of the scale and the total score of the abbreviated 10-item version is 0.95, indicating that very little has been lost in the selected deletion of the redundant items.

The final Self-Perceived Burden Scale produced scores ranging from 10 to 50. The distribution of the 10-item scale is shown in Figure 3 below.

**Score Distribution of Self-Perceived Burden Scores
(10-Item Scale) of 100 Hemodialysis Patients**

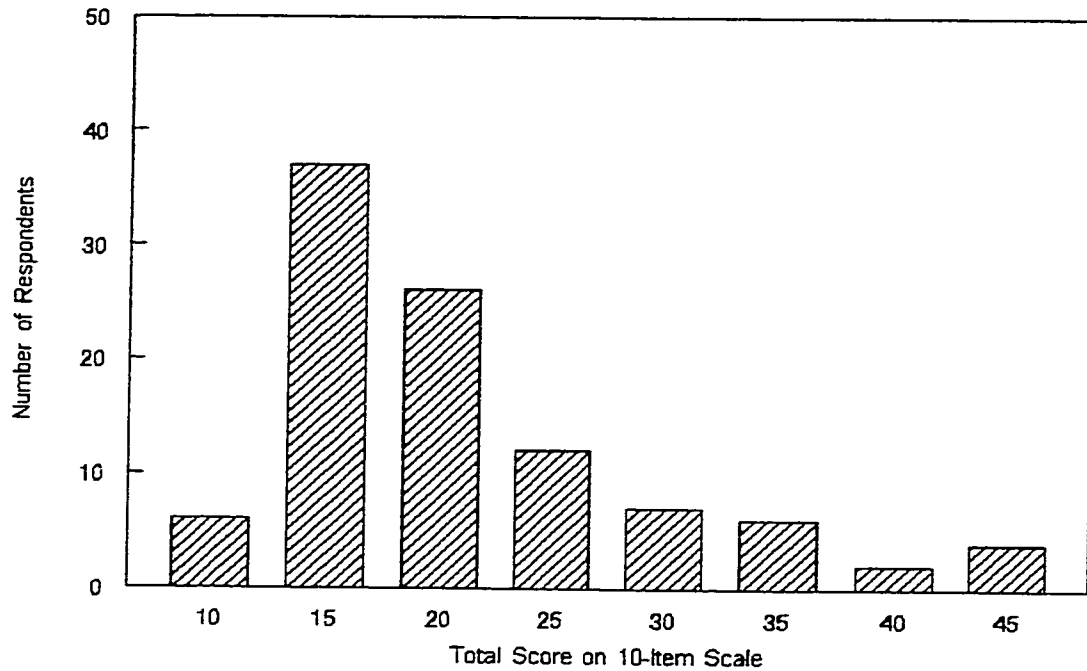


Figure 3: Score Distribution of 10-Item Self-Perceived Burden Scale as Administered to 100 Patients Undergoing Hemodialysis

Another principal components analysis was performed, using the new, abbreviated version of the Self-Perceived Burden Scale. This process extracted what could be interpreted as two factors, or as one factor with one item that did not fit into the primary factor. These results are shown below in Table 14:

Table 14: Factor Analysis of 10-Item Self-Perceived Burden Scale Using Principal Components Analysis

Factor #1	Factor #2
17. I am concerned that I am 'too much trouble' to my caregiver. (.83) 3. I worry that my caregiver is overextending themselves in helping me. (.81) 7. I feel guilty about the demands that I make on my caregiver. (.81) 2. I worry that the health of my caregiver could suffer as a result of caring for me. (.80) 19. I am concerned that because of my illness, my caregiver is trying to do too many things at once. (.77) 24. I think that I make things hard on my caregiver. (.75) 14. I am concerned that my caregiver is helping me beyond their capacity. (.73) 4. I am concerned that it costs my caregiver a lot of money to care for me. (.71) S4. I feel that I am a burden to my caregiver. (.69)	21. I am confident that my caregiver can handle the demands of caring for me. (.97)

4.2.4 Hypothesis Testing

The next stage in the preliminary testing of a new scale is using it to test hypotheses regarding its performance. For this purpose, questionnaires other than the new Self-Perceived Burden scale were administered to the patient population simultaneously. These included the FSI, the MOS Social Support Scale and the SF-36, as well as supplemental questions relating to burden, health, and receiving care. Using this additional information, it was possible to formulate hypotheses pertaining to correlations and relationships between the respondent's burden scores and other information provided. Results of these analyses are presented in Table 18.

Hypothesis: Gender will be likely to be significantly correlated with increasing feelings of being a burden, with men scoring higher on perceived burden than women.

The gender of the respondent was seen to be a significant predictor of burden. Men were significantly more likely to report feelings of being a burden than their female counterparts. The highly burdened population, as defined by a score on the Self-Perceived Burden Scale of 23 or greater, were 75% male, whereas the rest of the sample was evenly split between men and women. This relationship was significant to $p < 0.01$.

Hypothesis: A greater sense of being a burden will be significantly correlated with a decrease in help-seeking behaviour, as measured by two supplemental questions administered separately.

As expected, help-seeking behaviour was significantly correlated ($p < 0.01$) with the total score on the Self-Perceived Burden Scale. However, this relationship accounts for only 10% of the variance in feelings of burdensomeness as measured by the instrument ($r^2 = .10$)

Hypothesis: A greater sense of being a burden will be significantly correlated with less perceived control, as measured by the "General Health Perceptions" subscale of the SF-36.

As predicted, total scores on the Self-Perceived Burden Scale were correlated with the General Health Perceptions subscale of the SF-36. Although this correlation accounts for only 7% of the variance in self-perceived burden ($r^2 = .07$) this correlation was significant at $p < 0.01$. Self-Perceived Burden was also correlated significantly with other SF-36 subscales, including Physical Functioning ($r^2 = .09$, $p < 0.01$), Role-Physical Functioning ($r^2 = .06$, $p = .01$), Social Functioning ($r^2 = .07$, $p = .01$), Role-Emotional Functioning ($r^2 = .12$, $p < .01$) and Mental Health ($r^2 = .15$, $p < .01$).

Hypothesis: A greater sense of being a burden will be significantly correlated with increased social support as measured by the MOS Social Support Scale.

Contrary to expectations, total scores on the MOS Social Support Scale did not correlate to a significant degree with total scores on the Self-Perceived Burden Scale ($r^2 = .002$, $p = .65$). In addition, no significant correlations were observed between burden scores and any of the subscales of the MOS Social Support Scale, including Emotional/Informational Support ($r^2 = .001$, $p = .72$), Tangible Support ($r^2 < 0.001$, $p = .89$), Positive Social Interaction ($r^2 = .02$, $p = .16$) and Affection ($r^2 < .001$, $p = .93$).

None of the other demographic factors were significant predictors of feelings of burden: patient age, education, length of time on hemodialysis, previous experience with CAPD and etiology of renal failure all failed to show significant associations with overall burden scores. None of the various co-morbid conditions were associated with feelings of being a burden. What is interesting to note is that although no single co-morbid condition correlated significantly with global burden score, the number of co-morbid conditions reported by the respondent is positively correlated with increasing reports of burdensomeness. Complete results of all correlation testing is displayed in Tables 15 and 16.

Table 15: Correlation Testing of Total Self-Perceived Burden Scores Using Independent Samples t-Test

Variable to Correlate with Burden	Present \pm S.D.	Absent \pm S.D.	Diff.	Sig	95% C.I.
Gender (male)	21.0 \pm 8.9	16.6 \pm 6.0	4.4	.01	(1.35, 7.57)
Age (\geq 65)	19.0 \pm 7.8	19.3 \pm 8.5	0.3	.82	(-2.97, 3.72)
Education ($>$ high school)	19.3 \pm 8.6	18.8 \pm 7.4	0.5	.75	(-2.67, 3.69)
Months on Hemodialysis (\geq 12)	18.6 \pm 7.8	18.3 \pm 7.7	0.3	.83	(-3.02, 3.77)
Previously on CAPD (N=22)	18.1 \pm 7.5	18.9 \pm 8.1	0.8	.66	(-2.91, 4.63)
Previous Renal Transplant	16.2 \pm 3.8	19.3 \pm 8.5	3.1	.15	(-1.10, 7.26)
Presence of Any Co-Morbid Condition	20.8 \pm 9.6	18.2 \pm 7.5	2.6	.42	(-7.65, 2.39)
Arthritis (N=13)	18.7 \pm 6.0	18.7 \pm 8.2	0	.10	(-3.93, 3.96)
Angina (N=31)	19.5 \pm 8.5	18.3 \pm 7.7	0.8	.51	(-4.81, 2.41)
Congestive Heart Failure (N=24)	20.0 \pm 8.8	18.3 \pm 7.6	0.7	.38	(-5.88, 2.30)
Diabetes (N=23)	20.5 \pm 7.8	18.3 \pm 8.1	2.2	.25	(-5.97, 1.61)
Malignancy (N=3)	23.3 \pm 9.2	18.6 \pm 7.9	4.7	.31	(-27.0, 17.5)
Liver Cirrhosis (N=2)	30.5 \pm 17.7	18.5 \pm 7.6	12.0	.51	(-168, 144)
Respiratory Disease (N=11)	21.6 \pm 9.1	18.3 \pm 7.7	3.3	.19	(-9.58, 2.95)
Severe Neurologic Disease (N=5)	23.4 \pm 13.1	18.4 \pm 7.6	5.0	.17	(-12.1, 2.23)
Identity of Primary Caregiver (spouse vs. other)	20.7 \pm 8.3	16.1 \pm 6.8	4.6	.02	(0.65, 6.83)
Anything that Interferes with Caregiving	21.7 \pm 9.6	17.7 \pm 6.7	4.0	.02	(0.77, 7.25)

Table 16: Correlation Testing of Total Self-Perceived Burden Scores Using Pearson Correlation Coefficient

Variable to Correlate With Burden	r ²	Sig
Number of Co-Morbid Conditions	.04	.04
Help Available	.001	.73
Caregiver Health Problems	.10	<.01
Help Seeking Behaviour	.10	<.01
Single-Item Burden Measure	.35	<.01
Total Score on FSI	.07	.01
MOS Social Support	.002	.65
Emotional/Informational Support (MOS)	.001	.72
Tangible Support (MOS)	<.001	.89
Positive Social Interaction (MOS)	.02	.15
Affection (MOS)	<.001	.93
Physical Functioning (SF-36)	.09	<.01
Role-Physical Functioning (SF-36)	.06	.01
Bodily Pain (SF-36)	.01	.74
General Health Perceptions (SF-36)	.07	.01
Vitality (SF-36)	.04	.07
Social Functioning (SF-36)	.07	.01
Role-Emotional Functioning (SF-36)	.12	<.01
Mental Health (SF-36)	.15	<.01

Many aspects of the caring relationship showed slight significant correlations with high burden scores. These include a caregiver with health problems, the identification of a barrier to caregiving (e.g. competing depends on caregiver such as family, work), and help seeking behaviour, as assessed by combining scores for supplemental questions pertaining to help-seeking behaviour. As expected, the overall burden scores also correlated highly with the single-item direct assessment of burden.

