

**Family caregiver “perspective-taking”: A determinant of “empathic” accuracy on
symptom experience in advanced stage cancer patients**

by

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**FAMILY CAREGIVER "PERSPECTIVE-TAKING":
A DETERMINANT OF "EMPATHIC" ACCURACY ON SYMPTOM EXPERIENCE IN
ADVANCED STAGE CANCER PATIENTS**

BY

MICHELLE M. LOBCHUK

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

of

DOCTOR OF PHILOSOPHY

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ABSTRACT

The major purpose of this study was, first, to examine the degree of family caregiver empathic accuracy on the multidimensional symptom experience of advanced stage cancer patients and second, to identify whether perspective-taking by family caregivers and other factors play an influential role in their inferences and subsequent empathic accuracy outcomes on patient symptom experience. Using a descriptive comparative survey design, a convenience sample of 98 advanced stage cancer patient-primary family caregiver dyads completed the Memorial Symptom Assessment Scale (MSAS) and the Dyadic Perspective-Taking Scale (DPTS). Family caregivers also responded to self-report and induced perspective-taking instructional sets on two MSAS symptoms. Findings from parametric and non-parametric analyses confirm previously held trends that describe patient and family caregiver congruence on patient symptom experiences. In main group analyses, findings suggest that it is more of a challenge for family caregivers to inhibit their own symptom experience from interfering with their perception of the patient's viewpoint on psychological versus physical symptoms. In addition, depending on the physical or psychological nature of symptom items, induced perspective-taking activities can have differential effects on caregiver empathic accuracy. A major finding suggests that an imagine-other instructional prompt on physical symptoms and a neutral prompt on psychological symptoms might serve as simple clinical interventions that promote judgment accuracy by family caregivers. Recommendations for nursing practice and future research are made based on the study results.

CHAPTER ONE

Introduction

Statement of the problem

In light of aging populations and health care cost restraints in the area of cancer care worldwide, increasing numbers of family members are being expected to provide home health care. The provision of more complex caregiving by family members requires a level of knowledge and caregiving skill that is of concern to clinicians and researchers. The expectation that family caregivers provide this level of care is often based on the assumption that they already possess such requisite skills and knowledge, despite not having formal training (Gosselin, 2000; Pasacrete, Barg, Nuamah, & McCorkle, 2000).

Although health care literature documents the skills needed by family caregivers, very little to date has been developed in terms of family caregiver skill as a concept (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). In a recent attempt to conceptualize “family caregiving skill” involving caregivers in a cancer chemotherapy illness situation, Schumacher and colleagues identified nine family caregiving skill processes. Two of these skill processes are ‘monitoring’ and ‘interpreting’ that indicate or signify dimensions of the caregiving role. Underlying each of these processes are “indicators” which “are observable characteristics of caregiving that signify the level of skillfulness with which each caregiving process is carried out” (Schumacher et al., 2000, p. 195). The accurate observation by family caregivers of patients' symptom experiences is

one of the indicators that underlie the 'monitoring' process. 'Interpreting' requires, for instance, a complex reasoning activity by the family caregiver to comprehend the meaning of patient symptom events and an ability to recognize deviations from the norm (Schumacher et al., 2000). These authors suggested that clinicians should conduct clinical assessments on the basis of these indicators to determine the caregiver's ability to detect changes in the patient's condition.

Guided broadly by the respective indicators of 'monitoring' and 'interpreting' processes, this study made an attempt to make more explicit the level of family caregiving skill in regard to the current (versus retrospective) assessment of patient symptom experiences within the intimate patient-family carer relationship. It has been suggested that the cancer experience is best understood as an interpersonal one which is shared between patients and their loved ones (Ey, Compas, Epping-Jordan, & Worsham, 1998). The cancer experience provides a "strategic arena" where the perceptions of caregivers and patients on illness events like symptom experiences might be investigated (Clipp & George, 1992). The response comparability between patients and their family caregivers is an especially salient issue for health care professionals in palliative care. Frequently they face the question of whether family caregivers can serve as reliable surrogates in providing an accurate account of the patient's symptom experience, particularly when the patient becomes too ill or unable to communicate his or her needs.

Accumulated evidence suggests that in comparison to patients' current self-reports on symptom events, family caregivers' current ratings appear to be reasonably accurate representations in the terminal phase of the cancer experience (Hinton, 1996; Kristjanson, Nikoletti, Porock, Smith, Lobchuk, & Pedler, 1998; Kurtz, Kurtz, Given, & Given, 1996; Lobchuk, Kristjanson, Degner, Blood, & Sloan, 1997). Furthermore, based on an integrative review by Lobchuk (1999), evidence across health-related quality of life (QL) studies describes a consistent response bias of family caregivers to report more negatively than patients on patients' symptom experiences. However, investigators in general have concluded that these differences are of relatively small magnitude such that only a modest amount of bias would be introduced when substituting patients' reports for family caregivers' responses (Lobchuk, 1999).

Despite supportive evidence on the reliability of family caregivers as reasonable proxy respondents, two limitations currently exist in this body of literature. First, there is a growing consensus in health care literature that symptom experiences are not unifocal, but multifaceted events comprised of underlying components of symptom frequency, duration, severity or intensity, and distress. Nonetheless, some of the symptom tools employed in extant response comparability studies are flawed in that they tend to provide a unifocal measurement of symptoms (e.g., severity alone). Consequently there is a notable absence of comprehensive measurement on the interrelated but separate underlying symptom dimensions of severity, frequency, and distress.

Other response comparability studies employed symptom tools that tend to confound symptom occurrence with symptom distress items. Therefore, it remains difficult to discern the exact nature of symptom characteristics that family caregivers target in their estimates of patients' symptom experience.

Second, investigators have not been able to consistently describe specific sociodemographic, disease, and treatment-related variables that serve as reliable predictors of perceptual concordance on patient symptom experience. Some authors attributed these inconsistent findings to a general neglect of investigation on the dynamics of interpersonal relationships, such as empathic processes, that might at least partially account for family caregivers' reasonable estimates of a loved one's symptom experiences (Aaronson, 1991; Taylor, Ferrell, Grant, & Cheyney, 1993).

Numerous descriptive accounts in nursing suggest that family caregivers are sensitive to seeing the patient's world from the patient's cognitive and/or emotive point-of-view (e.g., Andershed & Ternstedt, 1999; Ferrell, Taylor, Grant, Fowler, & Corbisiero, 1993; Welch, 1981). Social scientists would describe this cognitive process as 'perspective-taking' or the imaginative tendency or ability of an observer to place oneself in another person's place in order to understand another's thoughts and feelings. In accordance with Davis's (1994) organizational model on empathy, perspective-taking is an empathic process that is assumed to enhance the observer's empathic accuracy or ability to successfully estimate how another person is feeling and thinking. The role of

perspective-taking in the patient and family caregiver context of symptom assessment, however, remains speculative and open to investigation. Whether the family caregiver actually engages in the empathic process of perspective-taking is not clearly understood. Furthermore, empiric nursing literature is non-existent in terms of addressing the relevance of perspective-taking by family caregivers to their judgment accuracy on patients' current symptom experiences.

Based on these shortcomings, first, there is a need for future efforts to explore next-of-kin current estimations on the patient's multidimensional symptom experience with separate symptoms. A comprehensive exploration of patients' symptom characteristics might prove helpful in understanding how and when family caregivers may be used for providing reliable alternate or complementary responses. In order to facilitate targeted and timely health care intervention, this investigator made an attempt to identify areas where caregivers are having difficulty in achieving accurate symptom assessments.

Second, extant research suggests that empathic processes are an essential component in helping relationships. Therefore, a closer examination as to whether empathic processes impact caregiver current ratings and accuracy on the symptom experience of advanced cancer patients is warranted. More specifically, it would appear that the relationship between the empathic process of perspective-taking and empathic accuracy as postulated in the empathy theorem by Davis (1994) might be precisely tested in the context of recent family caregiver and patient encounters. Ultimately if evidence is found to support this

linkage, then interventions can be designed and tested to optimize empathic processes that minimize perceptual differences among persons with end-stage cancer and their family caregivers when asked to provide assessments on current symptom experiences of patients.

Purpose of the study

The purpose of this descriptive comparative study was, first, to examine the degree of family caregiver empathic accuracy on the multidimensional symptom experience of advanced cancer patients and second, to identify factors affecting the degree of empathic accuracy by family caregivers. Guided by Davis's (1994) organizational theory of empathy and related studies, the factors whose effects were examined included: (a) the level of patient-reported symptom experience; (b) the symptom dimensions of frequency, severity, and distress; (c) the physical or psychological nature of symptoms; (d) family caregiver characteristics such as the level of education, the length of time the caregiver has cared for the patient, and the degree of acquaintance with the patient; and (e) dyadic perspective-taking tendencies by the family caregiver. The family caregiver characteristics and dyadic perspective-taking tendencies are factors purported in social psychological and health-related QL literature to depict aspects of an intimate relationship that might impact observer empathic accuracy on another person's thoughts and feelings (e.g., Hays et al., 1995; Magaziner, Bassett, Hebel, & Gruber-Baldini, 1996; Thomas & Fletcher, 1997; Thomas, Fletcher, & Lange, 1997).

The third purpose of this study was to explore whether family caregiver current perceptions on patient symptom experience are related to a self- or patient-oriented viewpoint. A fourth purpose was to explore whether induced perspective-taking can assist family caregivers who overestimate to achieve a more accurate symptom assessment on the cancer patient's symptom experience.

Theoretical Perspective

Overall this study was guided by the concepts of symptom experience, perspective-taking, and empathic accuracy. The organizational framework on empathy by Davis (1994) provided the broader context within which this program of research was embedded. This framework was modified to conceptualize the relationship between antecedent characteristics of family caregivers and the symptom situation, and empathic accuracy on the current symptom experience of advanced stage cancer patients.

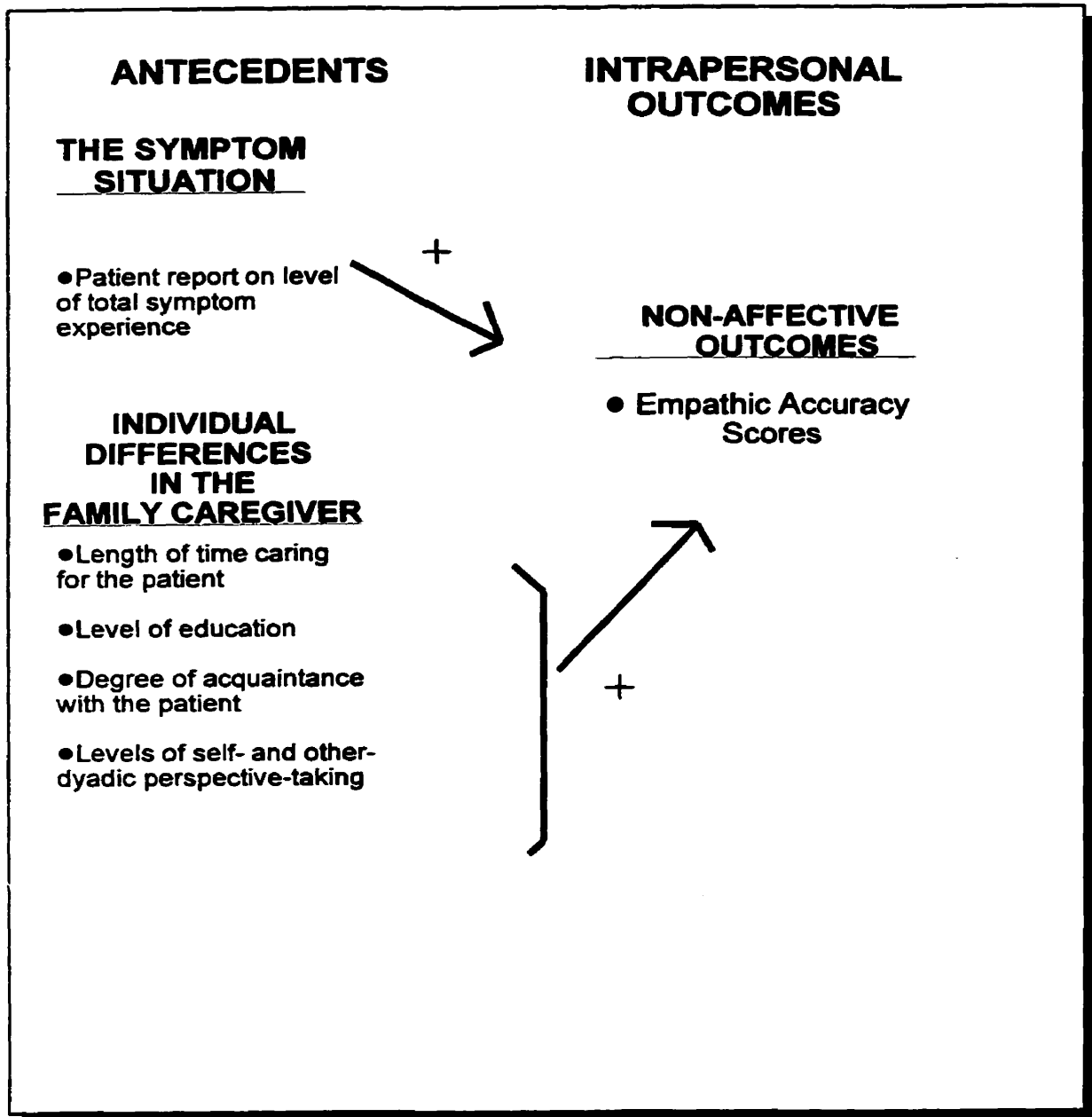
In accordance with Davis's (1994) empathy model, an empathy episode is a sequence of antecedent, process, and outcome events that occur when an observer is exposed to a weak or helpless victim who is in some sort of distress and when an empathic outcome occurs. Antecedents refer to observer, target, and/or situation characteristics that influence the likelihood of the observer either engaging in an empathy-related process or experiencing an empathy-related outcome during an empathy episode. Empathic processes, such as perspective-taking, are mechanisms that observers engage in, which result in an empathic

outcome. Empathic outcomes include non-affective, intrapersonal consequences of empathic accuracy or the observer's accurate estimate of another's thoughts and feelings (Davis, 1994).

With these specific variables, the formula for empathic accuracy developed by Davis (1994) was adapted for this study (see Figure 1). Antecedent variables included individual differences in the family caregiver (e.g., dyadic perspective-taking tendencies) and the strength of the patient's symptom situation (e.g., the level of patient-reported total symptom experience) that were tested for their potential to positively influence the likelihood of an experiencing an outcome of empathic accuracy (Lobchuk et al., 1997; Thomas, Fletcher & Lange, 1997). Additional family caregiver characteristics that found somewhat consistent support in research as determinants of judgment accuracy were explored as positive covariates; for instance, the level of family caregiver education, the length of time the caregiver cared for the patient, and the degree of patient and family caregiver acquaintance (e.g., Hays et al., 1995; Magaziner et al., 1996; Thomas & Fletcher, 1997).

Although family carers may possess varying tendencies to engage in perspective-taking and may be exposed to symptom situations that are powerful enough to evoke an empathic response, these factors do not ensure that the family caregiver actually engages in a perspective-taking process to achieve a successful understanding of the patient's symptom experience (Davis, 1994). Therefore this study assessed (a) whether family caregivers engaged in

Figure 1. Adapted organizational model on empathy by Davis (1994)



perspective-taking and, if they do, (b) the type of perspective-taking process that family caregivers engaged in by manipulating their perspective-taking activities through the use of 'imagine-other' and 'imagine-self' instructional sets. In addition, this study explored whether family caregivers projected their own symptom experience onto their assessments of the patient's experience with symptoms.

Although instructional sets designed to induce perspective-taking might make empathic accuracy more likely, it is difficult in naturalistic settings to precisely measure the cognitive processes that observers engage in to arrive at successful estimations of another's thoughts and feelings (Davis, 1994). This raises the important issue of not being able to determine the mediational logic of Davis's empathy model that hypothesizes perspective-taking processes mediate the effects of antecedent variables on empathic accuracy outcomes. However, based on the differential influences of variant instructional set conditions on empathic accuracy, it might be possible to infer that family caregivers actually engaged in perspective-taking activities. In this research, differential perspective-taking activities represented another category of independent variables that were tested as potential factors which influence empathic accuracy by family caregivers on patients' current symptom experiences.

Definition of terms

Symptom experience

A multidimensional construct that is comprised of two subcomponents of

occurrence and distress (Rhodes & Watson, 1987). In this study, symptom occurrence was the cognitive representation of a symptom that is comprised of severity and frequency items. Symptom distress was the affective representation of a symptom. The **total symptom experience score** was the average of symptom scores across frequency, severity, and distress items either for individual symptoms or across 32 symptoms measured on the Memorial Symptom Assessment Scale (MSAS) by Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Kiyasu, et al. (1994).

Symptom frequency

A symptom occurrence item that was measured by the sub-scale score on the four-point Likert-type scale of the MSAS in response to "Did you have any of the following symptoms?" and "If yes, how often did you have it?".

Symptom severity

A symptom occurrence item that was measured by the sub-scale score on the four-point Likert-type scale of the MSAS in response to "Did you have any of the following symptoms?" and "If yes, how severe was it usually?".

Symptom distress

A symptom experience item that was measured by the sub-scale score on the five-point Likert-type scale of the MSAS in response to "Did you have any of the following symptoms?" and "If yes, how much did it distress or bother you?".

Strength of patient situation

This concept refers to the potential of the patient's symptom situation to

evoke the family caregiver to achieve empathic accuracy on patient symptom experience. The strength of the patient's symptom situation was comprised of the level of patient-reported symptom experience as captured on the MSAS.

Empathic accuracy

The ability of family caregivers to accurately estimate the specific content of the patient's thoughts and feelings in relation to the patient's state of symptom experience (Ickes, 1993; Thomas & Fletcher, 1997). Empathic accuracy was evaluated by computing the discrepancy scores or the absolute value of the difference between the family caregiver's and the patient's MSAS symptom scores.

Perspective-taking

The ability to imaginatively put oneself in the patient's place and intellectually understand what the patient is thinking and feeling without vicariously experiencing the patient's emotions (Hogan, 1969).

Self dyadic perspective-taking

The family caregiver's self-report on perspective-taking tendencies within the context of the patient-family caregiver relationship as measured on Long's (1987) Self Dyadic Perspective-Taking Scale (SDPT).

Other dyadic perspective-taking

The patient's perception on the family caregiver's perspective-taking tendencies within the context of the patient-family caregiver relationship as measured on Long's (1987) Other Dyadic Perspective-Taking Scale (ODPT).

Family caregiver self-report instructional set

This instructional set asked family caregivers to report on how they *themselves* think and feel in relation to *their own* symptom experience in their current life situation when they responded to two MSAS symptom items.

Imagine-self instructional set

This perspective-taking instructional set asked family caregivers to identify with *their own* thoughts and feelings as they imagined *themselves* to be with the patient's diagnosis when they responded to two MSAS symptom items.

Imagine-other instructional set

This perspective-taking instructional set asked family caregivers to imagine how *the patient* feels and thinks by urging them to figuratively place themselves within *the patient's shoes* when they responded to two MSAS symptom items.

Neutral control instructional set

This is the unrevised instructional set provided on the MSAS. This instructional set was not designed to promote or eliminate perspective-taking when family caregivers responded to how they perceived the patient's symptom experience over the past week.

Research Questions

The first question was posed to direct a descriptive analysis on the multidimensional symptom experience in a population of advanced cancer patients as currently perceived by patients and their family caregivers. The

second question directed a series of comparative analyses on the degree of empathic accuracy of family caregivers on various dimensions of patient symptom experience for 32 MSAS symptom items.

1. What is the prevalence, frequency, severity, and distress of 32 MSAS symptoms in a sample of advanced stage cancer patients as reported by patients and as perceived by their family caregivers?
2. Are there differences and/or associations between patient and family caregiver MSAS ratings on (a) the absence or presence of symptom events, (b) the global scale across 32 symptoms and 32 separate MSAS symptom scales, (c) the frequency, severity, and distress sub-scales across 32 symptoms, and (d) the high prevalence physical and psychological sub-scales?

The following set of questions explored more precisely whether the family caregiver's current estimate on patient total symptom experience in the 'neutral control' condition was influenced by his or her own viewpoint (as measured in the 'imagine-self' and 'self-report' instructional sets) as opposed to the patient's viewpoint (as measured in the 'imagine-other' instructional set). The decision to target only two MSAS symptom items was based on the need to reduce subject burden for family caregivers who were asked to respond to three instructional sets in addition to the 32-item MSAS and the Other Dyadic Perspective-Taking Scale. The selection of 'lack of energy' and 'worrying' was based on their reported clinical relevance and high prevalence in terminal cancer patients (Donnelly & Walsh, 1995; Portenoy, Thaler, Kornblith, McCarthy-Lepore,

Friedlander-Klar, Coyle et al., 1994; Vainio & Auvinen, 1996), as well as in family caregivers (Cassileth, et al., 1985; Cherny, Coyle, & Foley, 1994; Hinds, 1985; Hinton, 1994; Howell, 1986; Jassak, 1992; Sales, 1992). In addition, the MSAS identifies 'lack of energy' as an indicator of physical symptomatology and 'worrying' as a symptom of psychological distress. Therefore the differential natures of these two symptoms were explored in terms of their potential effects on aspects of perspective-taking and empathic accuracy.

3. Are there differences and/or associations between family caregiver current estimates in the 'neutral control' condition and their estimates on their own hypothetical total symptom experience for 'lack of energy' and 'worrying' in the 'imagine-self' condition?

4. Are there differences and/or associations between family caregiver current estimates in the 'neutral control' condition and their reports on their own symptom experience with 'lack of energy' and 'worrying' in their current life situation (that is, their self-report)?

5. Are there differences and/or associations between family caregiver current estimates in the 'neutral control' condition and their estimates on patient total symptom experience for 'lack of energy' and 'worrying' in the 'imagine-other' condition?

The following research question compared the caregiver's perceptual accuracy on patient's current 'lack of energy' and 'worrying' in each of the instructional set conditions.

6. Are there differences and/or associations between patient and family caregiver current ratings on total symptom experience for 'lack of energy' and 'worrying' in the respective neutral control, self-report, imagine-self, and imagine-other instructional set conditions?

The following question examined the explanation for caregiver overestimation by Wright (1983) in her empathic "requirement of mourning" hypothesis. The empathic requirement of mourning hypothesis offers a theoretical basis for understanding why family caregivers perceive patients as experiencing worse symptom characteristics than patients really are. Lampic, von Essen, Peterson, Larsson, and Sjoden (1996) explained that in caregivers' efforts to comprehend the patient's symptom situation, they may perceive the patient as worse off because they project their beliefs as to how they would feel if they were in the patient's situation. It was expected that the previously reported trend for family caregivers to overestimate would hold in this study's sample of family caregivers who care for end-stage cancer patients.

7. When family caregivers over-report patients' current total symptom experience on 'lack of energy' and 'worrying', do their estimates relate to their own total symptom experience for 'lack of energy' and 'worrying' in the 'imagine-self' instructional set conditions?

The following question explored whether the subgroup of family caregivers who overestimated can modify their level of empathic accuracy when they are induced to imagine the point-of-view of the patient.

8. Are family caregivers (who overestimate) able to achieve enhanced empathic accuracy on patient total symptom experience for 'lack of energy' and 'worrying' when they are induced to imagine the patient's viewpoint?

In accordance with the adapted empathy model by Davis (1994), the following research questions were designed to explore the various theoretical linkages postulated to exist among the *antecedent events* of family caregiver characteristics (i.e., educational level, length of time caring for the patient, the degree of acquaintance with the patient, and individual differences in self and other dyadic perspective-taking), the strength of the patient's symptom situation (i.e., the patient's self-report on the level of total symptom experience for 'lack of energy' and 'worrying'), and the *empathic outcomes* of caregiver accuracy on patient total symptom experience on MSAS symptom items.

9. Does the degree of discrepancy between patient and caregiver current ratings on patient total symptom experience for 'lack of energy' and 'worrying' in the neutral control instructional set relate to (a) the level of patient-reported total symptom experience, (b) the family caregiver's length of time caring for the patient, (c) the family caregiver's degree of acquaintance with the patient, (d) the family caregiver's educational level, and (e) the levels of self and other dyadic perspective-taking by family caregivers?

Similar to question #9, the following study question will explore in accordance with Davis's (1994) model, the relationships of various symptom experience and family caregiver characteristics with empathic accuracy on the

separate symptom dimensions of frequency, severity, and distress across 32 patient symptom items on the MSAS.

10. Does the degree of discrepancy between patient and caregiver current ratings on the separate MSAS dimensions of severity, frequency, and distress across 32 patient symptoms relate respectively to: (a) the level of patient-reported total symptom experience, (b) the family caregiver's length of time caring for the patient, (c) the family caregiver's degree of acquaintance with the patient, and (d) the family caregiver's educational level, and (e) the levels of self and other dyadic perspective-taking by family caregivers?

Significance of the study

An integrative review of studies that explored the levels of response comparability between patients' and family caregivers' current perceptions on patient symptom experience, indicated that there is a notable absence of measurement on the underlying symptom dimensions of severity, frequency, and distress (Lobchuk, 1999). This is the first known study to comprehensively compare patient and family caregiver current perceptions on the advanced stage cancer patient's multidimensional symptom experience. This study's findings will assist health care professionals to garner an idea of what family caregivers do and do not know in terms of the patient's symptom experience. A thorough exploration of patients' underlying symptom characteristics might prove to be helpful in understanding how and when family caregivers may be used for providing reliable alternate or complementary responses. In order to facilitate

optimal symptom intervention, this study made an attempt to identify areas where caregivers are having difficulty in achieving accurate assessment on current symptom events experienced by cancer patients. This knowledge can aid health care professionals to understand in a systematic manner how to best assist family caregivers to develop their caregiving skills in managing the patient's illness in the home care setting.

Guided by empathy literature arising in social psychology, this study will also contribute new knowledge on how family caregivers come to know what the patient feels and how they behave as observers of patients' current symptom experiences in an intimate patient-caregiver relationship (Nickerson, 1999). This study embraced the broad perspective that empathic perspective-taking is a skill or a disposition that can assist family caregivers to accurately recognize, interpret and respond to patients' current needs arising from symptom experiences. Two instructional sets that induced differential perspective taking activities were compared to determine their potential as a simple clinical intervention that can impact enhanced judgment accuracy by family caregivers on patients' current symptom experiences.

In caregiving situations, there are three possible advantages for family members to be 'coached' by health care professionals via instructional sets to engage in the perspective-taking process. First, family members in current caregiving situations might be induced to realize the existence of another viewpoint. Second, instructional sets might teach family caregivers how to take

the position of the patient. Third, family caregivers might be induced to appreciate the potential of perspective-taking to facilitate a more effective style of communication within the current caregiving situation.

Once more information is known about the interrelationship of perceptual processes between patients and family caregivers, health care professionals can design interventions to optimize communication and thus, minimize differences in current perceptions between patients and family caregivers. In addition, this study will extend our limited understanding of family caregiving skill acquisition with regard to the real world cognitive and interpersonal skills possessed by family caregivers, that either aid or do not aid them in the provision of optimal symptom assessment and management to advanced stage cancer patients.

Summary

Empirically-based studies to understand the congruence of current perceptions on the multidimensional symptom experience of advanced stage cancer patients between patients and their family caregivers are needed. Health care professionals caring for these patients in the home care setting are challenged to know the family caregiver's contemporaneous level of skill in 'monitoring' and 'interpreting' patient symptom events in order to promote optimal symptom management.

Furthermore, there has been a general neglect of investigative work on the dynamics of empathic processes, such as perspective-taking in the context of current symptom assessment by family caregivers. Literature in social

psychology describes that individuals vary in their ability and/or motivation to understand what another person is thinking and feeling through the use of such processes as perspective-taking. However, the role of perspective-taking in the family caregiver context of symptom assessment remains open to investigation. Perspective-taking activities are real world cognitive and interpersonal heuristic devices that might at least partially account for family caregivers' reasonable current estimates of a loved one's symptom experience. If evidence is found to support a linkage between perspective-taking and empathic accuracy, then health care professionals can devise and test interventions that minimize perceptual differences among persons with end-stage cancer and their family caregivers.

CHAPTER TWO

Review of the literature

The literature reviewed for this study was grouped into three different areas: symptom experience and family reporting, measurement of symptom experience, and empathic accuracy. Under the broad heading of empathic accuracy, this chapter discusses the concepts that underlie Davis's (1994) organizational model of empathy that include: dispositional perspective-taking, strength of the situation, and the processes of perspective-taking.

Symptom experience and family caregiver reporting

Patient-family caregiver response comparability

Although patients themselves are widely recognized as the "gold standard" upon which to judge symptom experiences, palliative care patients at times may be unwilling or unable to communicate reliable accounts of their current needs (Hester, Miller, Foster, & Vojir, 1997; Sneeuw et al., 1998). However, health care professionals have been known to circumvent the problem by soliciting alternate or complementary reports on patients' symptom events from family caregivers.

Researchers in the various disciplines of epidemiology, medicine, and nursing have attempted to determine the extent to which family surrogates can reliably provide either retrospective or prospective (current view) information on factual data or broad health-related QL issues that is comparable to that of

patients in a variety of patient populations. In the United Kingdom, a body of related studies has evaluated hospice care by evaluating bereaved relatives' retrospective accounts of patients' terminal illness (e.g., Cartwright & Seale, 1990; Higginson, Priest, & McCarthy, 1994; Hinton, 1996). These studies indicated that current ratings (e.g., on a weekly basis) by patients and their family caregivers were always in better agreement than caregivers' retrospective or recollective ratings (e.g., four or seven months after the patient died). Also, authors have noted numerous difficulties in eliciting retrospective versus current accounts by family caregivers. For example, recall information is indirect and tends to be either polarized, biased by caregivers' own concerns, or distorted by memory difficulties (Higginson & McCarthy, 1993; Higginson et al., 1994). Part of the difficulty in finding significant correlations between patients' prospective and family caregivers' retrospective assessments on physical and psychological symptom events also might be related to mis-matching time frames for patients and their caregivers to assess patients' illness experiences (Higginson et al., 1994).

More specific to the aim of this study, which was to explore the current or contemporaneous views of patients and family caregivers, a smaller number of investigators explored the congruence between patients' current reports and family caregivers' current (versus retrospective) ratings on patient symptom experience in advanced stages of cancer (e.g., Hinton, 1994; Kristjanson et al., 1998; Kurtz et al., 1996; Lobchuk et al., 1997; McCusker & Stoddard, 1984) (see

Table 1). Although there is a need for additional evidence on the trends found in studies that explored response comparability between end-stage cancer patients' and family caregivers' current ratings, these patterns appear to be in accord with the following health-related QL study results as described more fully in two review articles (Lobchuk, 1999; Sprangers & Aaronson, 1992).

First, in studies that focussed specifically on patient symptom experience, the levels of agreement between cancer patients and family members were consistently high on a global basis for symptom presence/absence, symptom behaviour, or symptom distress scores (e.g., for approximate percent agreement [i.e., patient and family scores were within 5 or 6 units from each other] a range of 60 to 71% resulted; range for Pearson's r was 0.55 to 0.76). However, the range of agreement levels between patients and family members for individual symptom items was considerably wider, as measured by Kendall's τ (range across several studies: 0.18-0.60) (Kristjanson et al., 1998; Kurtz et al., 1996; Lobchuk et al., 1997). These trends are supported in related QL research where, in comparison with item specific scores, total scores across QL domains achieved higher ratings of agreement overall. In accordance with McCusker and Stoddard's (1984) conclusions, it would appear that greater reliance can be placed on family caregiver responses for global symptom experiences derived from group-level analysis versus individual-level analysis (i.e., there was less agreement on head-to-head symptom item comparisons between patients and family caregivers).

Table 1

Studies assessing response comparability between family caregivers' and patients' current accounts on patient symptom experience

Study	Subjects	Dimensions	Instruments	Statistics used	Authors' conclusions
Hinton (1994)	77 terminal cancer patients and spouse, child, child's spouse, sister, grandchild, friend	QL (symptoms, psychological status)	<p>The Spitzer Quality of Life Index</p> <ul style="list-style-type: none"> - a composite score reflecting activity, physical independence, well-being, support, and mood - psychological state, attitude, and opinion of care were rated on 3- or 5-point scales or linear analogue scales. 	<p>Agreement: Percentage frequencies Differences: Percentage frequencies (versus mean scores) and standard deviations; statistical differences reported with 95% confidence intervals. Volunteered problems; Similar reports provided with the exception of patients who provided more frequent malaise than caregivers for patients (difference 19%; CI 11-18%). Patients also provided lower reports of confusion (difference 12%; CI 5-19%).</p>	<p>Patients and relatives provided ratings each week for eight weeks on the duration and severity 'problems' or 'troubles'. In terms of volunteered problems, patients and relatives gave similar reports with scattered individual discrepancies. Relatives usually provided similar reports to patients on patient distress. Over the final eight weeks, patients' and families' reports were congruent on pain severity and duration.</p>

(table continues)

Table 1 continued

Study	Subjects	Dimensions	Instruments	Statistics used	Authors' conclusions
<p>Krisjanson et al. (1998)</p>	<p>78 hospice patients (Stage III or IV cancer) and family caregivers Family caregivers - 76.9% spouses</p>	<p>nausea (frequency) nausea (intensity) pain (frequency) pain (intensity) insomnia (frequency/intensity) fatigue (frequency) bowel (frequency/distress) breathing (frequency/intensity) cough (frequency/intensity) concentration (frequency) outlook (intensity) appetite (intensity) appearance (severity/distress)</p>	<p>McCorkle & Young's (1978) Symptom Distress Scale (SDS) 13 items; 5-point Likert-type scales</p>	<p><u>Agreement</u> Pearson's <i>r</i>: Overall symptom distress scores (0.76, $p < 0.001$). <u>Kendall's tau (individual items)</u>: Depending on the symptom, correlations ranged from 0.37 and 0.60 ($p < 0.001$). Highest correlation was for pain-frequency (0.60) and lowest for appearance (0.38) ($p < 0.01$). <u>Discrepancy scores (total SDS)</u>: Theoretical discrepancy can range from 0-52; actual discrepancy ranged from 0 to 19. Mean difference was 3.73. Percent agreement: 61% patients total SDS accurately (within 5 points of the patient's total score); 96% were within 12 points of the patient's self-report.</p>	<p>-Family members provide reasonable proxy ratings of advanced cancer patients' symptom distress. -Likely that long-term relationships, close proximity, and length of caregiving relationship influenced the concordant findings. -More caregivers overestimated than underestimated patient symptom distress (however, differences in ratings were small and consistent).</p>

(table continues)

Table 1 continued

Study	Subjects	Dimensions	Instruments	Statistics used	Authors' conclusions
Kristjanson et al. (1998)				<p>37% proxies tended to overestimate the patient's total symptom distress and 2% underestimated the overall SDS.</p> <p><u>Discrepancy scores (individual items):</u> Theoretical discrepancy can range from 0 to 4. Actual mean discrepancy ranged from 0 to 0.65. Between 71% and 91% of proxies rated individual symptoms accurately (0 or 1 point of difference). Between 4% and 23% overestimated a given symptom by more than 1 point.</p> <p>Very few (3-8%) proxies underestimated the patient's individual symptoms (magnitude ranged from 2 to 3 points).</p> <p>Regardless of level of symptom distress. <u>Kappa values</u> indicate fair to moderate levels of agreement: Highest kappa was for bowel (0.60; p = 0.00) and lowest was for outlook (0.26; p = 0.012).</p>	

(table continues)

Table 1 continued

Study	Subjects	Dimensions	Instruments	Statistics used	Authors' conclusions
Kurtz et al. (1996)	<p>216 cancer patients and their family caregivers</p> <p>Family caregivers - unreported relationship to the patient</p>	<p>symptom items -</p> <ul style="list-style-type: none"> - nausea - pain - appetite - insomnia - fatigue - cough - constipation - diarrhea 	<p>Modified version of the McCorkle & Young's (1978) SDS</p> <p>- absence or presence of the symptom in the past 2 weeks</p>	<p>Agreement</p> <p>Cross-tabulations: Fatigue was the most frequently cited symptom by both patient and caregiver.</p> <p>Rate of agreement was highest for fatigue and lowest for insomnia ($p < 0.001$)</p> <p>Patients reported on average 3.75 symptoms, and the average number of symptoms for which there was agreement was 5.69 out of 8 (71% agreement).</p>	<p>- The overall accuracy of caregiver reports was 71% and seemed to be independent of the number of symptoms reported by the patient.</p>

(table continues)

Table 1 continued

Study	Subjects	Dimensions	Instruments	Statistics used	Authors' conclusions
Lobchuk et al. (1997)	<p>37 lung cancer patients and their primary family caregivers</p> <p>Caregivers - 68% spouses</p>	<p>symptom items</p> <p>nausea (frequency)</p> <p>nausea (intensity)</p> <p>pain (frequency)</p> <p>pain (intensity)</p> <p>insomnia (frequency/intensity)</p> <p>fatigue (frequency)</p> <p>bowel (frequency/distress)</p> <p>breathing (frequency/intensity)</p> <p>cough (frequency/intensity)</p> <p>concentration (frequency)</p> <p>outlook (intensity)</p> <p>appetite (intensity)</p> <p>appearance (severity/distress)</p>	<p>McCorkle & Young's (1978) SDS</p> <p>13 items; 5-point Likert-type scales</p>	<p><u>Agreement</u></p> <p><u>Cohen's kappa statistic:</u> Moderate kappa values were observed for symptoms of fatigue, appetite, pain frequency, cough, nausea frequency, insomnia, and breathing (kappa > 0.40). Dyad members appeared to agree on symptoms patients rated as most distressing (exception of appetite and nausea frequency).</p> <p><u>Correlation</u></p> <p><u>Pearson's r</u></p> <p><u>Global SDS scores:</u> (r = 0.71; p < 0.001)</p> <p><u>Differences</u></p> <p><u>Wilcoxon signed rank test:</u> On the global scale, family caregivers overestimated patients' global distress (p < 0.001).</p>	<p>Family members appear to be reasonable proxy respondents for at least ten of thirteen symptoms on the SDS. Family members have a tendency to overestimate patient symptom distress, except for concentration. Family members tend to agree more on symptoms that are more overt (e.g. fatigue, pain, breathing) versus subjective or invisible (distress arising from appearance, insomnia, and outlook).</p>

(table continues)

Table 1 continued

Study	Subjects	Dimensions	Instruments	Statistics used	Authors' conclusions
Lobchuk et al. (1997)				<p>Theoretical range of differences is 0 to 52. The observed mean difference in global scores was 6.2 with a range of differences between 0 and 22. 65% of dyad members' scores were within 6 units of each other.</p> <p><u>Difference</u> <u>Wilcoxon signed-rank test</u> <u>Individual SDS items:</u> Significant differences ($p < 0.05$) occurred on insomnia, appearance, and outlook.</p> <p>Theoretical range of differences for individual items is between 0 and 4. Actual range of differences: outlook (0.94), appearance (0.81), and insomnia (0.92).</p> <p>For all 13 symptoms, dyad member scores were within 0 or 1 rating of one another 75% or more of the time.</p>	

(table continues)

Table 1 continued

Study	Subjects	Dimensions	Instruments	Statistics used	Authors' conclusions
<p>McCusker & Stoddard (1984)</p>	<p>66 chronically or terminally ill homebound patients and caretakers</p> <p>Caretakers - family member or a close friend</p>	<p>physical items - body care and movement, mobility, ambulation, psychosocial - emotional behaviour, social interaction, alertness behaviour, communication</p> <ul style="list-style-type: none"> - sleep/rest - eating - recreation/pastimes - home management - work 	<p>The Sickness Impact Profile (SIP)</p>	<p><u>Profile analysis</u> <u>Response bias</u> Patient and caretaker means were very similar, although patient means tended to be higher for all physical categories, recreation and pastimes, and home management. Caretaker means tended to be higher for all psychosocial categories and for sleep and rest.</p> <p><u>Differences</u> <u>Paired t-tests:</u> For recreation/pastime, patient score was significantly higher than the caretaker score ($p < 0.01$) and for sleep and rest, the caretaker score was significantly higher ($p < 0.04$).</p> <p><u>Correlation</u> <u>Spearman's rank order:</u> Total SIP (0.55)</p>	<p>The results indicate sufficient agreement between patients and caregivers to warrant use of surrogate SIPS, when necessary in group-level analyses of SIPS in patients with chronic, relatively stable conditions, and when the surrogate is a family member closely involved in the patient's care.</p> <p>In these cases, greater reliance should be placed on SIP total and dimension scores than on category scores because there was less agreement in the latter.</p>

(table continues)

Table 1 continued

Study	Subjects	Dimensions	Instruments	Statistics used	Authors' conclusions
McCusker & Stoddard (1984)				<p>Comparison of profiles Elevation scores: Neither mean nor median difference differed significantly from zero - no systematic difference between mean scores. Scatter - variability in category scores for patients and caregivers did not differ <u>Q-correlations:</u> median correlation was 0.69 and the mean 0.61.</p>	

Second, the reliability of family caregiver reports appears to be dependent on the symptom item being measured. Authors have suggested that better levels of agreement tend to occur on symptom experiences which are more concrete or observable; for instance, when symptoms are verbally reported by patients, when symptoms effect obvious changes in patient behaviour, or when symptoms require intervention by caregivers (Kristjanson et al., 1998). This is supported by related QL studies where the highest levels of agreement were found for referents that had more factual, concrete, or observable attributes, such as the presence of certain chronic conditions (Magaziner et al., 1996) or physical/instrumental activities of daily living (PADL/IADL) aspects in the QL physical functioning domain. Lower levels of agreement were found more often for less concrete or factual QL physical or symptom items (e.g., insomnia, outlook, and appearance) or emotional health items (e.g., depression or anxiety) that require some caregiver interpretation (Spiller & Alexander, 1993).

Third, as with patient/caregiver concordance on perceptions of patient symptom experience, overall trends on the magnitude and direction of differences in most QL studies described that a response bias to report more negatively on QL issues is common for family caregivers (e.g., Higginson & McCarthy, 1993). However, numerous authors suggested that these differences were of a relatively small magnitude, such that only a small amount of bias would be introduced when substituting patient reports for family caregiver responses (Kristjanson et al., 1998; Lobchuk et al., 1997; Sneeuw, Aaronson, de Haan, & Limburg, 1997, Sneeuw et al., 1998).

Predictor factors

Patient and family caregiver judgments on symptom severity, duration, frequency, or distress are but one aspect of comprehending symptom perception and evaluation (Yoos & McMullen, 1999). It is equally important to explore factors that the literature suggests might have an impact on perception and evaluation of symptom experience.

Over the past fifteen years, a number of multidisciplinary studies have identified factors that may impinge on how individuals perceive and evaluate symptom experience (Lobchuk, 1999). Most of the studies' analyses were univariate, while others included multivariate testing of interactions among various dimensions of influencing factors and their effects on symptom experience phenomena of distress, duration, severity, and/or frequency.

In regard to physiological, psychological, and situational determinants which potentially influence agreement levels and discrepancy scores, earlier work identified that depending on the individual symptom and its underlying dimensions, patient and proxy characteristics and the quality of relationship effects remained equivocal across investigations (Lobchuk, 1999). Across health-related QL studies, better agreement tended to occur when both patients and family carers attained a higher level of education (e.g., Hays et al., 1995), the proxy resided with the patient (e.g., Magaziner et al., 1996; O'Brien & Francis, 1988), the proxy had more frequent contact with the patient (e.g., Magaziner et al., 1996), and the patient had a better cognitive status (e.g., Kiyak, Teri, & Borson, 1994; Magaziner et al., 1996) (see Table 2).

Table 2. Determinants of response agreement and bias: Quality of life dimensions

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Disease stage: Newly diagnosed versus recurrent	Total quality of life*	Sneeuw, Aaronson, Osoba, et al. (1997)	None
Functional status	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	Poorer patient performance greater discrepancies in total qol (p = 0.07).
	Total quality of life	Sneeuw et al. (1998)	Poorer patient performance greater discrepancies in total qol.
Motor deficits	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	More motor deficits wider discrepancy scores (r = 0.23; p=0.05).
Mental confusion	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	Greater mental confusion wider discrepancies (p = 0.003).
	Total quality of life	Sneeuw et al. (1998)	Poorer mental health, wider discrepancies (r = -.13).
Cognitive impairment	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	More cognitive impairment wider discrepancies (p = 0.14).
	Functional status - physical ADLs and instrumental ADLs	Magaziner, Simonsick, Kashner, and Hebel (1988)	Poor patient cognitive status tends to predict low agreement (Kappa). Differences on the instrumental activities of daily living (ADL) were greater when the patient is moderately cognitively impaired. Differences on the physical ADL were smaller when the patient is moderately cognitively impaired.
	Multiple dimensions	Farrow and Samet (1990)	Agreement did not vary according to cognitive status.
	Functional status and global physical well-being	Kiyak et al. (1994)	Agreement was more poor between Alzheimer patients and their family members than healthy controls and their family members.
	Chronic conditions, symptoms, physical ADLs, and instrumental ADLs	Magaziner et al. (1996)	There is a trend for patients with cognitive limitations to show lower agreement with proxy respondents. Proxies appear to over report physical and instrument ADLs when subjects have cognitive limitations.
	social function and instrumental ADLs	Wyller, Sveen, and Bautz-Holter (1996)	None

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Cognitive Impairment	affect and depression	Bassett, Magaziner, and Hebel (1990)	None
Age - Proxy/Patient	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	None
	Total quality of life	Hays et al.	None
	Total quality of life	Sneeuw et al. (1998)	The older the patient, the wider the discrepancy ($r = 0.16$). The older the proxy, the wider the discrepancy ($r = 0.17$).
	Functional status	Magaziner et al. (1988)	Trend for older proxies to show better agreement (Kappa; correlation). Younger proxies (< 65 years) tend to underestimate patient functional independence with respect to instrumental activities and overall functional capacity (difference).
	Multiple dimensions	Farrow and Samet (1990)	Agreement did not vary according to age.
	Physical ADL'S	Magaziner et al. (1996)	Trend for proxies aged 60 years and older provided responses that were congruent to the respondents. Age of the proxy was not associated with agreement on other areas.
	social functions and Instrumental ADLs	Wyller et al. (1996)	None
	behaviour related health status	McCusker and Stoddard (1984)	None
	symptom distress	Kristjansson et al. (1998)	Older family caregivers (> 60 years of age) were less accurate than younger caregivers in reports of pain frequency (p 0.031).
	symptom presence	Kurtz et al. (1996)	Age did not appear to be an important variable; no consistence pattern across age groups for all symptoms. Some age effect, depending on the symptom (e.g., elderly caregivers had a higher rate of agreement for nausea, whereas younger caregivers had a higher rate of agreement for constipation).

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Age - Proxy/Patient (continued)	pain (typical)	O'Brien and Francis (1988)	Moderate agreement for various next of kin age groups: 55 to 61 years (Kappa = 0.47; p = 0.002); 62 to 85 (Kappa = 0.43; p = 0.01). Patient age group of 60 to 69 (Kappa = 0.37; p = 0.01).
Gender - Proxy/Patient	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	None
	Total quality of life	Grassi et al. (1996)	None
	Total quality of life	Hays et al. (1995)	None
	Total quality of life	Sneeuw et al. (1998)	Male proxy respondents had wider discrepancies.
	Functional status	Magaziner et al. (1988)	Gender does not appear related (Kappa). When the proxy is male there is better agreement on the physical ADLS (correlation). Female proxies who report they assist the patient underrate patient ability to independently perform instrumental and physical ADLs (difference).
	Functional status - physical ADLS	Magaziner et al. (1996)	Males proxies agreed more with respondents than female proxies on all areas of questioning, with statistical significance achieved for PADL.
	social functions and instrumental ADLs	Wyller et al. (1996)	None.
	symptom distress	Kristjanson et al. (1998)	Family were more accurate in rating pain frequency and pain intensity of male (p = 0.005) versus female patients.
	symptom presence	Kurtz et al. (1996)	Female caregivers had a higher percentage agreement with their patients and a higher level of association between patient and caregiver scores across symptoms. Male caregivers did not show a significant association between assessments of cough and insomnia.
	pain	O'Brien and Francis (1988)	Female next-of-kin (Kappa = 0.37; p < 0.001) showed better agreement than male next-of-kin (Kappa = 0.24; p < 0.001). Male patients showed better agreement (Kappa = 0.33; p = 0.001) than female patients (Kappa = 0.24; p = 0.28).
depression	Bassett et al. (1990)	Small negative bias for male proxies to underestimate respondent depression.	

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Culture - Proxy/Patient	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	None
Proxy's relationship with the patient	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	None
	Total quality of life	Rogers, Ridley, Chrispin, Scotton, and Lloyd (1997)	None
	Instrumental ADL and physical self-maintenance (PSMS)	Rubenstein, Schairer, Wieland, and Kane (1984)	More discrepancy when proxy was the spouse ($p < 0.02$) versus child or other relatives on the PSMS and on the IADL.
	Mastery, future orientation, anxiety, depression, and morale, self-esteem, functional health	Clipp and Elder (1987)	Strong positive association between proxy as the spouse; decreased association with self-esteem and functional level however.
	Functional status	Magaziner et al. (1988)	Better agreement when proxy is the sibling (Kappa = 0.57), followed by spouses (Kappa = 0.50), offspring (K = 0.41), non-relatives (Kappa = 0.38), and relatives (Kappa = 0.25). Non-first order relatives underrated patient ability to independently perform both instrumental and physical ADLs ($p < 0.01$).
	Health status	Farrow and Samet (1990)	Better agreement when the proxy is the spouse, then for the child and the friend (kappa)
	Life events		Better agreement for spouses and children than for friends (Kappa)
	Social Network		Better agreement for spouses than for other surrogate types (Kappa)
	Functional status		Better agreement for spouses than for other surrogate types (kappa)
	social function and instrument ADLs	Wyller et al. (1996)	None
	behaviour related health status	McCusker and Stoddard (1984)	None
	symptom distress	Krisjanson et al. (1998)	Spouses (versus other family caregivers) were less accurate in reporting the patient's outlook ($p = 0.005$). Wives were more accurate in estimating pain frequency than other caregivers ($p = 0.032$).
	pain (typical)	O'Brien and Francis (1988)	Other relatives showed better agreement (Kappa = 0.30; $p = 0.01$) than spouses (Kappa = 0.35; $p = 0.01$).

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Proxy's relationships with the patient (continued)	depression	Bassett et al. (1990)	Higher correlation between patient and offspring ($r = 0.60$) than patient and spouse ($r = 0.41$). Small negative bias for spouses to underestimate respondents' depression. Offspring tended to underestimate the respondents' affective state.
Living arrangement with the patient	Total quality of life	Sneeuw, Aaronson, Osoba, et al. (1997)	None
	Satisfaction with care	Epstein, Hall, Tognetti, Son, & Conant (1989)	Higher correlation when proxy lived with patient ($r = 0.58$) versus when the proxy did not live with the patient ($r = 0.12$)
	Total quality of life	Hays et al. (1995)	None
	Functional status	Magaziner et al. (1988)	Trend for proxies who live with patient to demonstrate better agreement (Kappa; correlation)
	Functional status - chronic conditions, physical symptoms, and PADL	Magaziner et al. (1996)	Proxies living with respondents had closer agreement on all with statistical significance achieved for PADL.
	social function and instrumental ADLs	Wyller et al. (1996)	None
	behaviour related health status	McCusker and Stoddard (1984)	Greater agreement tended to occur if the caretaker lived with the patient.
	symptom distress	Kristjanson et al. (1998)	Family members who did not live with the patient were more accurate in reports of distress arising from insomnia ($p = 0.04$).
	pain	O'Brien and Francis (1988)	Next of kin who lived with patient and claimed familiarity with the patient's pain (Kappa = 0.33; $p = 0.00$) exhibited more agreement than other next-of-kin (Kappa = 0.26; $p = 0.13$).
cognitive status	Bassett et al. (1990)	Proxies who lived with the respondent provided scores more highly related to respondent scores ($r = 0.75$) than those proxies who lived elsewhere ($r = 0.56$). Those not living with the respondent tended to underestimate the respondents' affective state (small negative bias only).	

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Passage of time	Total quality of life	Grassi et al. (1996)	Positive relationship between the passage of time and total quality of life ratings (time 1, $r = .73$, time 2, $r = .81$) and activity (time 1, $r = 0.50$; time 2; $r = 0.92$), health (time 1, $r = 0.46$; time 2; $r = .64$), and support to improve over time (time 1; $r = 0.23$; time 2; $r = .87$). Decreased agreement occurred for life satisfaction (time 1, $r = .80$; time 2; $r = .72$) and mood items (time 1, $r = .77$; time 2, $r = .69$).
	Total quality of life	Sneeuw, Aaronson, de Haan, and Limburg. (1997)	Over time, agreement levels grew higher for more private domains of feelings, social function, pain, and overall quality of life.
	Physical functioning, role physical, bodily pain, general health, social functioning, role emotional, and mental health	Rogers, Ridley, Crispin, Scotton, and Lloyd (1997)	A smaller discrepancy in scores after six months (mean increase in agreement of 0.03)
	behaviour related health status	McCusker and Stoddard (1984)	None; same as what was observed at entry into the study.
	symptom distress	Lobchuk et al. (1997)	The longer the time since diagnosis, the greater the discrepancy between patient and family member symptom distress scores (accounted for 13% of the variance in discrepancy scores).

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Frequency of patient-proxy contact	Total quality of life Functional status Social activity status	Epstein, Hall, Tognetti, Son, and Conant (1989)	Hours spent was positively related to patient global qol ($r = 0.59$). Hours spent was negatively related to functional status ($r = 0.44$; $p < 0.05$); the more hours spent with patient, the more discrepant the proxy's rating of functional status (more functionally impaired) Hours spent was negatively related to social activity status ($r = 0.38$; $p < 0.00$); the more hours spent helping, the less active the proxy reported the subject was
	Total quality of life	Hays et al. (1995)	None
	Instrumental ADL	Rubenstein, Schairer, Wieland, and Kane (1984)	More frequent visits, proxy rates functioning as lower.
	Instrumental ADL	Magaziner et al. (1988)	More frequent visits, proxy scores more comparable with patient scores (difference).
	Physical symptoms, PADL, and IADL, chronic condition	Magaziner et al. (1996)	Trend for those who visit more frequently to agree more on these items, except for chronic conditions. Proxies who visited less tended to overrate instrument ADLs and underrate health symptoms.

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Frequency of patient-proxy contact (continued)	Depression, cognitive status	Bassett et al. (1990)	Higher correlations occurred on depression for those who visited more frequently ($r = 0.68$) than those who visited less often ($r = 0.47$); higher correlations were found for cognitive status for those who visited more often ($r = 0.71$) than those who did not ($r = 0.51$).
Patient perception of overall health/Proxy perception of own health	Instrument ADL	Epstein et al. (1989)	Discrepancy was greater for proxies who rated patients as being in better health than subjects did themselves.
	Total quality of life	Sneeuw et al. (1998)	Proxies who reported poorer health or quality of life for themselves, had wider discrepancies ($r = -0.18$).
Education	physical functioning, pain overall qol, attention cognitive function, health discouragement, social function, and overall qol score	Hays et al. (1995)	Higher educational level (patients) less disagreement on overall qol and several subscales ($p < 0.05$).
	physical functioning, social isolation, role limitations-emotional, language cognitive function		Higher educational level (proxy) less disagreement on several subscales ($p < 0.05$).
	Total quality of life	Sneeuw et al. (1998)	Lower educational level (patient), wider the discrepancies ($r = -0.17$).
	behaviour based health status	McCusker and Stoddard (1984)	Greater agreement tended to be obtained if the patient had 12 or more years of education.

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Objective versus subjective items	behaviour based health status	McCusker and Stoddard (1984)	Symptoms that are more observable versus subjective achieved better agreement
	symptom presence	Kurtz et al. (1996)	Rate of agreement was highest for fatigue and lowest for insomnia.
	Multidimensional quality of life items	Swanson and Maruta (1980)	Highest congruency was noted for questions concerning disability payments, amount of work missed, duration of pain, effect of pain on work, and influence of time of day on pain. Least congruency on items associated with physical factors, description of the pain, location of the pain, relation to mood, and family responses. Items judged of less magnitude by relatives: word descriptions of pain, extent of pain, medications used, precipitating factors, and relieving factors. Those most often answered with greater emphasis by the relative were associated with physical factors, family response, effect on sleep, relation to mood, and patient behaviour when in pain.
Caregiver burden	Total quality of life	Sneeuw et al. (1998)	Proxies who reported greater caregiver intensity had wider discrepancies.
	Psychosocial health scores	Rothman, Hedrick, Bulcroft, Hickman, and Rubenstein (1991)	The proxies perceived burden contributes to differences in scores.
	symptom presence	Kurtz et al. (1996)	A caregiver who perceives caring to be a burden on his/her physical health, might over-report the patient's symptoms.
Weight loss	Total quality of life	Sneeuw et al. (1998)	Patients with greater weight loss, wider discrepancies noted.
Self-concept	Overall health	Clipp and Elder (1987)	Patients who rate their health more generously, have lower feelings of self-efficacy and self-esteem; feel less competent or in control of their aging
Quality of marriage	Functional status	Clipp and Elder (1987)	Most disagreement occurs in low quality marriages

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Affect (patient/proxy)	Functional status - total and Instrumental ADLs	Magaziner et al. (1988)	Poor patient affective status tends to predict low agreement (Kappa; correlation). When the patient scores in the depressed range, differences were greater on the Instrument ADL but smaller on the physical ADL.
	Psychosocial health scores	Rothman et al. (1991)	Proxies' own psychological distress contributed to differences in scores.
	Instrumental ADLs	Magaziner et al. (1996)	When patients had high levels of depressive symptoms, agreement was greater; the trend was the opposite for chronic conditions, symptoms, and physical ADLs. Proxies tend to under-report physical symptoms when respondents have a high level of depressive symptoms.
	symptom presence	Kurtz et al. (1996)	A patient who is depressed might be expected to over-report symptoms whereas an optimistic caregiver might tend to minimize or under-report patient's symptoms.
	pain	Madison and Wilkie (1995)	No relationship between patient state anxiety and agreement on location, quality, and pattern of pain.
	pain	Rowat and Knaf (1985)	Spouses in the low stress group perceived their mates' pain to be less than patients' themselves ($p < 0.10$). Spouses in the high anxiety group rated their mate's pain the same as the patient him- or herself.
	cognitive status	Bassett et al. (1990)	Higher correlations for cognitive status were found when respondents were depressed ($r = 0.78$) than not ($r = 0.62$). On the other hand, higher correlations for cognitive status were found when respondents were non-depressed ($r = 0.77$) than depressed ($r = 0.60$).
Prognosis	behaviour-based health status	McCusker and Stoddard (1984)	A trend for higher scores by caretakers than patients in the terminal group, with the greatest discrepancies in the psychosocial and home management categories.

(table continues)

Table 2 continued

Determinants	QOL Parameter (agreement/bias)	Author(s)	Determinant effects
Diagnosis	behaviour-based health status	McCusker and Stoddard (1984)	The scores did not differ with various neurologic and psychiatric disorders
	Total quality of life	Grassi et al. (1996)	None
	pain	O'Brien and Francis (1988)	Lung (Kappa = 0.26) and prostate cancer (Kappa = 0.38) (p = 0.02) showed better agreement than other types of cancer patients.
Family income	symptom distress	Kristjanson et al. (1998)	Family caregivers of patients who reported an adequate family income were more accurate in their overall reports of the patient symptom distress (p = 0.025), breathing (p = 0.008), and appearance (p = 0.018). Family caregivers of patients who reported stress associated with income were less accurate in rating the patient's pain intensity (p = 0.043). Lower income families were less accurate in detecting the patient's level of fatigue (p = 0.049) and outlook (p = 0.042).
Treatment	symptom distress	Kristjanson et al. (1998)	Family caregivers of patients receiving current chemotherapy tended to overestimate distress associated with concentration in comparison to patients not receiving this treatment (p = 0.036). Family caregivers of patients who had surgery previously, rated distress with bowel function as more distressing than patients who did not have previous surgery (p = 0.032).

* Total quality of life - a summation of scores across dimensions of physical, functional, social, and emotional health.

Thomas, Fletcher, and Lange (1997) explained that, in their sample of 74 married couples, individuals who were better educated achieved higher levels of empathic accuracy because they might have been better able to accurately detect and use a multiplicity of information to make empathic judgments. In regard to 'acquaintanceship effects' such as the frequency or length of contact, others suggested that 'close' versus 'stranger' partners share important diagnostic knowledge, jointly construct "intersubjective meaning structures", and/or possess common knowledge structures, which are based on their respective relationship histories that facilitate their understanding of one another (Colvin, Vogt, & Ickes, 1997; Stinson & Ickes, 1992).

Of note, numerous descriptive findings in nursing also raise suspicions about a possible interaction between interpersonal dynamics and family proxy reliability. For instance, it was found that family caregivers empathically identify with patients' pain by "analogy of experience" that conjures feelings of emotional and spiritual pain within themselves (Ferrell et al., 1993; Welch, 1981). Thorne (1985) described a shared perspective between family members and patients that appears to be a "product of, but not identical individual perspectives of family members." Other investigators found that family members are "involved at a deeper level" in the dying patient's world and live "through the situation" with the patient (Andershed & Ternstedt, 1999). The category "to be" with the dying patient illustrates the benefits that might be garnered by family caregivers who are cognitively and emotionally open with the patient, such as perceptual accuracy in terms of being able to successfully estimate how the patient thinks

and feels about his or her symptom experience (Andershed & Ternestedt, 1999).

Together these quantitative and qualitative findings suggest that within the social context of the family there are unique relationship dimensions of empathic support, cohesion, and affiliation which have positive influences on patient-family interaction and communication, hence improved reliability of family surrogate responses. Aaronson (1991) suggested that the quality of a relationship plays a significant role in the ability of the partner to 'empathize' with the patient's situation and to accurately rate the patient's experience. To date, however, it remains unclear what aspects of the caregiving relationship contribute to the close association between patient and family caregiver perspectives of the patient's symptom experience.

Statistical techniques used to explore response comparability

Several authors have offered a critical analysis of commonly employed techniques for evaluating the reliability and validity of proxy responses (Chambers, Reid, Craig, McGrath & Finley, 1998; Nelson, Longstreth, Koepsell, & van Bell, 1990; Sneeuw et al., 1998). These techniques consist of individual and group levels of analysis to test for agreement between patient and family caregiver responses (Sneeuw et al., 1998). At the individual level, agreement is often measured directly by means of correlations between responses. At the group level, family caregiver and patient mean scores are frequently compared. As noted from this review, most studies have not evaluated family caregiver reliability on the basis of a single test (e.g., either a correlational analysis or a

test for differences). Instead they have incorporated multiple analytic techniques to test for agreement at both levels.

Reliability - Individual level: response agreement. A major statistical technique commonly employed in these studies was the correlational analysis, that involved either the *Pearson's product-moment* correlation coefficient, the *Spearman rho*, or the *Kendall's tau* correlation coefficient (Epstein et al., 1989; Grassi et al., 1996; Hays et al., 1995; Sneeuw et al., 1998) for continuous data. Although these coefficients adjust for chance agreement, they fail to: (a) take into account error variance between the family caregiver and the patient that may result in overestimates of the relationship; (b) measure precise agreement, but rather reflect whether patient and family caregiver scores coincide; and (c) reflect family caregiver over- or under-estimation of the item being measured (i.e., systematic respondent bias) (Chambers et al., 1998; Nelson et al., 1990). Nelson et al. (1990) suggested that instead of the Pearson r correlation, the more appropriate choice for determining agreement on ordinal or continuous data is the *intraclass correlation coefficient* (ICC). Several studies have employed the ICC that corrects the correlation for any systematic bias or chance agreement (Magaziner, 1992; Sneeuw, Aaronson, Sprangers et al., 1997; Sneeuw et al., 1998).

Nelson et al. (1990) and Sneeuw, Aaronson, Osoba, et al. (1997) also purported that a common fault of proxy reliability studies is the calculation of *exact or approximate (global) percent agreement* for categorical data that do not adjust for chance agreement between patient and family caregiver respondents.

Instead, they calculate either the proportion of exact responses or the proportion agreement within one category in either direction, respectively. Although the *chi-square statistic* determines whether observed associations are greater than that expected by chance, it does not consider the direction of agreement or disagreement (Nelson et al., 1990). It is noted that only a few of the studies reviewed here have used either the percent agreement or chi-square test approach (Kiyak et al., 1994; Kristjanson et al., 1998; Kurtz et al., 1996). Instead, *Cohen's Kappa statistic* was commonly applied and is actually a measure of percent agreement between dichotomous variables that has been corrected for chance agreement (Kristjanson et al., 1998; Lobchuk et al., 1997).

Another method that was infrequently employed to determine agreement is the *multitrait-multimethod* product-moment correlation matrix (MTMM) (Hays et al., 1995; Sneeuw et al., 1998). This technique evaluates the degree of convergence and discrimination between correlations of patient and family caregiver reports (Hays et al., 1995). The MTMM entails calculating the average correlation between patient and family caregiver responses on corresponding measures and the average off-diagonal correlation between responses of different aspects of QL. If the correlations on corresponding domains are higher than for diverging domains, this suggests that family caregiver respondents are capable of making clear distinctions between QL domains (Sneeuw et al., 1998).

Reliability - Group level: response bias. Depending on the level of measurement, significant systematic response biases (or patterns of family caregiver over- or under-reporting in comparison to patient responses) were

determined in several ways. Most studies employed approaches that test for differences in continuous measures between patient and family caregiver mean responses (e.g., *Student's or paired t-tests, Wilcoxon matched-pairs signed-rank test, or analysis of variance [ANOVA]*), along with reported correlation coefficients (Kristjanson et al., 1998; Lobchuk et al., 1997; McCusker & Stoddard, 1984). Mean differences between patient and family caregiver ratings were calculated and then tested to determine if the mean difference score was significantly different from zero. This method takes into account the direction and magnitude of any response bias that might have been present in family caregiver reports (Sneeuw et al., 1998). Sneeuw and colleagues (1998) also advised examining the statistical magnitude of any observed bias by standardizing the mean difference score (i.e., relating the mean difference score to the standard deviation). Sneeuw et al. (1999) suggested that standardized differences might serve as an "alternative" for determining "at which size a systematic difference is clinically meaningful." One other approach that was popular among some authors is the exploration of systematic differences via the *scatterplot bias* technique (Hays et al., 1995; Sneeuw, Aaronson, de Haan, & Limburg, 1997). Scatterplot bias refers to a method of determining whether agreement varies across a range of QL scores by visual examination of a scatterplot. For each patient, the difference between the patient-family caregiver scores (generally family caregiver minus patient scores) was plotted against the average for each pair of scores (patient plus family caregiver score divided by two). Evidence of scatter bias was revealed when any observed difference

between the patient and family caregiver scores was seen as a function of the range of their average scores.

A comparison of the percentage of bias was also used to determine whether family caregivers under- or overrated patient health status. Magaziner and colleagues (1996) suggested various techniques to calculate the percentage of bias and the statistical significance of the percentage of bias for categorical (i.e., McNemar's chi-square test) and continuous (i.e., paired t-test) data. A few studies also determined the statistical significance of bias for correlational data by the standard error for Kappa and of the ICC (Sneeuw, Aaronson, de Haan, & Limburg, 1997; Sneeuw et al., 1998; Magaziner et al., 1996; Wyller et al., 1996).

Validity - Responsiveness to change. Aaronson (1991) and Sneeuw and colleagues (1998) have suggested that besides testing the reliability of family caregiver responses, future studies ought to explore or test the "relative validity" of family caregiver accounts over time. The majority of studies embraced a cross-sectional design that does not measure family caregiver ability to detect clinical changes in the patient over time. However, one method that has been recently employed is the calculation of *reliability validity* (RV) estimates (Sneeuw, Aaronson, Osoba, et al., 1997; Sneeuw et al., 1998). Here the analysis of variance approach tests for significant differences in 'same group' mean change scores over time from baseline to follow-up and between the respective respondent groups on analogous measures. In proportional terms, RV estimates indicate the ability of family caregivers to perceive changes over time in comparison to patients' perceptions of change over time in underlying QL

domains (i.e., a ratio of the proxy ANOVA F-value to the patient ANOVA F-value). The *repeated measures ANOVA* also has been employed to compare changes in patient and family caregiver mean scores (Kiyak et al., 1994) or in the number of discrepancies (Sneeuw, Aaronson, de Haan, & Limburg, 1997) as a function of time. Other authors have compared the levels of agreement or *intraclass correlations* between patient and family caregiver ratings at baseline and follow-up time-points (Sneeuw, Aaronson, Osoba, et al., 1997).

Family caregiver instructional sets

Various types of instructional sets were provided to family caregivers who were encouraged to respond to the patient's situation. First, numerous authors described that they slightly modified the patient's version of the measurement tool to elicit family caregiver perceptions or opinions on the patient's situation, feelings, or performance (Bassett et al., 1990; Clipp & George, 1992; Kiyak et al., 1994; Kristjanson et al., 1998; Kurtz et al., 1996; Madison & Wilkie, 1995; Magaziner et al., 1988; Magaziner et al., 1996; O'Brien & Francis, 1988; Rogers et al., 1997; Rowat & Knafl, 1985; Rubenstein et al., 1984; Sneeuw, Aaronson, de Haan, & Limburg, 1997).

Often other authors did not make explicit the instructions that were given to family respondents (Clipp & Elder, 1987; Dar, Beach, Barden, & Cleeland, 1992; Grassi et al., 1996; Hays et al., 1995; Hinton, 1994; McMillan, 1996; Rothman et al., 1991; Swanson & Maruta, 1980; Wyller et al., 1996; Yeager, Miaskowski, Dibble, & Wallhagen, 1995). Specific 'perspective-taking' instructional sets were also employed in a small set of studies. These

instructions simply prompted the family caregiver to respond as he or she believed the patient would (McCusker & Stoddard, 1984; Sneeuw, Aaronson, Osoba, et al., 1997). Other studies employed more 'potent' instructional sets in an attempt to evoke family caregivers to view the situation from the patient's perspective and to respond as they believed the patient would (Sneeuw, Aaronson, Osoba, et al., 1997; Sneeuw et al., 1998).

Typically, the design of the respective study instructional sets was characterized by differential prompts in terms of 'whose' perspective from which family caregivers were encouraged to derive their estimations of the patient's situation (i.e., either their own or the patient's viewpoint). This is important to consider as a potential contributor towards the inconsistent results found across the studies and the types of QL information requested from family caregivers.

Measurement of symptom experience

Besides the apparent lack of systematic discovery of certain interactive processes that translate into the accuracy of perception by family caregivers, one other limitation in this body of literature concerns the basis on which comparisons were made between family caregivers' and patients' responses to symptom events. Hegyvary (1993) and Ingham and Portenoy (1996) observed that inconsistencies in symptom assessment and/or measurement across patient diagnoses are likely related to two fundamental characteristics of symptom experience that include: multidimensionality and subjectivity.

The multidimensionality of symptoms refers to a range of content including physiological, sensory, affective, cognitive, behavioural, and

sociocultural factors. Symptom assessment is primarily derived from the patient's self-report on the subjective symptom experience(s) (Cleeland, 1990). Subjectivity refers to the fact that underlying characteristics of symptoms can only be understood from the patient's perspective (e.g., symptom severity, the quality of discomfort that symptoms cause, and symptom duration).

Despite their well established recognition in health care literature, subjective symptom characteristics and the multifaceted nature of symptom experience continue to lack definitive understanding. Although valid scales exist to assist in symptom assessment, they are limited in terms of their inadequate attention to (a) accurate symptom terminology and (b) a theoretical foundation that recognizes both the underlying multifaceted nature of subjective symptom experiences and the multiple relationships with determinants of symptom experiences.

Symptom experience and its underlying typologic dimensions

In the 1970's, increased attention was directed toward chemotherapy drugs with antiemetic efficacy and nurses became more concerned with the impact of the symptoms nausea and vomiting. Since that time, oncology nurse researchers Rhodes and Watson (1987) have recognized the need to address concept clarification and differentiation of the components and dimensions of these particular symptoms. Rhodes, Johnson, and McDaniel (1995) explained that accurate assessment and interpretation of symptoms require a concise and clear meaning of symptoms. In turn, health care professionals should be able to target more appropriate interventions that increase symptom amelioration and

enhance quality of life. In order to strive towards accurate assessment techniques, other authors have also petitioned the need for development of theory and reliable and valid measurement tools that cover separate components of symptom experience (Hegyvary, 1993; Sutcliffe-Chidgey & Holmes, 1996).

In response to the void of symptom theory and sound measurement of symptoms, Rhodes, Watson, Johnson, Madsen, and Beck (1987) defined two conceptually different components of *symptom experience*. Symptom experience is the overarching construct that encompasses two separate dimensions of symptoms, *occurrence* and *distress*. Rhodes (1987) and Simms, Rhodes, and Madsen (1993) described that symptom experiences are dynamic patient perceptions and responses to the occurrence and distress arising from symptoms. McDaniel and Rhodes (1995) further added that a patient's symptom experience is "the expression of the patient's reality of an experience." The University of California, San Francisco School of Nursing Symptom Management Faculty Group [UCSF] (1994) model conceptualized symptom experience as "a dynamic process that involves the perception, evaluation and meaning of, and response to a symptom."

The first of two underlying symptom experience components is symptom occurrence. *Symptom occurrence* refers to an individual's perception of subjective information with which the symptom occurs (Rhodes & Watson, 1987). Some nursing authors have conceptualized this term as "the recurrent configuration of the occurrence (frequency, amount, and duration)" of symptoms (Rhodes et al., 1987). Lenz, Pugh, Milligan, Gift, and Suppe (1997) stated that

"although symptoms differ from one another, several dimensions are common across symptoms and clinical populations." According to their formulation, symptom occurrence similarly embraces the dimensions of severity, timing, level of distress, and quality. What is notable about this formulation is that the authors do not regard the elements of symptom occurrence and the subcomponent of symptom distress as being distinct and separate. Although not specifically identified by medical anthropologists and sociologists as symptom occurrence, one author alluded to it as being "perceptual data on which a person draws, as the symptom experience is categorized, or defined, as illness," such as symptom visibility or frequency of symptom appearance (Chrisman, 1977, p. 355).

Blacklow (1983) described that as part of medicine's cross-examination technique in history-taking, the physician interrogates the patient concerning the nature or onset, quality, duration, and the intermittent or cyclic character of the symptom to help in the analysis of the true nature of the symptom and the accurate identification of the "hallmarks of organic disease."

Patients' self-reports on symptom location, duration, and onset are fairly accurate, easy to retrieve, and the most commonly measured parameters of symptom occurrence (Ahles, Blanchard, & Ruckdeschel, 1983; Cleeland, 1990). These elements are physiological dimensions of symptom occurrence that generally aid health care professionals to understand the organic basis of the symptom. The sensory dimension of symptom occurrence, on the other hand, is related to how the symptom actually feels to the individual (McGuire, 1992). Severity, quality, and pattern constitute this dimension that pertains to the

individual's discrimination of the symptom. Cleeland further explained that quality and severity aspects are "the more difficult to elicit" parts of the assessment. This may occur due to patients' vagueness in symptom reporting because of either their limitations in vocabulary or command of verbal descriptors, or their lack of knowledge in regard to the underlying physiological mechanisms of the symptom.

Symptom distress is the second component of symptom experience that is different from symptom occurrence. Rhodes and Watson (1987) defined it as the individual's awareness and ability to recognize the degree of physical or mental anguish arising from the symptom experience. Symptom distress is an affective or distress dimension that is related to how the symptom makes the individual 'feel' versus how the symptom is experienced as a quality or severity element of symptom occurrence. As an affective dimension, symptom distress refers to the distress evoked by a specific symptom and accompanying feelings (e.g., anger, fear, irritability, and sorrow). Symptom distress also has a motivational-behavioural aspect where "the generally aversive feelings. . . motivate the behavioural responses" to the specific symptom (Richardson, 1998). As a result of these negative feelings, there is a need for individuals to alter actions in response to the occurrence of specific symptoms (Rhodes, Watson, & Hanson, 1988). Besides having emotive and motivational attributes, Woodgate and McClement (1998) addressed symptom distress as a phenomenological experience that reflects one's personal meaning of the illness symptom. These authors concur with medical anthropological and sociological

opinion that symptom distress reflects a subjective expression of the patient's reality.

Other classification systems delineate the various characteristics of symptom experience as two dimensions, objective and subjective (Piper et al., 1998; Richardson, 1998). The subjective dimension includes the subdimensions of onset, temporality, severity, duration, quality, and distress or emotion. The objective dimension includes signs of symptoms that can be validated by organic-physiological, biochemical, and behavioural phenomena. Regardless of the classification system or typological arrangement of severity, duration, frequency, and distress, each element by itself is an indicator for specific intervention by health care professionals. For instance, using Morrow's (1984) example, there may be certain chemotherapy regimens that cause a low severity of vomiting and therefore there is limited concern about antiemetic intervention. However, when vomiting is assessed on the underlying element of distress, then there may be increased cause for aggressive treatment. This serves to illustrate that the need to delineate the occurrence attributes of a symptom from the amount of symptom distress should not be underestimated (Grant, 1992). Although occurrence and distress are depicted as two parallel, partially independent levels of response to symptoms, together they constitute the overarching multifaceted phenomenon of symptom experience (Rhodes, McDaniel, & Matthews, 1998; Rhodes et al., 1987; Wilson, 1993).

Validation of underlying concepts of the symptom experience construct

McClement, Woodgate, and Degner (1997) identified that several

instruments have been designed to measure symptom distress with items equated with symptom frequency and/or symptom severity. However, these authors argued that research has not verified that symptom frequency and/or severity are in fact equivalent to measuring symptom distress. In relation to this valid concern, the following will identify that a number of studies have provided evidence which delineate not only symptom distress from the symptom occurrence elements of severity, frequency, and duration, but also symptom occurrence elements from one another.

For instance, Morrow (1984) explored various symptom occurrence dimensions of nausea and vomiting and found separate categorizations of frequency, severity, and duration for each symptom event. Distinct dimensions also were found to characterize the symptom pain. Johnson and Rice (1974) found that the pain experience has two separate components of sensation (e.g., quality and severity of sensation) and reaction or distress (e.g., emotional property), which are recognized today as symptom occurrence and symptom distress characteristics, respectively. In regard to dyspnea, Wilson and Jones (1991) found that healthy subjects were able to differentiate between the severity of their breathlessness (an element of symptom occurrence) and their emotive reaction to breathlessness, such as the amount of symptom distress it caused subjects.

Furthermore, in recent years a number of authors have developed tools that measure the occurrence and distress dimensions of symptom experience (both separately and together) (e.g., Portenoy, Thaler, Kornblith, McCarthy-

Lepore, Friedlander-Klar, Kiyasu, et al., 1994; Wilson, 1993). A thorough discussion of these tools will be addressed in the following section under, "Measurement issues: Validation of symptom dimensions". The results of psychometric analyses of these tools provided evidence to verify not only the theoretical dimensions of symptom experience such as frequency, duration, severity, and distress, but also the distinction between these elements. Several statistical approaches were used to evaluate the independence of the elements of symptom occurrence and symptom distress measured by the various tools. Simple correlations and factor analysis of variance techniques were commonly employed to examine the degree to which the dimensions are related to or separate from each other.

Corroborating evidence suggest the benefits of a multidimensional symptom assessment. For example, the combination of distress scores with either frequency or severity measurement provided more information about the association between symptom events and quality of life, than symptom distress alone (Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Kiyasu, et al., 1994). In addition to her support for the distinct and separate components of occurrence and distress, Wilson (1993) suggested that future studies should explore the possibility of other symptom experience components, such as the influence of rank or importance of symptoms to patients. In fact, recent work by Tishelman, Degner, and Mueller (2000) found lung cancer patients weighted some symptoms as significantly more important to them than others. The ordering of symptoms was also found to differ by intensity and perceived

importance.

In summary of these studies where investigators have attempted to validate dimensions that underlie symptom experience, the following can be stated. First, the experience of symptoms is highly complex. Despite the preliminary testing of symptom assessment tools, the majority of findings supported the notion of theoretical and clinical importance in differentiating symptom occurrence from distress responses. Future testing of the relationships among symptom occurrence elements and symptom distress may clarify, for example, whether the sum of dimensions or a separate dimension is most representative of a specific symptom experience (Wilson, 1993).

Second, although this small number of study findings suggested patterns of independence among the symptom experience subcomponents, the results are not yet conclusive. A greater degree of confidence in these findings can be obtained only when future work confirms the presence and distinction of these dimensions by the consistent use of similar statistical tests, such as factor analyses. The lack of homogeneity in the statistical procedures used to date makes it difficult to interpret and synthesize findings overall. Third, the manner in which studies have explored symptom occurrence and distress dimensions is diverse, depending on whether they have included distress, frequency, severity, and/or duration in their respective assessment tools. In order to validate underlying symptom experience dimensions, researchers should work toward future consensus on what to target as separable, but consistent dimensions that would constitute a complete assessment of symptom experience. Fourth, future

descriptive studies might reveal other important dimensions of symptom experience, such as rank or importance of symptoms.

Overview of studies that measured symptom experience and its components

In a number of recent multidisciplinary studies (primarily in nursing and biomedicine) investigators have explored the potential relationships between various demographic, illness, and treatment-related variables and symptom experience arising from various diagnoses, including cancer. A smaller number of investigators explored perceptual congruence between patients' and family caregivers' current ratings on various patient symptom experiences. However, much of the extant work that explored the degree of agreement between self-reports and inferences on patient symptom experience does not appear to be based on a theoretical framework that recognizes the clear and separate underlying multidimensional nature of symptoms.

First, a number of studies explored the potential relationships of predictor factors with various symptom experiences arising mainly from cancer. In this body of investigative work, the measurement of symptom occurrence appears to vary in terms of whether the prevalence (e.g., Rose, Shrader-Bogen, Korlath, Priem, & Larson, 1996), duration, severity, quality, location, or frequency items were included as outcome variables (e.g., Bookbinder et al., 1996; Dunlop, 1989; Hockley, Dunlop, & Davies, 1988; Janjan et al., 1998; King, Nail, Kreamer, Strohl, & Johnson, 1985). However, a vast majority of occurrence studies

focussed on the severity outcomes of singular cancer symptom events like fatigue or dyspnea (e.g., Akechi, Kugaya, Okamura, Yamawaki, & Uchitomi, 1999; Bouley, Froman, & Shah, 1992; Currow, Coughlan, Fardell, & Cooney, 1997; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; Janson-Bjerklie, Carrieri, & Hudes, 1986; Syrjala & Chapko, 1995), or otherwise mainly on the severity of pain (e.g., Clotfelter, 1999; McMillan, 1989; 1996; Fields, 1991; Glover, Dibble, Dodd, & Miaskowski, 1995; Saxenan, Mendoza, & Cleeland, 1999; Sist, Florio, Miner, Lema, & Zevon, 1998; Zimmerman, Turner Story, Gaston Johansson, & Rowles, 1996).

A smaller number of studies focussed on symptom distress alone (e.g., Degner & Sloan, 1995; Ehkle, 1988; Graham & Longman, 1987; Holmes, 1991; McCorkle et al., 1994; Pasacreta, 1997; Reid-Pointe, 1992; Sarna & Brecht, 1997; Strauman, 1996; Tishelman, Taube, & Sachs, 1991). Other studies employed a combination of approaches in the investigation of total symptom experience, either across a variety of symptoms or on separate symptom events. Respective to each study, researchers sought to explore either (a) the total symptom experience, consisting of a composite of occurrence elements and symptom distress (Dodd, Onishi, Dibble, & Larson, 1996; Leddy, 1997; Simms et al., 1993; Wilson, 1993), (b) the total symptom experience, as well as the delineated outcome measures of symptom occurrence and symptom distress (Lough, Lindsey, Shinn, & Stotts, 1987; Rhodes et al., 1988), or (c) the components of symptom occurrence and symptom distress separately (e.g., Price, Harkins, & Baker, 1987).

Some studies that conducted a comparative analysis on patients' and family caregivers' responses did so on the basis of a unifocal assessment on either the 'presence' of symptoms (e.g., Kurtz et al., 1996) or the 'severity' of symptoms (e.g., Nekolaichuk, Maguire, Suarez-Almazor, Rogers, & Bruera, 1999). The studies by Kristjanson et al. (1998) and Lobchuk et al. (1997) measured response comparability on the Symptom Distress Scale (McCorkle & Young, 1978) that, first, confounds symptom dimensions on some symptom items and second, lacks consistency in terms of assessing the same symptom dimensions across symptom items. As criticized by McClement and colleagues (1997), some instruments have been designed to measure symptoms on the assumption that symptom distress, frequency, and severity are equivalent. Consequently, it remains difficult to decipher the exact nature of family caregivers' assessments or what underlying symptom dimensions family caregivers might be targeting in their estimates of patient symptom experience.

In summary, there have been no formal comparisons on the underlying multidimensional elements of symptom experience that can contribute to a greater understanding of what symptom characteristics are amenable to family proxy ratings. Most investigations have not compared patient and caregiver current perceptions with tools that provide a concise assessment or a clear differentiation of symptom occurrence from symptom distress items. By measuring all underlying symptom dimensions, researchers and clinicians might be better able to design or test interventions to minimize perceptual incongruence on a specific aspect of a symptom (Samarel et al., 1996).

Measurement issues

Table 3 depicts several comprehensive instruments that measure occurrence and distress across symptoms, either separately or together in a variety of patient populations. The instruments will be discussed in terms of how they address the multidimensional construct of symptom experience with multi-item scales which might be helpful in preventing the mistaken assumption that patients and family caregivers are rating the same aspect of symptom experience, when in fact they really are not (Brunier & Graydon, 1996). Other symptom measurement tools, like the Edmonton Symptom Assessment System (ESAS) (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1994) and the M.D. Anderson Symptom Inventory (MDAS) (Cleeland et al., 2000) will not be considered as these tools do not measure the multidimensional nature of symptom experience. Rather, they tend to focus on the measurement of symptom severity in palliative care and cancer patients, respectively. The following will consider the separate measurement issues of instrument construction, reliability and validity, widespread use of the tools, patient samples where the tools were developed, diverse conditions in which the tools were administered, and other broad concerns.

Common criticisms of symptom assessment tools. In health care literature, symptoms are commonly defined as subjective and multidimensional phenomenon (Hegyvary, 1993; Ingham & Portenoy, 1996). Symptoms are analysed in terms of either their occurrence (i.e., frequency, duration, and

Table 3

Instruments that assess symptom experience dimensions: Across symptoms

Tool	Author	Dimensions	Type	Administration	Reliability and Validity	Samples Tested	Strengths and Weaknesses
Memorial Symptom Assessment Scale (MSAS)	Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Kiyasu, et al. (1994)	Physical and psychological symptoms Severity Frequency Distress	32 items; separate four or five point Likert-type scales for frequency, severity, and distress	Patient self-report, paper-and-pencil tool; Completion rate is acceptable but additional studies are required to determine respondent burden	Validity - Content, construct (convergent and discriminant; contrasted group), factor analysis, and subscale correlations across symptoms for severity, frequency and distress (range 0.43 to 0.80) Reliability - Cronbach's alpha for groupings of symptoms (range 0.45 to 0.88)	Heterogeneous sample of cancer patients - breast, colon, and ovarian cancer in various stages of the cancer diagnosis; majority diagnosed with metastatic disease (n = 218)	Provides multi-dimensional information about a diverse group of common symptoms; Additional studies are needed to establish its reliability and validity. Promising results for MSAS-Global Distress Index (10 item subscale that reflects global distress scores).

(table continues)

Table 3 continued

Tool	Author	Dimensions	Type	Administration	Reliability and Validity	Samples Tested	Strengths and Weaknesses
Symptom Experience Scale (SES)	Samarel et al. (1996)	Physical symptoms Intensity Frequency Distress	24 items (eight symptoms); separate five point Likert-type scales for intensity, frequency, and distress	Patient self-report, paper-and-pencil tool; < 10 minutes to complete	Validity - Content, construct, factor analysis: all loadings met the criterion of at least .50 Reliability - Overall Cronbach's alpha (0.94) and subscale alphas (range 0.92 to 0.96); subscale symptom reliability coefficients met the cutoff for acceptable subscale subscale correlations of less than 0.70.	Breast cancer patients on average, slightly more than five months after surgery (n = 252)	Indeterminate applicability for men and women of diverse ethnic groups with various types of cancer; future testing of criterion validity and sensitivity of scale to change is recommended.
Transplant Symptom Frequency and Symptom Distress Scale	Lough et al. (1987)	Physical symptoms Frequency Distress	27 symptoms; separate five point Likert-type scales for frequency and distress	Patient self-report, paper-and-pencil tool; unreported ease or time to complete	Reliability - Cronbach's alpha for the frequency subscale (0.70) and for the distress subscale (0.87) Validity - Content	Heart transplant recipients (n = 104)	Content is specific to heart transplant patient population on immunosuppressive therapy

(table continues)

Table 3 continued

Tool	Author	Dimensions	Type	Administration	Reliability and Validity	Samples Tested	Strengths and Weaknesses
Adapted Symptom Distress Scale Form 2 (ASDS-2)	Rhodes, Watson, & Johnson (1984)	Physical symptoms Frequency Distress Intensity	31 items (14 symptoms); separate five point Likert-type scales for occurrence and distress; five point Likert-type scale for total symptom experience	Patient self-report, paper and pencil tool; makes efficient use of the nurses' and patients' contact time; does not deplete the hospice patient of energy	Reliability - Cronbach's alpha on two administrations (0.90 and 0.96); item-to-total correlations ranging from 0.30 - 0.76 Validity - content, constructive (contrasted group approach, concurrent), and predictive	Adult oncology patients receiving chemotherapy (n = 42); family members (n = 18); volunteer adult citizen group participants (unknown sample size)	Easily administered
Adapted version of the Rotterdam Symptom Checklist (RSCL) for the terminally ill	Sutcliffe-Chidgey & Holmes (1996)	Physical symptoms Frequency Distress	16 physical symptoms from the RSCL; four point Likert-type scales	Patient self report, paper-and-pencil tool; unreported ease of time to complete	Psychometric testing in progress Reliability: Not reported Validity: Content	Heterogeneous sample of terminally ill cancer patients from three hospice units (n = 29) and two oncology units (n = 20)	Psychometric testing for reliability and validity properties now in progress. Simple, quick, discriminatory, and easily understandable

(table continues)

Table 3 continued

Tool	Author	Dimensions	Type	Administration	Reliability and Validity	Samples Tested	Strengths and Weaknesses
Eating During Treatment Survey (EDTS)	Wilson (1993)	Oral/oesophageal, gastrointestinal, and related symptoms Frequency Duration Intensity Distress Effect on eating	20 items; five visual analog scales, 100 mm in length designed to measure each symptom dimension; five additional open-ended questions in relation to the EDTS	Patient self report, paper and pencil tool; second grade readability level; completion took 2 minutes	Reliability - Cronbach's alpha (> 0.70), test-retest, scale-to-scale correlations Validity - Content (> 0.80 interrater agreement), construct, factor analysis identified one factor containing all four dimensions of symptom experience: intensity (0.84), duration (0.84), frequency (0.82), and distress (0.74).	Head and neck, lung, and digestive tract cancer patients receiving chemotherapy or radiotherapy as outpatients; in various stages of disease with a majority in Stage III or IV (n = 127)	Can be used to describe a broad number of symptoms. Permits total self reporting on symptom experiences. People may have difficulty equating symptom experience with the visual analog scale or manipulating a pencil for 5 VAS per symptom (e.g., people who are blind, mentally challenged, or have limited hand mobility)

severity) and/or distress (i.e., physical and mental suffering arising from the occurrence of the symptom) (Giardino & Wolf, 1993; Rhodes & Watson, 1987). The selection of the approach taken to measure symptom experience is generally dependent on the intended clinical or research aim and symptom dimensions of most interest (Hazard-Vallerand, 1997). In the clinical setting, patients are frequently asked to describe what they feel or perceive as changes in bodily functions that may signal a disease. The objective of clinical assessment is to determine the efficacy of treatment and patient care by measuring, most commonly, the severity dimension of symptoms. On the other hand, researchers may be interested in a clear delineation of underlying symptom experience components for various reasons (Winningham et al., 1994). For instance, the occurrence and distress phenomena accompanying symptoms might be assessed to determine their distinct impact on the patient's quality of life.

Studies that measured individual symptoms have used a variety of assessment formats. Dichotomous (yes/no) classification scales have been used to determine whether patients experienced the symptom within a specific time frame (e.g., Kurtz et al., 1996; Vainio & Auvinen, 1996). Unidimensional scales such as the visual analog scale (VAS) and the verbal rating scale (VRS) are often utilized to measure the presence or the severity of symptoms, such as pain, dyspnea, and nausea/vomiting/retching (e.g., Giardino & Wolf, 1993; Hazard-Vallerand, 1997). Other scales, such as the Rotterdam Symptom Checklist (RSC) (de Haes, van Knippenberg, & Neijt, 1990) for cancer patients,

evaluate symptoms in terms of strictly distress or the degree of 'bother' arising from symptom events. Although various dimensions of symptoms have been measured in single instruments, none of these instruments offer a concise, separate measurement of all dimensions of a specific symptom.

Another common criticism is directed at tools that claim to measure symptom distress. McClement et al. (1997), Samarel et al. (1996), and Watson, Rhodes, and Germino (1987) identified that the popular McCorkle and Young (1978) Symptom Distress Scale (SDS) confounds symptom occurrence and symptom distress items. In other words, the SDS does not permit separate measurement of frequency, severity, and distress items, and is based on an untested assumption that symptom frequency and severity equate symptom distress. Of note is that three of the tools reviewed are derived from the respective authors' modifications on McCorkle and Young's SDS tool (e.g., the Symptom Experience Scale [SES], the Transplant Symptom Frequency and Symptom Distress Scale, and the Adapted Symptom Distress Scale Form 2 [ASDS-2]).

Instrument construction. Until recently, it appears that knowledge of underlying symptom characteristics, such as severity or distress, has been based on clinical practice observations. However, there are sufficient literature and related studies that have addressed a variety of subjective states arising from symptoms like dyspnea, pain, and nausea. The following describes vital work that is now emerging which confirms the presence of these distinct symptom characteristics in patients. This proliferation of data has been useful not only in

the development of theory on symptoms, but also in the construction of instruments (Richardson, 1998).

Symptom theory. Jacobson (1997) described that instrument development is often, or at least ought to be based on a theoretical model. However, many of the instruments included in Table 3 do not appear to be based on any explicit or identifiable theory. Nonetheless, one is able to detect certain theoretical perspectives, assumptions, or biases on dimensions of symptom characteristics that appear to underlie the development of these tools. The following provides a brief discussion on some examples of nursing theories that might serve as a basis for operationalizing conceptual ideas on the concise assessment of symptom characteristics.

A majority of the theoretical work done to date has focussed on separate symptom experiences, such as pain, fatigue, dyspnea, or nausea and vomiting. However, as a means of integrating existing information about a variety of symptoms, Lenz, Suppe, Gift, Pugh, and Milligan (1995) and Lenz et al. (1997) recently engaged in a collaborative effort that resulted in the development of a middle range nursing theory called the *Theory of Unpleasant Symptoms*.

This theory is based on the simultaneous, but separate work of investigators on dyspnea (Gift, 1990) and fatigue (Pugh, 1990). Although each symptom is distinct, these authors have found that these symptoms share common dimensions regardless of the clinical population: severity, timing (duration or frequency), distress, and quality. The Theory of Unpleasant Symptoms is depicted as a work-in-progress which assumes there are sufficient

commonalities among symptoms to warrant a theory that is not limited to one symptom, but one that regards an array of unpleasant symptoms. Furthermore, The University of California, San Francisco [UCSF] School of Nursing Symptom Management Faculty Group *Symptom Management Model* (1994) has also emerged as a parsimonious model which shares the basic underlying assumption of The Theory of Unpleasant Symptoms that multiple symptoms are similarly characterized by the underlying dimensions of severity, frequency, duration, and distress. In general, current theoretical frameworks in nursing are broad enough to regard an array of symptoms, along with their underlying characteristics that are common across symptoms and clinical populations.

It is important to note that theoretical development on symptom experience is accompanied by efforts directed at the construction of tools which are compatible with emergent thought about the multidimensional nature of underlying symptom characteristics. Since McCorkle's (1987) survey of a few data collection instruments that she deemed as "content appropriate for the general assessment of symptom occurrence or symptom distress" (p. 251), the number of tools that provide a clear delineation of symptom experience components has grown. In fact, Rhodes (1990) and McClement et al., (1997) have reviewed the adequacy of a mixture of symptom tools that measure either symptom occurrence or symptom distress occurring in the cancer patient population. However, these authors did not clearly delineate the underlying characteristics of symptoms captured within the tools. To satisfy the goal of the current study, it was important to identify and evaluate existing single

measurement tools in terms of whether they are adequate in assessing the total symptom experience for each symptom.