With the exception of the MOS Social Support Scale, all of the measurement instruments which were administered concurrently with the burden scale correlated with the overall burden score. This included significant correlations with the Functional Status Index, as well as with 6 of the 8 subscales of the SF-36.

4.2.5 Comparison of Burdened vs. Unburdened Patients on Hemodialysis

In order to compare the characteristics of individuals experiencing high feelings of being a burden with the rest of the population, respondents in the top quartile of burden scores (score ≥ 23) were designated as individuals with high feelings of being a burden. The average scores of this group on a number of measures was compared to the average scores of the rest of the study population. The results of this analysis are illustrated in Table 17:

Table 17: Characteristics of Burdened vs. Unburdened Individuals in a Sample of 100 Hemodialysis Patients Using an Independent Sample T-Test

Characteristic	Burdened	Unburdened	Sig.	95% C.I.
Age of Respondent (# of years)	65.4	64.4	.76	(-7.17, 5.28)
*Gender (% male)	75.0	50.0	.02	
*Education (% high school or higher)	39.3	29.2	.34	
*Any Comorbid Condition (%)	78.6	70.8	.34	
Number of Comorbid Conditions	1.54	1.17	.17	(-.89, .16)
Help Seeking Behaviour	5.30	3.65	<.01	(.55, 2.74)
Total Score of MOS	77.14	78.92	.65	(-5.95, 9.50)
Total Score of FSI	2.29	1.97	.07	(-.65, .023)
SF-36: Mental Health	21.12	24.35	<.01	(1.01, 5.45)
SF-36: Physical Functioning	17.27	19.86	.03	(.24, 4.94)
SF-36: Role Emotional Functioning	4.65	5.26	.04	(.017, 1.2)
SF-36: Role Physical Functioning	4.88	5.61	.03	(.09, 1.36)
SF-36: Pain	6.74	6.54	.24	(-.54, .14)
SF-36: Vitality	11.38	12.99	.11	(-.39, 3.6)
SF-36: Health Perceptions	9.77	11.40	.08	(-.17, 3.44)

* Significance calculated through Chi Square procedure

Individuals with high scores on the Self-Perceived Burden Scale differ from individuals without significant feelings of being a burden in gender, help seeking behaviour, mental health, physical functioning, and role functioning.

Chapter 5: DISCUSSION

5.1 *Summary of Findings*

Through the multiple steps in phase I, I developed a 24-item scale measuring the degree to which a chronically ill person feels that they are a burden to their caregiver. I believe that the new scale is based on a sound conceptual framework, thereby maximizing content validity. This framework was confirmed through detailed interviews with patients and health care providers. The subsequent administration of the 24-item scale to 100 chronically ill people resulted in modifications to the conceptual framework, decreased the number of items in the scale, and offered a preliminary assessment of the scale's validity by testing hypotheses outlined prior to scale development.

The original conceptual framework was derived from pre-existing caregiver burden literature,^{3,12-14,18,22,26-28,105} as well as interviews with patients requiring hemodialysis and health professionals. I proposed three dimensions of self-perceived emotional, physical, and financial burden. The existence of these general dimensions was supported by the results of the semi-structured patient and health care professional interviews. This process led to the development of 80 items hypothesized to measure the three dimensions of Self-Perceived Burden. These 80 items were reduced to 29 through consensus process involving all investigators. These 29 items were further reduced to 24 following a content validity exercise in which health professionals ranked each item on its relevance to the pre-defined conceptual framework. To further evaluate the items

relation to the conceptual framework, a factor analysis was undertaken using responses from 100 chronically ill patients requiring hemodialysis. The results of factor analyses did not support the three hypothesized dimensions of self-perceived burden. The four factors extracted were not readily identifiable as aspects of burden, and nearly all items loaded strongly on a sole burden factor.

A combination of information regarding each item's face validity, content validity, response pattern, α coefficient, correlation with other items and ranking on the single burden factor was combined in order to evaluate the utility and validity of each item in the scale. From this process, the number of items in the scale was reduced from 24 to 10 items. These items were each scored on a Likert-type scale with a total score range from 10 to 50.

These ten items were used to test hypotheses to provide evidence supporting the validity of the Self-Perceived Burden Scale. Four hypotheses were stated at the outset of the study, pertaining to factors expected to influence an individual's sense of being a burden. As expected, feelings of being a burden were significantly correlated with the General Health subscale of the SF-36. This subscale includes a measure of perceived control, which has been associated with better adjustment to illness¹⁰⁶. This correlation is negative, because the General Health subscale is scored so that a high score indicates better health perceptions⁸⁰. This finding implies that as an individual feels that they are losing control of their health, they are likely to have increased feelings of being a burden to others. This result lends further credence to the earlier suggestion that feelings of being a burden are linked to decreased feelings of control over one's health. It

must be noted, however, that none of the significant correlations accounted for a notable percentage of the variance in total scores on the Self-Perceived Burden Scale. The most sizable r^2 value was reported for the correlation between self-perceived burden and the mental health subscale of the SF-36, which accounted for only 15% of the variance in total self-perceived burden scores. Although many of the associations were statistically significant, they were still quite weak and should be interpreted with caution.

5.2 Correlates of Self-Perceived Burden

Three of the four hypotheses stated in Chapter 1 were found to be supported by the results of this study. As predicted, help seeking behaviour was significantly correlated with feelings of being a burden in this population of people dependent on hemodialysis. People experiencing feelings of being a burden were less likely to ask for help when it is needed. This finding satisfies the equity theory of social exchange, as set forth originally by Adams¹⁰⁷ which states that inequitable relations produce discomfort which motivates individuals to try to reduce the unpleasant feelings. When applied to the recipient of help, such as in a caregiving situation, the recipient experiences affective distress (e.g., feelings of indebtedness) which they try to eliminate via actual or psychological means.^{29,108-110} In this case, the person on hemodialysis feels as though they are a burden to their caregiver, and therefore ceases to ask for help in the hope that it will alleviate the burden to a degree.

Contrary to expectations, feelings of being a burden were not found to be significantly associated with perceived social support in this patient population. In

addition, burden scores were not found to be significantly associated with any of the subscales of the MOS Social Support Scale, including tangible support, affection, emotional and informational support, and positive social interaction. No significant correlation was observed between total self-perceived burden scores and scores on the MOS Social Support Scale. It must be noted, however, that the social support instrument exhibited large ceiling effects. This could indicate that all participants in this study had exceptional social support, as the scores on the MOS seem to indicate, but that no correlation exists between self-perceived burden and social support. There is evidence, however, that the MOS Social Support Scale did not perform well enough to allow any inferences regarding the relationship between social support and self-perceived burden. A principal components analysis of the MOS Social Support Scale showed only 2 factors with eigenvalues greater than one. As this scale should show 4 discernible subscales, this suggests that this instrument did not perform reliably in this patient population.

The relationship between social support and feelings of being a burden is not straightforward. A review by Jutras and Veilleux concerning caregiver burden²⁵ cited kinship as a determinant of caregiver burden—the closer the relationship between the caregiver and care recipient, the greater the burden. Our study supports this assertion, as respondents who identified their spouse as their primary caregiver had significantly greater feelings of being a burden than respondents citing other family members or friends ($p = 0.02$). Other studies have reported similar findings.^{111,112} Jutras and Veilleux also cited level of caregiving

responsibility as the factor most likely to increase caregiver burden.²⁵ This finding has been supported by other studies^{113,114} that reported that being the sole caregiver contributed significantly to the difficulties related to caregiving. This is closely related to social support, as the person with chronic illness who professes to have a strong social support network is likely to have more sources of help than those who rely entirely on their caregiver. Future examinations of the relationship between social support and self-perceived burden should take into account not only the quality of social support available to the individual living with chronic illness, but the quantity of social contacts. It is likely that the more sources of social support available, not only to the person with chronic illness but to their caregiver, the less the burden experienced by the caregiver and the less of a burden the help recipient perceives themselves to be.

5.3 How Does This Study Improve Our Understanding of Self-Perceived Burden?

The qualitative work in Phase I of the current study confirmed a number of aspects of the conceptual framework of burden found in the caregiving and helping literature. These include feelings of guilt, indebtedness, loss of control and dependence. In addition, by soliciting input from the people undergoing hemodialysis and their health professionals, the current study has further advanced the theoretical concept of burden. The semi-structured interviews identified many themes that chronically ill individuals associate with burden that had been overlooked by much of the pre-existing literature. Among those listed included worries regarding what they viewed as 'interference' in their caregiver's

lives, concern about the possibility of the physical strain of caregiving adversely affecting the caregiver's health, anger, resentment, frustration and helplessness.