Validation of symptom dimensions. Several recently validated tools are now available that were not only designed for various patient populations including cancer patients, but also constructed to measure total symptom experience and/or separate subtotal ratings on symptom occurrence and symptom distress across symptoms and for separate symptoms. The results of preliminary psychometric analyses of these tools provide evidence to verify not only the theoretical dimensions of symptom experience such as frequency, duration, severity, and distress, but also the distinction between these elements across symptoms (see Table 3).

As a measure of the construct validity of Wilson's (1993) Eating During Treatment Survey (EDTS), principal components factor analysis with varimax rotation revealed high factor loadings for all four dimensions. In other words, the results confirmed that frequency (0.82), duration (0.84), severity (0.84), and distress (0.74) are critical to the theoretical construct of symptom experience. Furthermore, the lower factor loadings of symptom distress ($t_1 = 0.69$; $t_2 = 0.72$) distinguished it from the occurrence dimensions of frequency ($t_1 = 0.88$; $t_2 = 0.90$), duration ($t_1 = 0.89$; $t_2 = 0.89$), and severity ($t_1 = 0.89$; $t_2 = 0.89$).

The Memorial Symptom Assessment Scale (MSAS) is a patient-rated measure that provides multidimensional information about 32 physical and psychological symptoms characterized in terms of severity, frequency, and distress (Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Kiyasu,

et al., 1994). Significant correlations were reported between mean severity and frequency scores ($r = 0.80$), mean severity and distress scores ($r = 0.70$), and mean frequency and distress scores ($r = 0.43$). Symptom severity was more closely related to frequency and distress, than frequency and distress were related together. The high correlation that resulted between severity and distress scores might be in relation to the two dimensions "sharing a force or stress component" (Wilson, 1993, p. 69). The poor correlation between frequency and distress scores supports the suggestion that a high prevalence of a symptom does not necessarily translate into a predictable correspondence with reports of high distress (McClement et al., 1997; Rhodes, 1997; Sutcliffe-Chidgey & Holmes, 1996). Furthermore, Portenoy et al. demonstrated that a combination of distress scores with either frequency or severity measurement provided significantly more information about the relationship between symptoms and quality of life than the distress measure alone.

In their exploratory factor analysis involving the SES, Samarel et al. (1996) expected to find three factors based on the frequency, severity, and distress of eight symptoms. Instead, they found that the symptoms themselves comprised the factor structure and the three dimensions of symptom experience were equally important to the total symptom experience of breast cancer patients. Morrow (1984) reported moderate correlations among pairwise comparisons of symptom experience dimensions in the Morrow Assessment of Nausea and Emesis scale. This author concluded that frequency, severity, and duration of nausea and vomiting are "reasonably distinct and separable

phenomenon" (Morrow, 1984, p. 2273). Similarly, Lough et al. (1987) found that symptoms which occurred most often were not always reported as most distressing (e.g., bruising, excessive hair growth, and changed bodily appearance) on their Transplant Symptom Frequency and Symptom Distress Scale. No inferential statistical testing with frequency data was reported.

The Rhodes Index of Nausea and Vomiting Form 2 (INV-2) provided ambiguous evidence that symptom occurrence is sufficiently different from symptom distress (Rhodes et al., 1987) (see Table 3). These authors were guided by Leventhal's Parallel Response Model that emphasized the difference between occurrence attributes and the emotional distress of symptom events. However, their results revealed a highly significant correlation of 0.94 ($n = 306$) between the occurrence and distress response items. This finding was interpreted as confirmation of Leventhal's Model, despite this model's emphasis on the dissimilarity between the two components. This interpretation is confusing, particularly in light of how others relied on different criteria on the magnitude of correlation to confirm the distinction, albeit linked relationship, between symptom occurrence items and symptom distress (i.e., a low but significant correlation) (e.g., Morrow, 1984, obtained significant pairwise correlations of ≤ 0.50 ; Moons, De Geest, Abraham, Van Cleemput, & Vanhaecke, 1998, obtained a correlation of 0.43; $p < 0.0001$). However, Rhodes et al. (1987) shared other findings that more clearly suggested the distinctiveness between the two symptom experience dimensions. For instance, they found that there was no logical match between individuals' response

patterns of minimal distress and sustained symptom occurrence.

Tool items. In general, there is consensus across the tools in terms of their respective measurement of major symptom experience components of symptom occurrence and symptom distress. The only tool where the theoretical source for the items was made explicit is the ASDS-2. Rhodes and colleagues' theoretical work on differentiating the underlying characteristics of symptom experience is clearly reflected in the development of their ASDS-2 scale (Rhodes, Watson, & Johnson, 1984). The ASDS-2 consists of the occurrence subscale (measures how often the respondent felt the symptom occurred or frequency) and the distress subscale (measures how much distress was felt when the symptom occurred).

However, the tools tend to differ in terms of what items to target as separable underlying dimension elements that would constitute a complete assessment of symptom experience. In particular, some variance exists regarding the specific occurrence items (e.g., frequency, duration, or severity) that are included in the respective measures of patient total symptom experience. Although all of these tools include items on symptom distress, several differ in terms of the selected symptom occurrence items. For instance, the MSAS and the SES target the measurement of symptom severity and frequency. Other tools, such as the Transplant Symptom Frequency and Symptom Distress Scale and the adapted version of the Rotterdam Symptom Checklist (Sutcliffe-Chidgey & Holmes, 1996) for the terminally ill ignore the symptom severity element, but include symptom frequency along with symptom

distress. The EDTS is a tool developed as part of Wilson's (1993) doctoral dissertation and represents the most detailed instrument with its inclusion of all symptom occurrence elements of frequency, duration, and severity, besides a symptom distress item.

Tool subscales. Each of these symptom experience questionnaires contain several subscales that address the two major symptom experience components. Because the adapted Rotterdam Symptom Checklist is in its early developmental stages, it is difficult to offer comments about its subscale dimensions. The remaining instruments have undergone different levels of psychometric testing to determine the validity of their respective multidimensional subscales and they appear reasonably sound, enough to deserve comment. The ASDS-2 yields a total symptom experience score, as well as separate subscale scores for the components of symptom distress and symptom occurrence for each symptom. Similarly, the SES allows for the separate measurement of frequency, severity, and distress of common symptoms associated with breast cancer, and the summation of these separate scores. Although the Transplant Symptom Frequency and Symptom Distress Scale delineates the concepts of frequency and distress, it does not use a total score for reasons discussed in the following section, "Weight of items." In regard to the EDTS, Wilson (1993) did not provide instructions about the summation of subscales and the calculation of the total scale score. However, it is inferred from the psychometric analyses of the EDTS, that subscale scores can be obtained across symptoms for frequency, duration, severity, and distress.

The total MSAS score consists of mean scores for all 32 symptoms across severity, frequency and distress items. The scoring of the MSAS also yields several subscale scores: a ten-item MSAS Global Distress Index score (MSAS-GDI) which is the average of the frequency of four psychological symptoms and the distress arising from six physical symptoms; a Physical Symptom subscale score (MSAS-PHYS) that includes the average of the frequency, severity, and distress associated with 12 prevalent physical symptoms; and a Psychological Symptom subscale score (MSAS-PSYCH) that includes the average of the frequency, severity, and distress associated with six prevalent psychological symptoms. Chang, Hwang, Corpion, and Feuerman (1997) recently validated the short form of the Memorial Symptom Assessment Scale (MSAS-SF), which is an abbreviated form of the MSAS that measures each symptom in terms of frequency or distress alone.

Source of items. As mentioned, assumptions on the underlying nature of symptoms are inherent to each of the tools, however the conceptual basis from which these assumptions are formulated is difficult to ascertain. Nonetheless, most of the authors of these tools described that ideas for the measurement of specific symptoms and their characteristics arose from their respective review of literature (Lough et., 1987; Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Kiyasu, et al., 1994; Sutcliffe-Chidgey & Holmes, 1996), a survey of existing tools (Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Kiyasu, et al., 1994; Rhodes et al., 1984; Samarel et al., 1996; Sutcliffe-Chidgey & Holmes, 1996; Wilson, 1993), and clinical experiences

(Lough et al., 1987; Rhodes et al., 1984).

A "superior" source of items for instruments originates from patients themselves who generate the tool's content (Levine et al., 1988). Although none of the tools relied solely on qualitative patient data, many enhanced their content validity by either: a) using a strategy of data source triangulation to maximize the range of symptom data obtained (Sutcliffe-Chidgey & Holmes, 1996); b) expanding on the item pool by having patients respond to open-ended questions about their symptom experiences and then adding frequent symptom events not already mentioned in the scale (Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Kiyasu, et al., 1994); c) asking patients to critique and suggest deletions of or revisions to items included in the instrument (Samarel et al., 1996); or d) interviewing patients about the language of an existing scale and key words used (Rhodes et al., 1984). As a standard of practice to improve symptom experience assessment, a majority of the authors of these tools were effective in providing patients and caregivers with an opportunity to supplement the item pool (King et al., 1997).

Weight of items. It has been suggested in quality of life literature that respondents should rank the importance of each item in relation to their quality of life, in addition to the occurrence of the item (King et al., 1997). King et al. argued that the custom of summing individual items on subscales to arrive at an aggregate score can be made more informative with the addition of a weighted score dimension. Numerous authors in nursing science concur that importance ratings are rarely accomplished in symptom instruments (Degner & Sloan, 1995).

In her dissertation, Wilson (1993) suggested that the conceptualization of symptom occurrence and symptom distress as being the only subcomponents of symptom experience may not be concise. Wilson proposed that the rank or importance of a symptom to the patient may be another subcomponent of symptom experience. Also in terms of rank, certain dimensions of occurrence may be more salient or significant to the patient depending on the symptom.

Other tool authors indicated that a summed score consisting of individual items on subscales was not appropriate, in light of their belief that not all symptoms are given equal weight by patients (i.e., the Transplant Symptom Frequency and Symptom Distress Scale; Lough et al., 1987) or that each symptom is a distinct entity (i.e., EDTS; Wilson, 1993). Other tools such as the SES, the ASDS-2, and the MSAS followed the traditional method of summing individual subscale items to obtain an aggregate score.

Reliability and validity issues. Total symptom experience is a new area of scientific inquiry. Just as in quality of life research, much activity on symptom experience has focussed on instrument development (King et al., 1997). Psychometric testing on these newly constructed instruments is still undergoing confirmation of their respective reliability and validity properties. One tool in particular that is in early developmental stages is Sutcliffe-Chidgey and Holmes's (1996) proposed symptom tool. These authors presented the results of an exploratory study that identified symptoms causing distress to a heterogeneous group of dying cancer patients. In comparing their findings with existing scales, these authors determined that the Rotterdam Symptom Checklist's physical

subscale would be appropriate for modification to suit the terminally malignant patient population. The psychometric assessment of this symptom scale is now in progress (Lough et al., 1987).

Despite their early developmental stages, some tools have been used in studies that did not conduct further reassessment or confirmatory analyses of their reliability and validity properties. For example, numerous authors concluded that the validity and internal reliability of the MSAS have already been well established by the tool's authors in preliminary validation analyses (e.g., Breitbart, McDonald, Rosenfeld, Monkman, & Passik, 1998; Harrison et al., 1997). The MSAS serves as one example of where significant gaps in reporting the results of ongoing psychometric assessment of tools remain, despite recent emphasis on the importance of using sound measurement principles (Waltz, Strickland, & Lenz, 1991). However, without sound psychometric properties that determine if the instrument measures accurately what it is supposed to measure, the results of studies can be misleading or meaningless (Rhodes, Johnson & McDaniel, 1995).

Evidence of reliability and validity. In accordance with Norbeck's (1985) and King et al.'s (1997) recommendations, we see in Table 3 that most instruments meet the minimum requirements of reporting one or two estimates of reliability, such as test-retest and/or internal consistency, and at least one type of content validity and construct (or criterion-related) validity. By attending to pre-set criteria described by Jacobson (1997) for interpreting reliability and validity correlational data, the overall strength of quality analyses for the respective

instruments was determined as follows.

Of all the tools reviewed herein, the most rigorous initial efforts in establishing the reliability and validity properties have been with the **MSAS**. Although a content analysis was performed that suggested revisions to the tool, the authors do not describe their method of discerning this type of validity. Based on data from 218 heterogeneous cancer patients, the measure demonstrates internal consistency results that ranged from being weak (i.e., concentration subscale had an alpha of 0.45) to high (high frequency physical symptoms subscale had an alpha of 0.88).

Utilizing the multitrait-multimethod approach to test convergent and discriminant validity, MSAS subscale scores were correlated with the scores on several validation measures that included, the Revised Rand Mental Health Inventory (RAND), the Functional Living Index-Cancer, the Karnofsky Functional Performance Scale, and mood VAS. Across the majority of correlations, the total MSAS and the MSAS subscales met the pre-set criterion of satisfactory coefficients (range: 0.40 to 0.60) with associations ranging between weak (e.g., 0.19 for gastrointestinal subscale and the mood VAS) and strong (e.g., 0.80 for the MSAS Psychological Symptom subscale and the RAND distress subscale). The contrasted-group approach in establishing construct validity revealed that the MSAS was able to discriminate the high symptom distress ratings of the inpatient group from the low ratings of the outpatient group ($p < 0.0001$) and the high distress ratings of the advanced disease group from the low ratings of the early disease group ($p = 0.018$). As discussed in the section, "Validation of

symptom dimensions", the validity of the MSAS dimensionality was also determined by respective pairwise correlations that resulted in moderate to strong associations among mean severity, frequency, and distress scores across symptoms and for separate symptoms. The factor structure of the MSAS was evaluated by a factor analysis of variance which revealed three major groupings of symptoms: *psychological state* (with two subgroupings of emotion and concentration), *prevalent physical symptoms* (with two subgroupings of pain/treatment and gastrointestinal distress), and the third, *low frequency physical symptoms* group.

For the **SES**, exploratory factor analysis yielded six symptom factors that accounted for 83.2% of the variance (i.e., nausea/appetite, fatigue/sleep, concentration, appearance, bowel patterns, and pain). Content validity was assessed by qualitative procedures with a panel of participants in a breast cancer support group. Cronbach's alpha internal consistency reliability coefficients were strong for both the subscales and the overall tool. In Leddy's (1997) sample of 53 breast cancer patients and 89 non-cancer volunteers, the Cronbach's alpha coefficient was 0.90. Subscale-to-subscale reliability coefficients ranged from 0.21 to 0.56. The contrasted-group approach was used to determine construct validity where the SES was able to significantly differentiate between the subgroups of time since surgery category and the subgroups of treatment regimen category on the total symptom experience across symptoms and for separate symptom items.

Lough et al. (1987) discussed little of the psychometric development of the **Transplant Symptom Frequency and Symptom Distress Scale**. Content validity was verified where eight symptoms were confirmed by a panel of postdoctoral fellows in psychosocial oncology, the authors' clinical experience, and a review of medical and nursing literature. The Cronbach's alpha coefficients for both the frequency and distress subscales were acceptable at the 0.70 criterion for early stages of tool development. De Geest et al. (1995) obtained a Cronbach's alpha coefficient of > 0.80 on the Dutch translation of the tool's frequency and distress scales. On their Dutch version of the tool, Moons et al. (1998) stated that an acceptable content and construct validity was obtained. The Cronbach's alpha coefficients ranged from high (0.83 for the symptom frequency scale) to very high (0.91 for the symptom distress scale).

Several studies have provided extensive, but preliminary quality evidence on the soundness of the **ASDS-2**. Content validity was established with qualitative data obtained from interviews held with patients in teaching and research hospitals, and in clinics. On two administrations, the Cronbach's alpha reliability estimates were 0.90 ($n = 40$) and 0.96 ($n = 29$). DeKeyser, Wainstock, Rose, Converse, and Dooley (1998) found a similar Cronbach's alpha of 0.91 ($n = 35$). Item-to-total correlations ranged from 0.30 to 0.76 ($n = 30$). Subscale reliability coefficients ranged between 0.42 (pain) and 0.84 (coughing and breathing), and were highly significant ($p = 0.02$ or lower). Construct validity, utilizing the contrasted group approach, found significant differences in symptom distress reports between a well citizen group and a chemotherapy patient group

($p = 0.0009$). Predictive validity was also determined, where the correlation for the total scale score prior to and after the second administration of chemotherapy was 0.54. It was predicted that the ASDS scores before chemotherapy would show a low to moderate correlation with scores from the next treatment cycle. The nausea scales on the ASDS and the Index of Nausea and Vomiting (Rhodes, Watson, & Johnson, 1984) were correlated at 0.93, which yielded evidence of concurrent validity for the ASDS nausea subscale.

For the **EDTS**, various techniques were used to determine its psychometric properties. Initial content validity was established by expert panel agreement (> 0.80 per symptom) and a second assessment of content validity occurred with patient identification of symptoms. Cronbach's alpha internal consistency estimates of > 0.70 indicated consistency for 19 of 21 symptoms. Scale-to-scale correlations of pairs of dimensions (frequency, severity, duration, and distress) were mixed (e.g., for diarrhea, the severity-duration correlation was 0.20; for vomiting, the severity-distress correlation was 0.95). Temporal stability (test-retest reliability) was tested by measuring factor loadings of two EDTS administrations. Both factor analyses resulted in one-factor solutions and high factor loadings for all four symptom dimensions. Construct validity was determined with factor analyses by diagnosis, treatment, trajectory, and symptoms, where one factor contained all four dimensions of symptom experience.

Studies using the tools. Generally it is advantageous for researchers to select a measurement technique that is commonly used (McDowell & Newell,

1996). However, the number of separate studies in which the various methods have been used is limited. The following commentary on how widely the instruments have been used is based on McDowell and Newell's (1996) rating criteria that includes the following three categories: a few (one to four published studies), several (five to eight), or many (nine or more) different studies have used the method. The rating refers to the number of separate studies where the instrument has been used, rather than to the number of publications that describe the tool (i.e., several publications may be derived from one study).

In accordance with this author's literature search, the EDTS was cited only once as part of the original author's unpublished doctoral dissertation which addressed the development of the tool (Wilson, 1993). A few studies have cited the use of the original Transplant Symptom Frequency and Symptom Distress scale, besides being mentioned in the initial methodological study by Lough and colleagues in 1987 (e.g., Baumann, Young, & Egan, 1992; Foley, Davis, & Conway, 1989; Jones et al., 1990). A few studies have used a modified and translated version of the original Transplant tool (De Geest et al., 1995; Grap, Savage, & Ball, 1996; Moons et al., 1998). Besides the original authors of the SES, Leddy (1997) was the only other author to identify the tool's use in her published study. On the other hand, the appeal in using the ASDS-2 appears to be wider where several published studies have used this measurement method (e.g., DeKeyser et al., 1998; Rhodes, McDaniel, & Matthews, 1998; Simms et al., 1993; Tanghe, Evers, & Paridaens, 1998). As with the other newly developed tools, an extensive list of published studies that have utilized the MSAS does not

exist (e.g., Breitbart et al., 1998; Harrison et al., 1997; Portenoy, Kornblith et al., 1994; Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al., 1994).

Nature of the samples. As part of the specific considerations on psychometric properties, Waltz et al. (1991) described that one must consider the nature of the samples from which quality estimates were obtained. Generally these instruments have undergone pilot testing in populations of patients who were on average 50 years of age and older, and who had attained a minimum of high school education. Most of the reliability and validity estimates of the various instruments were reported from, with some exceptions, heterogeneous samples of cancer patients of mixed gender.

Sutcliffe-Chidgey and Holmes's (1996) initial steps in modifying the physical symptom subscale of the Rotterdam Symptom Checklist occurred in a sample of dying malignant patients, where 69% of the patients had metastatic disease (type of cancer was not identified). Psychometric reports for the MSAS and the ASDS-2 arose from the following patient groups. The MSAS was tested in a mixed colon, prostate, breast, and ovarian cancer patient population (Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al., 1994), as well as with AIDS patients (Breitbart et al., 1998). These patients were in various stages of disease, with the most common profile of patients being those with metastatic disease. The ASDS-2 was tested with lung, breast, ovarian, testicular, head and neck, sarcoma, bladder, cervical, and lymphoma cancer patients receiving chemotherapy treatment in various stages of their

illness, including those with metastatic disease (DeKeyser et al., 1998; Simms et al., 1993; Tanghe et al., 1998). Other ASDS-2 patient populations included those with cancer and non-cancer related terminal illnesses together with hospice caregivers who were either registered nurses, licensed practical nurses, or medical social workers (Rhodes et al., 1998).

Psychometric analyses of the EDTS occurred in a heterogeneous sample of head and neck, lung, and digestive tract cancer patients who were undergoing chemotherapy. The majority of the subjects were receiving treatment for stages III or IV, or recurrent disease (Wilson, 1993). The Transplant Symptom Frequency and Symptom Distress tool targets heart transplant recipients (Lough et al., 1997), however, the tool has been tested also in renal transplant populations (De Geest et al., 1995). Of note is that this 'transplant' tool has been modified to document the symptom frequency and distress of gastrointestinal symptoms experienced by cardiac surgery patients who underwent coronary artery bypass grafting, valve replacement, or both (Grap et al., 1996). The Transplant Symptom Frequency and Symptom Scale also has a Dutch translation for use in renal transplant patients (De Geest et al., 1995). Although the SES has been restricted to testing with breast cancer patients undergoing treatment, reliability testing has occurred in a comparison group of healthy female volunteers as well (Leddy, 1997; Samarel et al., 1996).

Diversity of conditions. In light of their various stages of development, the tools have had different opportunities to be administered in varying conditions. This is important to consider in that instruments are often designed

for use in particular settings and cannot be transferred to another setting (Waltz et al., 1991).

With respect to the Transplant Symptom Frequency and Symptom Distress Scale, patients were allowed to complete the surveys either: at home and return them in the mail; over the telephone; or, in clinic or during hospitalization under the supervision of a research nurse. The SES was administered as a mailed questionnaire. With the MSAS, inpatients were generally administered a survey package by the research nurse. Outpatients were allowed to take the MSAS package home or to complete the survey in the clinic setting. In other studies, patients were directly mailed a MSAS questionnaire packet which they completed at home. With the ASDS-2, either: (a) the patients completed the 'research nurse administered' package at the time of the home-based hospice admission or in the clinic setting before treatment, (b) the hospice patients completed their package over the telephone and the individual hospice nurse completed the ASDS-2 in accordance with his or her hands-on assessment; or (c) the outpatients were allowed to complete the survey package at home and return the package by mail. The EDTS was completed by outpatients in a private area of the clinic setting before their chemotherapy or radiotherapy treatment. For each of the respective instruments that were mailed to patients, telephone contact by the research nurse was maintained to ensure prompt completion and return of the surveys.

Other instrumentation issues. Most authors reported that these instruments were relatively brief and easy to read, understand, and score.

However, the authors of the MSAS indicated that additional studies are needed to determine respondent burden because of the length of the tool (i.e., 32 items). Although Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al. (1994) acknowledged that some symptom information might be forfeited with the development of a more brief tool, the benefits of increased respondent compliance serves as an impetus for the current testing of a shorter version of the MSAS (i.e., one that measures each symptom in terms of distress or frequency alone) (Chang et al., 1997). On the other hand, the risk in reducing the scale to only major items may decrease the sensitivity of the scale and, according to Sutcliffe-Chidgey and Holmes (1996), may reduce the tool's clinical usefulness in assessing the patient's total symptom experience. These are important issues to consider, particularly in the context of debilitated patients who need to complete instruments that are relevant and manageable in length.

In accordance with Donovan, Sanson-Fisher, and Redman's (1989) outline of parameters for an acceptable QL instrument, all of these symptom tools include a closed question format, categorical scaling, comprehensible language to the majority of the population, and relevant items to the respondents. The ease of scoring these instruments stems from their Likert-type scale approach with ordinal/interval scales. Furthermore, some authors included word descriptors on Likert-type scales that allow for the absence of a symptom (e.g., Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al., 1994; Rhodes et al., 1994; Samarel et al., 1996). The common range of these Likert-type scales is between four and five points. Wilson (1993) preferred

the 100 mm line, visual analogue scale format for her EDTS measure because of its sensitivity as a self-report on subjective symptom experiences, ability to reduce respondent bias, and accuracy and simplicity of scoring.

Conclusion - selection of a tool. At present there are no known studies that explored next-of-kin current estimation on patient total symptom experience. However, if such an investigative effort was to be pursued, it would be important to select instrumentation that would offer a multidimensional measurement of symptom characteristics. The multifaceted assessment of symptom events might prove to be valuable in serving the basis for understanding how and when family caregivers may be used for making reasonable estimates of patient symptom experiences. Therefore, the purpose of this section was to review and analyse instrumentation designed to measure the multidimensional construct of symptom experience. As a result of this analysis, the following rationale is offered for selecting Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al.'s (1994) MSAS for use in the current study.

First, initial confidence in the validity of the MSAS is warranted. The MSAS appears to be a sound instrument that is capable of providing an overall multifaceted measurement of symptom experiences in a heterogeneous sample of cancer patients who are in various stages of disease. Second, although most of the tools addressed in this analysis are multidimensional in nature, the MSAS has a concise and clearly worded response format that does not confound symptom occurrence with symptom distress items. Furthermore, the multi-scale items of symptom occurrence and symptom distress on the MSAS would likely

promote a clear understanding of the underlying symptom characteristics that the family caregiver and patient are addressing in their respective reports on patient symptom experience.

Third, although the MSAS has not been tested in family caregiver populations, it appears that the tool might be easily adapted for use with family caregivers who must infer patient symptom experience. However, there is one concern related to the length of the 32 symptom item MSAS that might cause undue burden on advanced stage cancer patients. Although Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al. (1994) stated that the tool required further testing on respondent burden, they found that the tool's length did not deter their sample of patients (that included primarily metastatic participants) from completing the response items within a reasonable time frame.

In summary, this section covered measurement issues of instrument construction, reliability and validity, and various conditions where symptom experience instruments have been employed. As a result of this analysis, rationale for the selection of the MSAS for use in the current study is based on the tool's conceptual fit with a multidimensional theoretical view of symptoms. In addition, the MSAS appeared suitable for use in the current study that aimed for a concise comparison of patient and family caregiver perceptions on the underlying dimensions of patient total symptom experience.

Empathic accuracy

Empathic accuracy and dispositional perspective-taking

In order to fully comprehend the phenomenon of perceptual congruency,

the following bridges knowledge from social psychology with nursing science literature. In social psychology, the accuracy of interpersonal judgments has been explored under the rubric of empathic accuracy. As a recent emergent area in research, empathic accuracy focuses specifically on the intrapersonal, non-affective outcome of judgment accuracy and the influence of a wide range of factors that potentially serve as predictors of accuracy (Davis, 1994; Ickes, Stinson, Bissonnette, & Garcia, 1990). Empathic accuracy is defined as the perceiver's ability to accurately infer the specific content of another's thoughts and feelings (Ickes, 1993) without having to experience another's emotions or thoughts (Hogan, 1969). This concept is also known by a confusing array of synonyms such as accuracy, empathy, social skills, understanding, or sensitivity (Kenny & Albright, 1987); accurate empathy, discriminant accuracy, perceptual accuracy, social acuity, or social intelligence (Ickes et al., 1990); and, predictive empathy (Stotland, 1969).

One factor purported in Davis's (1994) empathy model to be influential in generating empathic accuracy in observers is perspective-taking (also known as role-taking). In nursing and social psychological literature, perspective-taking is viewed as either a trait, a capability, a skill, and/or a process that involves "stepping inside another's shoes" to predict another's thoughts and feelings. Individuals who adopt the cognitive and/or emotional point-of-view of others may be better able to respond sensitively to another's needs (Kochanska, 1997) or may possess communication effectiveness by being provided with information and insights about others (Redmond, 1995). A consensus across the literature

reveals that perspective-taking is: (a) a cognitive ability or process that involves an imaginative understanding of another's viewpoint (Bryant, 1987; Davis, 1980, 1983; Hogan, 1969; Kasch, 1983, 1985; Kasch & Dine, 1988; Kurdek, 1978; Long & Andrews, 1990); (b) an intrapersonal mechanism that involves 'decentering' or a conscious effort in differentiating one's personal view from the view of another (Arriaga & Rusbult, 1998; Davis, 1980, 1983; Hogan, 1969; Kasch, 1983; Kurdek, 1978; Underwood & Moore, 1982); and (c) a multidimensional understanding of another's thoughts and feelings (Arriaga & Rusbult, 1998; Bryant, 1987; Davis, 1980, 1983; Hogan, 1969; Kurdek, 1978; Underwood & Moore, 1982).

As a trait or disposition, perspective-taking is an ability that is not possessed equally by all and there are various degrees in which observers engage in perspective-taking (Betancourt, 1990; Davis, 1983; Franzoi, Davis, & Young, 1985; Hogan, 1969). As purported by Davis (1994), *individual differences* in the tendency to perspective-take represent one set of antecedent variables that might influence, for example, the family caregiver's likelihood of either engaging in perspective-taking or experiencing perceptual accuracy on patient symptom experience. Investigators have targeted mainly the impact of dispositional perspective-taking rather than the process of perspective-taking on empathic accuracy (Davis, 1994). None of these studies found dispositional perspective-taking to be significantly associated with the observer's ability to accurately infer the content of a videotarget's thoughts and feelings (e.g., Ickes et al., 1990; Marangoni, Ickes, Garcia, & Teng, 1995; Stinson & Ickes, 1992).

Each of these studies employed Davis's (1983) Interpersonal Reactivity Index (IRI) and its general perspective-taking subscale that measured the reported tendency of observers to spontaneously adopt the psychological viewpoint of another in everyday life. Similarly, a nursing investigation correlated nurse IRI perspective-taking tendency scores with nurse accuracy scores on patient pain severity, however, no significant results were discovered (Maciorowski, 1989). These indeterminate results might be related to the individual's lack of metaknowledge or insight concerning his or her own empathic skills such as perspective-taking (Ickes, 1993). Self-reports should be regarded not as the gold standard but as reasonable "ballpark" self-descriptions of an individual's perspective-taking ability (Thomas & Fletcher, 1997).

Davis (1994) further advised that the best predictors for accuracy might not be general perspective-taking tendencies of individuals, but "emergent phenomena" arising from communication factors in specific interactive situations. Dispositional perspective-taking abilities may not be stable across various interactions and therefore require the measurement of individual tendencies to perspective-take within the context of a specific relationship (Long & Andrews, 1990). As an example, Franzoi et al.'s (1985) study with 131 college student couples reported a low correlation between the IRI general perspective-taking subscale and relationship satisfaction. Although these students reported that they had general perspective-taking abilities, they may not have been motivated to use these skills with a specific partner.

One concept that taps into whether individuals use perspective-taking

skills within a specific social context is dyadic perspective-taking. Dyadic perspective-taking is a concept coined by Long (1987) that indicates whether or not an individual seeks to understand the point-of-view of the partner in a specific dyadic situation. There are two dimensions to dyadic perspective-taking: self and other dyadic perspective-taking (Long, 1987). The 'self' dimension concerns the observer's perception of one's own dyadic perspective-taking and the 'other' dimension recognizes the target's perception of the dyadic perspective-taking by the partner-observer within the context of the dyadic situation. Because perceivers generally fail to provide accurate self-reports on their inferential abilities (Ickes, 1993), the target's perception might reflect a more objective and perhaps more valid account of observer perspective-taking activities.

No nursing studies were identified that explored the influence of dyadic perspective-taking on empathic accuracy on patient symptom experience. In a related nursing study, Goodwin (1997) examined the relationship between chronic illness symptomatology and the empathic process of perspective-taking within a marital context. Utilizing Long's (1987) Dyadic Perspective-Taking Scale in a sample of 131 women diagnosed with chronic fatigue and immune dysfunction syndrome, Goodwin found that the husband's self-perceived empathic ability was the only marital variable sensitive to the number of symptoms reported by the wife; in other words, husbands who perceived themselves as empathic had wives who reported fewer symptoms ($r = -0.19$; $p = 0.03$). However, marital empathy scores were excluded from regression analysis due to their lack of support from literature and statistical analyses. Long

and Andrews (1990) assessed perspective-taking within the intimate marital relationship and found that both husbands' and wives' general perspective-taking tendencies as measured on the perspective-taking subscale of the IRI were predictive of the other spouse's marital adjustment. However, the dyadic perspective-taking measures of self and other were better predictors of marital adjustment than was the IRI measure of general perspective-taking.

In summary, it appears that exploring dyadic rather than general perspective-taking tendencies might be more helpful in understanding individual differences in perspective-taking that occur within the specific context of caregiving. For instance, if the patient perceives that the family carer engages in genuine efforts to understand his or her point-of-view on symptom events, then this may reflect one mechanism by which interpersonal friction produced by "the psychological proximity of two different points of view" is eliminated and intrapersonal accuracy is enhanced (Franzoi et al., 1985, p. 1592). While dyadic perspective-taking may be an important precursor of empathic accuracy, it may also serve as a reflection of the quality of interaction between the patient and family caregiver that is associated with measurable patient outcomes, such as lower ratings of patient perceived symptom experiences.

Empathic accuracy and strength of the situation

The reliable effects of a dispositional tendency to perspective-take as a single predictor of accuracy in specific and general social interactions are speculative because only a small amount of supportive evidence and mostly inconsistent patterns exist to date. Davis (1994) suggested that regardless of

the differences in dispositional tendencies to perspective-take, empathic situations are unique and tend to vary in their ability to evoke a response from observers. In other words, more intense empathic responses might be engendered in observers when there are more profound displays of emotion by weak or helpless victims. The *strength of the situation* is an antecedent variable that addresses the ability of a specific interactive situation to evoke an empathic process in or outcome from the observer. To date, however, it has been noted that stimulus factors in empathic episodes have not received much attention outside the laboratory setting (Strayer, 1987)

Notably, a few studies in nursing have explored the potential evocative power of behavioural cues arising from the naturalistic occurrence of patients' symptom events. Lobchuk and colleagues (1997) found that 37 pairs of family carers and lung cancer patients tended to agree most on symptoms that patients rated as most distressing, according to their rank order of mean scores on McCorkle and Young's (1978) Symptom Distress Scale (SDS). Similarly, Lampic et al. (1996) and Miaskowski, Zimmer, Barrett, Dibble, and Wallhagen (1997) found that less perceptual congruence occurred on symptoms of patients who were experiencing the least amount of anxiety and pain, respectively. Other investigators have suggested that negative behavioural cues are more "attention-grabbing" and thus, are more closely monitored in the interactional context than cues that are more positive or neutral in nature, as implied by their higher levels of judgmental accuracy (e.g., Gaelick, Bodenhausen, & Wyer, 1985; Sillars, 1985; Thomas & Fletcher, 1997).

However, Lobchuk and colleagues (1997) also found that although patients reported low levels of distress arising from symptoms like appetite and nausea frequency, these symptoms also attained reasonable levels of agreement between patients and family caregivers. On the other hand, the degree of agreement was poor on outlook even though patients reported it as one of the most distressing symptom events. These authors offered that symptoms like appetite are behaviourally more distinct, observable, or concrete than other symptoms such as outlook which have less obvious behavioural referents in light of their more invisible and private nature. Therefore, symptoms like appetite are at less risk for a potentially biased interpretation or a hazardous 'imaginative' translation by the caregiver in comparison to symptoms that are more psychological in nature. Of course it is plausible that the 'readability' of the patient might impact empathic accuracy on highly threatening symptoms like 'outlook' in terms of the patient masking or not wanting to disclose his or her true feelings in an attempt to protect the family caregiver (Hancock & Ickes, 1996; Lobchuk et al., 1997). Regardless, it would appear that the physical or psychological nature of symptoms respectively influence the diagnosticity or expressed behaviour of symptom cues available to family caregivers.

Overall these findings suggest that the strength of the patient's symptom situation is represented by a complex set of symptom information. However, extant research has not been able to clearly discern whether it is the interactive or separate effects of the level of symptom experience and/or the nature of symptoms that influence the ability of family caregivers to reasonably estimate

the status of patients' experiences with symptom events. Further analysis is therefore required to explore the differential impact of not only the respective nature of symptoms, but also the level of negativity of symptom experience as expressed by patients' ratings of symptom frequency, severity, and distress on empathic accuracy.

Other authors have suggested that the strength of the situation (e.g., the extent of behavioural cues arising from symptoms) is necessary but not sufficient for data driven empathic accuracy (Thomas & Fletcher, 1997). This is particularly pertinent to the theoretical understanding of the concept of symptoms. Regardless of the presence of behavioural cues which might indicate the extent of patient symptom experience, it is widely acknowledged that symptoms are subjective phenomena that can only be conjectured or imaginatively understood by the family caregiver from the patient's perspective (Rhodes & Watson, 1987). The following findings suggest that the family caregiver goes beyond the behavioural data to successfully estimate the patient's internal thoughts and feelings. Lobchuk and colleagues (1997) found that although family caregivers described they relied on only a minimal amount of behavioural data to help them determine the amount of patient symptom distress, they still managed to achieve reasonable estimations of patients' symptom distress. Similarly in studies by Simpson, Ickes, and Blackstone (1995) and Thomas et al. (1997) it was found that dating couples' empathic accuracy in threatening situations was not related to the diagnosticity of the partner's behaviour during their interactions.

Thomas and Fletcher (1997) suggested that there may be certain intra-individual effects that interact with behavioural cues which promote observer empathic accuracy. For instance, even if the observer has all the behavioural data necessary to make an accurate judgment, he or she may lack the cognitive ability to combine these cues to accurately discern the target's viewpoint (Colvin et al., 1997). Dyadic perspective-taking dispositions are cognitively-derived intra-individual effects that might be partially influential on how the observer in specific social contexts is able to appropriately integrate behavioural cues in order to attain judgment accuracy. In terms of symptom assessment, it might be found that family caregivers who report a low disposition to dyadic perspective-take are not able to attain empathic accuracy on high levels of patient-reported symptom experience and on physical symptoms that are more behaviourally overt.

In summary, despite whether relevant behavioural cues are made available to and appropriately detected and utilized by the perceiver, it appears that individuals in close relationships do not base their judgments solely on face value information arising from cues that hint at another's thoughts and feelings. In intimate interpersonal circumstances, like the patient-family caregiver one, study findings suggest that behavioural symptom cues are not used in a straightforward fashion as a primary source which serves the basis for empathic judgments. It is plausible that patient behavioural cues are more accurately interpreted by caregivers who possess dispositions to engage in perspective-taking within the specific caregiving relationship. This notion remains largely unexplored in the area of family caregiver empathic accuracy on patient

symptom experience.

Empathic accuracy and the process of perspective-taking

One empathic process within interpersonal relationships that has been purported to assist, at least partially, observers in arriving at accurate cognitive and emotive representations of the target's situation is the exercise of perspective-taking. Besides being depicted as a trait, perspective-taking is also portrayed as a state or a process that denotes an option taken by observers to interpret another's thoughts and feelings, depending on the situation (Arriaga & Rusbult, 1998; Davis, 1994; Hoffman, 1984; Long & Andrews, 1990; Redmond, 1995). This process is viewed as an essential component in effective social interaction in daily life, where individuals are able to overcome a natural tendency to evaluate another individual's feelings, thoughts, and actions from a personal viewpoint, and comprehend the difference between oneself and others (Franzoi et al., 1985).

To further an understanding on what is meant by perspective-taking, it is helpful to visit Higgins's (1981) critical examination and theorization on the different dimensions of role - or perspective-taking. Although Higgins concurred that role-taking involves taking into consideration another's viewpoint when making judgments, this author argued that perspective-taking should be discussed in relation to one's ability to control one's own viewpoint when making judgments of others. In considering the ability to control competing viewpoints when making judgments of others' thoughts and feelings, Higgins argued that a distinction should be made between two different kinds of competing viewpoints -

those that are “situational” and those that are “individual” viewpoints.

Higgins (1981) defined situational role-taking as basing one’s judgment of others’ thoughts and feelings on one’s own personal experiences in the same situation or circumstances. Similar to Higgins’s definition of situational role-taking, the “use-of-self” as described by Redmond (1995) is a response to another’s situation by “drawing upon one’s own previous experiences in similar situations or by imagining what it would be like to be in that particular situation” (p. 38). Higgins further explained that situational role-taking is a type of “inferred similarity” where people assume that another person’s response would be the same as their own in the same situation. Generally it is understood that in situational role-taking the judge either does not differentiate oneself from another or does not adequately inhibit one’s own viewpoint when judging others.

On the other hand, judgments derived from individual role-taking are not based on one’s own experiences because the target person’s experiences in the same situation are not assumed to be the same. Rather, individual role-taking is involved when judgments are based on an inference about the target’s response in situations where the observer’s own viewpoint is salient and different from the target’s (Higgins, 1981). The following explains this definition more fully. First, when in the same situation as the target, the observer is challenged not only to compare his or her own characteristics and viewpoint with the target’s characteristics and viewpoint, but also to inhibit one’s own characteristics and viewpoint from interfering or becoming confused with the target’s characteristics and viewpoint (Higgins, 1981). In other words, the observer must be able to

keep his or her own characteristics and viewpoint in mind when trying to understand the target's viewpoint. Second, the observer has to correctly judge the target whose characteristics and viewpoint are different from one's own even if they are in the same situation. Overall, individual role-taking involves the avoidance of making egocentric errors when making inferences on another individual's viewpoint by not assuming the target's experience is similar to one's own.

Despite theorization that the role- or perspective-taking process is a major "cognitive underpinning" of accuracy outcomes, there is little systematic investigation on this relationship (Davis, 1994). Although strong evidence exists in literature on the linkage between perspective-taking processes and the various empathic outcomes of affective reactions, attributional judgments, and helping behaviours, it remains unclear if perspective-taking activities lead observers to make accurate judgments about others (Davis, 1994). Most investigators appear to assume that perspective-taking precedes empathic accuracy without understanding the process by which it is accomplished (Krauss and Fussell, 1996).

One approach that appears promising in examining the relationship between perspective-taking processes and empathic accuracy is the use of instructional sets which induce or manipulate a perspective-taking process in observers. Induced perspective-taking is the result of adopting an observation set that is characterized by a concern for another person's situation (Betancourt, 1990). Batson, Early, and Salvarani (1997) made the distinction between two

different ways of perceiving the other's situation - 'imagine-other' and 'imagine-self' perspective-taking. The 'imagine-other' instructional set entails imagining how the other person perceives the situation and how that person feels as a result (which is similar to Higgins's, 1981, depiction of individual role-taking). Responses to 'imagine-self' instructions depict how you would perceive the situation if you were hypothetically in the other's position and how you would feel as a result (which is similar to Higgins's description of situational role-taking).

Stotland (1969) pioneered these instructional sets and found that induced 'imagine-other' subjects were more other-oriented versus self-oriented in their physiological reactions in comparison to the induced 'imagine-self' subjects. Batson and colleagues (1997) conducted a related study with 60 general psychology students who were asked to respond to another's severe, unexpected physical distress. These authors found that the 'imagine-other' instructional set produced an other-oriented emotional empathic response (e.g., tender, warm, or compassionate feelings) and the 'imagine-self' instructional set reflected self-oriented aversive emotional responses of discomfort evoked by witnessing the plight of another (e.g., alarm, grief, or upset). Davis (1994) identified sixteen related studies that explored the effect of induced perspective-taking on empathic concern. Over eighty percent of these studies found that 'imagine-other' instructions evoked greater sympathy for the target than the 'neutral control' set instructions.

Similarly, investigations on the linkage between helping behaviours and induced perspective-taking supported the view that instructions to imagine the

target's affect trigger a process that ends in helping activities by the observer (e.g., Cialdini et., 1987; Coke, Batson, & McDavis, 1978; Dovidio, Allen, & Schroeder, 1990; Oswald, 1996). Davis (1994) described several studies in the area of attributional judgments as prototypes for investigations that utilize instructional sets, designed either to inhibit or promote perspective-taking in order to alter the perspective of the observer to one that is comparable to that of the target. Regan and Totten's (1975) and Galper's (1976) work provided evidence that when observers are induced to take the perspective of the target, their attributions changed from imputing the target's behaviour to internal causes (e.g., the target's traits) to attributing the target's behaviour to external causes (e.g., the target's situation) upon their observance of the 'imagine-other' instructional set. These results indicated that in comparison to 'neutral-control' conditions, 'imagine-other' instructions can reliably alter the perspective of the observer, such that observer attributions become more closely aligned with the target's attributional perspective (i.e., more situational than dispositional).

A related nursing study utilized the instructional set design to determine the viewpoint of nurses when they estimated the cancer patient's experience on anxiety (Lampic et al., 1996). Utilizing a methodology that was similar to Stotland's (1969) 'imagine-self' model, the content of Lampic et al.'s instructions was intended to induce nurses to engage in situational role-taking by imagining how they would feel if they were faced with the patient's disease themselves and were in (a) their own situation or (b) the patient's life situation. The nurse was not asked to "step into the patient's shoes", which would have entailed 'imagine-

other' instructions designed to induce individual role-taking. In being encouraged to reference one's own characteristics rather than the patient's characteristics, the nurse needed to consider only him- or herself in the same situation as the patient (i.e., situational role-taking as described by Higgins, 1981). Support was found for the effects of projection where a moderate correlation occurred between the nurses' significant overestimations on patient anxiety and the nurses' hypothetical assessment of their own anxiety if they had the patient's disease and were in the patient's life situation.

Lampic et al. (1996) concluded that these findings lend support toward Wright's (1983) empathic "requirement of mourning" in cancer care. The nurses believed that patients were more distressed than they really were because they reasoned that the patient felt as they hypothetically would in the same situation ("If I had cancer, I would be very anxious!"). Furthermore, according to this hypothesis, caregivers need to perceive patients as suffering in order to protect their own value systems that place an emphasis on health. Wright (1983) suggested that caregivers might insist that a loved one who is diagnosed with cancer must be suffering (even if they are not), because to believe otherwise means that he or she devalues the ill individual.

Overall, the study findings by Lampic and colleagues (1996) suggested that nurses were self-oriented and possessed a negative affect of the patient because they focussed more on their own imagined distress, thoughts, or feelings. These findings also implied that 'imagine-self' activities can pose certain hazards in terms of caregivers making assumptions that patients'

responses would be similar to their own responses. Furthermore, 'imagine-self' perspective-taking may interfere with the caregiver's ability to concentrate on the patient in order to obtain a real understanding of the patient's needs. Ultimately, perceptual incongruence may result.

In a related study, Davis, Hull, Young, and Warren (1987) conducted a unique multivariate analysis on the effects of dispositional and induced perspective-taking variables on the concordance of affective reactions in 144 male undergraduate psychology students. Utilizing Stotland's (1969) 'imagine-him', 'objective', and 'neutral control' instructional sets, these authors found that only individuals who were higher in dispositional perspective-taking responded to instructions to imagine the videotarget's feelings, which resulted in congruent emotional reactions to videotargets in comparison to the neutral control condition. Instructional sets did not have an effect on low perspective-takers. These authors suggested that those higher in dispositional perspective-taking most likely made more use of this capacity and therefore, were more inclined to respond to an explicit instruction to do so. By this study's design that utilized both measures of dispositional and induced perspective-taking, it was possible to make convincing statements about the joint effects of these two types of perspective-taking as depicted in Davis's (1994) empathy model. Future work in the area of empathic accuracy might find that high dyadic perspective-taking caregivers are likely to be more responsive to instructions to 'imagine-other' perspective-take. Ultimately, their estimates on patient symptom experience are likely to be more accurate than low dyadic perspective-taking caregivers.

In summary, most studies that explored the relationship between aspects of perspective-taking and empathic accuracy bypassed efforts to examine the actual cognitive processes that individuals engage in to perceive another's cognitive and emotive states. Although caregivers may report a tendency to perspective-take in a specific dyad situation, there is no guarantee that they utilize this capacity when making estimates of the patient's symptom experience. Differential instructional sets that induce perspective-taking can be employed to indirectly measure whether the family caregiver made a deliberate imaginative effort to take the patient's cognitive and/or emotive point-of-view. Instructional sets might also be used in a way that allows family caregivers to be credited with perspective-taking only when their responses predicted for the patient are different from their own responses to the situation. By comparing the respective relationships between family caregiver responses to the induced perspective-taking and the neutral control instructional sets, it might be possible to determine if the caregiver is influenced by a patient- or a self-oriented perspective.

Summary

A review of the literature pertinent to the study of symptom experience in advanced stage cancer patients has been presented. The symptoms of advanced stage cancer patients are multidimensional phenomena that require further explication in terms of family caregiver current perceptions and accurate symptom assessment. Research findings reveal that family caregivers provide reasonable current estimates on various symptom events, with only a slight trend to overestimate in comparison to the self-reports of patients. This has been

attributed to factors within the intimate patient-family caregiver relationship, such as perspective-taking, that may contribute to the close understanding by family caregivers of the patient's experience with symptoms.