Feelings of guilt and feelings of indebtedness were particularly evident in discussions of respondent's feelings of being a burden. These feelings were mentioned by both the patients themselves and the health care professionals in the semi-structured interviews performed in Phase I. Items pertaining to feelings of indebtedness were later removed due to poor performance in Phase II. It is important to note that this finding does not invalidate the proposed conceptual framework, but suggests that in this population of people undergoing hemodialysis, feelings of indebtedness are not invariably linked to feelings of being a burden. This may be due to the fact that 60% of caregivers identified by respondents were spouses to the person receiving help. This spousal relationship often satisfies many of the conditions identified by Fisher, Nadler, and Witcher-Alagna as promoting positive responses to aid.¹¹⁵ These conditions include positive motivation to help, help that is offered rather than requested, and little threat to autonomy,¹¹⁵ all of which are usually true of the spousal relationship. As a result, people relying on a spouse for help would be less likely to experience negative emotions associated with needing help, such as feelings of indebtedness. Of course, this is not true of all spousal relationships—any marriage experiencing problems before experiencing a chronic illness may continue to deteriorate, depending on the reactions of both the person with the illness and the caregiving spouse to the new challenge of coping with this stressful situation.

Caregiving literature has identified guilt as one of the psychological aspects most frequently related to the caregiving experience.¹¹⁶⁻¹¹⁸ This feeling was mentioned frequently by dialysis patients in the semi-structured interviews of Phase I, and continued to play an important role in defining burden through Phase II. The question pertaining to guilt performed well throughout the item reduction and was retained in the final version of the Self-Perceived Burden Scale. Guilt has been shown repeatedly to be a prominent factor in caregivers—this includes guilt as a motivating factor in assuming the caregiving role,¹¹⁹ as well as guilt over not being able to care adequately and guilt associated with neglecting other aspects of one's life in order to provide care.^{116,117} The findings of this study show that guilt is also a burden to the people requiring hemodialysis, and comprises a significant portion of negative response to caregiving in this population.¹¹⁵

The findings of this study seem to indicate that self-perceived burden is a single construct comprised of three dimensions. This theory is supported by the results of the factor and principal components analyses, which showed the three hypothesized dimensions of self-perceived burden—physical, emotional and financial perceived burden—loading highly on one underlying factor. This factor was judged to be a general burden factor, engulfing the three dimensions and obscuring their identification through factor analytic methods. This theory is illustrated in Figure 4 below:

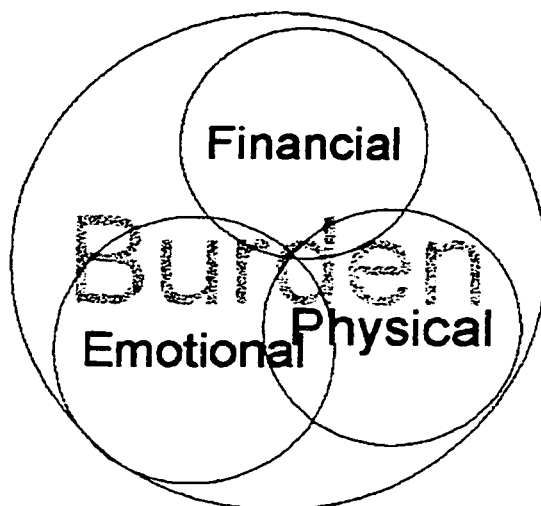


Figure 4: Suggested Structure of Self-Perceived Burden and its Underlying Dimensions

An alternate proposal for the structure of separate aspects of self-perceived burden is one in which physical, emotional and financial circumstances influence burden, but do not fall under the construct of general burden. Each of these influences are seen to correlate with general feelings of being a burden. The current study also supported aspects of this theory. Emotional influences, as measured by the mental health subscales of the SF-36, were found to correlated significantly with scores on the Self-Perceived Burden Scale. Physical circumstances, as measured by both the physical functioning subscale of the SF-36 and the Functional Status Index, were found to be significantly correlated with overall feelings of being a burden. This structure indicates how physical, emotional and financial burden contribute to the burden perceived by the individual, but are separate dimensions and must be measured independently

from the general burden factor. This figure suggests that the perception of burden is the same regardless of the cause, and that the causes of burden can be loosely grouped under these three main categories. The relationships between physical, emotional and financial influences and perceived burden may have a causal link, but are not part of the burden construct itself. This theory is illustrated in Figure 5 below:

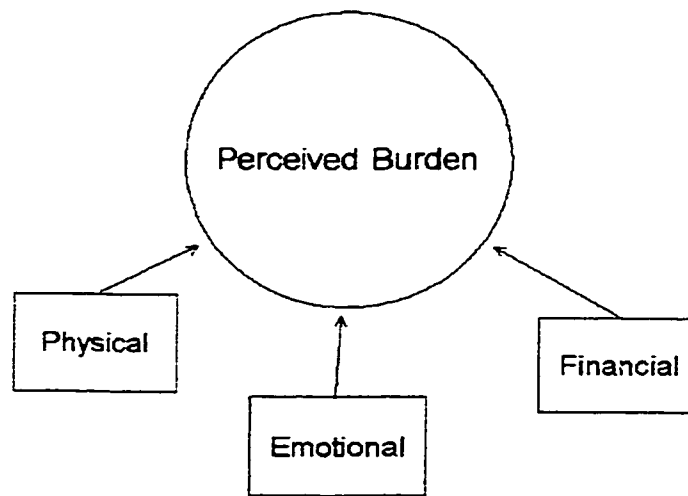


Figure 5: Alternate Proposal—Self-Perceived Burden and its Influencing Factors

5.4 What Determines a Person's Level of Self-Perceived Burden?

A factor seen to play a role in the hemodialysis patients' self-perceived burden is the degree of control they perceive themselves as having over both the progression of their disease and their treatment. A significant relationship was found between the subscale of the SF-36 which includes a measure of perceived control and the Self-Perceived Burden Scale. This strengthens the claims of

others that a sense of control accounts for a significant percentage of variance in psychological functioning,^{57,120,121} as well as the finding that patient's beliefs in personal control were related to their well-being, symptom complaints and activity levels.^{58,122} Newsom and Schulz³⁷ investigated predictors of negative reactions to assistance provided to a physically disabled spouse as part of a longitudinal study exploring the physical and psychological health effects of caregiving in marital pairs composed of spouses 65 years of age and older. They found perceived control to be an important predictor of negative reactions to assistance from caregivers. Helping distress in care recipients was also found to be a significant predictor of depressive symptoms, both concurrently and one year later.³⁷

Feelings of being a burden, as reported as the total score on the Self-Perceived Burden Scale, were found to be related to both physical functioning and mental health. Neither of these findings were surprising, as it is intuitive that with decreasing physical function, the need for assistance increases. As the need for assistance increases, demands on the caregiver will increase. This will result in increasing feelings of being a burden as the individual's illness progresses and physical functioning deteriorates. Mental health, as measured by the Mental Health subscale of the SF-36, was also associated with the respondent's total score on the Self-Perceived Burden Scale.

Another strong predictor of a respondent's feelings of being a burden is the perception of other demands being imposed on a caregiver's time and resources. This was expressed as a factor that interferes with the caregiver's

ability to care for the person requiring hemodialysis. The most commonly perceived obstacles to providing care were the caregiver's job, the caregiver's family (if the caregiver is someone other than a spouse) and the caregiver's health. The respondents seemed very aware of the competing demands on the caregiver's time and energy, and the presence of one or more of these factors was a strong predictor of high feelings of being a burden. None of the studies concerning the individual's reactions to needing help addressed this aspect of the caregiver/care recipient relationship. Although competing demands have been mentioned by caregiver burden studies, this factor has not been identified as one of the primary predictors of caregiver burden.^{18,25,123,124} This fact illustrates the importance of measuring self-perceived burden separate from caregiver burden, as discrepancies between the two may be an important source of distress to both the caregiver and the individual with chronic illness.

5.5 Do Hemodialysis Patients Believe They Are a Burden to Others?

Although overall scores on the Self-Perceived Burden Scale were relatively low, feelings of being a burden were very important to the respondents. Many of them were very aware of the burden that they place on their family members, and this feeling of burden made them hesitant to ask for help when it was needed. Other studies have found that when individuals do not anticipate being able to restore equity, they refrain from seeking needed help, or are slower to ask for it.^{33,52,115} This is often the case when a family member is caring for a chronically ill loved one, as the chronically ill person is unlikely to be in a position to reciprocate.

There exist many significant differences between individuals who report feelings of being a burden and those who do not. Individuals who perceive themselves to be a burden scored lower on both the Functional Status Index and the Physical Functioning subscale of the SF-36, indicating poorer physical functioning. This finding is in agreement with the caregiving literature, which identifies level of disability of the help recipient as an important predictor of caregiver burden.^{25,125,126} In this regard, it seems that patient perceptions of burden in this sample are in accordance with those of caregivers as reported in other studies.

In addition, this sample of people undergoing hemodialysis reporting high feelings of being a burden had lower scores on the Mental Health subscale of the SF-36. This adds to a divergent body of literature. Some studies have found negative reactions to being helped to predict both concurrent and future depression³⁷ while others have found no relationship between feelings of being a burden and current depression.³⁵ Further research comparing scores on the Self-Perceived Burden Scale with depressive symptoms at various points in time would be useful in settling this issue.

Patients who scored in the highest quartile on the Self-Perceived Burden Scale do not differ significantly from other respondents in age, social support, or number of months on hemodialysis.

5.6 Purpose of the Self-Perceived Burden Scale

The Self-Perceived Burden Scale will serve as a valuable assessment device for evaluating problems in adjustment to chronic illness. In the case where

a chronically ill individual is forced to rely on a family member for help, the Self-Perceived Burden Scale will serve to more precisely evaluate adjustment to the caregiving situation than a more general mental health, quality-of-life or depression instrument. In fact, the ability to measure feelings of being a burden separately may identify a sign of maladjustment in the absence of depression. At least one study (Wilson, K.W., unpublished data) found that feelings of being a burden (assessed through qualitative interview) were not correlated with depression scores.