Numerous studies in social psychology have been undertaken to examine the concept of perceptual congruence or 'empathic accuracy' and related aspects to perceptual congruence by observers on the target's experience. However, empiric nursing literature does not currently exist in terms of exploring the potential relationship between family caregiver perspective-taking and accuracy on patient symptom experiences.

It appears from this literature review that Davis's (1994) organizational model of empathy captures concepts reflective of those that potentially depict the patient-caregiver relationship and their influence on accuracy outcomes on patient symptom experience, thereby making this theoretical framework meaningful. For instance, family caregiver characteristics such as dyadic perspective-taking tendencies and characteristics of the symptom situation (e.g., the patient's report on total symptom experience) are hypothesized as antecedent variables that influence the family caregiver to arrive at empathic accuracy on patient symptom experience.

CHAPTER THREE

Methods

Given the paucity of research investigating the congruence of patient and family caregiver current perceptions on the patient's multidimensional symptom experiences, and the influence of perspective-taking on family caregiver empathic accuracy, a descriptive comparative survey with cross-sectional sampling was judged to be the most appropriate level of investigation to address the study questions.

Guided by the adapted organizational model of empathy by Davis (1994), this study was intended as an initial step in the process of systematically investigating the influence of various family caregiver and symptom situation characteristics on the family caregiver's current estimation of patient symptom experience. In addition, this study was designed to explore more precisely whether family caregiver current estimates on patient symptom experience are based on a self- or patient-oriented point-of-view. Finally, this study also attempted to explore whether a subgroup of family caregivers who overestimated on patient symptom experience can modify their level of empathic accuracy when they are induced to imagine the viewpoint of the patient.

Population, sample, and inclusion criteria

The population under scrutiny consisted of advanced stage cancer patients and family caregivers caring for these patients in the outpatient setting. Ninety-eight patient-family caregiver dyads comprised the sample for this study. Sample size was based on a power analysis for multiple regression. For six

independent variables, a sample of 98, alpha of .05, resulted in a power of 0.80 for an effect size of 0.13 (moderate effect) (Cohen, 1988).

To be included in the study, **patients** in the outpatient setting met the following criteria: (a) must be medically diagnosed with advanced stage cancer (Stage III or IV); (b) must be 18 years of age or older to qualify as an adult; (c) must be able to speak, read, and write the English language; (d) must be well enough to participate and give no evidence of mental confusion in his or her interactions with health care professionals, family, and the research nurse; and, (e) must be currently enrolled in a palliative home care program at either St. Boniface General Hospital, Grace General Hospital, or Riverview Health Center, or as an outpatient with CancerCare Manitoba, in the City of Winnipeg. The criteria for participation of **primary family caregivers** in this study included: (a) must be identified by the patient as being primarily involved in the care of the patient in the home setting (biological, legal, or functional relationships) and (b) must be able to speak, read, and write the English language.

Sample Recruitment Procedure

Written approval to conduct this study was obtained from the Ethical Review Committee, Faculty of Nursing at the University of Manitoba prior to implementation. Written approval to access subjects and medical records was sought from the Winnipeg Regional Health Authority, St. Boniface General Hospital, Riverview Health Centre, Grace General Hospital, and the Records and Registry Access Committee at CancerCare Manitoba. Verbal approval for the study from the Coordinators of the Palliative Home Care Programs at St.

Boniface General Hospital, Riverview Health Centre, Grace General Hospital, and the Director of Nursing at CancerCare Manitoba was granted. The following procedure for the recruitment of subjects was discussed with the respective Palliative Home Care Coordinators and Patient Care Managers, and the Director of Nursing, CancerCare Manitoba.

Recruitment of subjects from the home care setting

The investigator met with the respective Patient Care Managers and Home Care Coordinators of the Palliative Home Care Programs at St. Boniface General Hospital, Riverview Health Center, and the Grace General Hospital to explain the study. The Coordinators were provided with a list of inclusion criteria for patients and family caregivers who are eligible as participants in the study. The Home Care Coordinators provided patients and family caregivers with a letter requesting permission to release their names to the investigator as possible participants in the study (Appendix A). If the patient and family member did not wish their names to be released they contacted the respective Home Care Coordinators. The Home Care Coordinators then submitted to the investigator a list of names and telephone numbers of patients and primary family caregivers who had not called the Home Care Coordinators about not wanting the release of their names. The investigator then contacted patients and/or family caregivers by telephone and provided further information about the study. If the patients and family caregivers had agreed to participate, the investigator then scheduled a home visit at a date and time that was agreeable to the patient and primary family caregiver.

In addition, the Nurse Manager - Oncology/Palliative Care, Grace General Hospital verbally approved the display of a poster that described this research. This poster was prominently displayed in the waiting room area. Patients and family caregivers were invited to contact the investigator at the St. Boniface General Hospital, Cancer Nursing Research Group for more information about the study. In response to the poster's written invitation, only one family caregiver made telephone contact with the investigator over the seven month course of recruitment and data collection.

Recruitment of subjects from the in-patient setting

The investigator spoke with both the Liaison Nurse, St. Boniface General Hospital and the Patient Care Manager, Riverview Health Centre Palliative Care Units to explain the study and their role in facilitating access to the patient population. The following method was employed to recruit patients and family members in the respective inpatient settings. The Liaison Nurse and the Patient Care Manager were provided with a list of inclusion criteria for patients and family caregivers who were eligible as participants in the study.

St. Boniface General Hospital Palliative Care Unit. The Liaison Nurse had agreed to provide patients and family caregivers with a letter requesting permission to release their names to the investigator as possible participants in the study (Appendix B). If the patient and family caregiver wished their names to be released they would contact the Liaison Nurse. The Liaison Nurse agreed to then submit to the investigator a list of names and telephone numbers of patients and family caregivers who called her about giving their permission for the

investigator to contact them. The investigator would then contact patients and/or family caregivers by telephone and provide further information about the study. If the patients and family caregivers agreed to participate, the investigator would schedule a home visit at a date and time that was agreeable to the patient and the primary family caregiver. No patients or family caregivers were recruited at this in-patient setting.

Riverview Health Centre Palliative Care Unit. At discharge, the Patient Care Manager agreed to offer patients and their family caregivers a written invitation to speak with the investigator to discuss the study (Appendix C). On this written invitation, patients indicated whether they were willing to speak with the investigator so that she could make telephone contact with them upon discharge from the hospital. The investigator would then contact patients and family caregivers to describe the purpose of the study and elicit their voluntary participation. The investigator also explained that as part of the normal routine for all patients and family caregivers, the investigator will schedule a home visit on a one-time basis with them at the same time, and at a date and time that was convenient to them.

Recruitment of subjects from the clinical setting

The investigator met with the Director of Nursing and clinic nurses at CancerCare Manitoba to explain the study and their role in facilitating access to the patient population. It was agreed that the clinic nurse's role was to assist the investigator in recruiting patients and family caregivers from the respective

outpatient chemotherapy and radiation clinics in the City of Winnipeg. The following method was employed to recruit patients and family caregivers in the clinic setting.

On scheduled clinic days for the respective tumour type groups, the investigator met with clinic nurses who identified from the appointment lists and medical records, patients who met the inclusion criteria. Clinic nurses then approached the patients and their family caregivers (if present in the clinic), and offered them either a verbal or a written (Appendix D) invitation to speak to the investigator about the study. If the patient and/or family member agreed, then the nurse either provided the investigator with their names and telephone numbers or proceeded to have the investigator meet with them in the clinic, if the investigator was available. Either by way of telephone contact or a face-to-face meeting in the clinic with the patient and/or family caregiver, the investigator described the purpose of the study and elicited the patient's and the family caregiver's voluntary participation in the study. The investigator explained that as part of the normal routine for all patients and family caregivers, the investigator will schedule a home visit on a one-time basis with the patient and the family caregiver at the same time, and at a date and time that is convenient to them.

In addition, the Director of Nursing, CancerCare Manitoba verbally approved the display of a poster that briefly described the study and invited patients and family caregivers to contact the investigator to obtain more information about the study. This poster was displayed in the waiting and

treatment room areas at both the MacCharles and St. Boniface General Hospital Unit sites. However, the investigator was unsuccessful in recruiting patients and family caregivers from CancerCare Manitoba by this method of inviting participants to contact the investigator about the study.

Data Collection Protocol

Home care setting

Prior to the administration of questionnaire forms, the investigator provided a written consent to the patient (Appendix E) and a disclaimer to the primary family caregiver (Appendix F) in the home care setting. Once the consent and disclaimer were read and understood, the participants were asked to read the questionnaire instructions. After the participants verbalized an understanding of the procedure, they were instructed to complete the questionnaires. The investigator was available to answer any questions about the questionnaires and the study. The presence of the investigator was also necessary to ensure that the participants refrained from discussing their responses to survey items until after the questionnaires were returned to the investigator.

Clinic setting

If the patient and family caregiver agreed to participate, either they would ask the investigator to contact them at a later date to schedule a home visit or if convenient for them, patients and family caregivers would agree to complete their questionnaires while at the clinic. The investigator then provided a written consent to the patient (Appendix E) and disclaimer to the primary family

caregiver (Appendix F). Once the patient consent and family caregiver disclaimer were read and understood, the participants were asked to complete the questionnaires. Generally, when the questionnaires were completed in the clinic setting, staff accommodated the investigator by allowing patients and family caregivers to answer survey questions in a quiet clinic area. The investigator was available to answer any questions about the questionnaires and the study. The presence of the investigator was also necessary to ensure that the participants refrained from discussing their responses to survey items until after the questionnaires were returned to the investigator.

Instruments

Six types of measures were administered simultaneously to patients and family caregivers in this study. Prior to the administration of the patient questionnaire package, a formal mental status examination of the patient was administered by the investigator. The Folstein Mini-Mental Status Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) (see Appendix G) was administered to assure that data was collected from patients capable of responding reliably. Patients with scores greater than or equal to 24 of 30 were eligible to participate in the study. Similar cut-off scores on the MMSE were used in studies involving patients capable of responding reliably on self-reports of pain severity (e.g., Bruera, Fainsinger, Miller, & Kuhlen, 1992; Grossman et al., 1991). The patients then completed three questionnaires: the Patient Demographic Data Form (Appendix H), the MSAS (Appendix I), and the Other Dyadic Perspective-Taking Scale (Appendix J). These three forms were

completed within twenty to thirty minutes.

Family caregivers completed six measures in the following order: the Family Caregiver Demographic Data Form (Appendix K), the MSAS (Appendix L), the Self Dyadic Perspective-Taking Scale (Appendix M), and a set of three questions based on instructional sets designed to examine projection (Appendix N), 'imagine-self' perspective-taking (Appendix O), and 'imagine-other' perspective-taking (Appendix P) by the caregiver. It was important to administer the MSAS prior to the perspective-taking measures because its symptom scores provided the 'neutral control' set of responses that were compared with caregiver responses to differential induced perspective-taking instructional sets. These six measures were completed within twenty to thirty minutes.

Sociodemographic data on patients and family caregivers were elicited from patients and family caregivers. In instances of lack of clarity in demographic information (e.g., stage of illness, date of diagnosis, or type of treatment), chart review ensued for clarification and accuracy.

Dependent Variable

The central variable in this study was the degree of family caregiver empathic accuracy on patient symptom experience. Empathic accuracy was evaluated by computing the absolute value of the difference between family caregivers' and patients' total scale and subscale scores as measured on the MSAS (Appendices I and L). The MSAS is a patient-rated measure that provided multidimensional information on 32 physical and psychological symptoms characterized in terms of severity, frequency, and distress (Portenoy,

Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al., 1994). The MSAS has not been employed in a family caregiver study population.

The total MSAS score consisted of mean scores for all 32 symptoms across severity, frequency, and distress items. Separate four- or five-point Likert-type scales were created for these items and a response item is included that allows for the absence of a symptom. Higher values on the symptom items indicated more severity of the symptom, higher frequency with which the symptom occurred, and more distress that the symptom produced.

The MSAS has been tested with a heterogeneous group of cancer patients who were diagnosed primarily with metastatic disease (Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al., 1994), as well as with ovarian cancer patients (Portenoy, Kornblith, et al., 1994), breast cancer patients receiving chemotherapy (Ingham, Seidman, Yao, Lepore, & Portenoy, 1996), and patients diagnosed with AIDS (Breitbart, McDonald, Rosenfeld, Monkman, & Passik, 1998) and chronic obstructive pulmonary disease (Gift & Shepard, 1999).

The scoring of the MSAS also yields several subscale scores: a Physical Symptom subscale score (MSAS-PHYS) that includes the average of the frequency, severity, and distress associated with 12 prevalent physical symptoms - lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness; and, a Psychological Symptom subscale score (MSAS-PSYCH) that includes the average of the frequency, severity, and distress associated with six prevalent psychological symptoms - worrying, feeling sad, feeling nervous,

difficulty sleeping, feeling irritable, and difficulty concentrating. Summary scores may be supplemented by a description of separate subscale measures of the severity, frequency, or distress associated with MSAS symptoms (Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al., 1994; Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Kiyasu, et al., 1994).

Rigorous reliability and validity testing were reported with a sample of 218 heterogeneous cancer patients (Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al., 1994). Construct validity was established by the principal components factor analysis with varimax rotation that yielded two factors that distinguished three major symptom groups and several subgroups. The major groups comprised psychological symptoms (PSYCH), high prevalence physical symptoms (PHYS H), and low prevalence physical symptoms (PHYS L). Construct validity was also established by evaluating differences in symptom scores between inpatients and outpatients, and patients with early disease versus those with advanced disease. The internal consistency was high in the PHYS H and MSAS-PSYCH groups (Cronbach's alpha coefficients of 0.88 and 0.83, respectively), and moderate in the PHYS L group (alpha = 0.58). Approaches to evaluate the independence and importance of the three dimensions (frequency, severity, and distress) assessed by the MSAS included simple correlation coefficients, canonical correlation analyses, and multiple regression analyses. Criterion or concurrent validity was supported by high correlations with validation measures such as the Revised Rand Mental Health

Inventory, the Functional Living Index-Cancer, the Karnofsky Performance Status Scale, and the Symptom Distress Scale.

Although the MSAS was administered to patients generally by the research nurse, outpatients were allowed to take the MSAS package home or to complete the survey in the clinic setting (Portenoy, Kornblith, et al., 1994). According to the tool's authors, the MSAS was acceptable to participants in the study however additional analysis is required to determine respondent burden. Although the MSAS has not been tested in family caregiver populations, it appears that it might be easily adapted for use with family caregivers who must infer patient symptom experience.

Independent variables

Family caregiver characteristics. The family caregiver's level of education, length of time caring for the patient, and degree of acquaintance with the patient were derived from the investigator-developed demographic data form for family caregivers (Appendix K). The 'degree of acquaintance' was a composite score comprised of the average of three ratings on the family caregiver demographic data form: the extent to which the family caregiver assists the patient in coping with his/her medical condition and symptoms (Appendix K, Question #8), the family caregiver's perception on the degree of talking openly with the patient about the patient's symptoms (Appendix K, Question #9), and the family caregiver's reported degree of 'knowing' the patient's thoughts and feelings about his/her symptoms (Appendix K, Question #10). These are

'acquaintanceship factors' commonly surveyed in other response comparability studies on health-related quality of life issues (e.g., Epstein et al. ,1989; Magaziner et al., 1988; Rubenstein et al., 1984; Sneeuw et al., 1998).

This composite score was derived from a factor analysis on variables (Appendix K, Questions #8 to #11) purported in literature to depict the "degree of acquaintanceship" between the family caregiver and the patient. Results of the principal component analysis without rotation produced one factor (Question #11 or the amount of family caregiver contact with the patient) with an eigenvalue greater than 1.0. Efforts to interpret the factor analysis results in terms of substantive meaning revealed that the 'amount of contact with the patient' appeared to be more quantitative or objectively measurable in nature in comparison to the remaining three items (Questions #8 to #10) that required more subjective and interpretive responses by the family caregiver. Furthermore, the results of the bivariate correlational analyses revealed that the 'amount of contact with the patient' did not significantly correlate with any of the remaining three variables. However, these three variables revealed low to moderate positive correlations among each other ($r = 0.24$ to 0.38 ; $p \leq 0.05$).

Level of symptom experience. This variable was based on patient self-report and family caregiver assessment on patient symptom experience as measured on the total MSAS scale and on the separate subscales on symptom frequency, severity, and distress.

Symptom experience dimensions. This variable was derived from the separate subscale scores on frequency, severity, and distress as measured on

the MSAS.

Symptom nature. This variable was derived from the separate subscale scores for highly prevalent physical and psychological symptoms as measured on the MSAS, and from the separate MSAS symptom scores on the psychological symptom 'worrying' and the physical symptom 'lack of energy'.

Dyadic perspective-taking tendency. This variable was derived from the Dyadic Perspective-Taking Scale (DPT) which has two subscales (Long, 1987). The Self Dyadic Perspective-Taking Scale (SDPT) is a 13-item Likert-type scale that uses self-report to measure the caregiver's perspective-taking within the context of the patient-family caregiver relationship (Appendix M). The Other Dyadic Perspective-Taking Scale (ODPT) is a 20-item Likert-type scale that measures the patient's perception of dyadic perspective-taking by his or her caregiver (Appendix J). Responses were coded on five-point Likert-type scales ranging from *does not describe me (my caregiver) very well* (0) to *does describe me (my caregiver) very well* (4).

Reliability and validity were reported with a sample of 342 married couples (Long & Andrews, 1990). The items on the SDPT and ODPT were adapted from previous general perspective-taking measures (i.e., The Interpersonal Reactivity Index, The Relationship Inventory, The Hogan Empathy Scale, and The Peer Role-Taking Questionnaire). The alpha coefficient on the SDPT was 0.86 for husbands and 0.88 for wives. The alpha coefficient on the ODPT was 0.93 for husbands and 0.95 for wives. Convergent validity was supported by moderate correlations between general perspective-taking and SDPT scores for wives ($r =$

0.43; $p < 0.001$) and husbands ($r = 0.53$; $p < 0.001$). Factor analysis with varimax rotation was used to assess the validity of the items on the respective scales. Two interpretation factors with eigenvalues greater than one emerged in each of the two scales. Factor 1, the Strategies factor, delineated the attempts and strategies that the individual undertook to understand a partner better. Factor 2, the Cognizance factor, delineated an understanding and awareness of a partner's feelings, attitudes, and needs.

The DPT has been used in a variety of couple relationships, including college students who were either seriously dating or married (Long & Andrews, 1990), community-dwelling married couples who were the parents of students in human development and family studies classes (Long, 1990), and couples consisting of female patients who were diagnosed with chronic fatigue and immune dysfunction syndrome and patients' spouses (Goodwin, 1997). Although this tool has not been employed in the cancer patient population, it appeared to be an appropriate measure that can capture dyadic perspective-taking within the specific social context of patients and their family caregivers. In previous work that explored response comparability between cancer patients and their family caregivers on symptom events, the majority of the family caregivers were identified as the patient's spouse (e.g., Kristjanson et al., 1998; Kurtz et al., 1996; Lobchuk et al., 1997; Madison & Wilkie, 1995; McMillan, 1996; O'Brien & Francis, 1988; Yeager et al., 1995).

Induced perspective-taking. First, the 'neutral control' set variable effects were measured on the slightly reworded (for family caregiver use) MSAS

for 'lack of energy' and 'worrying' symptom items. In accordance with the standard instructions provided on the MSAS for 32 symptom items, family caregivers in the 'neutral control' set were not encouraged or prevented to engage in perspective-taking. The effects of the 'imagine-self' and 'imagine-other' perspective-taking instructional sets were measured on the MSAS symptom items, 'lack of energy' and 'worrying' (Appendices O and P). As an additional variable that might provide evidence that family caregivers are projecting their own negative feelings onto their estimates of patient symptom experience, a third instructional set was administered (Appendix N). Responses to all instructional sets were reported on the MSAS four-point Likert-type subscales for frequency and severity, and on the five-point Likert-type subscales for distress arising from the symptoms of 'lack of energy' and 'worrying'.

Pilot test

As part of the main study, a pilot test of the study protocol was conducted with 30 dyads of patients and family caregivers. This test was undertaken to evaluate any difficulties encountered in the accrual of subjects and to evaluate whether the 32-item, 5-point Likert-type MSAS is suitable for use with advanced stage cancer patients. None of the 30 patients and family caregivers found the procedure burdensome or had difficulty with reading or comprehending the information on the questionnaires. As a rule, the investigator assisted the patients in completing the MSAS. The investigator assisted most of the patients and only the caregivers who requested assistance in completing the MSAS.

A pilot test of the 'imagine-other' and 'imagine-self' instructional sets was

required to determine whether they can adequately serve as prompts that evoke family caregivers to engage in differential perspective-taking activities. A range of analytic strategies was conducted to examine levels of agreement and difference among the instructional sets (e.g., intraclass correlations, absolute differences, mean of directional differences, and standardized mean differences). In a sample of 30 dyads, the findings revealed that there were reliable differences in reported symptom experiences between the respective instructional sets.

Protection of human subjects

Written permission to conduct this study was obtained from the Ethical Review Committee, Faculty of Nursing at the University of Manitoba prior to implementation. Written permission from the Winnipeg Regional Health Authority, and the access committees at St. Boniface General Hospital, Riverview Health Centre, and Grace General Hospital to access patients and family caregivers, and patient's charts for data collection was obtained. Permission was also obtained from CancerCare Manitoba to access subjects and patients' medical records in instances of lack of clarity on illness and treatment-related information.

Only those subjects who voluntarily agreed to participate in the study were included. The investigator stressed that patients and family caregivers could withdraw at any time during the study with no effect on their care or treatment. A written explanation of the study was included in the consent for patients and disclaimer for family caregivers. The consent and disclaimer also contained a

written explanation that there are no risks or direct benefits associated with their participation in the study. However, findings from this study might be helpful to health professionals in providing information about how to improve the care they give to patients and family caregivers who are coping with symptom management in the community.

All information was gathered from the patients and their family caregivers themselves. Permission to access patients' charts was sought in the patient consent form for instances where a lack of clarity in demographic, illness, and treatment-related information existed. Demographic, illness, and treatment-related data was obtained to describe the sample and to determine if certain data items act as covariates with dependent variables.

Confidentiality of the information obtained in the questionnaires was guaranteed by the investigator. In any instance where demographic variables had a frequency lower than five, data were reported with larger group data to protect the anonymity of participants. A code number for each dyad pair of patients and family caregivers was assigned and written on all questionnaires. Participants were instructed not to write their names on the forms and were assured that no names will appear in reports of the study or in any future publications. The list connecting participants with code numbers will be kept separately under lock and key. The consent and disclaimer forms explained that the questionnaires will be securely locked up, and kept for seven to ten years and then destroyed. The investigator's advisor and dissertation committee (listed on the consent and disclaimer) will be the only other persons having

access to the data.

Data analysis

Descriptive Statistics

Data analysis included seven steps. Descriptive statistics such as frequency distributions, means, standard deviations, percentages, and confidence intervals were used to describe the overall sample characteristics in terms of sociodemographic, illness- and treatment-related variables, as well as patient symptom experience as reported by patients and family caregivers.

Reliability of the instruments

Internal consistency reliability of the MSAS and DPS instruments for the patients and family caregivers were analysed using Cronbach's alpha coefficient with a criterion of greater than or equal to 0.80 (Nunnally, 1978).

Analysis of research questions

The following analyses were based on the recommendations of Bland and Altman (1986), Chambers et al., (1998), Lee, Koh, and Ong (1989), Nelson et al. (1990), and Sneeuw et al. (1998) on preferable statistical techniques for evaluating patient-family caregiver response comparability. The aim of the current study was to explore broad patterns of levels of agreement within the intimate caregiving relationship without testing the precise effects of illness and treatment-related variables on symptom experience.

These authors concurred that it may not be possible to come to a conclusion on agreement using a single method for measuring a quantitative variable as being interchangeable with another quantitative variable. Although a

similarity of mean results is often used to support agreement at the aggregate level, it does not necessarily indicate individual-subject agreement (as might be better indicated by chance corrected correlation analysis). For instance, although two methods might show similar mean values, it does not necessarily imply good and consistent individual agreement. A comparison based solely on means is relevant only to assess for possible constant bias where either family caregivers or patients tend to give higher ratings than the other.

Therefore, this study employed a range of techniques that consisted of individual (levels of agreement) and group levels of analysis (presence and magnitude of systematic differences) to test for agreement between patient and family caregiver responses. The normality of data was evaluated using a normality probability plot and the Kolmogorov-Smirnov goodness of fit test. Statistical analyses were carried out using SPSS Base 9.0. Statistical significance was set at the $p \leq 0.05$ level.

A range of analyses was employed to explore the response comparability between patients and family caregivers on the MSAS items. First, to determine differences between categorical data, the paired Chi squared test or **McNemar's test** was conducted. To test agreement between categorical data on the MSAS scale, **Cohen's Kappa statistic** was calculated. Cohen's Kappa is a measure of agreement that allows you to compare the ratings of two observers for the same group of objects (Norusis, 1994). Kappa allows correction to be made for the amount of agreement expected by chance. The following guidelines were used to evaluate the relative strength of agreement associated with Kappa statistics

for individual MSAS items (Landis & Koch, 1977). These are guidelines commonly employed in related response comparability studies (Blazeby et al., 1995; Kristjanson et al., 1998; Lobchuk et al., 1997; Magaziner et al., 1996; Wyller et al., 1996).

Kappa Statistic	Strength of Agreement
< 0.00	Poor
0.00 - 0.20	Slight
0.21 - 0.40	Fair
0.41 - 0.60	Moderate
0.61 - 0.80	Substantial
0.81 - 1.00	Almost perfect

Second, due to the non-normal distribution and ordinal nature of patient and family caregiver data, data analyses included **intraclass correlation coefficients (ICC)** to test the strength of associations and to adjust for chance agreement on MSAS scale scores (Nelson et al., 1990). This correlation coefficient served to reflect the caregiver's ability to successfully detect variation in the patient's standing on symptom experience. The ICC is sensitive to systematic differences in mean levels of responding (e.g., cases where every individual's score differs by a constant) (Marshall, Hays, & Nicholas, 1994). The following guidelines were used to evaluate the relative strength of agreement associated with ICC statistics for total and individual MSAS items

(Landis & Koch, 1977).

ICC statistic	Strength of Agreement
≤ 0.41	Poor to fair
0.41 - 0.60	Moderate
0.61 - 0.80	Good
0.81- 1.00	Excellent

As an additional correlational measure on ordinal patient and family caregiver data, Spearman rank correlational analyses were conducted (not reported) and determined as comparable to the ICC results. A comparison of ICC correlations among instructional sets was also conducted by using the z statistic (z) (Volicer, 1984).

Third, **Wilcoxon matched-pairs signed rank tests** examined the degree of difference in group mean responses to ordinal MSAS items. For ease of interpretation, the mean directional difference scores (patient minus caregiver ratings) as determined by paired Student's t-tests were reported. Fourth, the **mean directional difference scores were standardized** by relating these scores to their standard deviations to interpret the size of observed differences. Although the MSAS scores were markedly non-normal, the standardized mean difference scores were presented for comparison with other study results and because their use is widespread in the health literature. The following guidelines by Cohen (1988) for effect size (*d*) calculations on paired observations were

employed:

Standardized difference (<i>d</i>)	Amount of Bias
0.2	Small
0.5	Moderate
0.8	Large

Fifth, as a measure of family caregiver empathic accuracy, **discrepancy variables** were created by calculating the absolute difference between group ratings on symptom experience item scores (i.e., irrespective of the direction of difference). As the empathic accuracy scores were derived from the same group of patients and family caregivers in each of the four instructional sets, the observations were not independent of one another. Therefore, the **Friedman's test** was used to compare the mean empathic accuracy (discrepancy) scores among the respective instructional set conditions. This test is the non-parametric alternative to a repeated analysis of variance test and is based on ranks within each case. Group one consisted of the empathic accuracy scores for family caregivers who responded to 'neutral control' instructions. Group two consisted of the empathic accuracy scores for family caregivers who responded to 'self-report' instructions. Groups three and four consisted of empathic accuracy scores for family caregivers who responded to 'imagine-self' and 'imagine-other' perspective-taking instructions, respectively. Based on the significance of the Friedman's test, Wilcoxon matched pairs signed rank test was used for

subsequent comparisons between groups with appropriate Bonferroni correction.

Sixth, **bivariate correlational analyses** were used to determine the extent and direction of separate relationships between the respective antecedent variables (i.e., patient-reported level of symptom experience, family caregiver level of education, family caregiver length of time caring for the patient, family caregiver degree of acquaintance with the patient, and family caregiver levels of self and other dyadic perspective-taking) and empathic accuracy scores on symptom experience items. Sociodemographic variables for patients and family caregivers (e.g., age, gender, and residence of the caregiver), illness (e.g., stage of disease and time since diagnosis), and treatment-related variables (e.g., type of treatment) were added to the correlation matrix to identify any relationship between these factors and empathic accuracy. To include nominal level variables (e.g., gender) in the respective multiple regression models, dummy codes were created.

The seventh step entailed analyses that was designed to test the postulated relationships in accordance with Davis's (1994) adapted empathy model. A series of **simultaneous regression models** were developed to determine which variables served as the best predictors of a number of criterion variables related to family caregiver empathic accuracy on MSAS symptom experiences.

Summary

This chapter outlined the methods that were used to carry out a comparative descriptive study aimed at exploring accuracy in family caregivers'

current perceptions on patient multidimensional symptom experience and the influence of perspective-taking instructional sets on caregiver empathic accuracy.

The theoretical framework in this study was used to examine the relationship between family caregiver and symptom situation characteristics, and family caregiver empathic accuracy on patient symptom experience. Based on previous studies conducted by researchers in social psychology, the independent variables of perspective-taking processes were manipulated by the investigator to assess congruency of perceptions. Associations at the individual-level and differences at the group-level on MSAS scores were explored where differential instructional sets, symptom dimensions, symptom nature, and patients and family caregivers represented different positions of the independent variable. Research questions explored outcomes among the groups and were based on scant theoretical knowledge that existed on perspective-taking influences on family caregiver current perceptions of patient symptom experience.

A formal mental status examination, ordinal scales, and demographic data forms were used to collect the data. Results of reliability and validity assessments for the MSAS, ODPTS, and SDPTS were discussed indicating that psychometric criteria were met. The subject criteria and data collection protocol were discussed. The data analysis plan was described that aimed to answer the questions, "What is the degree of family caregiver empathic accuracy on the multidimensional symptom experience of advanced stage cancer patients?", "What factors affect the degree of empathic accuracy by family caregivers?", "Are family caregiver perceptions on patient symptom experience related to a

self- or a patient-oriented viewpoint?”, and “Can a subgroup of family caregivers who overestimate achieve enhanced empathic accuracy (lower discrepancy) on patient symptom experience when they are induced to imagine the viewpoint of the patient?”. The procedure for assuring subject protection was also described.

CHAPTER FOUR

Results of data analyses

The purpose of this study was to:

1. To examine the degree of family caregiver empathic accuracy on the multidimensional symptom experience of advanced stage cancer patients.
2. To identify factors affecting the degree of empathic accuracy by family caregivers on patient symptom experience.
3. To explore whether family caregivers' current perceptions on patient symptom experience are related to a self-oriented or a patient-oriented viewpoint.
4. To explore whether induced perspective-taking can assist family caregivers who overestimate to achieve a more accurate symptom assessment on the cancer patient's symptom experience.

This chapter describes the characteristics of both the patient and the family caregiver samples and reports on the reliability of instruments with each group. Statistical analysis of the research questions is presented in conjunction with a report of the major findings.

Data for this study was collected over a seven month period between January and August 2000. Sites for recruitment of subjects in this study included: the Grace General Hospital Palliative Home Care Program, the St. Boniface General Hospital Palliative Home Care Program, the Riverview Health Centre Palliative Home Care Program, Riverview Health Centre Palliative Care Unit, the St. Boniface General Hospital Palliative Care Unit, and the Cancer Care

Manitoba radiotherapy and chemotherapy outpatient departments at the St. Boniface General Hospital and MacCharles units in the City of Winnipeg. Data collected from each of the participants included the Memorial Symptom Assessment Scale, the Dyadic Perspective-Taking Scales, and demographic data questionnaires. The investigator completed the Folstein Mini-Mental Status Examination for each participating patient. Family caregivers were requested to complete the differential perspective-taking instructional set questionnaires. The computer package SPSS Base 9.0 for Windows was utilized to analyse the results.

Description of the samples

Demographic Characteristics of Patients

A total of 186 patients was approached for participation in the study. Ninety-eight patients were included as participants. Eighty-eight patients were not surveyed for numerous reasons (see Table 4). The most frequently cited reasons for refusal were, "it's not the right time for me to do a study," "I don't feel appropriate for the study," and "I am not interested."

Thus, a convenience sample of 60 (61%) women and 38 (39%) men comprised the patient population for this study (see Table 5). Ages ranged from 35 years to 86 years ($M = 65$, $S.D. = 11.8$). Seventy-four (76%) of the patients were married. The length of the patient's relationship with the family caregiver was reported on average as 28 years ($S.D. 16.2$) by patients. The majority of the

Table 4

Reason for non-participation of patients/family caregivers (n = 88)

Reason	Number of Dyads
A. Recruitment difficulty	
- Patient too ill - admitted to hospital	15
- Wrong diagnosis for study	10
- Language Barrier	1
- Cognitive inability	1
B. Refusals	61
TOTAL	88

Table 5

Characteristics of the Patient Sample

Characteristic	# of Patients	Percent
Age (years)		
Mean (\pm S.D.)	64.73 \pm 11.81	
Range	35 to 86	
Marital status		
Single	2	2.0%
Married/common-law	74	75.5%
Divorced/separated	5	5.1%
Widowed	17	17.3%
Total	98	100.0%
Gender		
Female	60	61.2%
Male	38	38.8%
Total	98	100.0%
Tumour type		
Breast	17	17.3%
Prostate	5	5.1%
Lymphoma	3	3.1%
Gastrointestinal	23	23.5%
Lung	22	22.4%
Gynecological	19	19.4%
Urinary Tract	6	6.1%
Central Nervous System	1	1.0%
Unknown	2	2.0%
Total	98	100.0%
Time since diagnosis (months)		
0-9	43	43.9%
10-18	13	13.3%
19-36	10	10.2%
>36	32	32.7%
Total	98	100.0%

(table continues)

Table 5 continued

Characteristic	# of Patients	Percent
Current treatment		
none	50	51.0%
chemotherapy	41	41.8%
radiotherapy	10	10.2%
other	2	2.0%
Past treatment		
none	14	14.3%
chemotherapy	44	44.9%
radiotherapy	49	50.0%
other	1	1.0%
surgery	70	71.4%
Receiving nursing service		
Yes	23	23.5%
No	75	76.5%
Total	98	100.0%
Length of nursing service (weeks)		
Mean	1.11 weeks	
Range	0-13 weeks	
Ethnicity		
Canadian	59	60.2%
British Isles	3	3.1%
U.S.A.	1	1.0%
French	1	1.0%
German	2	2.0%
Russian/Ukrainian	3	3.1%
Aboriginal	1	1.0%
Jewish	4	4.1%
Other	1	1.0%
None	23	23.5%
Total	98	100.0%

(table continues)

Table 5 continued

Characteristic	# of Patients	Percent
Occupational status		
full-time	7	7.1%
part-time	4	4.1%
retired	59	60.2%
unemployed	9	9.2%
medical leave	19	19.4%
Total	98	100.0%
Occupation		
professional	22	22.4%
high level management	10	10.2%
low level management	17	17.3%
semi-skilled	22	22.4%
farm labourer	5	5.1%
homemaker	21	21.4%
other	1	1.0%
Total	98	100.0%
Annual family income		
below \$10,000	8	8.6%
\$10,000 - 20,000	19	20.4%
\$21,000 - 30,000	13	14.0%
\$31,000 - 40,000	18	19.4%
\$41,000 - 50,000	14	15.1%
\$51,000 - 60,000	7	7.5%
\$61,000 - 70,000	6	6.5%
>\$71,000	8	8.6%
Unsure	2	2.0%
Refused	3	3.1%
Total	98	100.0%
Educational level		
Some secondary/high school	48	49.0%
Completed secondary/high school	15	15.3%
Some community college	7	7.1%
Completed community college	11	11.2%
Some university	11	11.2%
Bachelor	5	5.1%
Refused	1	1.0%
Total	98	100.0%

(table continues)

Table 5 continued

Characteristic	# of Patients	Percent
Religiosity		
No preference	19	19.4%
Anglican	10	10.2%
Greek Orthodox	2	2.0%
Jewish	3	3.1%
Lutheran	6	6.1%
Mennonite	4	4.1%
Pentecostal	3	3.1%
Presbyterian	6	6.1%
Roman Catholic	18	18.4%
United Church	20	20.4%
Other	6	6.1%
Refused	1	1.0%
Total	98	100.0%

patients (n = 59, 60%) identified their ethnic affiliation as being Canadian; 23 (24%) reported no ethnic affiliation. Fifty-nine patients (60%) were retired. Twenty-two (22%) reported that they were employed (either past or present) as professionals; twenty-two (22%) were employed as semi-skilled or unskilled labourers; and, twenty-one (21%) were homemakers. Forty-eight (49%) reported having some secondary education or high school. Of 93 patients who reported their income, 58 (59%) reported an annual family income of less than \$40,000 per year. Twenty (20%) patients reported their religion as being United Church, 19 (19%) reported "no preference", and 18 (18%) were Roman Catholic. Of the 23 (24%) patients who reported receiving nursing care in the home, the length of home care ranged between less than one week and 13 weeks at the time of survey. The mean Mini-Mental Status Examination score for the entire group was 29 (S.D. 1.30), which is considered to be in the unimpaired range (Folstein et al., 1975). Patients with scores greater than or equal to 24 of 30 were eligible to participate in the study.

Primary diagnosis and time since initial diagnosis were noted to ascertain disease-related information. Diagnoses were grouped into nine categories and are described in Table 5. The most common malignancies were gastrointestinal (n = 23; 24%), lung (n = 22; 22%), gynecologic (n = 19; 19%) and breast (n = 17; 17%) cancer. Forty-three (44%) percent lived with the diagnosis for less than or equal to nine months and thirty-two (33%) lived with the diagnosis of cancer for more than 36 months. Treatment-related information included past and present cancer therapies and is also presented in Table 5.

The majority of the patients (n = 84; 86%) had received treatment in the past. Forty-four (45%) reported having received chemotherapy, 49 (50%) received radiotherapy, and 70 (71%) had surgery in the past. Of the patients who reported receiving current treatment (n = 48; 49%), most were receiving chemotherapy.

Based on 1995 Canadian Cancer Statistics, this patient sample was representative with respect to primary diagnosis, except that prostate cancer (5.1%) was somewhat under-represented (12%; National Cancer Institute of Canada [NCIC], 2000) and gynecological (19.4%) and lung (22.4%) cancers were over-represented (6% and 16%, respectively; NCIC, 2000). In accordance with new case estimates for the year 2000 for all sites combined, 70% will occur in those aged 60 years of age or more (NCIC, 2000). These estimates are comparable to this sample where 64% (63 of 98) of new cases occurred in those aged 60 years of age or more. In terms of gender for this sample, female patients (61.2%) were over-represented (48%; NCIC, 2000) and male patients (38.8%) were under-represented (52%; NCIC, 2000).

Demographic characteristics of primary family caregivers

A convenience sample of 70 (71%) women and 28 (29%) men comprised the primary family caregiver population for the study (see Table 6). The majority were less than 60 years of age (n = 58; 60%). Thirty-eight (39%) family caregivers reported their ethnicity as being Canadian and 32 (33%) reported no ethnic affiliation. Forty-one (42%) were retired and 42 stated they were employed either full-time (n = 29; 30%) or part-time (n = 13; 13%). Of the

Table 6

Characteristics of the Family Caregiver Sample

Characteristic	# of Family Caregivers	Percent
Age (years)		
Mean (\pm sd)	55.95 \pm 13.09	
Range	24-85 years	
Marital status		
Single	8	8.2%
Married/common-law	87	88.8%
Divorced/separated	3	3.1%
Total	98	100.0%
Gender		
Female	70	71.4%
Male	28	28.6%
Total	98	100.0%
Ethnicity		
Canadian	38	38.7%
British Isles	6	6.1%
French	1	1.0%
German	5	5.1%
Norwegian	2	2.0%
Polish	1	1.0%
Russian/Ukrainian	4	4.1%
Asia Oceanic	1	1.0%
Aboriginal	2	2.0%
Jewish	3	3.1%
Other	3	3.1%
None	32	32.7%
Total	98	100.0%
Occupational status		
full-time	29	29.6%
part-time	13	13.3%
retired	41	41.8%
unemployed	11	11.2%
medical leave	3	3.1%
student	1	1.0%
Total	98	100.0%

(table continues)

Table 6 continued

Characteristic	# of Family Caregivers	Percent
Occupation		
professional	34	34.7%
high level management	8	8.2%
low level management	22	22.4%
semi-skilled	15	15.3%
farm laborer	1	1.0%
homemaker	15	15.3%
other	3	3.1%
Total	98	100.0%
Duration of caregiving (months)		
0 - 9	50	51.0%
10-18	16	16.3%
19-36	8	8.2%
>36	24	24.5%
Total	98	100.0%
Degree of assistance		
Never assist	1	1.0%
Rarely	4	4.1%
Sometimes	21	21.4%
Frequently	27	27.6%
Always assist	45	45.9%
Total	98	100.0%
Degree of communication about symptoms		
Never	1	1.0%
Rarely	9	9.2%
Sometimes	23	23.5%
Frequently	33	33.7%
Usually	32	32.7%
Total	98	100.0%
Degree of perceived knowing patient thoughts and feelings re: symptoms		
Totally not at all	1	1.0%
Not very well	2	2.0%
Have some knowledge	19	19.4%
Adequate	33	33.7%
Very well	43	43.9%
Total	98	100.0%

(table continues)

Table 6 continued

Characteristic	# of Family Caregivers	Percent
Degree of contact with patient		
Daily, I live with patient	79	80.6%
Daily, I do not live with patient	12	12.2%
>weekly, I don't live with patient	3	3.1%
weekly, I don't live with patient	3	3.1%
<weekly, I don't live with patient	1	1.0%
Total	98	100.0%
Relationship to patient		
wife	38	38.8%
husband	25	25.5%
parent	2	2.0%
daughter	19	19.4%
son	2	2.0%
sister	4	4.1%
friend	2	2.0%
other	6	6.1%
Total	98	100.0%
Educational level		
Some elementary	1	1.0%
Finished elementary	3	3.1%
Some secondary/high school	21	21.4%
Completed secondary/high school	21	21.4%
Some community college	7	7.1%
Completed community college	11	11.2%
Some university	13	13.3%
Bachelor	17	17.3%
Master	1	1.0%
Ph.D.	2	2.0%
Missing	1	1.0%
Total	98	100.0%

(table continues)

Table 6 continued

Characteristic	# of Family Caregivers	Percent
Religiosity		
No preference	10	10.2%
Anglican	13	13.3%
Baptist	1	1.0%
Greek Orthodox	1	1.0%
Jewish	3	3.1%
Lutheran	8	8.2%
Mennonite	4	4.1%
Pentecostal	3	3.1%
Presbyterian	3	3.1%
Roman Catholic	20	20.4%
United Church	20	20.4%
Other	11	11.2%
No reply	1	1.0%
Total	98	100.0%

employed family caregivers, 34 (35%) stated they were employed in a professional field and 22 (22%) stated they were employed in low level management, skill crafts, trades, or technical fields. Twenty-one (21%) reported that they completed some secondary/high school and 21 (21%) reported that they had completed secondary/high school. Forty patients had reported their religion as either Roman Catholic (n = 20; 20%) or United Church (n = 20; 20%). Eighty-seven (89%) family caregivers stated that they were married.

In terms of the caregiving situation variables, 50 family caregivers (51%) reported that they cared for the patient between zero and nine months. Sixty-five (66%) family caregivers stated that they either “frequently” or “usually” talked openly with the patient about what the patients’ thoughts and feelings are in regard to their symptoms . Seventy-six (78%) stated that they either had an “adequate” or a “very well” perception of knowing how the patient thinks and feels about his or her symptoms. Seventy-nine (81%) stated that they lived with the patient. Sixty-three (64%) stated they were the patient’s spouse. Seventy-two (74%) stated they either “frequently” or “always” assisted the patient in coping with his or her medical condition and symptoms.

Overall, in comparing the patient and family caregiver groups on demographic characteristics, family caregivers were slightly younger than patients. Both patient and family caregiver groups were comprised mainly of females and the majority of dyad members were either married to or in a common-law relationship with one another. While most patients (60%) reported their ethnicity as Canadian, 39% family caregivers reported their ethnic origin as

Canadian. While a majority of patients (60%) reported their occupational status as being retired, an equal number of family caregivers reported either being retired (n = 41; 42%) or employed part-time or full-time (n = 42; 43%).

Instrument Reliability

Internal consistency reliability of the MSAS subscales and the ODPT and SDPT subscales were estimated for both the patient and the family caregiver groups using Cronbach's coefficient alpha. The criterion for adequate reliability was established at 0.80 (Nunnally, 1978). Interestingly, Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al. (1994) did not report on the internal consistency reliability of the total MSAS scale across 32 symptom items.

The internal consistency estimates on the MSAS high prevalence physical symptom subscale were 0.93 and 0.94 for patients and family caregivers, respectively. The reliability coefficient of 0.93 on the MSAS physical symptom subscale for this study's sample of patients was somewhat higher compared to Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al.'s (1994) finding of 0.88 for their patient group. The Cronbach's alpha for the MSAS psychological symptom subscale was 0.93 for patients and 0.94 for family caregivers. Again, the reliability coefficient of 0.93 on the MSAS psychological symptom subscale for this study's sample of patients was somewhat higher compared to Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al.'s (1994c) finding of 0.83 for their patient group. This is the first study to report the reliability of the MSAS in a family caregiver sample.

In the current study, the internal consistency reliability for the ODPT subscale as endorsed by advanced stage cancer patients was 0.93. This alpha coefficient is similar to Long's (1990) findings of 0.93 and 0.95 for his healthy husband and wife subgroups, respectively. Likewise, Goodwin (1997) reported in her sample of women with chronic fatigue and immune dysfunction syndrome and their husbands that the alpha coefficient for the ODPT was 0.94 and 0.96, respectively. The alpha coefficient for the SDPT subscale as endorsed by family caregivers in this study was 0.86. This coefficient is similar to Long's findings of 0.86 and 0.88 on the SDPT, for his respective husband and wife subgroups. Goodwin also found the SDPT to have alpha coefficients of 0.87 and 0.90 for her respective sub-samples of women and their husbands.

Normality of MSAS and DPTS item distributions

Using the Statistical Package for the Social Sciences (Procedure Examine; SPSS, Chicago, Illinois, USA), normality plots revealed the following about the distributions of MSAS items. First, the patient total MSAS scores were not normally distributed, with a kurtosis of 10.07 and skewness of 6.25. A Kolmogorov-Smirnov (Lilliefors Significance Correction) test gave $p = 0.02$. The family caregiver total MSAS scores were shown to be normally distributed with a kurtosis of 1.65 and skewness of -1.20. A Kolmogorov-Smirnov (Lilliefors Significance Correction) test gave $p = 0.84$. In addition, for each underlying dimension of frequency, severity, and distress across 32 MSAS items, the distributions remained non-normal despite logarithmic and square root transformations. Discrepancy scores between patients and family caregivers on

MSAS items also remained non-normal in accordance with the Kolmogorov-Smirnov test.

The ODPT results were shown to have a normal distribution, while having a kurtosis of -0.51 and a skewness of -1.39, and gave $p = 0.20$ on the Kolmogorov-Smirnov (Lilliefors Significance Correction) test. The SDPT had a kurtosis of -1.69 and a skewness of -1.51, and gave $p = 0.05$ on the Komogorov-Smirnov (Lilliefors Significance Correction) test. Overall, non-significant Kolmogorov-Smirnov test results indicated that the family caregiver MSAS scores, the ODPT, and the SDPT results did not differ from a normal distribution. A decision was made however to use the appropriate non-parametric analyses to explore associations and differences between the patients' and family caregivers' ordinal ratings on the MSAS and the Dyadic Perspective-Taking Scales.

Research Question #1

What is the prevalence, frequency, severity, and distress of 32 MSAS symptoms in a sample of advanced stage cancer patients as reported by patients themselves and as perceived by their family caregivers?