5.7 Possible Reasons for Negative Results

The most significant negative result was the failure of the Self-Perceived Burden Scale to load on the three hypothesized factors. This may be due to the fact that the overall level of self-perceived burden in the patient population was relatively low. Although this preliminary study focused on a patient population with varying levels of disability, future studies may be more successful in focusing their efforts on populations of more severely disabled individuals, such as people living with Amyotrophic Lateral Sclerosis, advanced stages of Multiple Sclerosis and paraplegia.

Also, we must take into consideration the health care system and support available to people undergoing hemodialysis. People with relatively few resources available to them will be forced to depend more heavily on their caregiver. This would be expected to impart a greater burden on the caregiver which may subsequently cause greater feelings of being a burden on the person undergoing hemodialysis. This is especially true when financial costs associated

with the illness are high, resulting in a significant financial burden for the hemodialysis patient and his or her family. Due to the nature of the Canadian health care system, people participating in this study had many sources of support available to them. It is for this reason that the item examining financial burden was retained in the final Self-Perceived Burden Scale in spite of poor psychometric properties.

5.8 *Limitations of the Study*

Developing a valid and reliable measurement instrument is a formidable task. Many of the limitations imposed on this project were designed to limit its overall length. Ideally, Phase I of this study would have included a greater diversity of patient population, in order to ensure that the resulting scale would be valid when applied to individuals living with other chronic illnesses. This would include individuals suffering from congestive heart failure, severe rheumatoid arthritis, and other disabling illnesses. Also, as many of the people undergoing hemodialysis are minimally disabled, it may have been more appropriate to use a more disabled population for a preliminary study.

In addition, the sample size employed in this study was the minimum acceptable for the use of factor analytic methods of scale development. A greater number of participants, specifically a greater number of more disabled participants, could likely have yielded more significant results. It is important to note that although factor analysis is more appropriate when the sample size is large, when the sample size is very large minor deviations may be statistically significant.¹²⁷ For this reason, rather than rely on the formal test alone, the

number of factors observed should be considered an indication of an upper limit. Only clinically significant and theoretically interpretable factors (after an examination of rotation results) should be retained.

Sample size considerations were especially evident in Phase II, where many of the co-morbid conditions under investigation for a possible correlation with burden scores had sample sizes far too small to allow for valid inferences. Further work should include a repeat of the factor analysis and correlations using data from a much larger group of respondents. Ideally, approximately 10 respondents should be enrolled for each item in the scale.¹²⁸ The minimum acceptable sample size for factor analysis is 3 respondents for each item.^{99,129} In the case of this study, the factor analysis was performed on the 24-item scale. This made the sample size of 100 respondents adequate, but certainly not ideal.

In addition, there was an unexpectedly high number of patients requiring the questionnaires to be administered verbally. Approximately 80% of respondents required the questionnaires to be administered in this manner. The most common reason for respondents to request verbal administration was poor eyesight, with fatigue and an impeded writing hand (due to the hemodialysis machine) also frequently cited. Unfortunately, due to the fact that this complication was unexpected, I was not prepared to identify those questionnaires completed by hand from those which were interviewer-administered. In order to ensure reliability of the final Self-Perceived Burden Scale, further work should include a subset of individuals using the self-administered Self-Perceived Burden Scale as well as a subset using the interviewer-administered scale. Results

would subsequently be analyzed for significant differences between the two methods of administration. It is predicted that the interviewer-administered version of the Self-Perceived Burden Scale will yield more valid results, as respondents completing the scale independently often seemed to answer items without reading them carefully. This was assumed to be the case when a respondent would mark a '1' (none of the time) for each item, including those worded negatively. This is hypothesized to be the reason why none of the respondents scored the lowest score possible on the 24-item scale. When the items worded in the negative are scored, the scoring is reversed; therefore, answering '1' to a negatively-worded question translates to a score of '5' in order to maintain a consistent scoring system where the final score increases with increasing feelings of being a burden. This problem seemed to be averted when the scale was interviewer-administered. It is possible that the interviewer purposefully emphasized the negative wording of the item in order to avoid reflexive responding, or that the respondent simply paid more attention when the items were read aloud than he would have if he were reading the items silently.

The length of the scale was chosen as a compromise on many fronts. The final draft of the Self-Perceived Burden Scale covers an adequate breadth of items, yet remains relatively brief in order to minimize burden on the respondent. Through the Phase II portion of this study, we attempted to ensure that the Self-Perceived Burden Scale was as parsimonious as possible. We were able to reduce the number of items on the scale from 24 to 10 without losing internal consistency. The coefficient α indicated that the 24-item scale had some

redundancy ($\alpha = 0.92$) and could be further abbreviated without major loss of reliability. The final 10-item scale retained a high degree of internal consistency ($\alpha = 0.85$).

5.9 *Is Burden Maladaptive Coping?*

In the introduction, the link between coping and self-perceived burden was discussed. The justification for considering feelings of being a burden as part of coping may not appear obvious. Coping is a complex process of both practical and cognitive adaptations in response to a challenge. Feelings form an integral part of such reactions, and to separate out feelings would abandon the chance of understanding the development of practical and behavioural reactions. Therefore, while feelings of burden are separate from problem-focused coping strategies, they are intimately linked to the pattern of coping behaviours used by a chronically ill individual.

Feelings of being a burden may not necessarily be a negative response to the caregiving situation. If feelings of being a burden are realistic, they are likely an adaptive coping mechanism, or a consequence of adaptive coping mechanisms. A chronically ill individual experiencing a strong sense of burdensomeness may be motivated to seek out ways to alleviate the burden he perceives on his caregiver. This may include seeking respite care, making a greater effort to accomplish tasks independently, and showing greater appreciation for the caregivers assistance. In more extreme situations, the chronically ill individual may agree to placement in a long-term care facility when

the caregiver is no longer able to manage to care on their own in order to alleviate caregiver burden. If a problem does exist, to recognize the existence of this problem constitutes appraisal. Appraisal is dependent on both the personal significance of the stressor and one's resources dealing with it,⁴⁴ and is the first step in any coping process.

The relation between self-perceived burden and maladaptive coping is evident when the level of self-perceived burden is mismatched with the actual burden level reported by the caregiver. This may occur in two ways—if the patient self-perceived burden is greater than the caregiver reported burden, the person receiving care may be feeling excessive guilt as well as depressive symptoms. Conversely, if the person receiving care reports much lower levels of self-perceived burden than the levels of burden reported by the caregiver, the caregiver will be at greater risk of feelings of resentment and burnout. Both of these consequences of mismatched perceptions of burden in the caregiver and the care recipient should be addressed with appropriate interventions.

In other people, feelings of being a burden may have no impact on behaviour at all. These people might not be affected by their sense of being a burden, or may simply be internalizing these negative feelings. This internalization could further lead to depression, suicidal thoughts and anxiety.

5.10 Future Directions

The first priority of further research pertaining to the Self-Perceived Burden Scale should be the thorough testing of the 10-item scale. This should include further interviews with individuals living with chronic illness to ensure that

the final scale is user-friendly, and that the items are considered pertinent and complete to burden as it is viewed by the respondent.

Another tool in ensuring proper scale development is the assessment of a scale's reproducibility when administered on different occasions. One method of evaluation involves administering the scale to a subset of the original sample on two occasions separated by some interval of time. Future testing of this scale should incorporate a measure of test-retest reliability.

Future research may also include the application of the Self-Perceived Burden Scale to other populations of people living with chronic illnesses. Groups of interest due to their high levels of disability include individuals with terminal cancer³⁵, multiple sclerosis^{12,130}, COPD¹³¹, and various skeletal and neuromuscular disorders.^{120,132} In addition, high levels of burden have been observed in caregivers of individuals living with Alzheimer's disease^{33,47} and mental illness^{10,11} but there are concerns regarding the validity of data from people with cognitive challenges.⁴⁷ Other comparisons of interest may include Self-Perceived Burden Scores of people undergoing hemodialysis compared to those being treated for renal failure by continuous ambulatory peritoneal dialysis, a treatment that allows the patient to undergo dialysis at home, thus increasing the responsibility shouldered by both the person undergoing dialysis and their family.^{68,133,134}

Another dimension of Self-Perceived Burden that should be investigated is a comparison of the Self-Perceived Burden scores of a sample of chronically ill individuals with the Caregiver Burden scores of their primary caregivers. This

would allow further investigation into the determinants and effects of discrepancies between the caregiver's perceived burden and the amount of burden that the chronically ill person feels that they are on the person caring for them.

Future research should further examine the methods of scoring the Self-Perceived Burden Scale. Currently, all items are worth equal weight and are scored equally. Scores range from 10 to 50. It is worth considering that some questions may be of more importance when evaluating burden than others. For example, an affirmative answer to the item "I feel that I am a burden to my caregiver" is very straightforward and would be likely to carry more weight than a negative answer to the item "I am confident that my caregiver can handle the demands of caring for me". In addition, we must consider the fact that not all people with chronic illness will express self-perceived burden similarly. When determining a cutpoint for further work with the Self-Perceived Burden Scale, it must be determined whether scoring a '5' (all of the time) on one item is equivalent to scoring a '3' (some of the time) on one item and a '2' (a little of the time) on another. These distinctions are lost in the current scoring system, which assigns one global Self-Perceived Burden score with no further distinctions. These issues should be further explored in future work with the Self-Perceived Burden Scale.

Chapter 6: CONCLUSION

Through the course of this study I, with the help of others, have developed a valuable instrument for describing feelings of being a burden. It is brief, easily self-administered, and reliably identifies individuals in emotional distress due to feelings of being a burden on others.

By identifying a more precise source of negative feelings, health care practitioners may be able to devise a more effective intervention aimed at alleviating feelings of being a burden. Possible interventions include altering the caregiving situation by arranging respite care or additional home care resources, or arranging counseling for both the help recipient and the caregiver.

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Appendix I**Patient Consent Form for Interview****Study:**Relying on Others for Help**Purpose:**

The purpose of this study is to learn more about the feelings that people living with chronic illness have about their caregivers. We're assuming that you need help with many of your day-to-day activities, such as getting dressed or running errands. We want to talk to you about how it feels to rely on other for help with these things. Your assistance will help us to understand what you're going through, and to eventually create a questionnaire to try to describe the situation of people living with chronic illness.

Procedure:

We would like to invite you to participate in a one-on-one interview with a trained research assistant. This will take about thirty minutes, and will take place at your convenience. The interview will be tape-recorded, but no names will be documented. Your participation is entirely voluntary and anonymous.

Risks and Benefits

There are no physical risks of participating in this project. However, you may find the information in the discussions upsetting. If this happens, arrangements can be made for you to see your physician, nurse or social worker, if you wish. The possible benefit of the study is to know that your participation may someday help others who find it difficult to rely on someone else for their care.

Rights of the Participant:

You have the right to refuse to participate in the study and the right to withdraw from the study at any time without any consequences. The information collected during this study will be kept confidential. A code number will be used to identify the information so that your name will not appear on any documents. If the results of the study are published, no personal identifying data will appear in the published work.

I fully understand the information presented to me on this form and my questions have been answered to my satisfaction.

 Study Participant

 Witness

If you have any further questions about this study, you can contact one of the researchers:

Natalie Cousineau, Research Co-ordinator

562-5800 ext:8144

Dr. Paul Hébert, Ottawa General Hospital

737-8197

Thank you for your help!

Appendix II

Phase I Patient Interviews— Semi-Structured Interview Schedule

We'd like to speak to you today about your relationship with the person who helps you with your everyday activities. This help can come from a paid helper, such as a nurse or housekeeper, or from an unpaid helper, such as a member of your family. We are interested mostly in the help that you get from a friend, spouse or other family member, especially the person who helps or supports you the most. Most people have both positive and negative feelings towards the person caring for them. Feel free to talk about both. There are no 'right' or 'wrong' responses to any of the topics that we will bring up. I'd like you to feel that you can be as open as possible— your opinions are valued, no matter what they are.

What are your living arrangements at home right now?

- who do you live with?
- who helps you with your day-to-day activities?
- what kinds of things do you need help with?
- when you need help, who do you ask?
- how does it feel to need their help?

When someone helps you, how does it make you feel?

- what do you think makes you feel that way?

Whom do you expect to offer help when you need it?

- when they don't offer, how do you feel about asking?
- in what ways does it feel different to receive help that you've asked for, rather than help that was offered?

What are you feeling about the amount of help that you get?

- in what situations do you feel that you need more/less help?
- what have you done to try to ensure that you have the help and support that you need?

What do you think about your caregivers ability to handle the physical demands of helping you?

- do you have any concerns?

How has needing help changed your relationship with your caregiver?

- in what ways has it changed?

How has your illness affected your other relationships/friendships?

Appendix III
Phase I— Health Professional Interviews— Semi-Structured Interview
Schedule

The purpose of this study is to create and validate a scale intended to measure the degree to which a chronically ill patient feels that they are a burden to those around them. Primarily, we are interested in the feelings of the patient towards the family member or friend most involved in their care. We are interested in the feelings of patients covering a wide range of ages and levels of disability. Please try to describe the feelings of the patients as you feel the patients themselves would have described them.

What is your title?

What kinds of patients do you counsel?

How disabled are these patients?

When patients can no longer care for themselves, what is done to ensure that they get the help that they need?

What issues have you noticed come up regularly when talking to patients about their caregiving arrangements?

How have your patients experienced increasing levels of dependence on their friends or family members?

Are feelings of burden a common occurrence among patients you have dealt with?

Do negative feelings about receiving care tend to influence the relationship between the patient and their caregivers? If so, how?

What sorts of issues and situations have you found to increase the sense of burden felt by your patients?

What other feelings have you found often associated with feelings of being a burden?

Appendix IV
Instructions Provided to Respondents for Content Validity Testing

Patient Perceived Burden Scale

Here is a list of items measuring burden compiled from interviews with nurses, social workers and chronically ill patients. Each item will be answered along a Likert-type scale ranging from “not at all” to “very much”. This scale is intended to measure the degree to which a chronically ill patient feels that they are a physical, emotional and financial burden on the unpaid person(s) caring for them. We are not interested in measuring the patient’s self-esteem, frustration, social support or physical functioning with this scale—those items will be measured separately. Please rank each of the following items according to how much you feel that they correspond with feelings of BEING A BURDEN. (1 = doesn’t correspond at all, 10 = corresponds perfectly)

Appendix V

Patient Consent Form for Item Clarity Testing

Study:

Relying on Others for Help

Purpose:

The purpose of this study is to learn more about the feelings that people living with chronic illness have about their caregivers. Specifically, we want to know how relying on another person for help makes you feel. Your assistance will help us to understand what chronically ill patients are going through, and to test a questionnaire that we've developed to try to describe the situation of people living with chronic illnesses.

Procedure:

We would like to invite you to participate in a brief interview to help us identify any problems with the questionnaire. You do not have to answer the questions, simply tell us if you understand them or not. The interview will take about 45 minutes, and will take place at your convenience. The interviews will be recorded, but no names will be used. Your participation is completely voluntary and anonymous.

Risks and Benefits:

This study involves no physical risks. However, the interview may bring up subjects that you find stressful or upsetting. If this happens, arrangements can be made for you to see your physician, nurse or social worker, if you wish. You may not benefit personally from taking part in this study, but the results may help others who find it difficult to rely on others for help.

Rights of the Participant:

Any information you tell us will be confidential. Your name or other identifying information will not appear on any report that come out of this work. You have the right to refuse to participate in the study and the right to stop the interview at any time without consequences.

Statement of Informed Consent:

I have been told about the purpose of the study. I understand that I will be taking part in an interview about 45 minutes long. I know that I can withdraw my consent at any time and the interview will be stopped. I agree to take part in the study with the understanding that information will be collected and used for research purposes only and will be treated as confidential. I understand that I am under no obligation to participate and may withdraw at any time. I also understand that I can refuse to answer any individual question in the interview, and that refusal to participate from the study will in no way affect my treatment at the hospital.

Signed: _____

Date: _____

Witness: _____

If you have any further questions about this study, you can contact one of the researchers:

Natalie Cousineau, Research Co-ordinator
Dr. Paul Hébert, Ottawa General Hospital

562-5800 ext:8144
737-8197

Appendix VI

Item Clarity Testing Questionnaire

Introduction

For the purpose of this study, we are interested in how you feel about the relationship that you have with the person (or people) who helps you out with your day-to-day activities. You may need a little bit of help with things like shoveling snow and carrying groceries, or a lot of help, like driving you to dialysis or preparing meals. We are interested in all the different kinds of help that you receive.

The person who helps you may be a friend, neighbour, or a member of your family, such as a spouse, son or daughter. For the purpose of this questionnaire, we will refer to this person (or people) as your caregiver. We are interested right now only in the people who are NOT paid to help you— this means that housekeepers, nurses and driving services would not be considered caregivers. If you do have more than one person who helps you, please answer these questions even if the feelings apply to only one of your caregivers.

This questionnaire consists of twenty-nine statements about feelings you may or may not have about your relationship with you caregiver. Please rate each statement on a scale of how often you feel this way, from “none of the time” to “all of the time”. Please consider your answers carefully— we would like you to be as honest as possible.

Do you understand what these instructions are asking you to do?

What kind of relationship is this questionnaire asking you about?

Is there anything in these instructions that is not clear to you?

Scaling

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

Do you see a difference between “none of the time” and “a little of the time”?

Do you see a difference between “a little of the time” and “some of the time”?

Do you see a difference between “some of the time” and “most of the time”?

Do you see a difference between “most of the time” and “all of the time”?

Do you understand how to use this scale?

Items

1. I am concerned that my caregiver will “wear out” because of the demands of helping me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
 (b) What is this statement talking about?
 (c) What specific things do you think of when you try to rate this statement?
 (d) Is there any part of this statement that you find unclear?

2. I worry that the health of my caregiver could suffer as a result of caring for me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
 (b) What is this statement talking about?
 (c) What specific things do you think of when you try to rate this statement?
 (d) Is there any part of this statement that you find unclear?

3. I worry that my caregiver is overextending him/herself in helping me out.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
 (b) What is this statement talking about?
 (c) What specific things do you think of when you try to rate this statement?
 (d) Is there any part of this statement that you find unclear?

4. I am concerned that it costs my caregiver a lot of money to care for me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

5. I am concerned that my caregiver doesn't "let" me do things for myself that I can do.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

6. I worry that my caregiver has to take time away from other things to help me

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

7. I feel guilty about the demands that I make on my caregiver.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

8. I feel guilty that my caregiver has to change their plans in order to help me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

9. I worry about my caregiver because they have to take on too much responsibility for me

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

10. I worry that my caregiver has lost control of their life due to caring for me

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

11. I'm concerned that my needs are so great that my caregiver can't handle them.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

12. It troubles me to ask my caregiver for help so I overextend myself.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

13. I am concerned that if I ask for help it will put too much pressure on my caregiver.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

14. I often find myself doing without some things rather than having to ask for help.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

15. I often feel dependent on others to get by.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

16. I am concerned that because of all they do for me, the person caring for me may not be able to do so much longer.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

17. I am concerned that my caregiver is helping me beyond their capacity.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

18. I am concerned that I won't be able to "repay" my caregiver for all they've done for me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

19. I find it easier to ask for help when I feel that I can give something in return.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

20. I am concerned that the demands of my care have strained my relationship with my caregiver.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

21. I am concerned that if I asked for outside help, my caregiver would resent it.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

22. I am concerned that I am "too much trouble" to those around me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

23. Receiving help from others makes me feel loved.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

24. I am concerned that because of my illness, my caregiver is trying to do too many things at once.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

25. I am concerned that because of caring for me, my caregiver is being pulled in too many directions.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

26. I am concerned about the negative effects of my illness on those around me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

27. I am confident that my caregiver can handle the demands of caring for me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

28. I am concerned that if my caregiver had a choice, they wouldn't be caring for me.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

29. I find it easier to accept help when it's offered, rather than when I have to ask.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

30. I think that I make things hard on my caregiver.

None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
------------------	----------------------	------------------	------------------	-----------------

- (a) Do you understand this statement?
- (b) What is this statement talking about?
- (c) What specific things do you think of when you try to rate this statement?
- (d) Is there any part of this statement that you find unclear?