Descriptive statistics were used to analyse the prevalence and characteristics of symptoms measured on the MSAS as reported by the respective patient and family caregiver groups and are summarized in Table 7. In addition to patient and caregiver reports on the presence of symptoms in the past week, the following percentages are reported: for severity, the percentages are based on patients and family caregivers who reported it was moderate (score of 2) to very severe (score of 4); for frequency, the percentages are based on

Table 7

Prevalence and characteristics of MSAS symptoms in cancer patients by patients and family caregivers

Symptom	Overall prevalence Patient %	Overall prevalence Caregiver %	Severity Mod-VSev* (%) Patient	Severity Mod-VSev* (%) Caregiver	Frequency Freq-Cont (%) Patient	Frequency Freq-Cont (%) Caregiver	Distress QB-VM‡ (%) Patient	Distress QB-VM‡ (%) Caregiver
Lack of energy	76.5	89.8	60.2	76.5	50.0	58.2	29.6	36.7
Pain	66.3	73.5	51.0	60.2	34.7	39.8	27.6	34.7
Feeling drowsy	61.2	72.4	49.9	53.1	39.8	33.7	25.5	12.2
Dry mouth	57.1	42.1	37.8	24.2	30.6	18.9	7.1	7.4
Worrying	52.0	82.5	41.8	66.0	25.5	35.1	14.3	21.6
Feeling irritable	51.0	60.2	10.2	33.7	15.3	14.3	13.3	6.1
Feeling sad	49.0	75.3	35.7	58.8	13.3	28.9	13.3	17.7
Difficulty sleeping	46.9	66.0	39.2	48.5	24.5	37.1	19.6	28.9
Lack of appetite	46.9	55.1	36.7	37.8	25.5	24.5	9.2	12.2
Cough	45.9	60.2	25.5	36.7	16.3	22.4	7.1	7.1
Nausea	41.8	41.2	19.4	24.7	13.3	15.5	7.1	15.5
Shortness of breath	41.8	54.1	29.6	32.7	17.3	16.3	13.3	11.2
Numbness/tingling in hands/feet	39.8	34.4	26.5	22.9	19.4	16.7	12.2	10.4
Itching	38.8	34.0	22.4	17.5	25.5	9.3	6.1	5.2
Feeling nervous	38.8	63.9	29.6	44.3	10.2	17.5	11.2	13.4
Feeling bloated	32.7	34.0	24.5	21.6	12.2	11.3	5.1	8.2
Change in the way food tastes	32.7	31.6	18.4	21.4	NE	NE	5.1	5.1
Difficulty concentrating	31.6	56.1	15.3	25.5	8.2	10.2	12.2	11.2
"I don't look like myself"	31.6	35.7	22.4	22.4	NE	NE	14.3	14.3
Constipation	30.6	40.6	21.4	24.0	NE	NE	7.1	17.7
Sweats	30.6	29.6	19.4	19.4	12.2	11.2	4.1	3.1
Dizziness	26.5	30.6	7.1	11.2	6.1	6.1	5.1	3.1
Swelling of arms or legs	23.5	33.7	17.3	21.4	NE	NE	7.1	8.2
Weight loss	23.5	32.7	10.2	15.3	NE	NE	2.0	6.1
Diarrhea	21.4	30.9	11.2	16.5	4.1	8.2	7.1	8.2
Problems with sexual interest or activity	18.4	31.5	13.3	21.7	10.2	15.2	8.2	7.6
Hair loss	17.3	23.5	12.2	16.3	NE	NE	6.1	5.2
Changes in skin	17.3	27.6	15.3	14.3	NE	NE	3.1	4.1
Problems with urination	13.3	21.9	7.1	7.3	5.1	3.1	2.0	3.1
Mouth sores	13.3	17.3	10.2	9.2	NE	NE	4.1	6.1
Difficulty swallowing	13.3	24.5	7.1	10.2	4.1	5.1	1.0	1.0
Vomiting	12.2	15.3	9.2	11.2	3.1	5.1	4.1	8.2

* Percentage moderate to very severe; †percentage frequently to constantly; ‡percentage quite a bit to very much; NE, not evaluated.

patients and family caregivers who reported it was frequent (score of 3) to almost constantly (score of 4); and, for distress, the percentages are based on patients and family caregivers who reported it was quite a bit (score of 3) to very much (score of 4). Frequency was not relevant for eight symptoms (e.g., hair loss). For these symptoms only severity and distress were assessed.

Prevalence

Patients (n = 98) and family caregivers (n = 98) were asked to reply to the response option “did not have” for each of the 32 MSAS symptom items during the prior week. Asked in this manner, the mean (\pm S.D.) number of patient symptoms as reported by the patient was 11.4 ± 6.06 and the range was zero to 26. The mean (\pm S.D.) number of patient symptoms as reported by family caregivers was 14.12 ± 6.86 and the range was zero to 31, which was significantly higher than the patient's report ($t = -4.539$, $df = 97$, $p = 0.00$).

The most prevalent symptoms that patients reported they experienced during the prior week were: lack of energy (experienced by 76.5% of the patients), pain (66.3%), and feeling drowsy (61.2%). Family caregivers reported the most prevalent symptoms for patients similarly as lack of energy (89.8%), worrying (82.5%), and feeling sad (75.3%). They over-reported the prevalence on 26 of 32 symptoms in comparison to patients' reports on the same symptoms. Family caregivers tended to reported a lower prevalence of symptoms than patients on the symptoms dry mouth, numbness/tingling in hands/feet, itching, change in the way food tastes, and sweats.

Frequency

As summarized from Table 7, fatigue was the most frequently occurring symptom as reported by patients and caregivers. Patients reported feeling drowsy and pain as the second and third most frequently occurring symptoms, whereas caregivers reporting pain and difficulty sleeping.

A comparison of the proportion of symptoms where family caregivers either under-reported or over-reported the frequency of 24 symptoms revealed the following. On ten of 24 (42%) symptoms, the proportion of family caregivers who reported the frequency of symptoms as being either 'frequent' or 'almost constantly' was lower than that of patients (e.g., feeling drowsy, dry mouth, and feeling irritable). On 13 of 24 (54%) symptoms, the proportion of family caregivers who reported 'frequent' or 'almost constantly' was higher than that of patients (e.g., lack of energy, pain, and worrying). It is noted that on the symptom dizziness, there was an equal proportion of patients and family caregivers who reported the presence of the symptom as being 'frequent' or 'almost constantly' frequent.

Severity

In terms of severity, patients and caregivers most frequently reported lack of energy as the most intense symptom. Where patients reported pain and feeling drowsy as the second and third most intense symptoms, family caregivers reported worrying and pain.

With patients' reports serving as the standard, a comparison of the proportion of family caregivers who either under-reported or over-reported the severity of 32 symptoms revealed the following. The percentage of family

caregivers who reported 'moderate' to 'very severe' severity was higher than that of patients on 24 of 32 (75%) symptoms (e.g., lack of energy, pain, and feeling drowsy). On 6 of 32 (19%) symptoms, the percentage of family caregivers who reported moderate or very severe intensity was lower than that of patients (e.g., feeling bloated, changes in skin, and mouth sores). On the other hand, there was an equal proportion of patients and family caregivers who reported the severity of "I don't look like myself" and sweats as 'moderate' to 'very severe'.

Distress

Similarly for distress, 'lack of energy' was reported by patients and caregivers as the most distressing symptom. Patients reported pain and feeling drowsy as the second and third most distressing symptoms. Caregivers reported pain and difficulty sleeping as the second and third most distressing symptoms.

As with frequency and severity, a comparison of the proportion of family caregivers who either under-reported or over-reported on the distress of 32 symptoms followed. The percentage of family caregivers who reported 'quite a bit' to 'very much' distress was lower than that of patients on 10 of 32 (31%) symptoms (e.g., feeling drowsy, feeling irritable, and shortness of breath). On 18 of 32 (56%) symptoms, the percentage of family caregivers who reported 'quite a bit' to 'very much' distress was higher than that of patients (e.g., lack of energy, pain, and worrying). It is noted that on the symptoms cough, change in the way food tastes, "I don't look like myself", and difficulty swallowing, there was an equal proportion of patients and family caregivers who reported 'quite a bit' or 'very much' distress.

Additional analysis of the severity, frequency, and distress MSAS sub-scales demonstrated that the proportion of patients who reported an intense level of distress was not always higher than the proportion of patients who described the symptom as relatively severe or relatively frequent. For example, on highly prevalent patient reported symptoms (i.e., lack of energy, pain, feeling drowsy, dry mouth, and worrying), the proportion of patients who reported a high level of distress was lower than the proportion of patients who described the symptom as relatively severe and frequent. On the other hand, there were other symptoms where the proportion of patients who reported a high level of distress was higher than the proportion of patients who described the same symptom as relatively frequent (e.g. feeling nervous, difficulty concentrating, vomiting, and diarrhea) or as relatively severe (e.g. feeling irritable).

Descriptive analyses also included a comparison of response comparability between patients and family caregivers on their respective mean total MSAS scores. The theoretical range of mean total MSAS scores was between zero to four. The total MSAS score was the average of the symptom scores across 32 symptoms on the global scale and the average of the symptom scores for individual MSAS symptom items. Total symptom scores consisted of the average of the scores on the severity, frequency, and distress sub-scales, or if appropriate, on the severity and distress sub-scales only. If a symptom dimension was not experienced, each dimension was scored zero, and the score for that dimension was zero. The values for the severity and frequency dimensions were scales one to four, where one was 'slight' on the severity scale

and 'rarely' on the frequency scale, and four was 'very severe' on the severity scale and 'almost constantly' on the frequency scale. In accordance with Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al.'s (1994) scoring instructions, the values on the distress scale were set to a range that was roughly similar to the other dimensions: 'not at all' was scored as 0.8, 'a little bit' was 1.6, 'somewhat' was 2.4, 'quite a bit' was 3.2, and 'very much' was 4.

The average total MSAS score on the global scale for patients was 0.79 and for caregivers was 0.90, as displayed in Table 8. The lowest total MSAS score on individual symptom scales for patients was 0.23 on difficulty swallowing and for family caregivers was 0.34 for mouth sores. The highest total MSAS score for patients was 1.93 and for family caregivers was 2.33 on lack of energy.

The most *frequent* symptoms as reported by patients in rank order of mean scores included lack of energy (2.27), pain (1.69), and feeling drowsy (1.65). The most *severe* symptoms for patients in rank order of mean scores included lack of energy (1.74), pain (1.47), and feeling drowsy (1.31). The most *distressing* symptoms for patients in rank order of mean scores included lack of energy (1.75), pain (1.67), and worrying (1.23).

The most *frequent* symptoms for patients as reported by caregivers in rank order of mean scores included lack of energy (2.63), worrying (2.00), and pain (1.90). The most *severe* symptoms for patients as rated by caregivers in rank order of mean scores included lack of energy (2.09), worrying (1.71), and

Table 8

Distribution of patient and family caregiver MSAS scores

Symptoms and symptom dimensions	Patient n ; range	Patient score (Mean \pm SD)	Patient mean score 95% Confidence Interval	Family Caregiver n; range	Family Caregiver score (Mean \pm SD)	Family mean score 95% Confidence Interval
Lack of energy						
frequency	98; 0-4	2.27 \pm 1.54	1.96 to 2.58	98; 0-4	2.63 \pm 1.26	2.25 to 2.84
severity	98; 0-4	1.74 \pm 1.26	1.48 to 1.99	98; 0-4	2.09 \pm 1.06	1.80 to 2.30
distress	98; 0-4	1.75 \pm 1.37	1.47 to 2.02	98; 0-4	2.29 \pm 1.17	1.98 to 2.52
Total*	98; 0-4	1.93 \pm 1.29	1.67 to 2.19	98; 0-4	2.33 \pm 1.09	2.12 to 2.55
Worrying						
frequency	98; 0-4	1.35 \pm 1.49	1.05 to 1.65	97; 0-4	2.00 \pm 1.20	1.74 to 2.24
severity	98; 0-4	1.08 \pm 1.18	0.85 to 1.32	97; 0-4	1.71 \pm 1.06	1.48 to 1.93
distress	98; 0-4	1.23 \pm 1.34	0.97 to 1.50	97; 0-4	1.89 \pm 1.21	1.64 to 2.15
Total	98; 0-4	1.24 \pm 1.30	0.98 to 1.50	97; 0-4	1.85 \pm 1.12	1.63 to 2.07
Feeling sad						
frequency	98; 0-4	1.06 \pm 1.23	0.81 to 1.31	97; 0-4	1.76 \pm 1.21	1.52 to 2.01
severity	98; 0-4	0.95 \pm 1.10	0.73 to 1.17	97; 0-4	1.51 \pm 1.09	1.28 to 1.73
distress	98; 0-4	1.08 \pm 1.28	0.82 to 1.33	96; 0-4	1.75 \pm 1.24	1.50 to 2.00
Total	98; 0-4	1.03 \pm 1.17	0.79 to 1.26	96; 0-4	1.67 \pm 1.13	1.44 to 1.90
Pain						
frequency	98; 0-4	1.69 \pm 1.43	1.41 to 1.98	98; 0-4	1.90 \pm 1.40	1.45 to 2.07
severity	98; 0-4	1.47 \pm 1.29	1.21 to 1.72	98; 0-4	1.69 \pm 1.27	1.32 to 1.90
distress	98; 0-4	1.67 \pm 1.42	1.38 to 1.95	98; 0-4	1.90 \pm 1.37	1.52 to 2.15
Total	98; 0-4	1.61 \pm 1.33	1.34 to 1.88	98; 0-4	1.83 \pm 1.31	1.57 to 2.09
Feeling nervous						
frequency	98; 0-4	0.83 \pm 1.17	0.59 to 1.06	97; 0-4	1.31 \pm 1.71	0.97 to 1.49
severity	98; 0-4	0.77 \pm 1.07	0.55 to 0.98	97; 0-4	1.18 \pm 1.06	0.85 to 1.32
distress	98; 0-4	0.87 \pm 1.23	0.62 to 1.11	97; 0-4	1.34 \pm 1.20	0.99 to 1.52
Total	98; 0-4	0.82 \pm 1.14	0.59 to 1.05	97; 0-4	1.27 \pm 1.12	1.05 to 1.50
Feeling drowsy						
frequency	98; 0-4	1.65 \pm 1.48	1.36 to 1.95	98; 0-4	1.81 \pm 1.27	1.53 to 2.04
severity	98; 0-4	1.31 \pm 1.22	1.06 to 1.55	98; 0-4	1.45 \pm 1.11	1.21 to 1.67
distress	98; 0-4	1.10 \pm 1.13	0.88 to 1.33	98; 0-4	1.37 \pm 1.41	1.11 to 1.58
Total	98-3.73	1.35 \pm 1.20	1.11 to 1.60	98; 0-4	1.54 \pm 1.12	1.32 to 1.77
Dry mouth						
frequency	98; 0-4	1.45 \pm 1.51	1.15 to 1.75	95; 0-4	1.02 \pm 1.37	0.73 to 1.37
severity	98; 0-4	1.16 \pm 1.23	0.92 to 1.41	95; 0-4	0.78 \pm 1.08	0.55 to 1.05
distress	98; 0-4	1.04 \pm 1.22	0.79 to 1.28	95; 0-4	0.76 \pm 1.09	0.53 to 0.98
Total	98; 0-4	1.22 \pm 1.27	0.96 to 1.47	95; 0-4	0.85 \pm 1.15	0.62 to 1.09
Difficulty sleeping						
frequency	98; 0-4	1.21 \pm 1.44	0.93 to 1.51	97; 0-4	1.73 \pm 1.46	1.42 to 2.02
severity	97; 0-4	1.09 \pm 0.14	0.83 to 1.36	97; 0-4	1.41 \pm 1.27	1.15 to 1.67
distress	97; 0-4	1.09 \pm 0.14	0.81 to 1.36	97; 0-4	1.63 \pm 1.43	1.33 to 1.92
Total	97; 0-4	1.13 \pm 1.34	0.86 to 1.40	97; 0-4	1.59 \pm 1.33	1.32 to 1.86
Feeling irritable						
frequency	98; 0-4	1.12 \pm 1.25	0.87 to 1.37	98; 0-4	1.21 \pm 1.16	0.98 to 1.45
severity	98; 0-4	0.98 \pm 1.15	0.75 to 1.21	98; 0-4	1.03 \pm 1.02	0.83 to 1.24
distress	98; 0-4	1.08 \pm 1.26	0.83 to 1.33	98; 0-4	1.10 \pm 1.09	0.88 to 1.32
Total	98; 0-4	1.06 \pm 1.19	0.82 to 1.30	98; 0-4	1.12 \pm 1.04	0.92 to 1.32
Nausea						
frequency	98; 0-4	0.88 \pm 1.20	0.64 to 1.12	97; 0-4	0.88 \pm 1.22	0.63 to 1.12
severity	98; 0-4	0.70 \pm 1.01	0.50 to 0.91	97; 0-4	0.79 \pm 1.12	0.56 to 1.02
distress	98; 0-4	0.78 \pm 1.09	0.57 to 1.00	97; 0-4	0.96 \pm 1.31	0.68 to 1.21
Total	98; 0-4	0.79 \pm 1.06	0.58 to 1.00	97; 0-4	0.88 \pm 1.18	0.64 to 1.11

(table continues)

Table 8 continued

Symptoms and symptom dimensions	Patient n; range	Patient score (Mean \pm SD)	Patient mean score 95% confidence interval	Family Caregiver n; range	Family Caregiver score (Mean \pm SD)	Family mean score 95% Confidence Interval
Lack of appetite frequency	98; 0-4	1.21 \pm 1.43	0.93 to 1.50	98; 0-4	1.33 \pm 1.37	1.06 to 1.62
severity	98; 0-4	1.05 \pm 1.27	0.80 to 1.31	98; 0-4	1.09 \pm 1.18	0.87 to 1.34
distress	98; 0-4	0.97 \pm 1.23	0.73 to 1.22	98; 0-4	1.12 \pm 1.24	0.88 to 1.38
Total	98; 0-4	1.08 \pm 1.27	0.83 to 1.33	98; 0-4	1.18 \pm 1.23	0.93 to 1.43
Difficulty concentrating frequency	98; 0-4	0.67 \pm 1.09	0.45 to 0.89	98; 0-4	1.12 \pm 1.11	0.83 to 1.35
severity	98; 0-4	0.51 \pm 0.87	0.34 to 0.68	98; 0-3	0.87 \pm 0.92	0.64 to 1.06
distress	98; 0-4	0.74 \pm 1.26	0.49 to 0.99	98; 0-4	1.13 \pm 1.18	0.86 to 1.41
Total	98; 0-4	0.64 \pm 1.04	0.43 to 0.85	98; 0-3.67	1.04 \pm 1.03	0.83 to 1.25
Feeling bloated frequency	98; 0-4	0.70 \pm 1.14	0.48 to 0.93	97; 0-4	0.74 \pm 1.15	0.52 to 0.98
severity	98; 0-4	0.62 \pm 0.98	0.43 to 0.82	97; 0-4	0.62 \pm 0.98	0.43 to 0.83
distress	98; 0-4	0.69 \pm 1.09	0.48 to 0.91	97; 0-4	0.73 \pm 1.14	0.50 to 0.97
Total	98; 0-4	0.67 \pm 1.05	0.46 to 0.88	97; 0-4	0.70 \pm 1.07	0.48 to 0.91
Change in the way food tastes severity	98; 0-4	0.61 \pm 1.03	0.41 to 0.82	98; 0-3	0.60 \pm 0.98	0.41 to 0.81
distress	98; 0-4	0.64 \pm 1.03	0.43 to 0.84	98; 0-4	0.68 \pm 1.10	0.46 to 0.91
Total	98; 0-3.5	0.63 \pm 1.01	0.42 to 0.83	98; 0-3.5	0.64 \pm 1.03	0.43 to 0.85
Numbness/tingling in hands/feet frequency	98; 0-4	1.02 \pm 1.46	0.73 to 1.31	96; 0-4	0.85 \pm 1.29	0.59 to 1.12
severity	98; 0-4	0.80 \pm 1.14	0.57 to 1.02	96; 0-4	0.68 \pm 1.07	0.46 to 0.89
distress	98; 0-4	0.84 \pm 1.25	0.59 to 1.09	96; 0-4	0.75 \pm 1.19	0.51 to 0.99
Total	98; 0-4	0.89 \pm 1.24	0.65 to 1.13	96; 0-3.73	0.76 \pm 1.16	0.53 to 0.99
Constipation severity	98; 0-4	0.63 \pm 1.10	0.41 to 0.85	96; 0-4	0.84 \pm 1.23	0.60 to 1.09
distress	98; 0-4	0.76 \pm 1.27	0.51 to 1.01	96; 0-4	1.00 \pm 0.48	0.72 to 1.29
Total	98; 0-4	0.70 \pm 1.17	0.46 to 0.93	96; 0-4	0.92 \pm 1.29	0.66 to 1.19
Cough frequency	98; 0-4	1.03 \pm 1.26	0.78 to 1.28	98; 0-4	1.35 \pm 1.30	1.05 to 1.66
severity	98; 0-3	0.79 \pm 0.99	0.59 to 0.98	98; 0-4	1.10 \pm 1.09	0.84 to 1.35
distress	98; 0-4	0.80 \pm 1.08	0.58 to 1.02	98; 0-4	1.18 \pm 1.20	0.91 to 1.48
Total	98; 0-3.4	0.87 \pm 1.07	0.66 to 1.09	98; 0-3.67	1.21 \pm 1.16	0.98 to 1.44
"I don't look like myself" severity	98; 0-4	0.73 \pm 1.24	0.48 to 0.97	98; 0-4	0.71 \pm 1.13	0.48 to 0.94
distress	98; 0-4	0.78 \pm 1.29	0.52 to 1.03	98; 0-4	0.87 \pm 1.32	0.61 to 1.14
Total	98; 0-4	0.75 \pm 1.24	0.50 to 1.00	98; 0-3.67	0.79 \pm 1.21	0.55 to 1.04
Itching frequency	98; 0-4	0.84 \pm 1.21	0.59 to 1.08	97; 0-4	0.68 \pm 1.09	0.46 to 0.90
severity	98; 0-4	0.73 \pm 1.06	0.51 to 0.94	97; 0-4	0.58 \pm 0.93	0.39 to 0.77
distress	98; 0-4	0.68 \pm 1.02	0.47 to 0.88	97; 0-4	0.63 \pm 1.02	0.42 to 0.83
Total	98; 0-4	0.75 \pm 1.06	0.53 to 0.96	97; 0-4	0.63 \pm 1.00	0.43 to 0.83
Swelling of arms or legs severity	98; 0-4	0.51 \pm 1.04	0.30 to 0.72	98; 0-4	0.67 \pm 1.09	0.44 to 0.89
distress	98; 0-4	0.52 \pm 1.08	0.31 to 0.74	98; 0-4	0.69 \pm 1.11	0.45 to 0.90
Total	98; 0-4	0.52 \pm 1.05	0.32 to 0.73	98; 0-4	0.68 \pm 1.08	0.46 to 0.90
Weight loss severity	98; 0-3	0.37 \pm 0.75	0.22 to 0.52	98; 0-4	0.55 \pm 0.94	0.37 to 0.75
distress	98; 0-4	0.34 \pm 0.76	0.19 to 0.49	98; 0-4	0.60 \pm 1.06	0.39 to 0.82
Total	98; 0-3.5	0.36 \pm 0.73	0.21 to 0.73	98; 0-4	0.57 \pm 0.98	0.38 to 0.77

(table continues)

Table 8 continued

Symptoms and symptom dimensions	Patient n; range	Patient score (Mean \pm SD)	Patient mean score 95% confidence interval	Family Caregiver n; range	Family Caregiver score (Mean \pm SD)	Family mean score 95% Confidence Interval
Diarrhea						
frequency	98; 0-4	0.44 \pm 0.93	0.25 to 0.63	97; 0-4	0.63 \pm 1.08	0.41 to 0.85
severity	98; 0-4	0.41 \pm 0.92	0.22 to 0.59	97; 0-4	0.58 \pm 1.04	0.37 to 0.79
distress	98; 0-4	0.46 \pm 1.03	0.25 to 0.66	97; 0-4	0.69 \pm 1.16	0.45 to 0.92
Total	98; 0-4	0.44 \pm 0.94	0.25 to 0.62	97; 0-4	0.63 \pm 1.07	0.42 to 0.85
Dizziness						
frequency	98; 0-3	0.47 \pm 0.89	0.29 to 0.65	98; 0-3	0.54 \pm 0.94	0.35 to 0.73
severity	98; 0-3	0.41 \pm 0.78	0.25 to 0.57	98; 0-3	0.48 \pm 0.85	0.31 to 0.65
distress	98; 0-4	0.52 \pm 1.03	0.32 to 0.73	98; 0-4	0.56 \pm 0.97	0.36 to 0.75
Total	98; 0-3.33	0.47 \pm 0.87	0.29 to 0.64	98; 0-4	0.52 \pm 0.90	0.34 to 0.70
Problems with sexual interest						
frequency	98; 0-4	0.51 \pm 1.19	0.27 to 0.75	92; 0-4	0.80 \pm 1.34	0.53 to 1.09
severity	98; 0-4	0.45 \pm 1.08	0.23 to 0.67	92; 0-4	0.66 \pm 1.12	0.44 to 0.91
distress	98; 0-4	0.47 \pm 1.14	0.25 to 0.70	92; 0-4	0.64 \pm 1.10	0.42 to 0.88
Total	98; 0-4	0.48 \pm 1.13	0.25 to 0.70	92; 0-3.73	0.70 \pm 1.15	0.47 to 0.94
Shortness of breath						
frequency	98; 0-4	0.96 \pm 1.32	0.70 to 1.22	98; 0-4	1.20 \pm 1.32	0.95 to 1.48
severity	98; 0-4	0.83 \pm 1.11	0.60 to 1.05	98; 0-4	0.95 \pm 1.03	0.75 to 1.17
distress	98; 0-4	0.93 \pm 1.30	0.67 to 1.19	98; 0-4	1.16 \pm 1.28	0.91 to 1.43
Total	98; 0-4	0.91 \pm 1.21	0.66 to 1.15	98; 0-4	1.10 \pm 1.18	0.87 to 1.34
Vomiting						
frequency	98; 0-4	0.26 \pm 0.78	0.09 to 0.41	98; 0-4	0.32 \pm 0.83	0.15 to 0.49
severity	98; 0-4	0.28 \pm 0.84	0.11 to 0.44	98; 0-4	0.34 \pm 0.87	0.17 to 0.52
distress	98; 0-4	0.29 \pm 0.87	0.11 to 0.46	98; 0-4	0.44 \pm 1.10	0.23 to 0.67
Total	98; 0-4	0.27 \pm 0.81	0.11 to 0.44	98; 0-3.33	0.37 \pm 0.91	0.18 to 0.55
Hair loss						
severity	98; 0-4	0.38 \pm 0.93	0.19 to 0.56	98; 0-4	0.50 \pm 1.04	0.27 to 0.66
distress	98; 0-4	0.39 \pm 1.02	0.19 to 0.60	97; 0-4	0.45 \pm 0.95	0.26 to 0.65
Total	98; 0-4	0.39 \pm 0.96	0.19 to 0.58	97; 0-3.6	0.46 \pm 0.94	0.27 to 0.65
Problems with urination						
frequency	98; 0-4	0.35 \pm 0.96	0.15 to 0.54	96; 0-4	0.41 \pm 0.85	0.23 to 0.58
severity	98; 0-3	0.23 \pm 0.64	0.09 to 0.35	96; 0-3	0.31 \pm 0.67	0.18 to 0.45
distress	98; 0-4	0.25 \pm 0.72	0.11 to 0.40	96; 0-3.2	0.42 \pm 0.85	0.24 to 0.59
Total	98; 0-3.67	0.28 \pm 0.76	0.12 to 0.43	96; 0-3.4	0.38 \pm 0.78	0.22 to 0.54
Mouth sores						
severity	98; 0-4	0.33 \pm 0.93	0.14 to 0.51	98; 0-4	0.34 \pm 0.87	0.16 to 0.51
distress	98; 0-3.2	0.29 \pm 0.82	0.13 to 0.46	98; 0-4	0.35 \pm 0.90	0.17 to 0.53
Total	98; 0-3.6	0.31 \pm 0.85	0.14 to 0.48	98; 0-4	0.34 \pm 0.88	0.17 to 0.52
Difficulty swallowing						
frequency	98; 0-3	0.25 \pm 0.70	0.10 to 0.39	98; 0-4	0.44 \pm 0.89	0.26 to 0.62
severity	98; 0-2	0.20 \pm 0.56	0.09 to 0.32	98; 0-3	0.36 \pm 0.69	0.22 to 0.50
distress	98; 0-3.2	0.25 \pm 0.67	0.11 to 0.38	98; 0-4	0.38 \pm 0.79	0.23 to 0.54
Total	98; 0-2.73	0.23 \pm 0.63	0.11 to 0.36	98; 0-3.67	0.39 \pm 0.77	0.24 to 0.55
Sweats						
frequency	98; 0-4	0.69 \pm 1.15	0.46 to 0.92	98; 0-4	0.66 \pm 1.13	0.45 to 0.91
severity	98; 0-4	0.59 \pm 1.02	0.39 to 0.80	98; 0-3	0.55 \pm 0.94	0.37 to 0.76
distress	98; 0-4	0.53 \pm 0.96	0.34 to 0.72	98; 0-3.2	0.51 \pm 0.89	0.34 to 0.70
Total	98; 0-4	0.61 \pm 1.00	0.41 to 0.81	98; 0-3.4	0.57 \pm 0.96	0.38 to 0.77

(table continues)

Table 8 continued

Symptoms and symptom dimensions	Patient n; range	Patient score (Mean \pm SD)	Patient mean score 95% confidence interval	Family Caregiver n; range	Family Caregiver score (Mean \pm SD)	Family mean score 95% Confidence Interval
Changes in skin severity	98; 0-4	0.38 \pm 0.88	0.20 to 0.55	98; 0-4	0.49 \pm 0.92	0.29 to 0.67
distress	98; 0-4	0.39 \pm 0.92	0.21 to 0.58	98; 0-4	0.52 \pm 0.98	0.32 to 0.72
Total	98; 0-4	0.39 \pm 0.89	0.21 to 0.56	98; 0-3.5	0.51 \pm 0.92	0.32 to 0.69
Total MSAS score ^b						
patent	98	0.79 \pm 0.55	0.68 to 0.91			
family caregiver				85	0.90 \pm 0.52	0.79-1.01

^a Total symptom score is the average of the scores on the severity, frequency, and distress sub-scales, or if appropriate, on the severity and distress sub-scales only.

^b Total MSAS score is the average of the total symptom scores across 32 symptoms.

pain (1.69). The most *distressing* symptoms for patients as perceived by caregivers in rank order of mean scores included lack of energy (2.29), pain (1.90), and worrying (1.89). Caregiver reports on the most frequent, most severe, and most distressing symptoms were similar to that of patients.

The symptoms that patients rated on average as least *frequent* were difficulty swallowing (0.25), vomiting (0.26), and problems with urination (0.35). Caregivers reported the following symptoms as being least frequently occurring over the past week: vomiting (0.32), problems with urination (0.41), and difficulty swallowing (0.36). The symptoms reported as least *severe* by patients were difficulty swallowing (0.20), problems with urination (0.23), and vomiting (0.28). Caregivers reported problems with urination (0.31), mouth sores (0.34), vomiting (0.34), and difficulty swallowing (0.44) as least severe. The symptoms reported by patients as least *distressing* were difficulty swallowing (0.25), problems with urination (0.25), mouth sores (0.29), and vomiting (0.29). Caregivers reported mouth sores (0.35), difficulty swallowing (0.38), and problems with urination (0.42) as least distressing. Caregiver reports on the least frequent, least severe, and least distressing symptoms were similar to that of patients.

Additional descriptive analysis, as reported in previous work (Deschler, Walsh, Friedman, & Hayden, 1999), included a comparison of the family caregiver's mean assessment on patient total symptom experience. Each symptom had a total symptom experience mean score and each symptom dimension had a mean score value ranging from 0 to 4, and a 95% confidence interval. Congruence was indicated if the caregiver's mean MSAS score fell

within the 95% confidence interval of the patient's mean MSAS score. If the caregiver's mean score fell outside that interval, it was distinguished as either over-estimating or under-estimating symptom frequency, severity, and distress for that symptom.

First, on total symptom experience for the global MSAS scale across 32 symptoms, the family caregiver's mean score fell within the patient's 95% confidence interval indicating congruence. On total symptom experience for individual MSAS symptom items, 21 of 32 symptom reports by caregivers were congruent with patient's reports. The remaining 11 mean symptom reports by caregivers fell outside the patient's 95% confidence interval, suggesting discrepant perceptions between the dyads. Of the discrepant perceptions, family caregivers tended to over-rate versus underrate, with the exception of dry mouth where they under-rated on total symptom experience.

In addition, of the total 88 possible dyadic score comparisons for three dimensions on 32 MSAS symptoms, 64% (56 of 88) of the patient and caregiver scores were congruent (i.e, fell within the patient 95% confidence interval). For 33% (29 of 88) of the compared patient and caregiver scores, caregivers tended to overrate across three dimensions. For 3% (3 of 88) of the compared scores, caregivers tended to underrate patient scores across three dimensions.

Second, each separate dimension of symptom severity, frequency, and distress was evaluated for level of congruence. Of the 56 possible symptom dimension comparisons where congruence occurred, congruence occurred most frequently on symptom severity (22/56; 39%), closely followed by symptom

distress (19/56; 34%) and then symptom frequency (15/56; 27%). Of the 29 possible symptom dimension comparisons where caregivers tended to overestimate, overestimation occurred most frequently on symptom distress (11/29; 38%), followed by symptom severity (9/29; 31%) and symptom frequency (9/29; 31%). Of the three possible symptom dimension comparisons where caregivers may underestimate, underestimation occurred with equal frequency on symptom severity (1/3; 33%), symptom frequency (1/3; 33%), and symptom distress (1/3; 33%). Of note is that underestimation by caregivers occurred only on the physical symptom dry mouth across all three dimensions.

Third, in accordance with the MSAS high prevalence physical symptoms ($n = 12$) (33 possible dyadic score comparisons across three dimensions) and MSAS psychological symptoms ($n = 6$) (18 possible dyadic score comparisons across three dimensions), overall congruence of scores occurred most frequently on physical symptom items (25/33; 76%) in comparison to psychological items (3/18; 17%). On the other hand, caregivers tended to overrate psychological symptoms more frequently (15/18; 83%) in comparison to highly prevalent physical symptoms (5/33; 15%). The tendency for caregivers to underestimate occurred only on the physical symptom dry mouth.

Fourth, each separate dimension of symptom severity, frequency, and distress for high prevalence physical symptoms and psychological symptoms was evaluated for level of congruence. Of the 25 possible physical symptom dimension comparisons where congruence occurred, congruence occurred with equal frequency on symptom severity (9/25; 36%) and symptom distress (9/25;

36%), closely followed by symptom distress (7/25; 28%). Of the five possible symptom dimension comparisons where caregivers tended to overestimate, overestimation occurred with equal frequency on symptom distress (2/5; 40%), and symptom severity (2/5; 40%), followed by symptom frequency (1/5; 20%). Of the three possible symptom dimension comparisons where caregivers tended to underestimate, underestimation occurred with equal frequency on symptom severity (1/3; 33%), symptom frequency (1/3; 33%), and symptom distress (1/3; 33%).

Of the three possible psychological symptom dimension comparisons where congruence occurred, congruence occurred with equal frequency on symptom severity (1/3; 33%), symptom distress (1/3; 33%), and symptom distress (1/3; 33%). Of the 15 possible symptom dimension comparisons where caregivers tended to overestimate, overestimation occurred with equal frequency on symptom distress (5/15; 33%), symptom severity (5/15; 33%), and symptom frequency (5/15; 33%). Caregivers did not underestimate on any symptom dimension for six psychological symptoms.

Overall, it was found that caregivers tended to achieve a level of congruence on total symptom experience on a global basis and for a majority of individual symptom items, and across three symptom dimensions. When incongruence occurred, family caregivers tended to over-rate versus under-rate patient symptom experience. On symptom dimensions, congruence occurred most frequently on symptom severity across 32 symptoms. When overestimation occurred, it occurred most often on symptom distress. It was also

discovered that congruence tended to occur most frequently on physical versus psychological symptoms. In fact, caregivers tended to overrate on psychological symptoms. For physical and psychological symptoms, a similar pattern occurred across symptom dimensions where equal frequencies of congruence, overestimation and underestimation were achieved by caregivers.

Research Question #2

Are there differences and/or associations between patient and family caregiver MSAS ratings on (a) the absence or presence of symptom events, (b) the global scale across 32 symptoms and the 32 separate MSAS symptom scales, (c) the frequency, severity, and distress sub-scales across 32 symptoms, and (d) the high prevalence physical and psychological sub-scales?

Absence or presence of symptoms

The results for cross-tabulations on patient and caregiver assessments on the presence/absence of 32 MSAS symptoms are provided in Table 9. Cohen's Kappa statistic was used to compare patient and family caregiver ratings on categorical data on the presence or absence of 32 symptoms. Substantial to almost perfect agreement (Kappa > 0.60) was observed on three of 32 symptoms. Moderate agreement (Kappa 0.41 to 0.60) was observed for 14 of 32 symptoms. Fair agreement (Kappa 0.21 to 0.40) was observed for 13 of 32 symptoms. Slight to poor agreement (Kappa <0.21) was observed for two of 32 symptoms. Agreement levels on symptom reports in terms of absence or presence were not uniformly high, but primarily in the fair to moderate range of agreement. The highest agreement was for vomiting (Kappa = 0.70); the lowest

Table 9

Cross tabulations of patient and family caregiver data on the presence/absence of 32 MSAS symptoms

Item	Patient's Score	Relative's score		Kappa	McNemar's Test (p)
		1 - Yes	2 - No		
Difficulty concentrating	1 - Yes 2 - No	23 32	8 35	0.22 (0.01)*	0.00*
Pain	1 - Yes 2 - No	59 13	6 20	0.52 (0.00)*	0.17
Lack of energy	1 - Yes 2 - No	73 15	2 8	0.40 (0.00)*	0.00*
Cough	1 - Yes 2 - No	39 20	6 33	0.48 (0.00)*	0.01*
Feeling nervous	1 - Yes 2 - No	29 33	8 27	0.21 (0.02)*	0.00*
Dry mouth	1 - Yes 2 - No	29 11	27 28	0.22 (0.02)*	0.02*
Nausea	1 - Yes 2 - No	29 11	11 46	0.53 (0.00)*	1.00
Feeling drowsy	1 - Yes 2 - No	50 21	10 17	0.30 (0.00)*	0.07
Numbness/Tingling	1 - Yes 2 - No	21 12	18 45	0.34 (0.00)*	0.36
Difficulty sleeping	1 - Yes 2 - No	41 23	5 28	0.43 (0.00)*	0.00*
Feeling bloated	1 - Yes 2 - No	17 18	15 49	0.28 (0.01)*	1.00
Problems with urination	1 - Yes 2 - No	7 14	6 69	0.29 (0.00)*	0.12
Vomiting	1 - Yes 2 - No	10 5	2 81	0.70 (0.00)*	0.45
Shortness of Breath	1 - Yes 2 - No	33 20	8 37	0.44 (0.00)*	0.04*
Diarrhea	1 - Yes 2 - No	13 17	8 59	0.34 (0.00)*	0.11
Feeling sad	1 - Yes 2 - No	44 29	3 21	0.35 (0.00)*	0.00*
Sweats	1 - Yes 2 - No	20 9	10 59	0.54 (0.00)*	1.00

(table continues)

Table 9 continued

Item	Patient's Score	Relative's score		Kappa (p)	McNemar's Test (p)
		1 - Yes	2 - No		
Worrying	1 - Yes 2 - No	45 35	5 12	0.16 (0.04)*	0.00*
Problems with sexual activity	1 - Yes 2 - No	10 19	8 55	0.24 (0.01)*	0.05*
Itching	1 - Yes 2 - No	22 11	15 49	0.42 (0.00)*	0.56
Lack of appetite	1 - Yes 2 - No	42 12	4 40	0.68 (0.00)*	0.08
Dizziness	1 - Yes 2 - No	14 16	12 56	0.30 (0.00)*	0.57
Difficulty swallowing	1 - Yes 2 - No	10 14	3 71	0.45 (0.00)*	0.01*
Feeling irritable	1 - Yes 2 - No	41 18	9 30	0.48 (0.00)*	0.12
Mouth sores	1 - Yes 2 - No	10 7	3 78	0.61 (0.00)*	0.34
Change in Taste	1 - Yes 2 - No	17 14	15 52	0.32 (0.00)*	1.00
Weight loss	1 - Yes 2 - No	17 15	6 60	0.48 (0.00)*	0.08
Hair loss	1 - Yes 2 - No	13 10	4 71	0.56 (0.00)*	0.18
Constipation	1 - Yes 2 - No	23 16	7 50	0.49 (0.00)*	0.09
Swelling of arms	1 - Yes 2 - No	19 14	4 61	0.56 (0.00)*	0.03*
"I don't look like myself"	1 - Yes 2 - No	22 13	9 54	0.50 (0.00)*	0.52
Change in skin	1 - Yes 2 - No	8 19	9 62	0.19 (0.05)*	0.09

*p ≤ 0.05

was for worrying ($Kappa = 0.16$) and change in skin ($Kappa = 0.19$).

To determine differences between categorical data, the paired Chi squared test or McNemar's test was conducted. As shown in Table 9, 12 symptom items revealed a disparity in dyad perceptions on the absence or presence of 32 MSAS symptoms. Significant differences were present between patient and caregiver reports on the absence or presence of symptoms for difficulty concentrating, lack of energy, cough, feeling nervous, dry mouth, difficulty sleeping, shortness of breath, feeling sad, worrying, problems with sexual activity, difficulty swallowing, and swelling of arms and/or legs. It is noted that significant differences occurred on five of six MSAS psychological symptoms where family caregivers tended to report the presence of symptoms when patients did not. From Table 9, it is also seen that where incongruence existed family caregivers tended to overestimate rather than underestimate the presence of 12 symptoms. The only exception was with dry mouth, where family caregivers tended to under-report the presence of the symptom.