Appendix VII**Patient Consent Form****Study:****Relying on Others for Help****Purpose:**

The purpose of this study is to test a questionnaire that has been developed to describe the experiences of chronically ill individuals, such as patients who need dialysis. Your answers will help us identify any problems with the questionnaire, which deals with how it feels to rely on others for help. Participating in this project will also help us to understand the experiences of patients undergoing dialysis.

Procedure:

We would like to invite you to participate in a short interview with a research assistant. This interview will take approximately 5 minutes of your time. After this interview, you may be invited to participate further, by filling out 4 questionnaires. These questionnaires may take up to 45 minutes to complete. A research assistant will also look at your medical record in order to record details of your medical condition. Your participation is entirely voluntary and anonymous. No names will be used, and no identifying details will be made public.

Risks and Benefits

There are no physical risks of participating in this project. However, you may find the information in questionnaire upsetting. If this happens, arrangements can be made for you to see your physician, nurse or social worker, if you wish. The possible benefit of the study is to know that your participation may someday help others.

Rights of the Participant:

You have the right to refuse to participate in the study and the right to withdraw from the study at any time without any consequences. The information collected during this study will be kept confidential. A code number will be used to identify the information so that your name will not appear on any documents. If the results of the study are published, no personal identifying data will appear in the published work.

I fully understand the information presented to me on this form and my questions have been answered to my satisfaction.

 Study Participant

 Witness

If you have any further questions about this study, you can contact one of the researchers:

Natalie Cousineau, Research Co-ordinator

562-5800 ext:8144

Dr. Paul Hébert, Ottawa General Hospital

737-8197

Thank you for your help!

Appendix VIII**Short Portable Mental Status Questionnaire**

Instructions: Ask question 1 to 10 in this list and record all answers. Ask question 4A only if patient does not have a telephone. Record total number of errors based on 10 questions:

1. What is the date today?
2. What day of the week is it?
3. What is the name of this place?
4. What is your telephone number?
- 4A. What is your street address? *(ask only if patient does not have a telephone)*
5. How old are you?
6. When were you born?
7. Who is the Prime Minister of Canada now?
8. Who was the Prime Minister before him?
9. What was your mother's maiden name?
10. Subtract 3 from 20 and keep subtracting 3 from each new number, all the way down.

Number of Questions Answered Correctly: _____

Appendix IX**Demographic Information****Participant Number:** _____

1) Age (in years): _____

2) Gender: M F

3) How far did you get through school? (check box)

- Less than grade 7
- Junior High School (grades 7-9)
- Partial High School (grades 10-12)
- High School Graduate
- Partial College (at least one year)
- College or University Graduate
- Postgraduate (masters or Ph.D.)
- Professional Degree

4) Etiology of Renal Failure:

5) Type of Dialysis Used:

a) Hemodialysis: Yes No # of Years _____

b) CAPD: Yes No # of Years _____

6) How long before dialysis were you aware of your kidney disease?

7) Kidney Transplants: Yes No How Many? _____

8) Co-Morbid Illnesses:

- a) Respiratory Disease (requiring supplemental O₂)
- b) Severe Heart Failure (NYHA class III-IV: SOB with orthopnea and paroxysmal nocturnal dyspnea— confirmed LV function by Swan Ganz, echo, LV gated scan and angiography)
- c) Severe Angina (NYHA class III-IV: history of past angina of admission compatible with MI, changes on ECG, stress test or angiography)
- d) IDDM
- e) Malignancy (evidence of cancer at more than one site)
- f) Severe Neurologic Disease (i.e. Alzheimers, stroke, etc.)
- g) Liver Cirrhosis
- h) Other: _____

9) Past Medical History:

a) Surgical Procedures:

- i) _____
- ii) _____
- iii) _____

b) Hospitalizations:

- i) _____
- ii) _____
- iii) _____

10) Medications:

- a) _____
- b) _____
- c) _____
- d) _____
- e) _____
- f) _____
- g) _____

Caregiving Arrangements

What kind of help do you get with your day-to-day activities?

Paid:

- a) Driving service
- b) Home nursing care
- c) Housekeeping
- d) Landscaping
- e) Snow removal
- f) Other _____

Unpaid:

- a) Spouse
- b) Son
- c) Daughter
- d) Neighbour
- e) Friend
- f) Other Family _____
- g) Other _____

Whom do you consider to be your **primary caregiver**?

What is your relationship to your primary caregiver?

With what kind of activities does this person help you?

- a) _____
- b) _____
- c) _____
- d) _____
- e) _____

Does this person have any health problems?

- a) No
- b) Yes

Please explain: _____

Are there other factors that interfere with the ability of your caregiver to help you?

Appendix X

Functional Status Index

During the past month, how much physical difficulty did you have....

	Usually Did With No Difficulty	Usually Did With Some Difficulty	Usually Did With Much Difficulty	Usually Did Not Do Because of Health	Usually Did Not Do for Other Reasons
1. Taking care of yourself, that is eating, dressing or bathing?	1	2	3	4	5
2. Moving in or out of a bed or chair?	1	2	3	4	5
3. Walking several blocks?	1	2	3	4	5
4. Walking <i>one</i> block or climbing <i>one</i> flight of stairs	1	2	3	4	5
5. Walking indoors, such as around your home	1	2	3	4	5
6. Doing work around the house such as cleaning, light yard work, home maintenance?	1	2	3	4	5
7. Doing errands, such as grocery shopping?	1	2	3	4	5
8. Driving a car or using public transportation?	1	2	3	4	5
9. Visiting with relatives or friends?	1	2	3	4	5
10. Participating in community activities such as religious services, social activities or volunteer work?	1	2	3	4	5
11. Taking care of other people such as family members?	1	2	3	4	5
12. Doing vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports?	1	2	3	4	5

Appendix XI**MOS Social Support Scale**

1. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
2. Someone to help you if you were confined to bed...	1	2	3	4	5
3. Someone you can count on to listen to you when you need to talk.....	1	2	3	4	5
4. Someone to give you good advice about a crisis.....	1	2	3	4	5
5. Someone to take you to the doctor if you needed it...	1	2	3	4	5
6. Someone who shows you love and attention.....	1	2	3	4	5
7. Someone to have a good time with.....	1	2	3	4	5
8. Someone to give you information to help you understand a situation.....	1	2	3	4	5
9. Someone to confide in or talk to about yourself or your problems.....	1	2	3	4	5
10. Someone who hugs you.....	1	2	3	4	5
11. Someone to get together with for relaxation.....	1	2	3	4	5
12. Someone to prepare your meals if you were unable to do it yourself.....	1	2	3	4	5
13. Someone whose advice you really want.....	1	2	3	4	5
14. Someone to do things with to help you get your mind off things.....	1	2	3	4	5
15. Someone to help with daily chores if you were sick..	1	2	3	4	5
16. Someone to share your most private worries and fears with.....	1	2	3	4	5
17. Someone to turn to for suggestions about how to deal with a personal problem.....	1	2	3	4	5
18. Someone to do something enjoyable with.....	1	2	3	4	5
19. Someone who understands your problems.....	1	2	3	4	5
20. Someone to love and make you feel wanted.....	1	2	3	4	5

Appendix XII

Short-Form 36 Health Survey

Instructions: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: (Circle one)

- Excellent.....1
- Very Good.....2
- Good.....3
- Fair.....4
- Poor.....5

2. Compared to one year ago, how would you rate your health in general now?

- Excellent.....1
- Very Good.....2
- Good.....3
- Fair.....4
- Poor.....5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Circle one number on each line)

Activities	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
i. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the *past four weeks*, have you had any of the following problems with your work or other regular daily activities as a result of your *physical health*?

(Circle one number on each line)

	Yes	No
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort?)	1	2

5. During the *past four weeks*, have you had any of the following problems with your work or other regular activities as a result of any *emotional problems* (such as feeling depressed or anxious)?

(Circle one number on each line)

	Yes	No
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

6. During the *past four weeks*, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

(Circle one)

- Not at all.....1
Slightly.....2
Moderately.....3
Quite a bit.....4
Extremely.....5

7. How much *bodily* pain have you had during the *past four weeks*?

(Circle one)

- None.....1
Very mild.....2
Mild.....3
Moderate.....4
Severe.....5
Very Severe.....6

8. During the *past four weeks*, how much did *pain* interfere with your normal work (including both work outside the home and housework)?

(Circle one)

- Not at all.....1
- A little bit.....2
- Moderately.....3
- Quite a bit.....4
- Extremely.....5

9. These questions are about how you feel and how things have been with you *during the past four weeks*. For each question, please give the answer that comes closest to the way you have been feeling. How much of the time during the *past four weeks*—

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the *past four weeks*, how much of the time has your *physical health or emotional problems* interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle one)

- All of the time.....1
- Most of the time.....2
- Some of the time.....3
- A little of the time.....4
- None of the time.....5

11. How TRUE or FALSE is *each* of the following statements for you?

(Circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

Appendix XIII

Self-Perceived Burden Scale (as administered to respondents)

For the purpose of this study, we are interested in how you feel about the relationship that you have with the person (or people) who helps you out with your day-to-day activities. You may need a little bit of help with things like shoveling snow and carrying groceries, or a lot of help, like driving you to dialysis or preparing meals. We are interested in all the different kinds of help that you receive.

The person who helps you may be a friend, neighbour, or a member of your family, such as a spouse, son or daughter. For the purpose of this questionnaire, we will refer to this person (or people) as your caregiver. We are interested right now only in the people who are NOT paid to help you— this means that housekeepers, nurses and driving services would not be considered caregivers. If you do have more than one person who helps you, please answer these questions even if the feelings apply to only one of your caregivers.

This questionnaire consists of thirty-three statements about feelings you may or may not have about your relationship with you caregiver. Please rate each statement on a scale of how often you feel this way, from “none of the time” to “all of the time”. Please consider your answers carefully— we would like you to be as honest as possible.

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
1. I am concerned that my caregiver will “wear out” because of the demands of caring for me	1	2	3	4	5
2. I worry that the health of my caregiver could suffer as a result of caring for me	1	2	3	4	5
3. I worry that my caregiver is overextending him/herself in helping me out	1	2	3	4	5
4. I am concerned that it costs my caregiver a lot of money to care for me	1	2	3	4	5
5. I worry that my caregiver has to take time away from other things in order to help me	1	2	3	4	5
6. I am concerned that I won’t be able to “repay” my caregiver for all they’ve done for me	1	2	3	4	5
7. I feel guilty about the demands that I make on my caregiver	1	2	3	4	5
8. I worry about my caregiver because they have to take on too much responsibility for me	1	2	3	4	5

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
9. I feel guilty that my caregiver has to change their plans in order to help me	1	2	3	4	5
10. I worry that my caregiver has lost control of their life due to caring for me	1	2	3	4	5
11. I'm concerned that my needs are so great that my caregiver can't handle them	1	2	3	4	5
12. I am concerned that if I ask for help it will put too much pressure on my caregiver	1	2	3	4	5
13. I am concerned that because of all they do for me, the person caring for me may not be able to do so much longer	1	2	3	4	5
14. I am concerned that my caregiver is helping me beyond their capacity	1	2	3	4	5
15. I find it easier to ask my caregiver for help when I feel that I can give something in return	1	2	3	4	5
16. I am concerned that the demands of my care have strained my relationship with my caregiver	1	2	3	4	5
17. I am concerned that I am "too much trouble" to my caregiver	1	2	3	4	5
18. Receiving help from others makes me feel that they care for me	1	2	3	4	5
19. I am concerned that because of my illness, my caregiver is trying to do too many things at once	1	2	3	4	5
20. I am concerned about the negative effects of my illness on those around me	1	2	3	4	5
21. I am confident that my caregiver can handle the demands of caring for me	1	2	3	4	5
22. I find it easier to accept help when it's offered, rather than when I have to ask	1	2	3	4	5
23. I am concerned that because of caring for me, my caregiver is being pulled in too many directions	1	2	3	4	5
24. I think that I make things hard on my caregiver	1	2	3	4	5

Appendix XIV**Supplemental Items**

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
1. I feel certain that I do not make too many demands on my caregiver	1	2	3	4	5
2. I am not worried that my caregiver is overextending him/herself in taking care of me	1	2	3	4	5
3. I don't think that I ask too much of my caregiver	1	2	3	4	5
4. I am concerned that I am a burden to my caregiver	1	2	3	4	5
5. I am concerned that my caregiver really doesn't want to help me	1	2	3	4	5
6. I am concerned that if I asked for outside help, my caregiver would resent it	1	2	3	4	5
7. I am concerned that my caregiver doesn't "let" me do things for myself that I can do	1	2	3	4	5
8. It troubles me to ask for help so I overextend myself	1	2	3	4	5
9. I often find myself doing without some things rather than having to ask for help	1	2	3	4	5
10. I often feel dependent on others to get by	1	2	3	4	5
11. I am concerned that if my caregiver had a choice, they wouldn't be caring for me	1	2	3	4	5

Appendix XV**Initial List of 80 Items**

Original Item	Eventual Fate of Item
1. Do you feel like you are 'dragging down' your caregiver?	Deleted—redundant
2. Do you find yourself getting angry at your caregiver?	Deleted—failed face validity
3. Does your caregiver have to take time away from other things to help you?	# 5 in final scale
4. Do you worry that your caregiver has too much control over your life?	Deleted—failed face validity
5. Do you overextend yourself before asking for help?	Supplemental Item # 8
6. Do you see asking for help as 'giving in'?	Deleted—failed face validity
7. Does it make you feel uncomfortable to ask for help?	Deleted—failed face validity
8. Does it make you feel uncomfortable to need help?	Deleted—failed face validity
9. Do you worry that you're losing your independence?	Deleted—failed face validity
10. Will you do 'whatever it takes' to get by on your own?	Deleted—redundancy/face validity
11. Do you worry that helping you will eventually 'wear out' your caregiver?	# 1 in final scale
12. Do you feel dependent on other to get by?	Supplemental Item # 10
13. Do you worry what the future holds?	Deleted—failed face validity
14. Do you feel that your health is 'out of your hands'?	Deleted—failed face validity
15. Do you worry that the person caring for you may not be able to continue doing so much longer?	# 13 in final scale
16. Does the possibility of having to leave your home frighten you?	Deleted—failed face validity
17. Do you worry about the financial costs of your illness?	# 4 in final scale
18. Do you worry that the health of your caregiver will suffer as a result of caring for you?	# 2 in final scale
19. Do you feel that most of your friends and family avoid you as a result of your illness?	Deleted—failed face validity
20. Do you feel that you receive 'too much help' from those around you?	# 14 in final scale
21. Do you sometimes feel frustrated by the people who are trying to help you?	Deleted—failed face validity
22. Does it make you feel guilty to ask for help?	Deleted—redundancy
23. Do the people helping you make you feel that there are other things that they'd rather be doing?	Deleted—failed face validity
24. As time goes on, do you find it gets easier to ask for or received help?	Deleted—failed face validity
25. Do you find it easier to accept help when it is offered to you, rather than having to ask?	# 22 in final scale
26. Does it make you feel loved to receive help from others?	# 18 in final scale
27. Do you worry that you will not be able to 'repay' your caregiver for helping you?	# 6 in final scale
28. Do you worry that your caregiver may 'burn out' as a result of caring for you?	Deleted—jargon
29. Does it bother you to be seen as dependent on others?	Deleted—failed face validity
30. Do you worry that if you ask for help, people will think you are 'needy'?	Deleted—failed face validity
31. Do you worry that your caregiver is trying to do too many things at once?	# 19 in final scale
32. Do you feel that if you ask for help, people will think you are 'too dependent'?	Deleted—failed face validity

33. Do you worry that if you ask for more help, it will cause bad feelings between you and your caregiver?	Deleted—redundancy
34. Do you feel that your illness has strained your relationship with your caregiver?	# 16 in final scale
35. Do you worry that your caregiver is being pulled in too many directions?	# 23 in final scale
36. Do you worry about the physical demands your illness makes on your caregiver?	Deleted—redundancy
37. Do you worry that helping you takes up too much of your caregivers time?	Deleted—redundancy
38. Does asking for help make you feel useless?	Deleted—failed face validity
39. Do you sometimes find yourself frustrated when you're not getting the right kind of help?	Deleted—failed face validity
40. Does needing help make you angry with yourself?	Deleted—failed face validity
41. Do you see your caregiver as the key to keeping your independence?	Deleted—failed face validity
42. Do you find yourself doing without some things rather than asking others for help?	Supplemental Item # 9
43. Do you avoid talking to others about your feelings because you don't want to burden them?	Deleted—failed face validity
44. Do you find yourself wishing that you could afford to pay for extra help?	Deleted—failed face validity
45. Do you feel a sense of loss when you have to rely on others for help?	Deleted—failed face validity
46. Do you wish that your caregiver had more outside help?	# 11 in final scale
47. Do you worry that if you asked for outside help, your caregiver would resent it?	Supplemental Item # 6
48. Do you feel as though you've lost control of your life since your illness?	# 10 in final scale
49. Do you worry that you're losing your independence?	Deleted—failed face validity
50. Are there specific people that you expect to offer you help?	Deleted—failed face validity
51. Do you worry that if your caregiver were no longer able to help you, you wouldn't be able to stay in your home?	Deleted—failed face validity
52. Do you ever find yourself wondering why you're still alive?	Deleted—failed face validity
53. Do you feel that your situation is hopeless?	Deleted—failed face validity
54. Do you worry about the effects of your illness on those around you?	# 20 in final scale
55. Do you feel that you fully understand your illness and treatment?	Deleted—failed face validity
56. Are you confident that the doctors and nurses can help you?	Deleted—failed face validity
57. Do you hope that your condition will improve?	Deleted—failed face validity
58. Do you have confidence that your caregiver can help you with your needs?	# 21 in final scale
59. Do you feel motivated to do everything you can to improve your health?	Deleted—failed face validity
60. Do you worry that you're 'too much trouble' to those around you?	# 17 in final scale
61. Do you feel that you should be doing more for those around you?	Deleted—failed face validity
62. Are you afraid of what the future holds for you?	Deleted—failed face validity
63. How often do you worry about managing by yourself?	Deleted—failed face validity
64. Do you feel embarrassed by your illness?	Deleted—failed face validity
65. Do you feel embarrassed by needing help?	Deleted—failed face validity
66. Do you feel guilty about the demands you make on your	# 7 in final scale

caregiver?	
67. Do you feel guilty about the demands you make on your family?	Deleted—redundancy
68. Do you get angry when you feel that others won't 'let' you do things for yourself?	Supplemental Item # 7
69. Do you worry that you're not good for much anymore?	Deleted—failed face validity
70. Do you prefer helping others to being helped yourself?	Deleted—redundancy
71. Do you find it easier to ask for help when you feel you can give something in return?	# 15 in final scale
72. Do you often find yourself lonely?	Deleted—failed face validity
73. Does it bother you to know that others have changed their plans in order to help you?	# 9 in final scale
74. Do you avoid asking for help because you are angry at the person helping you?	Deleted—failed face validity
75. Do you feel as though you owe the people who help you?	Deleted—redundancy
76. Do you wait until help is offered to you?	Deleted—failed face validity
77. Does having others do things for you make you feel 'left out'?	Deleted—failed face validity
78. Do you worry that your caregivers are overextending themselves?	# 3 in final scale
79. Do people tell you that you are stubborn about receiving help?	Deleted—failed face validity
80. Does it bother you to feel that people pity you?	Deleted—failed face validity