Global and individual MSAS symptom ratings

The comparison of patient and caregiver global and individual item total MSAS scores, and subscale scores for total frequency, severity, and distress on 32 separate MSAS symptom items involved several analyses (see Table 10). First, intraclass correlations (ICC) were calculated between patient and caregiver ratings on the corresponding measures. Second, the means of the absolute patient-caregiver difference (i.e., irrespective of the direction of differences) on the total MSAS score for each symptom and on each separate dimension for 32

Table 10

Patient-Family Caregiver agreement on the MSAS (n = 98)

	Patient - Family Caregiver correlation	Absolute difference ^a		Directional difference ^b	
	ICC (CI)	Mean \pm SD	Mean \pm SD	d ^c	
Lack of energy					
frequency	0.41* (.23-.56)	1.10 \pm 1.12	-0.37 \pm 1.53*	-0.24	
severity	0.52* (.36-.65)	0.83 \pm 0.85	-0.36 \pm 1.13*	-0.32	
distress	0.39* (.21-.55)	1.11 \pm 1.01	-0.55 \pm 1.40*	-0.39	
Total ^d	0.51* (.34-.64)	0.92 \pm 0.86	-0.41 \pm 1.19*	-0.35	
Worrying					
frequency	0.38* (.19-.53)	1.27 \pm 1.06	-0.66 \pm 1.51*	-0.44	
severity	0.32* (.13-.49)	1.06 \pm 0.98	-0.63 \pm 1.31*	-0.48	
distress	0.40* (.22-.56)	1.18 \pm 1.02	-0.67 \pm 1.39*	-0.48	
Total	0.39* (.20-.54)	1.12 \pm 0.96	-0.61 \pm 1.34*	-0.46	
Feeling sad					
frequency	0.48* (.31-.62)	0.99 \pm 1.05	-0.72 \pm 1.25*	-0.58	
severity	0.43* (.25-.58)	0.90 \pm 0.94	-0.57 \pm 1.17*	-0.49	
distress	0.49* (.32-.63)	1.04 \pm 1.02	-0.71 \pm 1.27*	-0.56	
Total	0.49* (.33-.63)	0.96 \pm 0.92	-0.67 \pm 1.16*	-0.58	
Pain					
frequency	0.69* (.57-.78)	0.76 \pm 0.85	-0.20 \pm 1.12	-0.18	
severity	0.64* (.51-.75)	0.69 \pm 0.85	-0.22 \pm 1.08*	-0.21	
distress	0.62* (.48-.73)	0.81 \pm 0.93	-0.23 \pm 1.21	-0.19	
Total	0.69* (.57-.78)	0.69 \pm 0.81	-0.22 \pm 1.04*	-0.21	
Feeling nervous					
frequency	0.39* (.20-.54)	0.99 \pm 0.96	-0.50 \pm 1.29*	-0.38	
severity	0.41* (.24-.57)	0.86 \pm 0.88	-0.42 \pm 1.15*	-0.37	
distress	0.42* (.24-.57)	0.96 \pm 1.00	-0.49 \pm 1.30*	-0.37	
Total	0.42* (.24-.57)	0.93 \pm 0.90	-0.47 \pm 1.12*	-0.39	
Feeling drowsy					
frequency	0.49* (.32-.62)	1.10 \pm 0.95	-0.15 \pm 1.40	-0.11	
severity	0.49* (.33-.63)	0.86 \pm 0.81	-0.14 \pm 1.18	-0.12	
distress	0.47* (.30-.61)	0.92 \pm 0.97	-0.27 \pm 1.67*	-0.23	
Total	0.52* (.36-.65)	0.88 \pm 0.74	-0.19 \pm 1.14	-0.17	
Dry mouth					
frequency	0.40* (.22-.56)	1.15 \pm 1.18	0.47 \pm 1.58*	0.30	
severity	0.39* (.20-.55)	0.93 \pm 0.98	0.42 \pm 1.29*	0.33	
distress	0.42* (.24-.57)	0.83 \pm 0.76	0.31 \pm 1.24*	0.25	
Total	0.43* (.25-.58)	0.95 \pm 0.97	0.40 \pm 1.29*	0.31	
Difficulty sleeping					
frequency	0.57* (.42-.69)	0.92 \pm 1.11	-0.51 \pm 1.35*	-0.38	
severity	0.56* (.40-.68)	0.84 \pm 0.94	-0.30 \pm 1.23*	-0.25	
distress	0.49* (.33-.64)	0.98 \pm 1.13	-0.51 \pm 1.41*	-0.36	
Total	0.58* (.43-.70)	0.87 \pm 0.96	-0.43 \pm 1.23*	-0.35	

(table continues)

Table 10 continued

	Patient - Family Caregiver correlation	Absolute difference ^a	Directional difference ^b	
	ICC (CI)	(Mean \pm SD)	Mean \pm SD	d ^c
Feeling irritable				
frequency	0.56* (.41-.68)	0.75 \pm 0.85	-0.98 \pm 1.13	-0.08
severity	0.49* (.32-.63)	0.70 \pm 0.84	-0.05 \pm 1.10	-0.05
distress	0.50* (.34-.64)	0.83 \pm 0.83	-0.02 \pm 1.17	-0.02
Total	0.55* (.39-.67)	0.72 \pm 0.78	-0.06 \pm 1.06	-0.06
Nausea				
frequency	0.69* (.57-.78)	0.55 \pm 0.78	-0.01 \pm 0.95	-0.01
severity	0.61* (.47-.73)	0.55 \pm 0.76	-0.93 \pm 0.94	-0.10
distress	0.65* (.52-.75)	0.64 \pm 0.80	-0.18 \pm 1.01	-0.18
Total	0.70* (.58-.79)	0.54 \pm 0.70	-0.09 \pm 0.88	-0.10
Lack of appetite				
frequency	0.73* (.62-.81)	0.56 \pm 0.78	-0.11 \pm 1.03	-0.11
severity	0.75* (.64-.82)	0.55 \pm 0.76	-0.04 \pm 0.87	-0.05
distress	0.72* (.61-.80)	0.64 \pm 0.80	-0.15 \pm 0.93	-0.16
Total	0.78* (.68-.85)	0.48 \pm 0.69	-0.10 \pm 0.83	-0.12
Difficulty concentrating				
frequency	0.35* (.16-.51)	0.89 \pm 0.99	-0.45 \pm 1.26*	-0.36
severity	0.38* (.19-.53)	0.70 \pm 0.79	-0.36 \pm 0.20*	-0.36
distress	0.27* (.08-.44)	1.00 \pm 1.14	-0.38 \pm 1.42*	-0.27
Total	0.35* (.16-.51)	0.83 \pm 0.93	-0.39 \pm 1.18*	-0.33
Feeling bloated				
frequency	0.39* (.20-.54)	0.75 \pm 1.02	-0.03 \pm 1.27	-0.02
severity	0.39* (.21-.55)	0.63 \pm 0.88	0.02 \pm 1.09	0.01
distress	0.44* (.26-.59)	0.69 \pm 0.97	-0.23 \pm 1.19	-0.02
Total	0.42* (.24-.57)	0.66 \pm 0.93	-0.02 \pm 1.14	-0.02
Change in the way food tastes				
frequency	0.37* (.19-.53)	0.62 \pm 0.94	-0.01 \pm 1.23	-0.01
severity	0.39* (.20-.54)	0.69 \pm 0.96	-0.04 \pm 1.18	-0.03
distress	0.40* (.21-.55)	0.64 \pm 0.92	-0.02 \pm 1.12	-0.02
Total				
Numbness/tingling in hands/feet				
frequency	0.48* (.32-.62)	0.85 \pm 1.12	0.19 \pm 1.40	0.13
severity	0.53* (.37-.66)	0.64 \pm 0.87	0.14 \pm 1.07	0.13
distress	0.53* (.37-.66)	0.71 \pm 0.96	0.11 \pm 1.19	0.09
Total	0.53* (.36-.66)	0.73 \pm 0.92	0.14 \pm 1.17	0.12

(table continues)

Table 10 continued

	Patient - Family Caregiver correlation	Absolute difference ^a		Directional difference ^b
	ICC (CI)	Mean \pm SD	Mean \pm SD	d ^c
Constipation				
severity	0.53* (.37-.66)	0.59 \pm 0.98	-0.20 \pm 1.13	-0.18
distress	0.50* (.34-.64)	0.72 \pm 1.15	-0.23 \pm 1.34	-0.17
Total	0.53* (.37-.66)	0.62 \pm 1.04	-0.21 \pm 1.20	-0.18
Cough				
frequency	0.62* (.48-.73)	0.75 \pm 0.89	-0.32 \pm 1.12*	-0.28
severity	0.69* (.58-.79)	0.56 \pm 0.66	-0.32 \pm 0.81*	-0.39
distress	0.58* (.43-.70)	0.74 \pm 0.83	-0.38 \pm 1.05*	-0.36
Total	0.66* (.53-.76)	0.66 \pm 0.72	-0.34 \pm 0.92*	-0.37
"I don't look like myself"				
severity	0.57* (.41-.69)	0.60 \pm 0.93	0.01 \pm 1.11	0.01
distress	0.54* (.38-.67)	0.69 \pm 1.05	-0.10 \pm 1.25	-0.08
Total	0.57* (.42-.69)	0.63 \pm 0.94	-0.04 \pm 1.14	-0.04
Itching				
frequency	0.55* (.39-.68)	0.62 \pm 0.91	0.14 \pm 1.09	0.13
severity	0.63* (.49-.73)	0.52 \pm 0.71	0.14 \pm 0.87	0.17
distress	0.61* (.47-.72)	0.54 \pm 0.71	0.03 \pm 0.89	0.04
Total	0.62* (.48-.73)	0.55 \pm 0.71	0.11 \pm 0.89	0.12
Swelling of arms or legs				
severity	0.67* (.54-.76)	0.43 \pm 0.77	-0.16 \pm 0.87	-0.19
distress	0.66* (.53-.76)	0.46 \pm 0.80	-0.16 \pm 0.90	-0.18
Total	0.68* (.56-.77)	0.43 \pm 0.75	-0.16 \pm 0.83	-0.19
Weight loss				
severity	0.56* (.40-.68)	0.43 \pm 0.70	-0.18 \pm 0.80*	-0.23
distress	0.57* (.42-.69)	0.45 \pm 0.77	-0.25 \pm 0.86*	-0.30
Total	0.57* (.41-.69)	0.44 \pm 0.71	-0.22 \pm 0.80*	-0.28
Diarrhea				
frequency	0.56* (.41-.68)	0.50 \pm 0.83	-0.19 \pm 0.95	-0.19
severity	0.52* (.36-.65)	0.52 \pm 0.83	-0.17 \pm 0.97	-0.17
distress	0.54* (.39-.67)	0.55 \pm 0.92	-0.22 \pm 1.05	-0.21
Total	0.55* (.40-.68)	0.52 \pm 0.82	-0.19 \pm 0.96	-0.20

(table continues)

Table 10 continued

	Patient - Family Caregiver correlation	Absolute difference ^a		Directional difference ^b
		(Mean \pm SD)	Mean \pm SD	d ^c
Dizziness				
frequency	0.33* (.15-.50)	0.58 \pm 0.88	-0.07 \pm 1.06	-0.07
severity	0.38* (.20-.54)	0.48 \pm 0.78	-0.07 \pm 0.91	-0.07
distress	0.42* (.24-.57)	0.59 \pm 0.90	-0.03 \pm 1.08	-0.03
Total	0.39* (.21-.54)	0.53 \pm 0.82	-0.06 \pm 0.98	-0.06
Problems with sexual interest or activity				
frequency	0.34* (.15-.51)	0.83 \pm 1.25	-0.26 \pm 1.47	-0.18
severity	0.27* (.07-.45)	0.75 \pm 1.13	-0.19 \pm 1.34	-0.14
distress	0.18* (.03-.37)	0.82 \pm 1.21	-0.14 \pm 1.46	-0.09
Total	0.28* (.08-.46)	0.80 \pm 1.15	-0.19 \pm 1.38	-0.14
Shortness of breath				
frequency	0.61* (.47-.72)	0.76 \pm 0.92	-0.25 \pm 1.17*	-0.21
severity	0.55* (.39-.67)	0.67 \pm 0.77	-0.12 \pm 1.02	-0.12
distress	0.57* (.42-.69)	0.74 \pm 0.97	-0.23 \pm 1.19*	-0.19
Total	0.61* (.47-.72)	0.69 \pm 0.82	-0.20 \pm 1.05*	-0.19
Vomiting				
frequency	0.73* (.63-.81)	0.20 \pm 0.56	-0.06 \pm 0.59	-0.10
severity	0.58* (.43-.70)	0.25 \pm 0.75	-0.06 \pm 0.78	-0.08
distress	0.60* (.45-.71)	0.30 \pm 0.85	-0.16 \pm 0.89	-0.18
Total	0.65* (.52-.75)	0.25 \pm 0.68	-0.09 \pm 0.72	-0.13
Hair loss				
severity	0.55* (.40-.67)	0.37 \pm 0.87	-0.12 \pm 0.93	-0.13
distress	0.63* (.50-.74)	0.37 \pm 0.87	-0.07 \pm 0.85	-0.08
Total	0.60* (.45-.71)	0.35 \pm 0.78	-0.08 \pm 0.85	-0.09
Problems with urination				
frequency	0.42* (.24-.57)	0.45 \pm 0.88	-0.05 \pm 0.99	-0.05
severity	0.42* (.24-.57)	0.31 \pm 0.64	-0.08 \pm 0.71	-0.12
distress	0.41* (.22-.56)	0.39 \pm 0.79	-0.16 \pm 0.87	-0.18
Total	0.43* (.25-.58)	0.38 \pm 0.74	-0.10 \pm 0.83	-0.12
Mouth sores				
severity	0.69* (.57-.78)	0.28 \pm 0.66	-0.01 \pm 0.71	-0.01
distress	0.78* (.68-.84)	0.22 \pm 0.54	-0.06 \pm 0.58	-0.10
Total	0.77* (.67-.84)	0.22 \pm 0.54	-0.03 \pm 0.59	-0.05

(table continues)

Table 10 continued

	Patient - Family Caregiver correlation	Absolute difference ^a		Directional difference ^b	
		ICC (CI)	Mean \pm SD	Mean \pm SD	d ^c
Difficulty swallowing					
frequency	0.68* (.56-.78)	0.30 \pm 0.60	-0.19 \pm 0.64*	-0.31	
severity	0.62* (.49-.73)	0.26 \pm 0.50	-0.15 \pm 0.54*	-0.28	
distress	0.67* (.54-.77)	0.25 \pm 0.56	-0.14 \pm 0.60*	-0.23	
Total	0.67* (.57-.78)	0.27 \pm 0.52	-0.16 \pm 0.56*	-0.29	
Sweats					
frequency	0.63* (.50-.74)	0.50 \pm 0.84	0.03 \pm 0.98	0.03	
severity	0.61* (.47-.72)	0.45 \pm 0.75	0.04 \pm 0.87	0.05	
distress	0.65* (.52-.75)	0.40 \pm 0.66	0.02 \pm 0.77	0.03	
Total	0.67 (.54-.77)	0.43 \pm 0.67	0.03 \pm 1.80	0.04	
Changes in skin					
severity	0.05 (-.15-.24)	0.66 \pm 1.06	-0.11 \pm 1.24	-0.09	
distress	0.14 (-.06-.33)	0.65 \pm 1.07	-0.13 \pm 1.25	-0.11	
Total	0.10 (-.10-.29)	0.65 \pm 1.04	-0.12 \pm 1.22	-0.10	
Total MSAS score^d	0.67* (.54-.77)	0.31 \pm 0.29	-0.11 \pm 0.41*	-0.27	

^aAbsolute difference between patient and family caregiver score (indicator of agreement)

^bDifference between patient and caregiver score (indicator of bias); Wilcoxon matched-pairs signed-rank test; (Patient score minus family caregiver score)

^cStandardized mean difference scores (as determined by paired Student's t-tests); a standardized difference d = mean difference/standard deviation of difference (d = 0.2 small, d = 0.5 moderate, d = 0.8 large difference)

^d Total symptom score is the average of the scores on the severity, frequency, and distress scales, or if appropriate, on the severity and distress scales only

^eTotal MSAS score is the average of the symptom scores for all 32 symptoms

* $p \leq 0.05$

symptoms were calculated. This not only determined the empathic accuracy score, but also provided an additional indicator of agreement between patient and caregiver responses (Sneeuw et al., 1998). Third, the means of directional differences (i.e., accounting for the direction of differences) were also calculated, being indicative of bias in caregiver scores relative to those of the patient. Evidence of systematic bias was revealed when the mean of the directional differences was significantly different from zero, as determined by Wilcoxon matched-pairs signed rank test of differences on ordinal data. Fourth, to examine the statistical magnitude of any observed systematic bias, the mean difference score was standardized by relating the mean difference score to its standard deviation.

Intraclass correlation coefficient results. The ICC correlation between patient and caregiver total MSAS scores on the global MSAS was significant at 0.67, indicating good agreement. For 32 separate MSAS symptoms, significant ICC correlations on corresponding symptom item total scores ranged from 0.28 (problems with sexual activity) to 0.78 (lack of appetite). Non-significant correlations occurred on total symptom scores for sweats and changes in skin. On the frequency dimension across 24 MSAS symptoms, 71% (17/24) of the ICC correlational results ranged from moderate to good. For severity, 75% (24/32) of the ICC correlational results ranged from moderate to good. Eighty-one per cent (81%; 26/32) of the ICC results ranged from moderate to good for distress.

The level of agreement on total symptom scores across 12 high prevalence physical symptoms fell primarily (83%; 10/12) in the good to

moderate range. The ICCs on total symptom experience for physical symptoms ranged from 0.39 (dizziness) to 0.78 (lack of appetite). The ICCs for frequency ranged between 0.33 for dizziness and 0.73 for vomiting and lack of appetite. The ICC results for severity ranged between 0.38 for dizziness and 0.75 for lack of appetite. For distress, the ICC results ranged between 0.39 for lack of appetite and change in the way food tastes, and 0.72 for lack of appetite.

For level of agreement on total symptom experience for six MSAS psychological symptoms, 67% (4/6) of the ICC results fell in the moderate range and 33% (2/6) were in the poor to fair range. The ICCs on patient total symptom experience ranged from 0.35 (difficulty concentrating) to 0.58 (difficulty sleeping). The ICCs between patient and caregiver frequency scores ranged between 0.35 for difficulty concentrating and 0.57 for difficulty sleeping. The ICCs for severity scores ranged between 0.32 for worrying and 0.56 for difficulty sleeping. For distress, the ICCs ranged between 0.27 for difficulty concentrating and 0.50 for feeling irritable.

Means of absolute differences. The theoretical range of absolute differences on total mean scores for the global MSAS scale, individual symptom items, and the respective MSAS symptom dimension sub-scales across 32 symptoms ranged from zero to four.

The absolute mean differences between patient and caregiver total MSAS scores on the global scale was 0.31, and on each individual symptom sub-scale ranged between 0.22 (mouth sores) and 1.12 (worrying). On frequency across 32 symptoms, the range of absolute mean differences was 0.20 (vomiting) to 1.27

(worrying) points. On severity or intensity, the range of absolute mean differences was 0.25 (vomiting) to 1.06 (worrying) points. The symptom dimension of distress had a range of absolute mean differences between 0.22 (mouth sores) to 1.18 (worrying) points.

On high prevalence physical MSAS symptom items (n = 12), the range of absolute differences on total symptom scores was between 0.25 (vomiting) and 0.95 (dry mouth). The following range of absolute differences are reported in accordance with the separate symptom dimensions of frequency, intensity or severity, and distress. On frequency, the range of absolute mean differences was between 0.20 (vomiting) and 1.15 (dry mouth) points. On severity, the range of absolute mean differences was between 0.25 (vomiting) and 0.95 (dry mouth) points. On distress, the range was 0.30 (vomiting) to 1.11 points (lack of energy). Overall, the range of absolute differences on high prevalence physical MSAS symptom scores across the three dimensions was between 0.20 and 1.15.

On psychological MSAS symptom items (n = 6), the range of absolute differences on total symptom scores was between 0.72 (feeling irritable) and 1.12 (worrying). On frequency, the range of absolute mean differences was between 0.75 (feeling irritable) and 1.27 (worrying) points. On severity or intensity, the range of absolute mean differences was between 0.70 (feeling irritable and difficulty concentrating) and 1.06 (worrying) points. On distress, the range was 0.83 (feeling irritable) and 1.18 (worrying) points. Overall, the range of absolute mean differences on psychological MSAS symptom scores across

the three dimensions ranged between 0.70 and 1.27. On comparing the range of absolute mean differences between the physical and psychological MSAS symptom sub-groups, it is noted that the degree of difference was slightly higher in the psychological versus physical symptom subgroup.

Means of directional differences and response bias. The results in Table 10 under "Directional difference" account for the direction of the difference between patient and caregiver ratings on the separate symptom dimensions for 32 symptoms, and on total MSAS scores for both the global scale and the separate symptom sub-scales. Based on the Wilcoxon matched-pairs signed rank test for differences, there was a significant difference in the total MSAS scores provided on a global basis by patients and family caregivers. However on a theoretical range of differences between 0 and 4, the mean difference score was small at - 0.11 (S.D. 0.41). This result indicates that family caregivers tended to over-rate patient global symptom experience.

On the total score for each symptom, significant mean differences ranged from - 0.16 to - 0.67. Statistically significant mean differences between patient and caregiver total scores were found on 12 of 32 total MSAS symptom item measures. On frequency, significant differences were found on lack of energy, worrying, feeling sad, feeling nervous, dry mouth, difficulty sleeping, difficulty concentrating, shortness of breath, cough, weight loss, and difficulty swallowing. In all instances where significant differences occurred, family caregivers tended to over-rate on symptom frequency, with the exception of dry mouth where they under-rated on frequency.

On severity, significant differences were found on lack of energy, worrying, feeling sad, pain, feeling nervous, dry mouth, difficulty sleeping, difficulty concentrating, cough, weight loss, and difficulty swallowing. As with symptom frequency, where significant differences occurred family caregivers tended to over-rate patient symptom severity, with the exception of dry mouth where they under-rated on severity.

On distress, significant differences existed on lack of energy, worrying, feeling sad, feeling nervous, feeling drowsy, dry mouth, difficulty sleeping, difficulty concentrating, shortness of breath, cough, weight loss, and difficulty swallowing. Again, family caregivers tended to significantly over-rate patient symptom distress, with the exception of distress arising from a dry mouth where they under-rated on distress.

On high prevalence physical MSAS symptom items ($n = 12$), significant mean differences between patient and caregiver scores were found on four of 12 individual MSAS symptom measures (i.e., lack of energy, pain, dry mouth, and weight loss). On frequency, significant mean differences were found on lack of energy and dry mouth only. On severity, there were significant differences between patient and caregiver ratings on lack of energy, pain, dry mouth, and weight loss. On distress, patients and caregivers significantly differed on lack of energy, feeling drowsy, dry mouth, and weight loss. Across all dimensions where significant differences occurred, family caregivers provided estimates on patient physical symptom experiences that were higher than patient self-reports. The one exception was with dry mouth where caregivers under-rated patient

frequency, severity, and distress.

On MSAS psychological symptoms ($n = 6$), significant mean differences between patient and caregiver reports were found on five of six individual MSAS symptom measures (i.e., worrying, feeling sad, feeling nervous, difficulty sleeping, and difficulty concentrating). Family caregivers significantly over-reported on patient frequency, severity, and distress on worrying, feeling sad, feeling nervous, difficulty sleeping, and difficulty concentrating. No significant differences in ratings were found on frequency, severity, and distress for the symptom feeling irritable.

Statistical magnitude of bias. As discussed in the above, when the mean of the directional bias was significantly different from zero, this was interpreted as evidence of systematic bias. To examine the statistical magnitude of any observed systematic bias, the mean difference score was standardized by relating this score to its standard deviation. Cohen's (1988) guidelines for effect size (d) calculations for paired observations were employed.

On the total MSAS scale across 32 symptoms, the systematic bias was $d = -0.27$. In other words, family caregivers rated the patients as having more symptom experience than patients themselves. This systematic bias, however, represents a modest degree of bias to over-report on global MSAS ratings provided by family caregivers versus cancer patients themselves.

Where significant differences existed on total MSAS scores for individual symptoms, the most pronounced systematic bias for caregivers to over-report was observed on feeling sad ($d = -0.58$) (moderate bias). The smallest

statistical magnitude of bias for caregivers to over-report ($d = - 0.19$) (small bias) was found on shortness of breath. Dry mouth was the only symptom where there was a moderate bias for caregivers to under-report on total symptom experience and on each separate dimension sub-scale score.

Where significant differences existed on symptom frequency, the largest systematic bias for caregivers to over-report was $d = - 0.58$ (moderate bias) on feeling sad and the lowest systematic bias was $d = - 0.21$ (small bias) on shortness of breath. For symptom severity, the largest systematic bias for caregivers to over-report was $d = - 0.49$ (moderate bias) on feeling sad. The lowest amount of systematic bias was $d = - 0.21$ (small bias) on pain. For symptom distress, the largest systematic bias for caregivers to over-report was $d = - 0.56$ (moderate bias) on feeling sad and the lowest systematic bias was $d = - 0.19$ (small bias) on shortness of breath.

Where significant differences existed on high prevalence physical symptoms, the bias for caregivers to overestimate on total symptom experience ranged from $d = - 0.21$ (pain) to $d = - 0.35$ (lack of energy). For frequency on high prevalence physical MSAS symptoms, the only significant difference occurred on lack of energy where the systematic bias to over-report was $d = - 0.24$ (moderate bias). For severity on physical symptoms, the largest significant systematic bias for caregivers to overestimate was $d = - 0.32$ (low moderate bias) on lack of energy and the smallest was $d = - 0.21$ (small bias) on pain. For distress, the largest systematic bias for caregivers to over-report was $d = - 0.39$ (low moderate bias) on lack of energy and the smallest was $d = - 0.23$ (small

bias) on feeling drowsy.

Where significant differences occurred on five of six psychological symptoms, the bias for caregivers to overestimate on total symptom experience ranged from $d = -0.33$ (difficulty concentrating) to $d = -0.58$ (feeling sad). There was no tendency for family caregivers to significantly under-report on psychological symptoms. For frequency on psychological symptoms, the largest systematic bias was $d = -0.58$ (moderate bias) on feeling sad and the smallest was $d = -0.36$ (low moderate bias) on difficulty concentrating. For severity, the largest systematic bias was $d = -0.49$ (moderate bias) on feeling sad and the smallest systematic bias was $d = -0.25$ (small bias) on difficulty sleeping. For distress, the largest systematic bias was $d = -0.56$ (moderate bias) on feeling sad and the smallest was $d = -0.27$ (small bias) on difficulty concentrating.

Frequency, severity, and distress

The following results are presented in response to the question that asks whether there are any differences and/or associations between patient and family caregiver ratings on the total MSAS symptom scores for frequency, intensity, and distress across 32 symptoms. Table 11 reveals the results of respective statistical analyses. First, it is noted that the ICC results between patient and caregiver reports on the symptom frequency, severity, and distress sub-scales were consistently good (range: 0.63 to 0.69). The highest correlation occurred on the symptom dimension frequency, closely followed by severity and distress. There were no significant differences found among the ICC correlations on patient frequency, severity, and distress (see Table 11).

Table 11

Family caregiver empathic accuracy across 32 symptoms on frequency, severity,**and distress**

Symptom Dimension	n	Mean \pm SD
patient frequency total	87	0.96 (0.57)
family frequency total	87	1.12 (0.58)
patient severity total	87	0.73 (0.45)
family severity total	87	0.84 (0.48)
patient distress total	85	0.77 (0.53)
family distress total	85	0.95 (0.56)

Symptom Dimension	Patient-Family Caregiver correlation	Absolute difference ^a		Directional difference ^b	
		Mean \pm SD	Mean \pm SD	d ^c	
	ICC (p)				
frequency	0.69 (0.00) ^{d,e}	0.37 (0.31) ^{g,h}	-0.15 (0.45)*		-0.33
severity	0.66 (0.00) ^f	0.29 (0.26) ⁱ	-0.11 (0.38)*		-0.29
distress	0.63 (0.00)	0.36 (0.34)	-0.18 (0.46)*		-0.39

^aAbsolute difference between patient and family caregiver neutral instructional set scores across 32 symptoms

^bDifference between patient and family caregiver mean neutral scores; Wilcoxon matched-pairs signed rank tests; (Patient score minus family caregiver score)

^cStandardized difference $d = \text{mean difference} / \text{standard deviation of difference}$ ($d = 0.2$ small, $d = 0.5$ moderate, $d = 0.8$ large difference)

^dNon significant difference in ICC coefficients between frequency and severity across 32 MSAS symptom items ($z = 0.42$; $p = 0.68$)

^eNon significant difference in ICC coefficients between frequency and distress across 32 MSAS symptom items ($z = 0.85$; $p = 0.40$)

^fNon significant difference in ICC coefficients between severity and distress across 32 MSAS symptom items ($z = 0.39$; $p = 0.70$)

^gSignificant difference in empathic accuracy scores between frequency and severity across 32 MSAS symptom items ($z = -3.751$; $p = 0.00$); Bonferroni correction ($p \leq 0.025$)

^hNon significant difference in empathic accuracy scores between frequency and distress across 32 MSAS symptom items ($z = -0.64$; $p = 0.52$); Bonferroni correction ($p \leq 0.025$)

ⁱSignificant difference in empathic accuracy scores between severity and distress across 32 MSAS symptom items ($z = -3.27$; $p = 0.001$); Bonferroni correction ($p \leq 0.025$)

* $p \leq 0.05$

In terms of the degree of absolute mean difference (empathic accuracy) between dyad members, the largest discrepancy occurred on the dimension frequency, closely followed by distress. The smallest absolute difference score occurred on the symptom dimension severity. The Friedman's test for differences ($\chi^2 = 14.543$, $df = 2$, $p = 0.00$) followed by Wilcoxon matched-pairs signed rank test revealed that significant differences existed between discrepancy scores on frequency (mean = 0.37) and severity (mean = 0.29), and between severity (mean = 0.29) and distress (mean = 0.36). No significant differences existed between the discrepancy scores for frequency (mean = 0.37) and distress (mean = 0.36).

Taking into account the degree of directional difference, significant differences occurred between patient-family caregiver ratings on each of the symptom dimensions. Family caregivers significantly over-rated patient symptom frequency, severity, and distress. However, the statistical magnitude of this systematic bias was the largest for distress ($d = -0.39$), closely followed by frequency ($d = -0.33$) and severity ($d = -0.29$). These results tend to suggest that family caregivers might achieve better empathic accuracy (i.e., least discrepancy) and report the smallest amount of bias on symptom severity in comparison to symptom frequency and distress.

Physical and psychological symptoms

Table 12 reveals analyses that explored differences and associations between total MSAS scores for high prevalence physical symptoms and MSAS psychological symptoms. The ICC results revealed that patient and caregiver

Table 12

Family caregiver empathic accuracy on high prevalence MSAS physical symptoms (n = 12) and MSAS psychological symptoms (n = 6)

Symptom Nature	n	Mean \pm SD
patient physical total	92	0.94 (0.64)
family physical total	92	0.96 (0.67)
patient psychological total	94	1.09 (1.47)
family psychological total	94	1.42 (0.83)

Symptom Nature	Patient-Family Caregiver correlation	Absolute difference ^a		
		Mean \pm SD	Directional difference ^b	d ^c
	ICC (p)	Mean \pm SD	Mean \pm SD	d ^c
physical	0.68 (0.00) ^d	0.39 (0.35) ^e	-0.02 (0.52)	-0.10
psychological	0.32 (0.00)	0.77 (1.12)	-0.34 (1.32) ^e	-0.25

^aAbsolute difference between patient and family caregiver neutral instructional set scores

^bDifference between patient and family caregiver neutral scores; Wilcoxon matched-pairs signed rank tests; (Patient score minus family caregiver score)

^cStandardized difference $d = \text{mean difference} / \text{standard deviation of difference}$ ($d = 0.2$ small, $d = 0.5$ moderate, $d = 0.8$ large difference)

^dSignificant difference in ICC coefficients between physical and psychological MSAS symptoms across 32 MSAS symptom items ($z = 5.71$; $p = 0.00$)

^eSignificant difference in absolute difference scores between physical and psychological MSAS symptoms across 32 MSAS symptom items ($z = -4.88$; $p = 0.00$)

* $p \leq 0.05$

reports on the physical symptoms were more highly correlated (ICC = 0.68) in comparison to their reports on psychological symptoms (ICC = 0.32). Table 12 also reveals that there is a statistical difference between patient-family caregiver ICC ratings on physical and psychological symptoms.

Furthermore, the absolute difference between dyad member reports was significantly less on the physical symptom sub-group versus the psychological symptom sub-group (see Table 12). The differences in mean ratings between patients and caregivers were not significant for the physical symptom sub-grouping, but caregivers significantly over-reported on patient symptom experience for the psychological sub-grouping. The amount of systematic bias for family caregivers to over-report was small on psychological MSAS symptoms. These results tend to suggest that family caregivers might achieve better empathic accuracy (i.e., least absolute mean difference scores) and report a scant amount of bias on physical symptoms as measured on the MSAS in comparison to psychological symptom items.

Research Question #3

Are there differences and/or associations between family caregiver estimates in the 'neutral control' condition and their estimates on their own hypothetical total symptom experience for 'lack of energy' and 'worrying' in the 'imagine-self' condition?

Research Question #4

Are there differences and/or associations between family caregiver

estimates in the 'neutral control' condition and their reports on their own total symptom experience for 'lack of energy' and 'worrying' in their current life situation (that is, their self-report)?

Research Question #5

Are there differences and/or associations between family caregiver estimates in the 'neutral control' condition and their estimates on patient total symptom experience for 'lack of energy' and 'worrying' in the 'imagine-other' condition?

Lack of energy

In an attempt to determine whether family caregivers (n = 98) were sensitive to seeing the patient's total symptom experience from the patient's or their own point of view, the following results were found on 'lack of energy' (see Table 13). First, the Friedman's test revealed that significant differences existed among the instructional set group mean scores ($\chi^2 = 70.693$, df 3, $p = 0.00$). The Wilcoxon matched-pairs signed rank test (with a Bonferroni correction; $p \leq 0.02$) found no significant difference between the caregiver's neutral control mean score on patient symptom experience (2.34) and his or her imagine-other mean score (2.37) ($z = -0.324$, $p = 0.75$). The caregiver neutral control score was, however, significantly lower than his or her imagine-self mean score (2.77) ($z = -2.978$, $p = 0.00$) and significantly higher than the caregiver self-report mean score (1.46) ($z = -5.439$, $p = 0.00$). Therefore, when caregivers were instructed in the neutral control condition to report on patient 'lack of energy', they appeared to concentrate more on their perception of the patient's viewpoint than

Table 13

Comparison between family caregiver neutral control and other instructional set scores

Symptom/ Instructional Set	n	Family caregiver Instructional set score (Mean \pm SD)	ICC (p)	Absolute Difference (mean; SD) ^a
Lack of Energy				
Neutral	98	2.34 (1.09)		
Self-report	98	1.46 (1.14) [*]	0.26 (0.01) [*]	1.22 (1.06)
Imagine-self	98	2.77 (0.94) [*]	0.29 (0.00) ^{*,b,c}	0.89 (0.93) ^{h,i}
Imagine-other	98	2.37 (0.94)	0.53 (0.00) ^{*,d}	0.71 (0.69) ^j
Worrying				
Neutral	98	1.85 (1.12)		
Self-report	98	2.40 (1.08) [*]	0.39 (0.00) [*]	0.96 (0.92)
Imagine-self	98	3.07 (0.85) [*]	0.27 (0.00) ^{*,e,f}	1.37 (1.02) ^{k,l}
Imagine-other	98	2.44 (0.98) [*]	0.52 (0.00) ^{*,g}	0.95 (0.71) ^m

^aAbsolute difference between the family caregiver neutral control score and each of the other instructional set scores

^bSignificant difference in ICC coefficients between imagine-self and imagine-other on 'lack of energy'; (z = -4.00; p = 0.00)

^cNon-significant difference in ICC coefficients between imagine-self and self-report on 'lack of energy'; (z = 0.5; p = 0.62)

^dSignificant difference in ICC coefficients between imagine-other and self-report on 'lack of energy' (z = 3.86; p = 0.00)

^eSignificant difference in ICC coefficients between imagine-self and imagine-other on 'worrying' (z = -3.97; p = 0.00)

^fSignificant difference in ICC coefficients between imagine-self and self-report on 'worrying' (z = 2.18; p = 0.03)

^gNon-significant difference in ICC coefficients between imagine-other and self-report on 'worrying' (z = 1.625; p = 0.10)

^hNon-significant difference in absolute difference scores between imagine-self and imagine-other on 'lack of energy' (z = -1.701; p = 0.09); Bonferroni correction (p \leq 0.025)

ⁱSignificant difference in absolute difference scores between imagine-self and self-report on 'lack of energy' (z = -2.376; p = 0.02); Bonferroni correction (p \leq 0.025)

^jSignificant difference in absolute difference scores between imagine-other and self-report on 'lack of energy' (z = -3.664; p = 0.00); Bonferroni correction (p \leq 0.025)

^kSignificant difference in absolute difference scores between imagine-self and imagine-other on 'worrying' (z = -4.146; p = 0.00); Bonferroni correction (p \leq 0.025)

^lSignificant difference in absolute difference scores between imagine-self and self-report on 'worrying' (z = -4.720; p = 0.00); Bonferroni correction (p \leq 0.025)

^mNon-significant difference in absolute difference scores between imagine-other and self-report on 'worrying' (z = -0.172; p = 0.86); Bonferroni correction (p \leq 0.025)

^{*}p \leq 0.02 (Bonferroni correction; 05/3 comparisons); Wilcoxon matched-pairs signed rank test

they did in the imagine-self and the self-report conditions.

Second, in light of the non-significant difference between caregiver imagine-other and neutral control scores, the next set of analyses tested for differentiation between the caregiver imagine-other score and the respective scores obtained in the imagine-self, and self-report groups. The caregiver imagine-other mean score was significantly higher than their response given in the self-report condition ($z = -5.564$, $p = 0.00$), and significantly lower ($z = -3.491$, $p = 0.00$) than their response given in the imagine-self condition. Therefore, it appeared that when caregivers were instructed to imagine the patient's viewpoint, they were able to differentiate between what they perceived to be the patient's experience and their own viewpoint as captured in the imagine-self and self-report conditions.

The ICCs between the caregiver neutral control and the imagine-self (ICC = 0.29) response, and the self-report (ICC = 0.26) conditions were small. However, the ICC was moderate between the caregiver neutral control and the imagine-other (ICC = 0.53) instructional sets. By calculating a z score to determine differences among correlation coefficients, it was noted that the caregiver neutral/imagine-other ICC was significantly different from the caregiver neutral/imagine-self and the caregiver neutral/self-report instructional set ICCs.

The absolute difference mean score on the caregiver neutral/caregiver imagine-other instructional set was the smallest ($m = 0.71$) in comparison to the caregiver neutral/caregiver imagine-self ($m = 0.89$) and the caregiver neutral/self-report ($m = 1.22$) instructional set scores. The Friedman's test revealed that

significant differences on absolute difference mean scores existed among the instructional set groups ($\chi^2 = 9.461$, $df 2$, $p = 0.01$).

The absolute difference mean score on the caregiver neutral/imagine-other instructional set was significantly lower than the absolute difference mean score on the caregiver neutral/self-report instructional set. Although the absolute difference mean score in the caregiver neutral/imagine-other instructional set did appear to be lower than the absolute difference mean score in the caregiver neutral/imagine-self instructional set, the difference between these instructional sets was not significant.

In summary, the findings suggest that the family caregiver's interpretation of patient symptom experience on 'lack of energy' was influenced by an imagine-other perspective-taking activity versus their own experience with the symptom. It would appear that, because the caregiver imagine-other response was (a) strongly correlated with and not significantly different from the caregiver neutral response set and (b) significantly different from the caregiver self-report and imagine-self responses, family caregivers attempted to understand patient 'lack of energy' from the point-of-view of the patient.

Although there was some overlap in absolute difference mean scores between the caregiver imagine-self and imagine-other instructional sets, a subtle difference does exist. Because the absolute difference with the caregiver neutral response was less in the imagine-other instructional set (in comparison to the absolute difference score in the imagine-self instructional set), it appears that caregivers might be influenced more by an imagine-other versus imagine-self

perspective-taking process. Furthermore, the findings suggest that family caregivers did not appear to be projecting their own current 'lack of energy' symptom experience onto their assessments of patient symptom experience.

Worrying

In an attempt to determine whether family caregivers (n = 98) were sensitive to seeing the patient's total symptom experience on worrying from the patient's or their own point of view, the following results are reported (see Table 13). The Friedman's test revealed that significant differences on mean scores existed among the instructional set conditions ($\chi^2 = 91.530$, df 3, $p = 0.00$). The Wilcoxon matched-pairs signed rank test (with Bonferroni correction; $p \leq 0.02$) found that the family caregiver neutral control mean score on patient worrying (1.85) was significantly lower than his or her respective imagine-other (2.44) ($z = -5.287$, $p = 0.00$), imagine-self (3.07) ($z = -7.20$, $p = 0.00$), and self-report (2.40) ($z = -4.27$, S.D. = 0.00) mean scores (see Table 13). Additional analysis revealed that the caregiver self-report mean score was not significantly different from the imagine-other mean score ($z = -0.57$, $p = 0.57$). Based on this sole analysis of mean differences, it appears that family caregivers did not engage in any perspective-taking or projection mechanisms to interpret patient 'worrying'.

However, there were fair ICCs found between the caregiver neutral control and imagine-self (ICC = 0.27), and the caregiver self-report (ICC = 0.39) responses. There was a moderate ICC found between the caregiver neutral control and imagine-other instructional set responses (ICC = 0.52). By calculating a z score to determine differences among correlation coefficients, it is

noted that the ICC in the caregiver neutral/imagine-other (ICC = 0.52) was significantly different from the ICC in the caregiver neutral/imagine-self (ICC = 0.27) instructional set. However, the caregiver neutral/imagine-other ICC (0.52) was not significantly different from the caregiver neutral/self-report ICC (0.39).

The absolute difference mean score on the caregiver neutral control/imagine-other instructional set was the smallest (0.95) in comparison to the caregiver neutral/imagine-self (1.37) and the caregiver neutral/self-report (0.96) instructional set mean scores. The Friedman's test revealed that significant differences on absolute difference scores existed among the instructional set groups ($\chi^2 = 27.153$, $df = 2$, $p = 0.00$).

The absolute difference mean score on the caregiver neutral/imagine-other instructional set (0.95) was significantly lower than the absolute difference mean score in the caregiver neutral/imagine-self instructional (1.37). However, the caregiver neutral/imagine-other absolute difference mean score (0.95) was not significantly lower than the caregiver neutral/self-report mean score (0.96).

Based on these results, it is difficult to interpret whether the family caregiver's neutral response was influenced by a self- or a patient-oriented viewpoint on worrying. However, based on (a) the high correlation between the family caregiver imagine-other and neutral control responses and (b) the lowest absolute difference mean score (albeit subtle) between the family neutral control and imagine-other response sets, it appears that to a certain degree family caregivers were influenced by a patient-oriented viewpoint. It is plausible that the order of administering the self-focused instructional sets first made it difficult

for family caregivers to provide an 'unbiased' response in the imagine-other instructional set condition. A more complete discussion on this potential confounding effect on caregiver responses will be discussed below.

Research Question #6

Are there differences and/or associations between patient and family caregiver ratings on total symptom experience for 'lack of energy' and 'worrying' in the respective neutral control, self-report, imagine-self, and imagine-other instructional set conditions?

As described earlier, the purpose of this question was to compare caregiver perceptual accuracy on patient 'lack of energy' and 'worrying' total symptom experiences in each of the instructional set conditions. The results pertaining to agreement at the individual level and differences at the group level between patient and family caregiver scores on the MSAS symptoms of 'lack of energy' and 'worrying' in accordance with four differential instruction sets are summarized in Table 14.

Lack of energy

As suggested by earlier findings, family caregivers appear to be influenced by a patient-oriented viewpoint when they assessed patient total symptom experience on 'lack of energy'. As addressed in this question, the next step was to compare the level of empathic accuracy that caregivers achieved in each of the instructional sets.

The Friedman's test revealed that significant differences existed among the instructional set group mean scores ($\chi^2 = 71.933$, $df = 4$, $p = 0.00$). The

Table 14

Comparison between patient neutral control and family caregiver instructional set scores

Symptom/ Instructional Set	n	Instructional set scores (Mean ± SD)	ICC (p)	Absolute Difference ^a (mean; SD)
Lack of Energy				
Patient Neutral	98	1.93 (1.29)		
Family caregiver #1 Neutral	98	2.34 (1.09)*	0.51 (0.00) ^{b,c,d}	0.92 (0.86) ^{n,o,p}
#2 Self-report	98	1.46 (1.14)*	0.25 (0.01)	1.18 (1.02)
#3 Imagine-self	98	2.77 (0.94)*	0.25 (0.01) ^{e,f}	1.16 (1.13) ^{q,r}
#4 Imagine-other	98	2.37 (0.94)*	0.49 (0.00) ^g	0.87 (0.86) ^s
Worrying				
Patient Neutral	98	1.24 (1.30)		
Family caregiver #1 Neutral	98	1.85 (1.12)*	0.39 (0.00) ^{h,i,j}	1.12 (0.96) ^{u,v}
#2 Self-report	98	2.40 (1.08)*	0.13 (0.10)	1.58 (1.15)
#3 Imagine-self	98	3.07 (0.85)*	0.05 (0.33) ^{k,l}	1.99 (1.28) ^{w,x}
#4 Imagine-other	98	2.44 (0.98)*	0.30 (0.00) ^m	1.45 (1.11) ^y

Note: Group #1 - patient neutral and caregiver neutral responses; Group #2 - patient neutral and caregiver self-report responses; Group #3 - patient neutral and caregiver imagine-self responses; Group #4 - patient neutral and caregiver imagine-other responses

^aAbsolute difference between patient 'neutral' and family caregiver instructional set scores (empathic accuracy scores)

^bSignificant difference in ICC coefficients between groups #1 and #2 on 'lack of energy'; (z = 3.71; p = 0.00)

^cSignificant difference in ICC coefficients between groups #1 and #3 on 'lack of energy'; (z = 3.71; p = 0.00)

^dNon-significant difference in ICC coefficients between groups #1 and #4 on 'lack of energy' (z = 0.26; p = 0.80)

^eSignificant difference in ICC coefficients between groups #3 and #4 on 'lack of energy' (z = - 3.43; p = 0.00)

^fNon-significant difference in ICC coefficients between groups #3 and #2 on 'lack of energy' (z = 0; p = 1.00)

^gSignificant difference in ICC coefficients between groups #2 and #4 on 'lack of energy' (z = 3.43; p = 0.00)

^hSignificant difference in ICC coefficients between groups #1 and #2 on 'worrying' (z = 4.73; p = 0.00)

ⁱSignificant difference in ICC coefficients between groups #1 and #3 on 'worrying' (z = 6.18; p = 0.00)

^jNon-significant difference in ICC coefficients between groups #1 and #4 on 'worrying' (z = 1.429; p = 0.15)

^kSignificant difference in ICC coefficients between groups #3 and #4 on 'worrying' (z = -4.55; p = 0.00)

^lNon-significant difference in ICC coefficients between groups #2 and #3 on 'worrying' (z = - 1.78 p = 0.08)

^mSignificant difference in ICC coefficients between groups #2 and #4 on 'worrying' (z = 3.09; p = 0.00)

ⁿNon-significant difference in absolute difference scores between groups #1 and #2 on 'lack of energy' (z = - 2.16; p = 0.03); Bonferroni correction (p ≤ 0.02)

^oNon-significant difference in absolute difference scores between groups #1 and #3 on 'lack of energy' (z = 1.66; p = 0.10); Bonferroni correction (p ≤ 0.02)

^pNon-significant difference in absolute difference scores between groups #1 and #4 on 'lack of energy' (z = - 0.82; p = 0.41); Bonferroni correction (p ≤ 0.02)

^qSignificant difference in absolute difference scores between groups #3 and #4 on 'lack of energy' (z = - 2.27; p = 0.02); Bonferroni correction (p ≤ 0.02)

^rNon-significant difference in absolute difference scores between groups #2 and #3 on 'lack of energy' (z = - 0.30; p = 0.76); Bonferroni correction (p ≤ 0.02)

^sSignificant difference in absolute difference scores between groups #2 and #4 on 'lack of energy' (z = - 2.26; p = 0.02); Bonferroni correction (p ≤ 0.02)

'Significant difference in absolute difference scores between groups #1 and 2 on 'worrying' (z = - 3.96; p = 0.00); Bonferroni correction (p ≤ 0.02)

'Significant difference in absolute difference scores between groups #1 and #3 on 'worrying' (z = - 5.97; p = 0.00); Bonferroni correction (p ≤ 0.02)

'Significant difference in absolute difference scores between groups #1 and #4 on 'worrying' (z = 3.19; p = 0.00); Bonferroni correction (p ≤ 0.02)

'Significant difference in absolute difference scores between groups #3 and #4 on 'worrying' (z = - 4.84; p = 0.00); Bonferroni correction (p ≤ 0.02)

'Significant difference in absolute difference scores between groups #2 and #3 on 'worrying' (z = - 4.91; p = 0.00); Bonferroni correction (p ≤ 0.02)

'Non-significant difference in absolute difference scores between #2 and #4 on 'worrying' (z = - 1.37; p = 0.17); Bonferroni correction (p ≤ 0.02)

***p ≤ 0.01; Bonferroni correction (0.5/4 comparisons); Wilcoxon matched-pairs signed rank tests**

Wilcoxon matched-pairs signed rank test (with a Bonferroni correction; $p \leq 0.01$) found the caregiver neutral control (2.34) ($z = - 2.70$, $p = 0.01$), imagine-self (2.77) ($z = - 5.0$, $p = 0.00$), and imagine-other (2.37) ($z = - 3.23$, $p = 0.00$) mean instructional set responses to be significantly higher than the patient's mean self-report (1.93) on 'lack of energy'. On the other hand, family caregivers reported on average that their own 'lack of energy' mean symptom experience (1.46) was significantly less than the patient's mean self-report (1.93) ($z = - 3.04$, $p = 0.00$).

Overall, when the caregivers were given the neutral control instructions versus the other instructional sets, they appeared to be more objective in relation to the patient's mean score (albeit significantly different). It was also found that, of the two perspective-taking manipulations, the family caregiver's mean score in the imagine-other condition approximated the patient's mean score better than the caregiver's imagine-self mean score.

There were fair ICCs between the patient self-report and the caregiver imagine-self (ICC = 0.25), and between the patient self-report and the caregiver self-report (ICC = 0.25) instructional sets. The ICC between the patient self-report and caregiver neutral control (ICC = 0.51), and between the patient self-report and the caregiver imagine-other (ICC = 0.49) response sets were moderate.

By calculating a z score to determine differences among correlation coefficients, it was found that there was no significant difference between the respective patient neutral/caregiver neutral (Group #1, ICC = 0.51) and the patient neutral/caregiver imagine-other (Group #4, ICC = 0.49) ICC correlations

(see Table 14). However, significant differences existed between the patient neutral/caregiver neutral (Group# 1, ICC = 0.51) and the patient neutral/caregiver self report (Group #2, ICC = 0.25), and between the patient neutral/caregiver neutral (Group #1, ICC = 0.51) and the patient neutral/caregiver imagine-self (Group #3, ICC = 0.25) ICC correlations. Furthermore, significant differences also were found between the patient neutral/caregiver imagine-other (Group #4, ICC = 0.49) and the patient neutral/caregiver imagine-self (Group #3, ICC = 0.25), and between the patient neutral/caregiver imagine-other (Group #4, ICC = 0.49) and the patient neutral/caregiver self-report (Group #2, ICC = 0.25) ICC correlations.

The absolute difference mean score in the patient neutral/caregiver imagine-other instructional set was the smallest (0.87) in comparison to the patient neutral/caregiver neutral (0.92), patient neutral/caregiver imagine-self (1.16), and patient neutral/caregiver self-report (1.18) instructional set mean scores. The Friedman's test revealed that significant differences on absolute difference mean scores existed among the instructional set groups ($\chi^2 = 8.015$ with 3 df, $p = 0.05$).

The Wilcoxon matched-pairs signed rank test (with a Bonferroni correction; $p \leq 0.02$) was conducted to determine where the differences existed. There were no significant differences on the absolute difference mean scores between the patient neutral/caregiver neutral (Group #1) and (a) the patient neutral/caregiver self-report (Group #2), (b) the patient neutral/caregiver imagine-self (Group #3), and (c) the patient neutral/caregiver imagine-other (Group #4)

instructional sets. Although not statistically significant, the absolute difference mean score in the patient neutral/caregiver imagine-other instructional set (0.87) was lower (albeit subtle) than the absolute difference mean score in the patient neutral/caregiver neutral (0.92) instructional set. Furthermore, the absolute difference mean score in the patient neutral/caregiver imagine-other (Group #4) instructional set was significantly lower than the absolute difference mean scores in the patient neutral/imagine-self (Group #3) and the patient neutral/caregiver self-report (Group #2) instructional sets.

First, based on earlier findings, family caregivers appear to have attempted to perceive the patient's total symptom experience on 'lack of energy' from the patient's viewpoint. However, in terms of the level of accuracy attained in each of the instructional sets, there were no significant differences in comparison to the level of accuracy attained in the caregiver neutral control set. Subsequent analyses found that neither of the perspective-taking instructional sets had a statistically significant effect in helping the family caregiver to achieve improved empathic accuracy (or less discrepancy) on patient total symptom experience for 'lack of energy' (i.e., there were no significant differences in empathic accuracy scores found across the instructional sets in comparison to the patient neutral/caregiver neutral instructional set accuracy score). Regardless, the empathic accuracy score in the patient neutral/caregiver imagine-other instructional set (Group #4) was (a) non-significantly lower than the empathic accuracy score in the patient neutral/caregiver neutral instructional set (Group #1) and (b) significantly lower than the respective empathic accuracy

scores in the patient neutral/caregiver imagine-self (Group #3), and the patient neutral/self-report (Group #2) instructional sets. These results suggest that family caregivers who engage in imagine-other perspective-taking on 'lack of energy' can achieve an enhanced level of empathic accuracy (a difference of less than one unit) in comparison to each of the other instructional sets, including the caregiver neutral control empathic accuracy score.

Worrying

Although it appeared in earlier findings that family caregivers were somewhat influenced by a patient viewpoint, it remains difficult to distinguish the respective influences of caregiver self-report and imagine-other viewpoints on caregiver neutral control responses for 'worrying'. In other words, while there appeared to be a difference in the respective relationships between the caregiver neutral response and their responses given in the imagine-other and self-report instructional sets, the difference was rather subtle and the overlap was notable. However, this next question was designed to compare the level of empathic accuracy that family caregivers achieved on patient total symptom experience for 'worrying' in each of the four instructional set conditions.

The Friedman's test revealed that significant differences existed among the instructional set group mean scores ($\chi^2 = 132.081$, $df = 4$, $p = 0.00$). Based on the Wilcoxon matched-pairs signed rank test (with a Bonferroni correction; $p < 0.01$), it is noted that the caregiver neutral control (1.85) ($z = -4.05$, $p = 0.00$), imagine-self (3.07) ($z = -7.71$, $p = 0.00$), imagine-other (2.44) ($z = -6.66$; $p = 0.00$), and self-report (2.40) ($z = -5.92$, $p = 0.00$) instructional set mean

responses were all significantly higher than the patient's mean self-report on 'worrying' (1.24). Of all the instructional set scores, the caregiver neutral control mean score was the closest to the patient's self-report on 'worrying' (see Table 14).

There were fair ICCs found between the patient self-report and the caregiver neutral (ICC = 0.39), and the patient self-report and the caregiver imagine-other (ICC = 0.30) response sets. However, the ICCs for the respective caregiver self-report and imagine-self response sets with the patient self-report were non-significant. By calculating a z score, there was no significant difference found between the respective patient neutral/caregiver neutral (Group #1) and the patient neutral/caregiver imagine-other (Group #4) ICC correlations (see Table 14).

The absolute difference mean score in the patient neutral/caregiver neutral instructional set was the smallest (1.12) in comparison to the patient neutral/caregiver imagine-other (1.45), patient neutral/caregiver self-report (1.58), and patient neutral/caregiver imagine-self (1.99) instructional set mean scores. The Friedman's test revealed that significant differences on absolute difference mean scores existed among the instructional sets ($\chi^2 = 51.312$ with 3 df, $p = 0.00$).

Based on Wilcoxon matched-pairs signed rank test (with a Bonferroni correction; $p \leq 0.02$) there were significant differences on the absolute difference mean scores between the patient neutral/caregiver neutral (Group #1) and each of the other instructional sets, with the exception of the patient neutral/caregiver

imagine-other set where there was no significant difference with the patient neutral/caregiver self-report absolute difference mean score. There was a significant difference between the patient neutral/caregiver imagine-other and the patient neutral/caregiver imagine-self instructional set absolute difference mean scores.

Based on earlier findings, it is difficult to determine whether the family caregiver's neutral response set on 'worrying' was influenced by imagine-other perspective-taking or by projection of one's own symptom experience. In terms of the level of empathic accuracy attained in each of the instructional sets, the caregiver neutral control set was the most effective in prompting caregivers to provide the least discrepant estimation on patient 'worrying'. Neither of the perspective-taking instructional sets had a statistically significant effect in helping the family caregiver to achieve improved empathic accuracy (less discrepancy) on patient total symptom experience for 'worrying' (i.e., there were significantly worse empathic accuracy scores across the instructional sets in comparison to the patient neutral/caregiver instructional set). All instructional sets produced a discrepancy score that was greater than one (on a theoretical range of absolute differences between 0 and 4). This finding is presented in contrast to the 'lack of energy' condition, where both the patient neutral/caregiver neutral and the patient neutral/caregiver imagine-other instructional sets produced absolute difference scores that were less than one.

Of the two perspective-taking manipulations, the imagine-other manipulation appeared more assistive in helping caregivers to achieve better

empathic accuracy (significantly less discrepant with the patient's self-report) than the imagine-self instructional set. But the patient neutral/caregiver imagine-other absolute difference score was not significantly lower than the patient neutral/caregiver self-report absolute difference score. This suggests that the caregiver's response in the imagine-other instructional set was potentially influenced by his or her own actual experience with worrying.

As mentioned earlier, it is important to consider the demand placed on caregivers who were asked to respond to self-oriented instructional sets prior to the patient-oriented set. In light of the lack of differentiation in empathic accuracy scores between the imagine-other and self-report response sets on worrying, there is the suspicion that it was difficult for family caregivers to differentiate between their own emotional viewpoint and the patient's viewpoint.

Summary (main group analyses)

First, family caregivers appeared to be influenced to a certain degree by a patient-oriented viewpoint on 'lack of energy' and 'worrying'. However, there was a lack of differentiation or considerable overlap between the respective influences of the self-report and imagine-other responses by caregivers in their neutral control responses in the 'worrying' instructional set condition. On the other hand, the caregivers' imagine-other perspective-taking responses had a more differentiated association with the caregiver's neutral assessment on patient 'lack of energy' in comparison to the other instructional sets.

Second, the following is a summary of the level of family caregiver empathic accuracy achieved on patient total symptom experience for 'lack of

energy' and 'worrying' in the respective instructional sets. First, it appears that the interpretative processes employed by family caregivers in the neutral control set (where they were not induced to perspective-take) were most effective in helping them to achieve accuracy on the psychological symptom of worrying. The provision of instructions to 'imagine-other' and 'imagine-self' perspective-take created greater discrepancies between the caregivers' respective responses to these instructional sets and the patient's self-report on worrying.

On 'lack of energy', the level of family caregiver accuracy in each of the instructional sets indicates that there were no significant differences among the instructional set responses. Induced perspective-taking activities were not significantly effective in improving caregiver empathic accuracy on patient total symptom experience. However, in comparison to the accuracy scores obtained in the induced imagine-self set, the imagine-other instructional set did not deter caregivers from achieving enhanced empathic accuracy on 'lack of energy'.

Research Question #7

When family caregivers over-report patient total symptom experience on 'lack of energy' and 'worrying', do their estimates relate to their own total symptom experience for 'lack of energy' and 'worrying' in the 'imagine-self' instructional set conditions?

The main purpose of this question was to determine more precisely whether family caregivers' overestimates on patient total symptom experience in the 'neutral control' set were influenced by their own viewpoint (imagine-self). In accordance with Wright's (1983) empathic 'requirement of mourning' hypothesis,

it is suggested that caregiver overestimation is associated with an assumption of their own symptom experience if they were in the patient's situation. Additional analyses included a comparison of the caregiver neutral control response with the caregiver responses provided in the self-report and imagine-other perspective-taking conditions.

Lack of energy

Table 15 shows that 51 of 98 (52%) caregivers provided mean ratings that were higher (significantly and non-significantly) than patient mean self-reports on total symptom experience for 'lack of energy'. Thirteen of 98 (13%) caregivers provided mean ratings that were equal to patient ratings; 34 of 98 (35%) caregivers provided mean ratings that were lower than patient self-reports on 'lack of energy'.

First, the Friedman's test revealed that significant differences in mean scores existed among the instructional set conditions ($\chi^2 = 36.799$, $df = 3$, $p = 0.00$). Based on the Wilcoxon matched-pairs signed rank test (with a Bonferroni correction; $p \leq 0.02$), there were significant differences between the caregiver mean neutral control score (2.81) and caregiver mean scores in the imagine-other (2.42) ($z = -3.076$, $p = 0.00$), and the self-report (1.57) ($z = -4.991$, $p = 0.00$) instructional set conditions. However, there was no significant mean difference between the caregiver's neutral control report (2.81) and his or her imagine-self (2.76) score ($z = -0.514$, $p = 0.61$). Therefore it appears that, when this sub-group of caregivers were asked to report on patient 'lack of energy' in the neutral control set, they concentrated more on their own hypothesized

Table 15

Comparison of caregiver subgroup neutral scores and instructional set scores

Symptom/ Instructional Set	n	Family caregiver instructional set score (Mean \pm SD)	ICC (p)	Absolute Difference ^a (mean; SD)
Lack of Energy				
Neutral	51	2.81 (0.79)		
Self-report	51	1.57 (0.19)*	0.11 (0.23)	1.47 (1.10)
Imagine-self	51	2.76 (0.96)	0.49 (0.00) ^{b,c}	0.69 (0.55) ^{h,i}
Imagine-other	51	2.42 (0.95)*	0.49 (0.00) ^d	0.70 (0.66) ^j
Worrying				
Neutral	52	2.33 (0.75)		
Self-report	52	2.62 (0.82)	0.19 (0.09)	0.83 (0.62)
Imagine-self	52	3.19 (0.80)*	0.08 (0.28) ^{e,f}	1.12 (0.77) ^{k,l}
Imagine-other	52	2.55 (1.06)	0.47 (0.00) ^g	0.77 (0.59) ^m

^aAbsolute difference between the family caregiver's 'neutral control' set score and each of the other instructional set scores

^bNon-significant difference in ICC coefficients between imagine-self and imagine-other on 'lack of energy'; (z = 0.00; p = 1.00)

^cSignificant difference in ICC coefficients between imagine-self and self-report on 'lack of energy'; (z = 6.03; p = 0.00)

^dSignificant difference in ICC coefficients between imagine-other and self-report on 'lack of energy' (z = 6.03; p = 0.00)

^eSignificant difference in ICC coefficients between imagine-self and imagine-other on 'worrying' (z = 4.17; p = 0.00)

^fNon-significant difference in ICC coefficients between imagine-self and self-report on 'worrying' (z = -1.83; p = 0.07)

^gSignificant difference in ICC coefficients between imagine-other and self-report on 'worrying' (z = 4.00; p = 0.00)

^hNon-significant difference in absolute difference scores between imagine-self and imagine-other on 'lack of energy' (z = -0.01; p = 0.99); Bonferroni correction (p \leq 0.025)

ⁱSignificant difference in absolute difference scores between imagine-self and self-report on 'lack of energy' (z = -4.01; p = 0.00); Bonferroni correction (p \leq 0.025)

^jSignificant difference in absolute difference scores between imagine-other and self-report on 'lack of energy' (z = -3.74; p = 0.00); Bonferroni correction (p \leq 0.025)

^kSignificant difference in absolute difference scores between imagine-self and imagine-other on 'worrying' (z = -2.97; p = 0.00); Bonferroni correction (p \leq 0.025)

^lSignificant difference in absolute difference scores between imagine-self and self-report on 'worrying' (z = -3.13; p = 0.00); Bonferroni correction (p \leq 0.025)

^mNon-significant difference in absolute difference scores between imagine-other and self-report on 'worrying' (z = -0.58; p = 0.56); Bonferroni correction (p \leq 0.025)

*p \leq 0.02 (Bonferroni correction; 05/3 comparisons); Wilcoxon matched-pairs signed rank test

experience when diagnosed with the patient's condition than they did in the imagine-other and self-report instructional sets.

Second, in light of the non-significant difference between the caregivers' imagine-self and neutral control mean scores, the next set of analyses tested for differentiation between the caregivers' imagine-self scores and their respective scores obtained in the imagine-other, and self-report instructional sets.

Additional analysis revealed that the mean score in the imagine-self group was significantly higher than the imagine-other group mean score ($z = -1.938$; $p = 0.05$) and significantly higher than the self-report group mean score ($z = -5.230$; $p = 0.00$). In other words, when the caregivers were instructed to imagine their own 'lack of energy' when diagnosed with the patient's condition, they reported higher levels of total symptom experience than when they imagined the patient's point-of-view and when they reported on their own 'lack of energy'.

There were significant moderate ICCs between the caregiver neutral control and the imagine-self ($ICC = 0.49$), and the imagine-other ($ICC = 0.49$) instructional set responses. However, there was no significant association between the caregiver neutral control and self-report ($p = 0.23$) instructional sets. In accordance with the z score test for differences, the caregiver neutral/caregiver imagine-other instructional set ICC was not significantly different from the caregiver neutral/caregiver imagine-self instructional set.

The absolute mean difference in the caregiver neutral control/caregiver imagine-self condition was the lowest ($m = 0.69$) in comparison to the caregiver neutral/caregiver imagine-other ($m = 0.70$) and the caregiver neutral/caregiver

self-report ($m = 1.47$) instructional set mean scores. The Friedman's test for differences revealed that significant differences existed among the instructional set absolute difference scores (Chi-square = 14.237; $df = 2$; $p = 0.00$).

Subsequent Wilcoxon matched-pairs signed rank tests (with a Bonferroni correction; $p < 0.025$) revealed that the absolute difference score on the caregiver neutral/caregiver self-report instructional set was significantly higher than both the caregiver neutral/caregiver imagine-self and the caregiver neutral/caregiver imagine-other instructional set absolute difference scores. However, the absolute difference scores between the caregiver neutral/caregiver imagine-self and the caregiver neutral/caregiver imagine-other instructional sets were not significantly different.

Based on these results, it appears that family caregivers who overestimated on patient total symptom experience for 'lack of energy' based their interpretation on some type of perspective-taking activity. However, the differentiation between the two perspective-taking conditions is not clear. Although there was some difference in the relationship between the caregiver neutral control and the two imagine responses (i.e., mean response scores), the difference was subtle and the overlap was notable (i.e., ICC results). Regardless, it seems that caregivers who overestimate do not project their own self-reports onto their estimates of patient total symptom experience for 'lack of energy'.

Worrying

Table 15 shows that 52 of 98 (53%) caregivers provided mean ratings that

were higher (significantly and non-significantly) than patient self-reports for total symptom experience on 'worrying'. Seventeen of 98 (17%) caregivers provided mean ratings that were equivalent to patient ratings; 29 of 98 (30%) caregivers provided mean ratings that were lower than patient self-reports on 'worrying'.

The Friedman's test revealed that significant differences on mean scores existed among the instructional set conditions ($\chi^2 = 34.285$, $df = 3$, $p = 0.00$). Subsequent Wilcoxon matched-pairs signed tests (with a Bonferroni correction; $p \leq 0.02$) revealed that there were no significant differences in mean scores between the caregiver neutral control (2.33) and the self-report (2.62) ($z = -2.042$, $p = 0.04$), and imagine-other (2.55) ($z = -1.965$, $p = 0.05$) instructional sets on worrying. However, a significant difference in mean scores was found between the neutral control and the imagine-self (3.19) ($z = -4.60$, $p = 0.00$) instructional sets.

Although it would appear that the mean score in the imagine-other condition (2.55) was closely approximated to the neutral control set score (2.33), it was also somewhat similar to the caregiver's score in the self-report condition (2.62). Additional analyses revealed that there was no significant difference between the imagine-other and self-report mean ratings given by family caregivers ($z = -0.163$; $p = 0.87$). However, the caregiver imagine-other mean score was significantly different from the caregiver imagine-self mean score ($z = -3.553$, $p = 0.00$).

Second, the ICCs for the caregiver neutral/caregiver imagine-self ($p = 0.28$) and the caregiver neutral/caregiver self-report ($p = 0.09$) instructional sets

were non-significant. The only significant ICC occurred on the caregiver neutral/caregiver imagine-other instructional set (ICC = 0.47).

The absolute difference mean score appeared to be the smallest in the caregiver neutral/caregiver imagine-other instructional set (0.77), followed by the caregiver neutral/caregiver self-report (0.83) and the caregiver neutral/caregiver imagine-self (1.12) absolute difference mean scores. The Friedman's test revealed that significant differences existed among the three instructional sets ($\chi^2 = 8.897$; $df = 2$; $p = 0.01$).

In accordance with the Wilcoxon matched-pairs signed rank test, the absolute difference mean score in the caregiver neutral/caregiver imagine-other instructional set (0.77) was significantly lower than the absolute difference mean score in the caregiver neutral/caregiver imagine-self (1.12) instructional set. However, no significant difference in absolute difference mean scores was found between the caregiver neutral/caregiver imagine-other (0.77) and the caregiver neutral/caregiver self-report (0.83) instructional set conditions. Furthermore, the caregiver neutral/caregiver imagine-self (1.12) absolute difference mean score was significantly higher than the caregiver neutral/caregiver self-report (0.83) absolute difference score.

Overall, family caregivers who overestimated on patient total symptom experience for 'worrying' appeared to be influenced by an attempt to take the patient's viewpoint. However, the findings also suggest that caregivers' imagine-other responses were influenced by their own symptom situation on worrying (self-report), which might have resulted in their inflated responses in the imagine-

other condition. In other words, the caregivers' own experiences with worrying might have provided an informational base for them to imagine how the patient feels based on their own viewpoint on worrying.

Research Question #8

Are family caregivers (who overestimate) able to achieve enhanced empathic accuracy on patient total symptom experience for 'lack of energy' and 'worrying' when they are induced to imagine the patient's viewpoint?

The main purpose of this question was to determine the effect of an imagine-other instructional set on the empathic accuracy scores of caregivers who overestimated on the respective patient 'lack of energy' and worrying' total symptom experiences. Essentially, this query sought to determine whether two sub-groups of caregivers who overestimated could achieve enhanced empathic accuracy (less discrepant scores with the patient's self-report) when they were induced to imagine the patient's viewpoint. Additional analyses explored how the imagine-other instructional set performed in relation to the other instructional sets. Directional differences in mean scores and ICC correlations among the respective instructional set conditions were also included in the analyses of this question (see Table 16).

As previously described, family caregivers appear to have made an attempt to imagine-other perspective-take on the respective patient 'lack of energy' and 'worrying' total symptom experiences. However, any effort made by family caregivers to imagine the patient's vantage point appears to have been biased by either the caregiver's hypothesized view of how he or she would feel in

Table 16

Induced imagine-other perspective-taking effects on empathic accuracy

Symptom/ Instructional Set	n	Instructional set scores (Mean \pm SD)	ICC (p)	Absolute Difference ^a (mean; SD)
Lack of Energy				
Patient				
Neutral	51	1.54 (1.16)		
Family caregiver				
#1 Neutral	51	2.81 (0.79)*	0.54 (0.00) ^{b,c,d}	1.27 (0.96) ^{n,o,p}
#2 Self-report	51	1.57 (0.19)	0.13 (0.19)	1.17 (1.01)
#3 Imagine-self	51	2.76 (0.96)*	0.26 (0.03) ^{a,f}	1.37 (1.14) ^{q,r}
#4 Imagine- other	51	2.42 (0.95)*	0.45 (0.00) ^g	1.04 (0.96) ^s
Worrying				
Patient				
Neutral	52	0.70 (1.01)		
Family caregiver				
#1 Neutral	52	2.33 (0.75)*	0.50 (0.00) ^{h,i,j}	1.63 (0.89) ^{t,u,v}
#2 Self-report	52	2.62 (0.82)*	0.12 (0.19)	2.00 (1.07)
#3 Imagine-self	52	3.19 (0.80)*	0.06 (0.36) ^{k,l}	2.57 (1.10) ^{w,x}
#4 Imagine- other	52	2.55 (0.82)*	0.22 (0.06) ^m	1.94 (1.14) ^y

Note: Group #1 - patient neutral and caregiver neutral scores; Group #2 - patient neutral and caregiver self-report scores; Group #3 - patient neutral and caregiver imagine-self scores; Group #4 - patient neutral and caregiver imagine-other scores

^aAbsolute difference between patient 'neutral' and family caregiver instructional set scores (empathic accuracy scores)

^bSignificant difference in ICC coefficients between groups #1 and #2 on 'lack of energy'; (z = 5.13; p = 0.00)

^cSignificant difference in ICC coefficients between groups #1 and #3 on 'lack of energy'; (z = 2.95; p = 0.00)

^dNon significant difference in ICC coefficients between groups #1 and #4 on 'lack of energy' (z = 0.9; p = 0.37)

^eSignificant difference in ICC coefficients between groups #3 and #4 on 'lack of energy' (z = -2.02; p = 0.04)

^fNon significant difference in ICC coefficients between groups #2 and #3 on 'lack of energy' (z = -1.69; p = 0.09)

^gSignificant difference in ICC coefficients between groups #2 and #4 on 'lack of energy' (z = -3.86; p = 0.00)

^hSignificant difference in ICC coefficients between groups #1 and #2 on 'worrying' (z = 4.27; p = 0.00)

ⁱSignificant difference in ICC coefficients between groups #1 and #3 on 'worrying' (z = 5.71; p = 0.00)

^jSignificant difference in ICC coefficients between groups #1 and #4 on 'worrying' (z = 3.15; p = 0.00)

^kSignificant difference in ICC coefficients between groups #3 and #4 on 'worrying' (z = -2.54; p = 0.01)

^lNon significant difference in ICC coefficients between groups #2 and #3 on 'worrying' (z = 1.09; p = 0.28)

^mNon significant difference in ICC coefficients between groups #2 and #4 on 'worrying' (z = -1.41; p = 0.16)

ⁿNon significant difference in empathic accuracy scores between groups #1 and 2 on 'lack of energy' (z = -0.31; p = 0.75); Bonferroni correction (p \leq 0.02)

^oNon significant difference in empathic accuracy scores between groups #1 and #3 on 'lack of energy' (z = -0.95; p = 0.34); Bonferroni correction (p \leq 0.02)

^pNon significant difference in empathic accuracy scores between groups #1 and #4 on 'lack of energy' (z = -1.68; p = 0.09); Bonferroni correction (p \leq 0.02)

^qSignificant difference in empathic accuracy scores between groups #3 and #4 on 'lack of energy' (z = -1.94; p = 0.05); Bonferroni correction (p \leq 0.02)

^rNon significant difference in empathic accuracy scores between groups #2 and #3 on 'lack of energy' (z = -1.32; p = 0.19); Bonferroni correction (p \leq 0.02)

*Non-significant difference in empathic accuracy scores between #2 and #4 on 'lack of energy' ($z = -0.71$; $p = 0.48$); Bonferroni correction ($p \leq 0.02$)
†Significant difference in empathic accuracy scores between groups #1 and #2 on 'worrying' ($z = -2.72$; $p = 0.01$); Bonferroni correction ($p \leq 0.02$)
‡Significant difference in empathic accuracy scores between groups #1 and #3 on 'worrying' ($z = -5.12$; $p = 0.00$); Bonferroni correction ($p \leq 0.02$)
§Significant difference in empathic accuracy scores between groups #1 and #4 on 'worrying' ($z = -2.75$; $p = 0.01$); Bonferroni correction ($p \leq 0.02$)
¶Significant difference in empathic accuracy scores between groups #3 and #4 on 'worrying' ($z = -3.94$; $p = 0.00$); Bonferroni correction ($p \leq 0.02$)
**Significant difference in empathic accuracy scores between groups #2 and #3 on 'worrying' ($z = -5.03$; $p = 0.00$); Bonferroni correction ($p \leq 0.02$)
††Non-significant difference in empathic accuracy scores between groups #2 and #4 'worrying' ($z = -0.33$; $p = 0.74$); Bonferroni correction ($p \leq 0.02$)
* $p \leq 0.01$; Bonferroni correction (0.5/4 comparisons); Wilcoxon matched-pairs signed rank tests

the patient's symptom situation (on lack of energy) or the caregiver's own experience with the symptom (on worrying). This next step was an attempt to determine whether these caregivers can achieve better empathic accuracy when they engage in imagine-other perspective-taking in comparison to the other instructional sets.

Lack of energy

The Friedman's test revealed that significant differences on mean scores existed among the instructional sets ($\chi^2 = 74.330$, $df = 4$, $p = 0.00$). In accordance with the Wilcoxon matched-pairs signed rank test (with a Bonferroni correction; $p \leq 0.01$), when caregivers ($n = 51$) were given the neutral control instructions they reported a mean score (2.81) that was significantly higher than the patient self-report mean score (1.54) ($z = -6.217$, $p = 0.00$). However, when they were next administered the self-report instructional set, their mean response (1.57) was not significantly lower than the patient's own viewpoint (1.54) on 'lack of energy' ($z = -0.100$; $p = 0.92$). When caregivers then responded to the imagine-self instructional set, their mean score (2.76) became significantly elevated in comparison to patient's mean self-report (1.54) ($z = -5.156$, $p = 0.00$). When the same group of caregivers were lastly induced to imagine the patient's perspective, their mean rating (2.42) became less than their imagine-self rating (2.76). However, it was still significantly higher than the patient's mean rating (1.54) ($z = -4.698$, $p = 0.00$) (see Table 16).

Overall it appeared that when this sub-group of caregivers ($n = 51$) were given the self-report instructional set they reported a mean score that was most

congruent to the patient mean score. In other words, when they were asked to provide a report on their own symptom experience on 'lack of energy', they appeared to have a similar level of symptom experience as the patient. Significant differences were found between the caregiver self-report and imagine-self ($z = - 5.320$, $p = 0.00$), and the imagine-other ($z = - 3.755$, $p = 0.00$) instructional sets. Although the caregiver imagine-other mean score better approximated the patient mean score in comparison to the imagine-self mean score, both perspective-taking activities resulted in respective mean scores that were significantly different from the patient's self-report on 'lack of energy'.

The ICC between the patient self-report and the caregiver self-report ($p = 0.19$) was non-significant. However, there were significant moderate ICCs between the patient self-report and the caregiver imagine-other (ICC = 0.45), and between the patient self-report and the caregiver neutral control (ICC = 0.54) response sets. The ICC between the patient self-report and the caregiver imagine-self response was 0.26.

By calculating a z score to determine differences among correlation coefficients, it was found that there was a significant difference between the patient neutral/caregiver neutral (Group #1) and the patient neutral/caregiver imagine-self (Group #3) ICCs. However, there was no significant difference between the patient neutral/caregiver neutral (Group #1) and the patient neutral/caregiver imagine-other (Group #4) ICCs. There was a significant difference found between the patient neutral/caregiver imagine-other (Group #4) and the patient neutral/caregiver imagine-self (Group #3) response sets.

The absolute difference mean score between the patient neutral/caregiver imagine-other instructional set was the smallest (1.04) in comparison to the patient neutral/caregiver self-report (1.17), patient neutral/caregiver neutral (1.27), and patient neutral/caregiver imagine-self (1.37) mean instructional set scores. The Friedman's test revealed that no significant differences on absolute difference mean scores existed among the instructional set groups ($\chi^2 = 4.129$, $df = 3$, $p = 0.25$). However, the Wilcoxon matched-pairs signed rank test (with a Bonferroni correlation; $p < 0.02$) found a significant borderline difference ($p = 0.05$) on absolute difference scores between the imagine-self and imagine-other instructional sets.

Overall it appeared that none of the instructional sets had a significantly different effect on family caregiver empathic accuracy scores on patient total symptom experience for 'lack of energy'. However, the patient neutral/caregiver imagine-other instructional set had an empathic accuracy score that was not only lower than the empathic accuracy score in the patient neutral/caregiver neutral control (Group #1) (albeit non-significant), but also significantly lower than the patient neutral/imagine-self (Group #2) and the patient neutral/caregiver self-report (Group #3) (albeit non-significant) instructional sets. Although the results remain inconclusive, they suggest that family caregivers who attempt to understand the patient's 'lack of energy' from the patient's viewpoint can better enhance their level of empathic accuracy (a difference of about one unit on a theoretical range of differences between zero and four) in comparison to an imagine-self or a neutral response stance.

Worrying

Based on earlier analyses, it appeared that family caregivers who overestimated on patient worrying were influenced by an attempt to take the patient's viewpoint on the same symptom. However, the findings suggest that caregivers' imagine-other responses were influenced by their own symptom situation on worrying (self-report) which may have resulted in their inflated responses on the imagine-other condition. The following will determine whether the caregiver can achieve improved empathic accuracy when induced to imagine-other perspective-take in comparison to the other types of inference processes.

The Friedman's test revealed that significant differences on mean scores existed among the instructional sets ($\chi^2 = 103.778$, $df = 4$, $p = 0.00$). In accordance with the Wilcoxon matched-pairs signed rank test, when caregivers ($n = 52$) were given the neutral control instructions they reported a mean score (2.33) that was on average significantly higher than the patient mean score (0.70) ($z = -6.279$, $p = 0.00$). When they were next administered the self-report instructional set their mean response score (2.62) was also significantly higher than the patient's own viewpoint (0.70) ($z = -5.907$, $p = 0.00$). The caregivers then responded to the imagine-self instructional set that resulted in mean scores (3.19) which were significantly elevated in comparison to patient's self-report (0.70) ($z = -6.144$, $p = 0.00$). Of all the mean score instructional set responses, the family caregiver imagine-self report was the most elevated in the 'worrying' condition. However, when the same group of caregivers were lastly induced to

imagine-other perspective-take, their mean rating (2.55) became significantly less ($p = 0.00$) than their imagine-self mean rating (3.19). Nonetheless, the caregiver imagine-other mean score remained significantly higher than the patient's mean rating (0.70) ($z = - 5.774$, $p = 0.00$). Each of the caregiver instructional set mean scores were significantly elevated in comparison to the patient's self-report on 'worrying' total symptom experience (see Table 16).

Overall it appeared that when this sub-group of caregivers ($n = 52$) were given the neutral control instructions, they reported a mean score which was the most congruent to the patient mean score (albeit significantly different) in comparison to the other instructional set scores. Although it appears that the caregiver's imagine-other mean score approximated the patient neutral score better than the caregiver imagine-self mean score, both perspective-taking activities resulted in respective mean scores which were significantly different from the patient's self-report on 'worrying'.

In terms of ICCs, the only significant correlation occurred between the patient self-report and the caregiver's neutral response on 'worrying' (ICC = 0.50). None of the other instructional response sets were significantly correlated with the patient self-report on 'worrying'. However, the caregiver's imagine-other response set approached a level of significant correlation with the patient's self-report on total symptom experience for 'worrying' (ICC = 0.22; $p = 0.06$). By calculating a z score, it was found that there was a significant difference between the respective patient neutral/caregiver neutral (Group #1, ICC = 0.50) and the patient neutral/caregiver imagine-other (Group #4, ICC = 0.22) ICCs.

The absolute difference mean score of the patient neutral/caregiver neutral instructional set was the smallest (1.63) in comparison to the patient neutral/caregiver imagine-other (1.94), patient neutral/caregiver self-report (2.00), and patient neutral/caregiver imagine-self (2.57) instructional set scores. The Friedman's test revealed that significant differences on absolute difference mean scores existed among the instructional sets ($\chi^2 = 39.499$ with 3 df, $p = 0.00$). According to the Wilcoxon matched-pairs signed rank test, the only instructional sets where a significant difference in absolute mean differences did not exist was between the patient neutral/caregiver self-report (2.00) and the patient neutral/caregiver imagine-other (1.94) conditions.

Overall it appears that none of the perspective-taking instructional sets had a statistically significant effect in helping the family caregiver to achieve improved empathic accuracy (or less discrepancy with the patient's self-report) on 'worrying', in comparison to the caregiver neutral mean score. As with the main study group of caregivers ($n = 98$), all instructional sets produced absolute difference mean scores on 'worrying' that were greater than one in this subgroup of caregivers ($n = 52$). However, the most effective instructional set in terms of assisting caregivers to achieve the best empathic accuracy on patient total symptom experience for 'worrying' appears to be the caregiver neutral control instructional set. Of the two perspective-taking manipulations, however, the caregiver imagine-other absolute difference score was significantly lower than the imagine-self absolute difference score. On the other hand, statistical analysis also revealed that the imagine-other absolute difference score was not

significantly lower than the caregiver self-report score.

Again, it is important to consider the hazard associated with the expectation that the differential instructional sets would serve as adequate prompts for caregivers to be able to distinguish their self-oriented viewpoint from a patient-oriented viewpoint. Because the caregivers were initially induced to focus on their own viewpoint before considering the patient's viewpoint, this might partially explain why imagine-other perspective-taking was not effective in improving the family caregiver empathic accuracy score on 'worrying'. It is possible that family caregivers were so attuned to their own worrying that it detracted from their capability to view the situation from the patient's viewpoint which, in turn, reduced the opportunity for caregivers to attain a more accurate assessment on the patient's symptom experience for worrying.

Summary (sub-group analyses)

First, it was difficult to determine whether family caregivers (n = 51) who overestimated on patient 'lack of energy' were influenced by their hypothesized view of how they would feel in the patient's situation (imagine-self) or by how they perceived the patient responded to the symptom experience (imagine-other). However, they did not appear to have projected their own experiences onto their estimates of patient 'lack of energy'. Similarly, it was difficult to determine whether family caregivers who overestimated on patient 'worrying' (n = 52) were influenced by their own experience with 'worrying' or by their perception of how the patient responded to the symptom experience (imagine-other).

Second, the following is a summary of perspective-taking influences on

family caregiver empathic accuracy on patient total symptom experience for 'lack of energy' and 'worrying'. In regard to the symptom 'worrying', it appeared that the effects of perspective-taking found in the sub-group of family caregivers who overestimated (n = 52) parallel those found in the main study sample of caregivers (n = 98). In both study groups, when family caregivers were not induced to perspective-take on patient 'worrying' they were more effective in achieving empathic accuracy. In other words, prompting the caregivers to either imagine-other or imagine-self perspective-take resulted in larger discrepancies with patients' self-report responses in comparison to the discrepancies found between patients' self-report responses and caregivers' neutral control ratings.

However, as with caregivers in the main study sample (n = 98), the imagine-other perspective-taking instructional set had the same effect on empathic accuracy for 'worrying' in terms of assisting caregivers who overestimate to provide closer estimates on patient 'worrying' in comparison to the effect of the imagine-self instructional set. As seen in Tables 14 and 16, the patient/caregiver imagine-other discrepancy scores were significantly lower than the patient/caregiver discrepancy scores found in the imagine-self instructional sets.

For 'lack of energy', the two perspective-taking instructional sets had no statistically significant advantage in comparison to the caregiver neutral control instructional set on enhancing caregivers' empathic accuracy on patient total symptom experience. However, the imagine-other instructional sets had the same impact in the sub-group of caregivers (n = 51) as it had in the main group

(n = 98), in terms of assisting caregivers who overestimate to provide more accurate assessments on patient 'lack of energy' in comparison to the imagine-self instructional sets. Furthermore, caregiver empathic accuracy scores in the imagine-other instructional sets were better (i.e., lower patient and family caregiver discrepancies) than the empathic accuracy scores in the neutral control sets for the main study group (n = 98) and the sub-group (n = 52) of caregivers (see Tables 14 and 16).

Research Question #9

Does the degree of discrepancy between patient and caregiver ratings on patient total symptom experience for 'lack of energy' and 'worrying' in the neutral control condition relate to (a) the level of patient-reported total symptom experience, (b) the family caregiver's length of time caring for the patient, (c) the family caregiver's degree of acquaintance with the patient, (d) the family caregiver's educational level, and (e) the levels of self and other dyadic perspective-taking by family caregivers?

A series of simultaneous regression models were developed to determine which variables serve as the best predictors of family caregiver empathic accuracy on patient total symptom experience for 'lack of energy' and 'worrying'. At the bivariate level, several factors were found to be significantly associated with the respective empathic accuracy (patient-caregiver absolute difference) scores. Tables 17 and 18 show the bivariate correlations (r), beta coefficients (B), and the adjusted R squares for the variables in the simultaneous regressions.

Table 17

Bivariate and multivariate correlates of family caregiver empathic accuracy in the neutral control condition on lack of energy (n = 98)

Variable	Absolute Differences*	
	Bivariate correlation (<i>r</i>)	Beta Coefficient (<i>B</i>)
Patient		
- Time since diagnosis	- 0.27 ^b	- 0.12
- Gender	+ 0.25 ^b	+ 0.02
- Self-report on lack of energy	- 0.37 ^a	- 0.68 ^a
Family Caregiver		
- Length of care time	- 0.22 ^b	- 0.01
- Gender	- 0.20 ^c	- 0.13
- Neutral report on lack of energy	+ 0.29 ^b	+0.61 ^a

Note: Simultaneous multiple regression was used, with predictors entered only when being statistically significant at the bivariate level

R = 0.696; Adjusted R² = 0.45; F = 14.213; F significance = 0.00

^ap ≤ 0.001

^bp ≤ 0.01

^cp ≤ 0.05

*Greater absolute difference = poorer family caregiver empathic accuracy

Table 18

Bivariate and multivariate correlates of family caregiver empathic accuracy in the neutral control condition on worrying (n = 98)

Variable	Absolute Differences*	
	Bivariate correlation (<i>r</i>)	Beta Coefficient (<i>B</i>)
Patient		
- Self-report on lack of energy	- 0.39 ^a	- 0.58 ^a
Family Caregiver		
- Amount of contact with patient**	- 0.22 ^c	- 0.13
- Neutral report on worrying	+ 0.30 ^b	+ 0.52 ^a

Note: Simultaneous multiple regression was used, with predictors entered only when being statistically significant at the bivariate level.

R = 0.64; Adjusted R² = 0.39; F = 21.686; F significance = 0.00

^ap < 0.001

^bp < 0.01

^cp < 0.05

*Greater absolute difference = poorer family caregiver empathic accuracy

**Amount of contact with the patient; lower ratings represented more family caregiver and patient contact

Lack of energy

With the exception of the family caregiver's length of time caring for the patient and the level of patient-reported 'lack of energy', none of the predictor factors that were tested in accordance with the adapted empathy model by Davis (1994) were associated with the empathic accuracy score on 'lack of energy'. Additional bivariate analyses found other significant, but weak relationships between the empathic accuracy score on 'lack of energy' and patient, and family caregiver characteristics. Poorer family caregiver empathic accuracy scores (i.e., greater absolute differences) on 'lack of energy' were noted for patients who lived with the cancer diagnosis for a shorter length of time, reported a lower symptom experience score (i.e., a less intense total symptom experience score on 'lack of energy'), and were male. In addition to these patient characteristics, certain family caregiver characteristics were significantly associated at the bivariate level with the empathic accuracy score on 'lack of energy'. Family caregivers who cared for the patient for a shorter period of time, were female, and reported a higher level of patient symptom experience on 'lack of energy' had poorer empathic accuracy scores on 'lack of energy'.

In the multivariate analysis, however, most of these variables were excluded from the prediction model due to their lack of statistical support. Both the patient's report on 'lack of energy' and the caregiver's neutral report on the patient's 'lack of energy' explained 45% of the variance in absolute patient-family caregiver differences. However, the empathic accuracy score on 'lack of energy' is derived from the difference between the patient's self-report on 'lack of energy'

and the caregiver's assessment on patient 'lack of energy'. One would expect that the two variables would contribute significantly to the variance in empathic accuracy scores. Regardless, 55% of the variance in the empathic score on 'lack of energy' remains unexplained.

Worrying

With the exception of the patient's self-report on worrying, none of the predictor factors that were tested in accordance with Davis's (1994) model were associated with the empathic accuracy score on 'worrying'. Additional bivariate analyses found significant associations between the empathic accuracy score on 'worrying' and the family caregiver's neutral report on patient 'worrying', and the amount of caregiver contact with the patient. No other associations were found between the empathic accuracy score on 'worrying' and demographic, illness, and treatment-related characteristics of patients and family caregivers. Poorer family caregiver empathic accuracy scores (i.e., greater absolute differences) on patient 'worrying' were noted for patients who reported a lower symptom experience score (i.e., a less intense total symptom experience score on 'worrying'). In addition, family caregivers who had more contact with the patient and reported a higher level of patient symptom experience on 'worrying' had poorer empathic accuracy scores on 'worrying'.

In the multivariate analysis, the patient's self-report and the caregiver's neutral response assessment on patient symptom experience for 'worrying' together explained 39% of the variance in absolute patient-family caregiver differences. However, as stated in the above, significant correlations were

expected between empathic accuracy and these variables. Sixty-one per cent of the variance in the empathic score on 'lack of energy' remains unexplained.

Research Question #10

Does the degree of discrepancy between patient and caregiver ratings on the respective MSAS dimensions of severity, frequency, and distress across 32 patient symptoms relate to: (a) the level of patient-reported total symptom experience, (b) the family caregiver's length of time caring for the patient, (c) the family caregiver's degree of acquaintance with the patient, (d) the family caregiver's educational level, and (e) the levels of self- and other-dyadic perspective-taking by the family caregiver?

A series of simultaneous regression models were developed to determine which variables served as the best predictors of family caregiver empathic accuracy on MSAS frequency, severity, and distress dimensions. At the bivariate level, several factors were found to be significantly associated with the respective empathic accuracy scores (patient-caregiver absolute differences). Tables 19 and 20 show the bivariate correlations (r), beta coefficients (B), and the adjusted R squares for the variables in the simultaneous regression models for empathic accuracy scores on symptom frequency and severity dimensions, respectively. The family caregiver's neutral rating on patient symptom distress was the only significant bivariate correlation with the empathic accuracy score on patient distress ($r = 0.55$; $p = 0.00$; $n = 85$). In other words, family caregivers who reported a higher level of patient symptom distress had poorer empathic accuracy scores on symptom distress.

Table 19

Bivariate and multivariate correlates of family caregiver empathic accuracy on the frequency dimension across 32 MSAS symptoms (n = 82)

Variable	Absolute Differences*	
	Bivariate correlation (<i>r</i>)	Beta Coefficient (<i>B</i>)
Patient		
- Past surgery	- 0.23 ^b	- 0.10
- Annual family income	- 0.22 ^c	- 0.19
Family Caregiver		
- Neutral frequency report	+ 0.46 ^a	+ 0.43 ^a

Note: Simultaneous multiple regression was used, with predictors entered only when being statistically significant at the bivariate level.

R = 0.51; Adjusted R² = 0.23; F = 8.979; F significance = 0.00

^ap ≤ 0.001

^bp ≤ 0.01

^cp ≤ 0.05

*Greater absolute differences = poorer family caregiver empathic accuracy

Table 20

Bivariate and multivariate correlates of family caregiver empathic accuracy on the severity dimension across 32 MSAS symptoms (n = 82)

Absolute Differences*		
Variable	Bivariate correlation (<i>r</i>)	Beta Coefficient (<i>B</i>)
Patient		
- Annual family income	- 0.25 ^c	- 0.21
- Past surgery	- 0.22 ^c	- 0.07
- Past other treatment	- 0.21 ^c	- 0.17
Family Caregiver		
- Neutral severity report	+ 0.52 ^a	+ 0.50 ^a

Note: Simultaneous multiple regression was used, with predictors entered only when being statistically significant at the bivariate level.

R = 0.60; Adjusted R² = 0.32; F = 10.635; F significance = 0.00

^ap ≤ 0.001

^bp ≤ 0.01

^cp ≤ 0.05

*Greater absolute differences = poorer family caregiver empathic accuracy

Frequency

No significant bivariate associations were found between the family caregiver's empathic accuracy score on patient frequency across 32 symptoms and patient-reported frequency, family caregiver length of time caring for the patient, family caregiver degree of acquaintance with the patient, family caregiver level of education, or the levels of self- and other-dyadic perspective-taking by the family caregiver (see Table 19). However, additional analyses revealed that poorer empathic accuracy scores (i.e., greater absolute differences) resulted when the patient had past surgery related to the cancer diagnosis, had a lower annual family income, and when the family caregiver reported a more intense level of symptom frequency for the patient. Multivariate analysis revealed that only the family caregiver's neutral report on patient symptom frequency predicted the degree of empathic accuracy on patient symptom frequency. More descriptive in nature, this variable accounted for only 20% of the variance in the empathic accuracy score for symptom frequency.

Severity

As with symptom frequency, there were no significant bivariate relationships found between the family caregiver empathic accuracy score on patient severity and the predictor variables that were tested in accordance with Davis's (1994) adapted empathy model. However, bivariate analyses with additional patient and caregiver characteristics revealed that empathic accuracy scores were worse (i.e, greater absolute differences) when the patient had past surgery and 'other' treatments related to cancer, and a lower annual family

income (see Table 20). Again, it was found that when family caregivers reported a higher level of patient symptom severity, this was associated with a worse empathic accuracy score (greater absolute difference) on patient symptom severity. Multivariate testing revealed that only the family caregiver's neutral report on patient symptom severity entered into the regression model, accounting for only 32% of the variance in the empathic accuracy score on symptom severity.

Summary

The analyses and interpretation of data collected from 98 advanced stage cancer patient and family caregiver dyads were the focus of this study. The demographic characteristics of each group were described. Acceptable internal consistency reliability estimates on the MSAS, ODPTS, and SDPTS were established for both groups. Patients' and family caregivers' current perceptions on the prevalence, frequency, severity, and distress of 32 MSAS symptom items were analysed using descriptive statistics. A variety of statistical techniques for evaluating patient-family caregiver response comparability at the group level (i.e., absolute patient-family caregiver mean differences, mean of directional differences, and standardized mean differences) and at the individual level (i.e., ICC) were employed.

On the presence of symptoms, Kappa levels ranged from fair to moderate between patients and family caregivers. A disparity in perceptions between patients and family caregivers occurred on 12 of 32 symptom items. When incongruence existed, family caregivers tended to overestimate versus

underestimate the presence of symptom items.

On the global MSAS total symptom experience score across 32 symptoms, the level of agreement was good. On a theoretical range of absolute mean differences (0 to 4 units), the difference between patient and family caregiver ratings was less than one unit. Although there was a significant difference in mean global ratings, the amount of bias for family caregivers to overestimate was modest.

On MSAS total symptom experience scores for 32 individual symptoms, the levels of agreement ranged between fair and good. On a theoretical range of absolute differences (0 to 4 units), differences ranged between 0.22 and 1.12. There were statistically significant differences in mean ratings on 12 of 32 symptom items. The largest systematic bias for family caregivers to overestimate occurred on feeling sad (moderate bias) and the smallest occurred on shortness of breath (small bias).

The levels of agreement for 12 high prevalence physical symptoms most frequently (83% of the ICC results) fell in the moderate to good range. For six psychological symptoms, the levels of agreement were primarily (67%) in the moderate range. On a theoretical range of absolute differences (0 to 4 units) on total symptom experience, for physical symptoms the range was between 0.25 (vomiting) and 0.95 (dry mouth). For psychological symptoms, the range of absolute differences was between 0.72 (feeling irritable) and 1.12 (worrying). On physical symptoms, significant differences in mean scores were found on four of 12 symptom items (i.e., lack of energy, pain, dry mouth, and weight loss). On

psychological symptoms, significant differences were found on five of six symptoms (i.e., worrying, feeling sad, feeling nervous, difficulty sleeping, and difficulty concentrating). The degrees of bias for family caregivers to over-report on physical symptoms ranged between being small (pain) and low moderate (lack of energy). On psychological symptoms, the amount of bias for family caregivers to over-report ranged between being low moderate (difficulty concentrating) and moderate (feeling sad).

At the group level of analyses, it was determined that there was a significant difference in levels of agreement between physical and psychological symptoms. The ICC results between patient and family caregiver ratings were strong on physical symptoms versus moderate on psychological symptoms. It was also found that the absolute mean difference score was significantly lower in the physical versus the psychological symptom nature group. In addition, the amount of family caregiver bias to over-report was scant on physical symptoms in comparison to psychological symptoms where the tendency to over-report was small.

The levels of agreement on the frequency dimension for 32 individual symptom items ranged primarily (71% of the ICC results) between moderate and good. On severity, the levels of agreement ranged primarily (75%) between moderate and good. On distress, the levels of agreement ranged primarily (81%) from moderate to good. The range of absolute differences were as follows: on frequency (0.20 to 1.27); on severity, (0.25 to 1.06); and, on distress (0.22 to 1.18). On frequency, there were significant differences on 11 of 24

symptoms. On severity, statistically significant differences occurred on 11 of 32 symptoms, and on distress, significant differences occurred on 12 of 32 symptoms. The bias for family caregivers to significantly over-report on symptom dimensions were as follows: on frequency, the bias ranged between small (shortness of breath) and moderate (feeling sad); on severity, the bias ranged between small (pain) and moderate (feeling sad); and, on distress the bias ranged between being small (shortness of breath) to moderate (feeling sad). It is noted that family caregivers tended to significantly underestimate only on dry mouth.

At the group level across 32 symptom items, the levels of agreement on symptom frequency, severity, and distress were consistently good (range between 0.63 to 0.69). There were no significant differences in ICCs among the symptom dimensions. The mean absolute difference score on symptom severity was significantly lower than the respective absolute difference scores on symptom distress and frequency. Although family caregivers tended to significantly over-report on patient total symptom experience for each of the symptom dimensions, the smallest bias occurred on the dimension severity.

In an attempt to determine whether family caregivers were influenced by a self- or a patient-oriented viewpoint during their interpretation of patient symptom experience, a series of analyses explored agreement at the individual level and differences at the group level. In the main study group (n =98), it was determined that family caregivers appeared to be influenced by a patient-oriented viewpoint when assessing patient 'lack of energy'. On the other hand, it

was difficult to determine whether they were influenced by a patient- or a self-oriented viewpoint when they reported on patient 'worrying'.

In sub-group analyses, the results were not as clear. For family caregivers who overestimated on patient 'lack of energy', it appeared that perspective-taking was involved. However, it was difficult to distinguish whether imagine-other or imagine-self perspective-taking played a major influence on caregivers' overestimates. Family caregivers did not appear to project their own experience (i.e., self-report) with 'lack of energy' onto their inferences of patient 'lack of energy'. On 'worrying', while it appeared that family caregivers might have made an attempt to imagine the patient's viewpoint, any effort to do so might have been biased by their own experience with 'worrying'.

To determine the differential impact of perspective-taking instructional sets on caregiver empathic accuracy, the following results were found. On 'lack of energy', it was discovered that when caregivers (in both the main group and sub-group levels of analyses) were prompted to engage in the patient's viewpoint, they achieved enhanced (albeit non-significant) empathic accuracy scores (less discrepancy with the patient's self-report) in comparison to their responses provided in the neutral control conditions. On the other hand, family caregivers (in both the main group and sub-group levels of analyses) did not attain enhanced empathic accuracy on 'worrying' when they engaged in imagine-other perspective-taking (nor in any other instructional set). In fact, each of the instructional sets prompted inflated responses from family caregivers in comparison to the patient's self-report on 'worrying'. The caregiver neutral

control instructional set appeared to be the most effective in terms of evoking the least discrepant estimation by family caregivers on patient 'worrying'.