Appendix XVI**Factor Loadings– Principal Components Analysis**

Number	Item	Factor			
		I	II	III	IV
17	I am 'too much trouble' to caregiver	.82	.05	.06	.25
10	Caregiver lost control of life	.80	-.16	-.17	-.10
3	Overextending caregiver	.79	.13	-.26	-.01
2	Health of caregiver could suffer	.77	-.07	-.36	.13
19	Trying to do too much at once	.77	.13	.15	-.26
7	Guilty about demands	.76	.14	-.17	.03
23	Caregiver pulled in too many directions	.75	-.04	.14	.26
14	Helping beyond their capacity	.75	-.08	.33	-.02
8	Take on too much responsibility	.74	.10	-.28	-.14
24	Make things hard on caregiver	.72	-.01	.12	.24
11	Needs too great for caregiver to handle	.72	-.11	.26	-.33
9	Guilt that caregiver has to change plans	.70	-.24	-.25	-.12
20	Negative effects of illness	.70	-.09	.05	.22
12	Asking for help puts pressure on caregiver	.70	-.16	.03	-.04
16	Strained relationship with caregiver	.69	-.09	.28	.21
4	Costs caregiver a lot of money to care	.69	-.11	.01	-.29
5	Takes time away from other things	.68	-.13	-.23	-.15
13	May not be able to care much longer	.65	-.15	.32	.34
1	Caregiver will wear out	.63	.07	-.43	.06
6	Won't be able to repay caregiver	.63	.10	.21	-.35
15	Giving something in return	.45	.38	.41	-.05
21	Confident that caregiver can handle demand	-.11	-.75	.06	.33
22	Easier to accept help that's offered	.26	.69	.18	.23
18	Makes me feel that they care for me	.15	.43	-.38	.35

Appendix XVII

Rotated Factor Structure (Varimax)

Factor #1	Factor #2	Factor #3	Factor #4
2. I worry that the health of caregiver could suffer as a result of caring for me. (.783)	13. I am concerned that the person caring may not be able to do so much longer. (.775)	11. I'm concerned that my needs are so great that my caregiver can't handle them. (.666)	21. I am confident that my caregiver can handle the demands of caring for me. (-.749)
1. I am concerned that my caregiver will "wear out" as a result of caring for me. (.732)	16. I am concerned that the demands of care have strained my relationship with my caregiver. (.691)	6. I am concerned that I won't be able to repay my caregiver for all they've done for me. (.593)	22. I find it easier to accept help when it's offered, rather than when I have to ask. (.736)
3. I worry that my caregiver is overextending themselves in helping me out. (.728)	23. I am concerned that because of caring for me, my caregiver is being pulled in too many directions. (.673)	19. I am concerned that because of my illness, my caregiver is trying to do too many things at once. (.547)	15. I find it easier to ask for help when I feel I can give something in return. (.480)
8. I worry about my caregiver because they have to take on too much responsibility for me. (.721)	17. I am concerned that I am "too much trouble" to caregiver. (.639)	4. I am concerned that it costs my caregiver a lot of money to care for me. (.497)	
10. I worry that my caregiver has lost control of their life due to caring for me. (.692)	24. I think that I make things hard on my caregiver. (.634)	14. I am concerned that my caregiver is helping me beyond their capacity. (.460)	
9. I feel guilty that my caregiver has to change their plans in order to help me. (.690)	14. I am concerned that my caregiver is helping me beyond their capacity. (.605)	18. Receiving help from other makes me feel that they care for me. (-.450)	
5. I worry that my caregiver has to take time away from other things in order to help me. (.661)	20. I am concerned about the negative effects of my illness on those around me. (.582)	15. I find it easier to ask for help when I feel I can give something in return. (.368)	
7. I feel guilty about the demands I make on my caregiver. (.636)	12. I am concerned that if I ask for help it will put too much pressure on my caregiver. (.425)		
4. I am concerned that it costs my caregiver a lot of money to care for me. (.506)	11. I'm concerned that my needs are so great that my caregiver can't handle them. (.366)		
17. I am concerned that I am "too much trouble" to caregiver. (.504)	2. I worry that the health of caregiver could suffer as a result of caring for me. (.364)		
12. I am concerned that if I ask for help it will put too much pressure on my caregiver. (.482)	7. I feel guilty about the demands I make on my caregiver. (.356)		
19. I am concerned that because of my illness, my caregiver is trying to do too many things at once. (.454)	10. I worry that my caregiver has lost control of their life due to caring for me. (.347)		
20. I am concerned about the negative effects of my illness on those around me. (.438)	19. I am concerned that because of my illness, my caregiver is trying to do too many things at once. (.344)		

Appendix XVIII

Oblimin Oblique Rotations ($\Delta 0.25$)

Factor #1	Factor #2	Factor #3	Factor #4
8. I worry about my caregiver because they have to take on too much responsibility for me. (.794)	21. I am confident that my caregiver can handle the demands of caring for me. (-.814)	18. Receiving help from other makes me feel that they care for me. (-.628)	13. I am concerned that the person caring may not be able to do so much longer. (.882)
9. I feel guilty that my caregiver has to change their plans in order to help me. (.777)	22. I find it easier to accept help when it's offered, rather than when I have to ask. (.614)	11. I'm concerned that my needs are so great that my caregiver can't handle them. (.482)	16. I am concerned that the demands of care have strained my relationship with my caregiver. (.741)
2. I worry that the health of caregiver could suffer as a result of caring for me. (.774)	15. I find it easier to ask for help when I feel I can give something in return. (.524)	6. I am concerned that I won't be able to repay my caregiver for all they've done for me. (.379)	23. I am concerned that because of caring for me, my caregiver is being pulled in too many directions. (.679)
1. I am concerned that my caregiver will "wear out" as a result of caring for me. (.771)	6. I am concerned that I won't be able to repay my caregiver for all they've done for me. (.350)	22. I find it easier to accept help when it's offered, rather than when I have to ask. (-.331)	24. I think that I make things hard on my caregiver. (.634)
5. I worry that my caregiver has to take time away from other things in order to help me. (.753)	19. I am concerned that because of my illness, my caregiver is trying to do too many things at once. (.345)	4. I am concerned that it costs my caregiver a lot of money to care for me. (.313)	17. I am concerned that I am "too much trouble" to caregiver. (.599)
3. I worry that my caregiver is overextending themselves in helping me out. (.738)			14. I am concerned that my caregiver is helping me beyond their capacity. (.597)
10. I worry that my caregiver has lost control of their life due to caring for me. (.735)			20. I am concerned about the negative effects of my illness on those around me. (.554)
7. I feel guilty about the demands I make on my caregiver. (.603)			15. I find it easier to ask for help when I feel I can give something in return. (.442)
4. I am concerned that it costs my caregiver a lot of money to care for me. (.584)			21. I am confident that my caregiver can handle the demands of caring for me. (.402)
19. I am concerned that because of my illness, my caregiver is trying to do too many things at once. (.460)			22. I find it easier to accept help when it's offered, rather than when I have to ask. (.381)
12. I am concerned that if I ask for help it will put too much pressure on my caregiver. (.450)			12. I am concerned that if I ask for help it will put too much pressure on my caregiver. (.315)
11. I'm concerned that my needs are so great that my caregiver can't handle them. (.388)			

Appendix XIX

Oblimin Oblique Rotation ($\Delta 0.5$)

Factor #1	Factor #2	Factor #3	Factor #4
8. I worry about my caregiver because they have to take on too much responsibility for me. (.869)	21. I am confident that my caregiver can handle the demands of caring for me. (-.837)	18. Receiving help from other makes me feel that they care for me. (-.652)	13. I am concerned that the person caring may not be able to do so much longer. (1.013)
9. I feel guilty that my caregiver has to change their plans in order to help me. (.852)	22. I find it easier to accept help when it's offered, rather than when I have to ask. (.521)	11. I'm concerned that my needs are so great that my caregiver can't handle them. (.475)	16. I am concerned that the demands of care have strained my relationship with my caregiver. (.835)
1. I am concerned that my caregiver will "wear out" as a result of caring for me. (.844)	15. I find it easier to ask for help when I feel I can give something in return. (.497)	22. I find it easier to accept help when it's offered, rather than when I have to ask. (-.369)	23. I am concerned that because of caring for me, my caregiver is being pulled in too many directions. (.754)
5. I worry that my caregiver has to take time away from other things in order to help me. (.829)	6. I am concerned that I won't be able to repay my caregiver for all they've done for me. (.389)	6. I am concerned that I won't be able to repay my caregiver for all they've done for me. (.369)	24. I think that I make things hard on my caregiver. (.704)
2. I worry that the health of caregiver could suffer as a result of caring for me. (.822)	19. I am concerned that because of my illness, my caregiver is trying to do too many things at once. (.359)	4. I am concerned that it costs my caregiver a lot of money to care for me. (.309)	17. I am concerned that I am "too much trouble" to caregiver. (.652)
3. I worry that my caregiver is overextending themselves in helping me out. (.787)			14. I am concerned that my caregiver is helping me beyond their capacity. (.649)
10. I worry that my caregiver has lost control of their life due to caring for me (.786)			20. I am concerned about the negative effects of my illness on those around me. (.600)
4. I am concerned that it costs my caregiver a lot of money to care for me. (.630)			15. I find it easier to ask for help when I feel I can give something in return. (.531)
7. I feel guilty about the demands I make on my caregiver. (.624)			22. I find it easier to accept help when it's offered, rather than when I have to ask. (.505)
19. I am concerned that because of my illness, my caregiver is trying to do too many things at once. (.467)			21. I am confident that my caregiver can handle the demands of caring for me. (.453)
12. I am concerned that if I ask for help it will put too much pressure on my caregiver. (.449)			