It was suggested that this study's protocol, where caregivers were expected to differentiate their responses on multiple instructional sets, might have confounded empathic accuracy consequences. Because caregivers were initially induced to strongly focus on their own viewpoint, this might have provided an information base for them to imagine how the patient felt based on their own viewpoint. Once they were focused on their own viewpoint, they might not have been able to distinguish their own viewpoint from their perception of how the patient would respond. However it should be pointed out that, in comparison to the imagine-self effects on empathic accuracy for 'lack of energy' and 'worrying', imagine-other perspective-taking consistently resulted in enhanced empathic accuracy scores by family caregivers. Despite the demand placed on caregivers to differentiate between their respective responses, they appeared capable of engaging in some level of mental adjustment reflective of being able to separate their own viewpoint from their perceptions of the patient's viewpoint.

A series of multiple regression analyses were conducted to ascertain the impact of a set of family caregiver and symptom situation characteristics on empathic accuracy on total symptom experience for 'lack of energy' and 'worrying', and for symptom frequency, severity, and distress across 32 MSAS symptoms. At the bivariate level, several factors were found to be weakly associated with empathic accuracy scores (i.e., the degree of absolute difference between patient and family caregiver ratings) on 'lack of energy' and 'worrying,

as well as the on frequency, severity, and distress dimensions.

However, apart from (a) the levels of patient reported symptom experience that served as negative predictors (or the lower the patient's report on symptom experience, the lower the level of empathic accuracy) and (b) the levels of family caregiver neutral control responses that served as positive predictors (or the higher the family caregiver's neutral report on patient symptom experience, the lower the level of empathic accuracy) on the degree of absolute difference for 'lack of energy' and 'worrying', none of the patient and family caregiver characteristics entered into the respective regression models. Similarly with the respective regression models for symptom distress, frequency, and severity, only the levels of family caregiver neutral reports on the respective symptom dimensions entered as positive predictors on the degree of absolute difference (or the higher the family caregiver's neutral report on patient symptom experience, the lower the level of empathic accuracy).

CHAPTER FIVE

Discussion

The overarching construct of “family caregiving skill” by Schumacher et al. (2000) broadly guided this study’s aim to make more explicit the status of family caregiver skill in ‘monitoring’ and ‘interpreting’ the cancer patient’s symptom experience. This study was operationalized by the concepts of symptom experience, dyadic perspective-taking, and empathic accuracy. The theoretical framework by Davis (1994) provided the foundation for conceptualizing the respective relationships between family caregiver and symptom situation characteristics, and family caregiver empathic accuracy on patient symptom experiences. This adapted framework also guided an exploration of the effects of dispositional and induced perspective-taking activities on family caregiver empathic accuracy.

This comparative descriptive study was designed to, first, examine the degree of family caregiver empathic accuracy on the multidimensional symptom experience of advanced cancer patients and second, to identify factors affecting the degree of empathic accuracy by family caregivers. The third purpose of this study was to explore whether family caregiver current perceptions on patient symptom experience are related to a self- or a patient-oriented viewpoint. The fourth purpose was to explore whether induced perspective-taking can assist family caregivers who overestimate to achieve more accurate symptom assessment on the cancer patient’s total symptom experience.

Major findings are interpreted, major limitations are discussed, and

subsequent conclusions are presented in this chapter. Recommendations for further research and nursing practice implications are offered.

Interpretation of the Findings

This study's findings are important in that they address two shortcomings identified in previous investigative work that explored patient-family caregiver response comparability on patient symptom experiences. First, this study comprehensively explored next-of-kin current estimations on the patient's multidimensional symptom experience (i.e., frequency, intensity, and distress). Second, the current study addressed the gap in empiric nursing literature that has not examined the relevance of perspective-taking by family caregivers to their judgment accuracy on patients' current symptom experiences.

The following section will address the first shortcoming. Currently it is difficult to clearly discern the exact nature of symptom characteristics that family caregivers might target in their current estimates on patient symptom experience. This is due to a notable absence of measurement on the interrelated but separate underlying symptom dimensions of severity, frequency, and distress items. A comprehensive exploration of patient symptom characteristics might prove to be helpful in serving the basis of understanding how and when family caregivers may be used for providing reliable alternate or complementary responses. In order to facilitate targeted and timely health care interventions, this study made an attempt to identify areas where caregivers are having difficulty in achieving accurate symptom assessments.

Multidimensional symptom measurement

This is the first known study to identify the reliable use of the MSAS in a sample of family caregivers who cared for advanced stage cancer patients in the home care setting. The MSAS demonstrated strong reliability on the physical and psychological symptom sub-scales, in both samples of patients and family caregivers. Furthermore, the length of the MSAS and the appropriateness of the symptom items appeared reasonable to cancer patients. However, missing data by family caregivers existed on several MSAS items where they expressed either that it was “not an appropriate item” for them to assess or that they simply did not wish to “guess” on the patient’s experience with that particular symptom. For example, six family caregivers did not respond to the symptom ‘sexual interest/activity’. Three participants in this sub-grouping of family caregivers identified themselves as the patient’s daughter. The other participants identified themselves as either the patient’s parent, son, or ‘no relation’ to the patient. The remaining symptoms with missing data included family caregivers who identified themselves as either the patient’s spouse, daughter, son, or ‘other’ relation. These symptoms included: dry mouth, problems with urination, constipation, feeling nervous, nausea, difficulty sleeping, feeling bloated, diarrhea, feeling sad, worrying, hair loss, and itching.

The rationale for missing responses on some symptoms by family caregivers warrants further speculation. First, some of these symptoms may pose as ‘taboo’ topics for family caregivers to discuss with the patient (e.g., sexual activity and bathroom activities). Symptoms such as hair loss or itching may be perceived as being innocuous to the patient’s condition or treatment,

therefore they were not talked about. Emotional symptoms, like feeling nervous, feeling said, and worrying, might be threatening to talk about with the patient.

In the current study, the MSAS demonstrated its 'usefulness' in providing information about the patient's and family caregiver's perceptions on and responses to both the occurrence of (which includes frequency and severity) and the distress arising from the patient's symptoms. Across 32 MSAS symptoms, it was noted that the proportion of patients and caregivers who reported a high level of distress was not always higher than the proportion of patients and caregivers who described the same symptom as being relatively severe or relatively frequent (as noted on the high prevalence physical items of lack of energy, pain, feeling drowsy, dry mouth, and worrying). The findings by Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al. (1994) were similar and underscore the need to acquire a multidimensional assessment on each symptom dimension. As discussed in the literature review, each element by itself is an indicator for specific intervention by health care professionals (Morrow, 1984). Rhodes, McDaniel, Simms Homan, Johnson, and Madsen (2000) further described that while the occurrence elements can provide information on how to assist patients to manage their symptoms, the distress sub-scale can assist health care practitioners to decipher the patients' perceptions of their needs and problems, and to determine the effectiveness of interventions for symptom management. Furthermore, Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al. (1994) found that symptom distress yields more information about the clinical impact of a symptom

on quality of life than severity or frequency alone.

The Self-Regulation Theory by Leventhal and Johnson (1983) might be helpful in interpreting why the proportion of patients and caregivers who viewed patient distress as intense was less than the proportion of patients and caregivers who viewed the occurrence elements of frequency and severity as intense on similar symptoms. Essentially this theory postulates that when people know what sensations to expect or have the experiential background to reference new experiences, the emotional response or distress decreases (Rhodes et al., 2000). For instance, the Self-Regulation Theory helped Rhodes and colleagues (2000) to explain the difference in the lack of improvement in occurrence scores versus the improvement in distress scores over time, in a sample of hospice patients. These authors suggested that the patients and their caregivers may have developed better self-care actions for the patient's symptom occurrence, and thus avoided the patient's distress response.

In the current study it is noted that most patients had received active cancer treatment in the past and many were still receiving either active or palliative treatment for their disease. It is possible that due to the 'chronicity' of their respective oncologic conditions and the repeated episodes of treatment, patients and family caregivers learned how to live with the disease and knew what to expect, and how to manage the symptoms (Rhodes et al., 2000).

Absence or presence of symptoms

Descriptive statistics revealed that a small number of symptoms were highly prevalent across the tumour types. Forty-two to 77% of the cancer

patients experienced a lack of energy, pain, feeling drowsy, dry mouth, worrying, feeling irritable, feeling sad, difficulty sleeping, lack of appetite, cough, nausea, and shortness of breath. These findings are remarkably similar to those reported in Portenoy, Thaler, Kornblith, McCarthy-Lepore, Friedlander-Klar, Coyle, et al.'s (1994) study that employed the MSAS in a heterogenous sample of cancer patients who were diagnosed with similar tumour types and stages of disease. However, this current study's results indicated that cough and shortness of breathe were highly prevalent, whereas these symptoms were not highly prevalent in Portenoy et al.'s study.

In terms of levels of agreement at the individual symptom level on categorical data, this study's results confirm previously held trends that describe patient-family caregiver congruence on symptom experiences (e.g., Clipp & George, 1992; Magaziner et al., 1996). In this study, the Kappa results concerning the absence/presence of symptoms revealed that agreement beyond chance between patient and family caregiver reports ranged primarily between fair and moderate on 32 MSAS symptoms. It is important to note that there are no pre-defined ways to interpret levels of agreement at the individual level (Lampic & Sjoden, 2000; Sprangers & Sneeuw, 2000). However, this study employed general guidelines provided by Landis and Koch (1977) and Altman (1991) to interpret Kappa statistic results that are commonly employed in related studies (Hinton, 1996; Kristjanson et al., 1998; Sneeuw et al., 1999). The more stringent guidelines provided by Fleiss (1981) might have been employed (i.e., where values above .75 are considered excellent, values above .40 are

considered acceptable, and values less than .40 are considered poor agreement). However, other authors have found that low Kappa correlations determined by conservative guidelines might lead readers to conclude that proxy ratings are unacceptable for clinical use (Sneeuw et al., 1999). In addition to calculating chance-corrected Kappa coefficients on categorical data, this study might have employed a more liberal and clinically plausible criterion based on approximate agreement which would be defined as the proportion of agreement within one response category in either direction on the MSAS (Sneeuw, Aaronson, Sprangers, et al., 1997).

Higher Kappa levels of agreement on the presence of symptoms occurred primarily on those that were more observable in nature (e.g., pain, vomiting, lack of appetite, and mouth sores) versus those that were more invisible and subject to observer interpretation (e.g., worrying, difficulty concentrating, problems with sexual activity, and feeling nervous). When differences occurred, family caregivers tended to over-report the presence of symptoms. This finding is supported by previous work that compared current reports by patients and their family caregivers where, with few exceptions, relative caregivers were more likely to report a condition, symptom, or disability in patients (Kristjanson et al., 1998; Lobchuk et al., 1997; Magaziner et al., 1996). On the other hand, retrospective accounts on symptom prevalence revealed a bias for bereaved caregivers to overestimate pain and to underestimate patient weakness and depression (Hinton, 1996). Higginson et al. (1994) found that in comparison to their current ratings, bereaved caregivers tended to polarize their assessments of patients'

symptoms (i.e., provide either mild or severe ratings). Furthermore, these authors found that agreement and correlations between patients' and family caregivers' prospective ratings were higher than those found for caregivers' retrospective ratings.

It is also possible that, although patients' responses were regarded in this study as the 'standard', their reliability in providing accurate responses on the presence or absence of their symptom experiences is questionable. For instance, based on the investigator's experience with the participants, it was noted that occasionally the patients and family caregivers provided divergent reports on the presence of patient symptoms over the past week. After the surveys were completed, the investigator included in the protocol an informal opportunity for patients and family caregivers to share, but not alter their responses on the MSAS. When discrepancies occurred, the family caregiver often prompted the patient to recall that the symptom event had indeed occurred in the past week. Family caregivers usually expressed their appreciation in having had an opportunity to elicit feedback directly from patients on their assessment skills. Other authors suggested that it is important to discuss a patient's report on symptoms with family caregivers, not only to assist health care professionals obtain a more valid symptom picture (Sohier, 1995), but also to reassure the spouse (Dar et al., 1992).

Interestingly, in the current study three family caregivers refused the opportunity to validate their perceptions with the patient for reasons such as, "I don't really need to know that information!" Although they did not provide a full

explanation for their refusal to share their responses, it appears that their motivation might be similar to the situational motivation which underlies “motivated inaccuracy” (Ickes & Simpson, 1997). Borrowing from the principles associated with motivated inaccuracy, it is plausible that these caregivers acted on a need to protect or stabilize themselves from either (a) the distress or feeling of inadequacy which their inaccurate inferences might engender or (b) the feeling of threat in being exposed to information on the patient’s ‘true’ symptom picture (more worse than they are aware of) which would signify the unpleasant reality of the patient’s imminent deterioration.

Global and individual MSAS symptom ratings

The second aspect of analyses concerned whether there was agreement at the individual level (i.e., associations) and differences at the group level (i.e., means) between patient and family caregiver ordinal ratings on the total MSAS scale and on the separate MSAS symptom sub-scales. The examination of patient-proxy congruency at the group level is important to clinical trials where family caregivers may serve as proxy respondents and where group versus individual level comparisons generally occur. On the other hand, levels of agreement at the individual level are of concern to practitioners in cancer practice settings where the provision of care occurs generally at the individual patient-family caregiver unit level (Sneeuw et al., 1999).

At the group level, the current study found that family caregivers significantly over-estimated on patient total symptom experience as reported on the global MSAS scale across 32 symptoms. However, it is encouraging that on

a theoretical range of absolute differences from zero to four, family caregivers' reports differed from patients' reports by a difference of less than one unit on a global basis. Furthermore, only a modest amount of bias would be introduced when substituting patients' self-reports with global ratings provided by family caregivers. These findings are supported by previous work on response comparability where there is reported trend for caregivers to over-estimate (Higginson & McCarthy, 1993), with only a modest amount of bias on global items (Sneeuw, Aaronson, Osoba, et al., 1997).

When the patient's and the caregiver's responses on individual symptom items were compared, it was also found that the caregiver almost consistently rated the patient as having more intense symptom experience on most MSAS symptom items. However, the amount of bias that would be introduced appears to be highly dependent on the MSAS symptom itself. For instance, more bias to over-report was found on feeling sad and worrying, as opposed to a lower amount of bias to over-report by family caregivers on shortness of breath and pain. Furthermore, the range of absolute differences on individual scale items (0.22 to 1.12) was wider than the average absolute differences that occurred on the global MSAS scale across 32 symptoms (0.31), the physical symptom subscale (0.39), and the psychological symptom subscale (0.77). This indicates that, depending on the symptom family caregivers may provide information that is different on the MSAS than patients would themselves. However, on a range of theoretical differences (zero to four units), health care professionals could expect patient and family caregiver reports on individual symptoms to be

considerably less than one unit away from one another.

When assessing patient-caregiver agreement at the individual level of the patient, the current study found that a wider range of variability in levels of agreement had occurred in comparison to agreement levels found at the global level. These findings support the work of McCusker and Stoddard (1984) who reported similar results. For instance, this study found that on separate symptom items the levels of agreement ranged between slight (change in skin) to substantial (lack of appetite). On the other hand, good levels of agreement were found on the global MSAS scale across 32 symptoms and on the physical symptom sub-scale, and also on the separate severity, frequency, and distress sub-scales. Sneeuw and colleagues (1998) found similar results in their quality of life study. They attributed higher levels of agreement that occur on global scores to the “psychometric benefits of a composite score” (Sneeuw et al., 1998, p. 626).

In summary, it appears that for agreement at the individual level (i.e., associations) and differences at the group level (i.e., means) greater confidence can be placed on caregivers to respond with more reliable estimates on patients' global versus individual symptom experiences. There was less head-to-head (or more inconsistent) agreement on individual symptoms in comparison to family caregivers' global perceptions on patient symptom experience. However, the reliability of family caregiver reports at the individual symptom level is likely related to the factual, concrete, or observable attributes of symptoms.

Frequency, severity, and distress across 32 symptoms

This is the first known study that systematically compared patient and family caregiver congruency on the separate symptom dimensions of frequency, severity, and distress. The high levels of agreement that were found at the individual level of the patient were comparable on each of the three dimensions. Health care professionals can be assured that the family caregiver's ratings would be reasonably related to the patient's self-reports on the respective global symptom dimensions. The lowest amount of caregiver bias to over-report and the least amount of discrepancy between the respective patient and caregiver reports occurred on symptom severity. The highest amount of caregiver bias to over-report occurred on symptom distress. Because the experience of symptom distress is highly subjective, it may be more difficult for family caregivers to interpret this symptom dimension with greater accuracy (McClement et al., 1997). However it appeared that, on any of the symptom dimensions, clinicians could expect the degree of patient-family caregiver absolute discrepancy to be considerably less than one unit.

Physical and psychological symptoms

On symptom nature, it appears that patients and family caregivers tended to agree more on physical symptoms versus those in the psychological domain (i.e., where the level of agreement was less, the absolute difference was more great, and caregivers significantly overrated the patient's psychological symptom status). These findings lend empirical support toward previous work where authors suggested that physical symptoms may in general be more objective in nature and accompanied by more visual cues which lend themselves toward

better agreement or empathic accuracy (Grassi et al., 1996; Nekolaichuk et al., 1999; Rogers et al., 1997; Rothman et al., 1991; Spiller & Alexander, 1993).

On the other hand, these findings conflict with Sprangers and Aaronson's (1992) review of findings that suggested family caregivers may be more accurate in assessing patients' psychological health. This pattern of divergent study findings on levels of agreement is well known, but not easily reconciled due to the different patient-proxy samples and instrumentation that were employed across related studies (Magaziner, 1992). Nonetheless a number of study findings, including those found in this current study, support the generalization that the reliability of family caregivers would be less on the psychological symptom dimension (Brunelli, Costantini, & Di Giulio, 1998; Carlson, Ottenbreit, St. Pierre, & Bultz, 2001; Spiller & Alexander, 1993). Therefore, on symptoms like worrying and feeling sad, health care professionals should take caution when soliciting family caregivers' 'proxy' or 'complementary' reports on the patient's psychological symptom status in order to plan for appropriate intervention.

In summary, the current study extends previous work on patient-family caregiver response comparability by its systematic exploration on the levels of individual agreement and differences in group means on the multidimensional nature of cancer patients' symptom experiences. As anticipated, the current study's findings support the currently held view that family caregivers rate patients as having more symptom experience at both the global and individual symptom levels. However, the amount of bias to overestimate by family caregivers at the global level was less than that found at the individual symptom

level. Furthermore, the bias to overestimate by family caregivers and the level of discrepancy appear to be dependent on the individual symptoms being measured. Based on this investigator's experience and informal interviews held with patients and their caregivers (as described earlier on p. 247), it is also important to be aware that advanced stage cancer patients may provide questionable accounts, due to a compromise in their self-report capabilities even on recall information related to recent (i.e., past week) symptom events. A compromise in self-report capabilities is likely a result of illness- and/or treatment-related effects (e.g., fatigue, pain, confusion) that are commonly depicted in literature as being experienced by advanced stage cancer patients (Bruera, 1993; Dunlop, 1989; Walsh, Donnelly, & Rybicki, 2000; Vainio & Auvinen, 1996). In regard to family caregiver assessments on symptom frequency, severity, and distress, it appears that health care professionals can feel reasonably assured that family caregivers provide responses that are comparable to patients' self-reports on the same symptom dimensions. On the other hand, health care professionals need to exercise caution when soliciting the family caregiver's report on the patient's psychological or emotional symptom status due to the exhibited tendency of family caregivers to significantly overestimate on this genus of symptoms.

Perspective-taking and empathic accuracy

This next section will address the second shortcoming identified in nursing literature where extant research has tended to neglect investigation on the dynamics of perspective-taking activities that might at least partially account for

family caregivers' reasonable estimates on patient symptom experience. More specific, the current study attempted to investigate induced conditions under which judgment accuracy might be achieved by family caregivers. But first, there is one limitation of the current study that should be considered carefully at this point - that is, the results could be an artifact or a product of the mental challenge placed on caregivers to respond without bias to multiple, successive instructional sets.

In each symptom condition of 'lack of energy' and 'worrying', a protocol was adhered to where family caregivers replied to a set of four explicit instructional sets that were administered in a predetermined sequence. The particular order of delivering the instructional sets was not informed by previous investigative work, as the current study was being conducted in an unexplored area of patient-family caregiver response comparability. First, the family caregivers were asked to simply infer the patient's symptom experience over the past week (neutral control instructional set); second, they were asked to report on their own symptom experience with respect to each of the two symptom conditions (self-report instructional set); third, they were asked to provide their estimated view on how they believed they would feel if they had the patient's diagnosis (imagine-self perspective-taking instructional set); and, lastly, family caregivers were induced to provide their estimation on how they believed the patient would respond by placing themselves within the patient's shoes (imagine-other perspective-taking instructional set).

Because the investigator attempted to determine the effects of

perspective-taking on family caregiver empathic accuracy, providing explicit instructions seemed appropriate. However one might question whether, as a result of administering the self-report and imagine-self instructional sets prior to the imagine-other instructional set, family caregivers were so strongly induced to self-focus that it tended to bias their subsequent response to the imagine-other perspective-taking instructional set. In consequence, it is possible that their self-centered focus might have prevented them from embracing a viewpoint other than their own. This is a distinct possibility, albeit more so in the psychological symptom 'worrying' conditional set versus the physical symptom 'lack of energy' conditional set.

Higgins (1981) offered a similar explanation that cannot be ruled out as a potential determinant of the lack of clear differentiation in caregiver responses among the respective instructional sets. This author posited that individual (imagine-other) perspective-taking can be difficult, depending on the extent to which competing information in relation to one's own characteristics and viewpoint is accessible. In other words, as a result of initially being induced to concentrate on one's own viewpoint, family caregivers were challenged to totally inhibit their own experience with worrying from influencing their perception of the patient's viewpoint on worrying. Tversky and Kahneman (1974) offered a similar but more concise explanation based on an "anchor-and-insufficient adjustment" judgmental heuristic employed by individuals who do not sufficiently adjust or 'correct' enough away from their initial anchor for the adjustment. In other words, the caregiver's self-report and imagine-self perspective sets might have provided

a high anchor that consequently influenced the family caregiver to provide inflated inferences in the latter imagine-other response set.

A manipulation check, perhaps based on open-ended questions, might have been helpful in determining whether family caregivers actually experienced this challenge and whether they actually did as they were instructed in the differential instructional sets. For example, assuming that the family caregiver had been given the “imagine-other” instruction, the study protocol could have included questions like, “How exactly did you go about imagining the lack of energy of the patient?” or “Did you repeatedly ask yourself how the patient feels?”

Whose point-of-view are family caregivers taking?

Main study group (n = 98). As expected from previously described trends in related studies, family caregivers systematically overestimated patient ‘lack of energy’ and ‘worrying’ in the main study sample. A variety of recommended analyses on levels of agreement at the individual level and levels of mean difference at the group level were conducted to determine the perspective that family caregivers might have embraced when they made an inference on patient ‘lack of energy’ and ‘worrying’.

Caution is however warranted when inferring parallel processes from ‘matches’ in mean responses to differential instructional sets. First, it is risky to conclude that similar mean responses indeed reflect similar judgment processes by family caregivers in, for example, the neutral control and imagine-other response sets. In other words, it is difficult in naturalistic settings to precisely

measure the cognitive processes that observers engage in when responding to instructional sets that may or may not induce differential cognitive representations of the symptom situation (Davis, 1994).

Second, Lee and colleagues (1989) advised that although a comparison of means is appropriate to assess for possible constant bias, it is inappropriate for judging the interchangeability of two methods (e.g., neutral control and imagine-other instructional sets). Caregiver responses which show similar mean values (good aggregate agreement) may not necessarily imply good individual-subject agreement, but perhaps poor and inconsistent individual agreement (Lee et al., 1989). Therefore, correlational results might be more convincing when inferring parallel judgment responses by individual caregivers to differential instructional conditions. However, counterbalancing caregiver exposure to instructional sets would have allowed for a more persuasive argument that parallel inferential processes were employed by caregivers in the respective instructional sets. In addition, counterbalancing the sequence of instructional sets would have allowed for a more convincing interpretation of potential order effects as described earlier.

Confirmation as to whether the family caregiver engaged in a perspective-taking process from the patient's or one's own viewpoint is based on Higgins's (1981) definition of role-taking. The reader is asked to recall Higgins's (1981) postulation that "judgments involve role-taking [or imagine-other perspective-taking] when there is an inference about a target's view-point (or response) under circumstances where the judge's own viewpoint is salient and different

from the target's" (p. 133). First, this postulation says that role-taking occurs only when the judge is able to inhibit competing information from interfering with one's judgment on the other person (i.e., non-egocentrism). Often this competing information is one's own 'salient' viewpoint that the judge has to prevent from "dominating" one's inference on others. Higgins described that the salience of a judge's viewpoint is an important condition of role-taking because it makes the judge "susceptible to egocentric errors". However, when a judge is able to make non-egocentric judgments of others, he or she meets one of the two conditions of role-taking.

In the current study, it was assumed that 'lack of energy' and 'worrying' would be 'salient' symptom experiences of family caregivers. This assumption was based on literature that reported the clinical relevance and high prevalence of these symptoms in family caregivers caring for cancer patients. In addition, the caregiver's self-report on 'worrying' was significantly higher than both the caregiver's neutral inference on patient 'worrying' and the patient's self-report on 'worrying'. It appeared that 'worrying' was a profound feature of caregivers which might have posed a threat to their ability to take the patient's viewpoint. On the other hand, the caregiver's self-report on 'lack of energy' was significantly lower than both the caregiver's neutral inference on patient 'lack of energy' and the patient's self-report on 'lack of energy'. It is possible that the caregiver's self-report on 'lack of energy' might have been "sufficiently non-salient" that there was little need for control (Higgins, 1981). In other words, the caregiver might have regarded the patient's 'lack of energy' as being so profound or important,

that there was no need for the caregiver to inhibit his or her own experience from dominating one's inference on the patient's 'lack of energy'.

Second, in terms of the observer's own viewpoint being different from the target's viewpoint, this means that the caregiver is able to compare and differentiate one's own and the patient's viewpoint in the same situation (Higgins, 1981). If, on the other hand, the observer assumes that the target's viewpoint is similar to his or her viewpoint, then the observer would not necessarily have to consider the target's characteristics or viewpoint. Rather, the observer infers that the other person's response would be the same as his or her own. The observer uses oneself as the basis for making judgments about 'similar' others. In terms of the instructional set procedure used in the current study, this conditional feature of role-taking was easier to determine as having (or not having) been met by family caregivers.

In this study, cumulative correlational results suggested that caregivers were able to take into account the patient's viewpoint and differentiate it from their own viewpoint when inferring the patient's symptom experience on 'lack of energy'. First, the caregiver's imagine-other response was strongly correlated with both the patient's self-report on 'lack of energy' and the caregiver's neutral inference on patient 'lack of energy'. Additional analysis based on mean scores revealed that the caregiver's imagine-other mean response was significantly different from his or her self-report response. Second, the correlation between the caregiver's imagine-other and neutral control responses was significantly different from the correlation between the caregiver's neutral control and self-

report responses. Third, the caregiver's self-report was significantly less than and weakly correlated with both the patient's report on 'lack of energy' and the caregiver's neutral inference on patient lack of energy.

Higgins (1981) explained that observers who are able to put themselves in the different situation of another person and differentiate their present viewpoint from the other person's viewpoint, do so because there is no assumption that the other person's thinking and feeling would be similar to one's own. The family caregiver's self-reported mental representation of his or her own 'lack of energy' was different from both his or her neutral inference and imagine-other perception of the loved one who currently suffers from cancer, as well as from the patient's self-report on the symptom. Family caregivers did not appear to be projecting their own 'lack of energy' onto their neutral estimates of the patient's experience or their imagine-other responses. There did not appear to be any assumptions made by family caregivers that their 'lack of energy' was similar to the patient's 'lack of energy' symptom experience. Of course it is also possible that, as the caregiver's own experience with lack of energy was significantly lower than both the patient's self-report and the caregiver's neutral perception on the patient's lack of energy, the caregiver's own experience was not salient enough for him or her to consider and prevent from being confused with his or her judgement of the patient's viewpoint on lack of energy. Regardless, it seems that the caregivers were able to take into account the patient's viewpoint when the patient's viewpoint was significantly different from their own experience with 'lack of energy'. On physical symptoms, like 'lack of energy', it would appear that family

caregivers can serve as reasonable judges of patient symptom experience as they are capable of making a non-egocentric judgment of the patient's symptom experience.

As alluded to earlier, the scenario of results on the psychological symptom 'worrying' was not easy to comprehend. From a superficial view of the correlational results, caregivers appeared to be somewhat sensitive in comprehending patient worrying from the patient's viewpoint. However, further testing could not support this cursory analysis in accordance with Higgins's (1981) defining attributes on role-taking. Statistical testing revealed that, first, the caregiver's imagine-other response was moderately correlated with the patient's self-report and strongly correlated with the caregiver's neutral inference on patient worrying. Next, the caregiver's self-report was significantly higher than and not correlated with the patient's report on 'worrying'. The caregiver's self-report was also significantly higher than his or her neutral inference on patient 'worrying'. However, the caregiver's imagine-other mean response was not significantly different from his or her self-report on worrying. Furthermore, the correlation between the caregiver's imagine-other and neutral control responses was not significantly different from their neutral control response correlation with their self-report on worrying. The results indicate that family caregivers were able to appreciate the patient's viewpoint but not differentiate it from their own viewpoint when inferring patient 'worrying'.

Therefore, in accordance with Higgins's (1981) formulation on individual role-taking, it cannot be said that family caregivers embraced a non-egocentric

view of the patient's worrying experience. In other words, because of the non-significant difference between the caregiver's imagine-other and self-report responses, it cannot be accurately stated that the family caregiver was able to differentiate his or her perception of the patient's viewpoint from his or her own experience with worrying. It is likely that the caregiver's own experience with the symptom interfered with his or her ability to predict how the patient actually experienced worrying when they suffered from worrying themselves.

Overall it appears that family caregivers were better able at keeping their own characteristics and viewpoints on physical symptoms like 'lack of energy' in check by not letting them interfere with their inference of the patient's viewpoint on the symptom. However, it is also important to consider that perhaps the caregivers had less of a challenge to differentiate between their own and the patient's physical status, as opposed to their capability to differentiate their own viewpoint from the patient's viewpoint on psychological symptoms like 'worrying'. Previous literature described that caregiving is performed "in a context that is far from [being] objective and affectively neutral" and is driven by emotional attachments (Yates, 1999, p. 68). Yates further described that family caregivers are vicariously effected by the cancer illness experience in ways that appear more psychological than physical in nature. Therefore it can be assumed that, because the caregivers were emotionally deeply enmeshed in the cancer situation, it would have been difficult for them to distinguish the patient's experience from their own psychological or emotive experience.

As pointed out earlier, it is also possible that this study's methodology had

an impact that biased family caregivers' responses to the imagine-other perspective-taking set on worrying. Markus and Wurf (1987) described that, when individuals have a great deal of salient information about themselves, there is a tendency to judge others based on this information. In this study it is noted that family caregivers' neutral control responses (where caregivers were not induced to self-report or imagine-self perspective) were most similar to the patient's self-report on 'worrying'. However, when they were then prompted to consider their own viewpoint (self-report and imagine-self) followed by the patient's viewpoint (imagine-other), the results indicate that they might not have been able to distinguish their own profound 'worrying' from their imagine-other perception of the patient's 'worrying'. The family caregivers likely found it difficult to deal with competing information related to their own viewpoint on 'worrying' which was made immediately accessible to them. Perhaps a research methodology that does not 'prime' caregivers to focus on their own 'worrying', in addition to considering the patient's viewpoint on 'worrying', would not confound their responses in the imagine-other perspective-taking set.

Sub-group analyses (family caregivers who overestimated on patient 'lack of energy' and 'worrying'). This next component of the study explored Wright's (1983) 'requirement of mourning' hypothesis in terms of being able to explain why the respective sub-groups of family caregivers over-reported on patient 'lack of energy' and 'worrying'. This hypothesis suggests that caregiver overestimation on patient symptom experience is associated with the caregiver's assumption of one's own symptom experience if he or she was in the patient's

situation (i.e., imagine-self or situational perspective-taking).

However, the current study's findings did not lend unequivocal support for Wright's (1983) empathic "requirement of mourning" hypothesis. The family caregiver's neutral response on patient 'lack of energy' appeared to be equally associated with an imagine-self perspective taken by the family caregiver and the family caregiver's response to the imagine-other instructional set. Furthermore, the absolute difference scores between the caregiver neutral/caregiver imagine-self and the caregiver neutral/caregiver imagine-other instructional sets were not significantly different. The neutral response by caregivers appeared to be somewhat influenced by the patient's viewpoint rather than totally by their own self-view if they were in the same situation as the patient. Therefore, it can not be concluded that family caregivers simply projected their beliefs as to how they would feel on 'lack of energy' if they were in the patient's situation. Briefly, the caregiver's response to the imagine-self instructional set on 'worrying' was significantly higher than and not correlated with the caregiver's neutral response.

Batson and colleagues (1997), and Davis, Conklin, Smith, and Luce (1996) found much of the same overlap between their imagine-other and imagine-self manipulations in their respective work. While these studies found some difference in the perspective of participants in the imagine-other and imagine-self conditions, this difference was "rather subtle and the overlap was notable" (Batson et al., 1997, p. 754). These authors also suggested that imagine-self instructions provide an informational base for imagining how another person feels. This, in turn, may prompt an identification process where

one may tend to project one's own imagined distress in the other's situation onto one's subsequent response to the situation. It is highly plausible that this study's self-focussed instructional sets provided an informational base from which family caregivers inferred the patient's 'lack of energy' in the imagine-other instructional set, thus resulting in the noted overlap in their respective responses.

It is also important to consider Nickerson's (1999) contention that as a "default measure", observers tend to impute one's knowledge to specific others when the observer feels a need to "fill in the gaps" or when the observer does not have direct knowledge of what the specific other knows. In regard to understanding another person's symptom experiences, it is generally acknowledged that symptoms are subjective phenomenon. Because observers have no direct knowledge of the other person's symptom experience, a certain degree of conjecture is required to infer what the other person is indeed experiencing. Despite this study's sample of family caregivers who reported considerable familiarity with the patient, there will always remain a degree of uncertainty as to how the patient really experiences symptom events. In the current study, it is noted that the family caregivers' neutral control responses were consistently elevated in relation to the patients' self-reports on 'lack of energy' and 'worrying'. It is plausible that these family caregivers were aware of their inability to possess direct knowledge on the patient's experiences. In that case, as a "default measure" these family caregivers might have naturally imputed some of their own knowledge (e.g., either their self-reports or their hypothesized view on how they would feel in the patient's situation) onto their

inferences of the patient's symptom experiences to "fill in the gaps" in their knowledge. As revealed in the current study, this type of heuristic device can lead to mis-estimations of another person's reality.

These results are difficult to explain and therefore any interpretation is based on pure speculation. However, the limited number of studies that explored perspective-taking in nursing literature have tended to measure congruence outcomes on patients' emotional responses between nurses and patients (e.g., Lampic et al., 1996). In the study by Lampic and colleagues, it was suggested that the nurses' overestimations on cancer patients' anxiety were strongly associated with the nurses' estimations on their own hypothetical anxiety if they were to be in the patient's situation. The findings in the current study, however, do not clearly corroborate those found by Lampic and colleagues. Instead, this study's findings appear to be confounded by a research methodology that might have biased family caregivers' imagine-other responses with their imagine-self or self-report responses. Hence, it is difficult to discern whose viewpoint influenced family caregivers' overestimations on patient 'lack of energy' and 'worrying' symptom experiences.

Effects of instructional sets on empathic accuracy

This study's findings revealed that, depending on the physical or psychological nature of the symptom, induced perspective-taking can have a different impact on caregiver empathic accuracy. First, it appeared that the most effective instructional set that assisted family caregivers (in the main study group and in the subgroup of caregivers who over-reported) to achieve the best

empathic accuracy on 'worrying' was the neutral control set, which did not encourage or discourage perspective-taking. When caregivers were not influenced to perspective-take on worrying, their responses were more 'in line' with the patients' responses. On the other hand, when caregivers were induced to either imagine-other or imagine-self perspective-take, their empathic accuracy scores became worse in comparison to their scores in the neutral control set.

So what potentially happened? Why didn't the caregivers' empathic accuracy scores on worrying improve when they were induced to perspective-take? One possible reason is offered by Coke et al., (1978) who found that both (a) imagining how a person in need is feeling (imagine-other) and (b) imagining your own feelings (imagine-self) produced an increase in one's empathic emotional response. In the current study, we also saw that induced imagine-self and imagine-other perspective-taking by caregivers resulted in elevated mean responses and discrepancy scores in comparison to their neutral results (albeit elevations in the imagine-other mean response and discrepancy scores were not as high as the imagine-self results) on patient worrying. However, this study's methods did not include a measure of the caregivers' empathic emotional status subsequent to their being induced to perspective-take. Therefore, it can only be speculated that the caregivers experienced an increase in emotional reaction which influenced their elevated discrepancy scores (worse empathic accuracy) in both perspective-taking instructional sets on 'worrying'.

Second, Coke and colleagues (1978) also described that, in addition to an increase in one's empathic emotional response, the imagine-self condition could

produce an increase in personal distress. In the current study, when the caregivers were prompted to imagine how they would feel in the patient's situation, their mean responses and discrepancy scores were more elevated in comparison to their results in the other instructional set conditions. This elevation in the caregivers' mean results might serve as a reflection of an evoked personal distress that made it difficult for them not to focus on one's own distress when they were induced to imagine the patient's response to 'worrying' (Batson et al., 1997).

So, why did the neutral control instructional set prompt more accurate responses from caregivers on 'worrying'? One might consider that perhaps this instructional set evoked more of a cognitive or objective attempt in the caregiver to understand the patient's viewpoint without resulting in an empathic feeling; thus, the consequence was better empathic accuracy. Because the neutral control set was administered prior to the perspective-taking instructions, perhaps the family caregiver's self-knowledge was not made accessible enough to pose a hazard for him or her to take a more objective stance in comprehending the patient's symptom experience.

In regard to 'lack of energy', the most effective instructional set that assisted the caregivers (in both the main study group and the sub-group of caregivers who over-reported) to achieve the best empathic accuracy was the one which evoked imagine-other perspective-taking. Caregivers appeared capable of taking into account the patient's viewpoint and differentiating it from their own characteristics and viewpoints in their attempt to entertain the patient's

perspective on 'lack of energy'. In contrast to the influence of induced imagine-other perspective-taking on elevated caregiver mean responses and discrepancy scores for 'worrying', the same effect was not apparent in the 'lack of energy' condition. In the main study group for 'lack of energy', we saw that induced imagine-other perspective-taking by caregivers did not result in elevated mean response and discrepancy scores in comparison to their neutral results. In the sub-group, the caregivers' mean response and discrepancy scores in the imagine-other set were lower than their neutral results.

However unlike Coke and colleagues (1978), Higgins (1981) stated that individual (or imagine-other) role-taking might produce an understanding of how another person thinks and feels without evoking an empathic feeling. He argued that imagine-other perspective-taking tends to produce a cognitive response to another person's thoughts and feelings. This cognitive response involves controlling and inhibiting the 'self' from interfering with one's inference of another's experience. This is plausible in this study where caregivers achieved more patient-focussed empathic accuracy scores in the imagine-other versus imagine-self instructional sets for 'worrying' and 'lack of energy', albeit in varying degrees. This interpretation becomes more clear when we consider the following pattern of sequential responses by caregivers to this study's instructional sets in the 'lack of energy' and 'worrying' symptom conditions.

As gleaned from Tables 14 and 16, there is a distinct pattern of caregiver responses to induced perspective-taking activities that warrants further discussion. First, it is noted that generally the poorest empathic accuracy scores

(or highest discrepancy scores) occurred after the family caregiver had been induced to focus on one's self-report or on one's hypothesized view of how one would feel in the patient's situation. However, with the family caregiver's absolute difference scores in the neutral response conditions for 'lack of energy' and 'worrying' serving as the reference points, the family caregiver's respective absolute difference scores consistently became less discrepant in the imagine-other instructional sets in comparison to their self-report and imagine-self scores. This pattern suggests that family caregivers were capable of engaging in some level of cognitive or mental adjustment that allowed them to not only appreciate, but also to control their variant perspectives on the patient's symptom experience. However, the degree of family caregiver success in having been able to control differential perspectives appears to be dependent on whether the symptom was physical or psychological in nature. The family caregiver's ability either to control 'self' focus or to differentiate between one's own and the patient's experience was apparently more of challenge when they are asked to infer the patient's experience on psychological or emotive symptoms, like worrying.

Overall, it is difficult to directly or objectively know whether the family caregiver's neutral inference on patient 'worrying' and the family caregiver's imagine-other inference on patient 'lack of energy' involved controlling the self viewpoint or that the self viewpoint simply did not intrude when the caregiver responded to these instructional sets. Furthermore, it is difficult to know whether the family caregiver actually recognized that one's own characteristics and

viewpoint differed from the viewpoint of the patient (Higgins, 1981). Davis (1994) described that researchers generally explored imagine-other and imagine-self differential effects under the assumption that subjects do as they are told. However, this study reflects the current state-of-the-science that has neglected to explore the precise mental activities that ensue when neutral control and perspective-taking instructions are followed.

Factors that impact empathic accuracy

Guided by Davis's (1994) organizational model on empathy, this study was designed to take an initial step in systematically testing the relationships between family caregiver empathic accuracy and family caregiver characteristics (i.e., educational level, length of time caring for the patient, acquaintance factors, and individual differences in dyadic perspective-taking), and symptom situation characteristics (i.e., patient's self-report on level of symptom experience). These are factors purported in social psychology and health-related quality of life literature to depict aspects of the intimate patient-caregiver relationship that might impact family caregiver empathic accuracy on patient symptom experience.

A series of five multiple regression analyses were used to ascertain the impact of a set of family caregiver and symptom situation characteristics on empathic accuracy on total symptom experience for 'lack of energy' and 'worrying', and on sub-scale scores for symptom frequency, severity, and distress across 32 MSAS symptoms. Apart from the central focus of this research, which was an examination of the influence of the patient's symptom

situation and family caregiver characteristics on caregiver accuracy, there may be additional explanatory factors that were uncontrolled for in this convenience sample. However, bivariate analyses attempted to isolate additional sociodemographic, illness, and treatment-related factors as covariates that might account for empathic accuracy by family caregivers.

At the bivariate level, several factors were weakly associated with empathic accuracy scores (i.e., absolute difference between patient and family caregiver total symptom experience ratings) on 'lack of energy' and 'worrying, as well as with the separate empathic accuracy scores for frequency, severity, and distress. However the results made it clear that, apart from the patient's self-report and/or the family caregiver's neutral inference, the bivariate correlates did not translate into powerful predictor factors in multivariate analyses on empathic accuracy. Sneeuw and colleagues suggested that the low proportion of explained variance in their study (15% in absolute patient-proxy differences) by patient and proxy characteristics might mean that either certain factors were overlooked or the predictor factors were not adequately measured due to random error in both sources of information (e.g., lack of concreteness of the MSAS and/or dyadic perspective-taking scales, different interpretations of the response items, lack of attention in completing questions, or moodiness). Any one of these threats might have contributed toward the lack of predictive power of the variables tested in the current study.

In the current study, the degree of family caregiver empathic accuracy could not be predicted by age, gender, or educational level of the patient or

caregiver, time since patient diagnosis, current or past treatment received by the patient, length of time nursing care received in the patient's home, annual family income as reported by the patient, length of time the family member cared for patient, patient-caregiver acquaintanceship factors, or dispositional traits of the family caregiver to perspective-take. Specific to the patient-family caregiver 'relationship' variable effects on empathic accuracy, that were explored in accordance with Davis's (1994) model and related studies, the homogeneity of this particular study sample may have prevented the investigator from detecting significant predictors of caregiver empathic accuracy. For instance, the typical length of time that 67% of the family caregivers reported caring for the patient was less than or equal to 18 months. The typical degree of patient-family caregiver acquaintance for 64% of the dyads was high (i.e., on a range of zero [low] to five [high], the mean score was four) and 81% of the family caregivers had daily contact with the patient as they lived in the same household as the patient.

The level of family caregiver education was also explored in accordance with Davis's (1994) model and related studies that found it to be associated with judgment accuracy (e.g., Ickes et al., 1990; Thomas et al., 1997). However, the results indicated that there was no significant bivariate correlation between the family caregiver's level of education and empathic accuracy on patient symptom experience. Homogeneity of the sample did not appear to be a contributing factor as this study's sample of family caregivers had attained a range of educational levels. However, the generality of this null finding must remain open

to question, given that a number of related studies have found significant associations between patient and family caregiver levels of education, and judgment accuracy (e.g., Thomas et al., 1997; Hays et al., 1995; McCusker & Stoddard, 1984; Sneeuw et al., 1998). A more recent study by Sneeuw and colleagues (1999) found that the proportions of large patient-caregiver discrepancies on patient quality of life varied within narrow margins across the education subgroups of family caregivers.

In the context of the current study, the family caregiver's dyadic perspective-taking tendencies as reported by both the family caregiver and the patient were not associated with empathic accuracy. Extant research that has documented evidence depicting the linkage between dispositional perspective-taking and empathic accuracy is mixed. The reliable effects of dispositional perspective-taking on accuracy was shown to be largely dependent on the type of information being assessed across related studies. For instance, by employing the perspective-taking sub-scale of the IRI by Davis (1980), Bernstein, McGuire, Raskin, Ganzach, and Thiry (1988) found significant associations between perspective-taking and accuracy at distinguishing the target's personality traits, and Bernstein and Davis (1982) found perspective-taking accuracy on self-descriptions. Other studies, however, found no significant relation between perspective-taking and accuracy on non-verbal decoding of information (e.g., Hart & Rosenthal, 1988). Furthermore, numerous studies conducted by Ickes and colleagues (e.g., Ickes et al., 1990; Marangoni et al., 1995; Stinson & Ickes, 1992), found that no measure of dispositional

perspective-taking was associated with empathic accuracy on inferring another person's thoughts and feelings in naturalistic settings.

Davis (1994) cautioned that the findings where linkages were found between dispositional perspective-taking and empathic accuracy were highly speculative, based on the small number of studies that found this association. He suggested that the best predictors of accuracy are most likely not individual dispositions to perspective-take, but emergent verbal and non-verbal interactions in specific situations. Davis further described numerous bodies of work by Ickes (as above noted) that lend support toward specific features of observer-target interactions as being associated with greater accuracy, while dispositional perspective-taking scores were not.

In summary, it was surprising that none of the anticipated factors (besides the patient's self-report and the caregiver's neutral inference on patient total symptom experience) were found to have sufficient explanatory power for family caregiver empathic accuracy on the respective patient symptom experiences. The results of this study make it clear that other variables remain unidentified as predictors of caregiver empathic accuracy. In the current study, there is insufficient evidence for health care professionals to prefer one type of proxy family caregiver over the other, as suggested in other bodies of investigative work on patient-family caregiver response comparability.

Limitations

There are some possible generalizability and methods limitations that caution the reader to carefully interpret the current study's results. The ensuing

discussion adds to the major limitation highlighted earlier about potential artifactual effects that might have been introduced when it was assumed family caregivers would be able to respond to differential instructional sets in an unbiased manner.

First, the results are based on a heterogeneous sample of persons diagnosed with either Stage III or Stage IV cancer that may limit a more concise understanding of perceptions of symptoms experienced by patients with differential diagnosis and stage of disease. Some literature suggests that regardless of age and gender of patients, there is a “final common pathway” of symptom experiences in advanced cancer (Donnelly & Walsh, 1995) which resembles that found in this study’s sample of patients. However, conflicting evidence suggests that there are significant differences in symptoms experienced by patients depending on the primary site of cancer (Vainio & Auvinen, 1996). Other authors reported that, although patients who were approaching the terminal phase of their illness reported higher levels of overall symptoms, there remained an irregular fluctuation in frequencies and severities of the individual symptoms (Coyle, Adelhardt, Foley, & Portenoy, 1990; Kurtz, Given, Kurtz, Given, 1994). Because the current study’s sample consisted of patients with different types of cancer and different types of treatment, it was difficult to separate the effects of treatment from disease processes on patients’ and caregivers’ perceptions. However, the central issue underlying the research questions was not the source of symptom experience, but the measurement of symptom experience experienced from whatever source, and the levels of

agreement between patients' and family caregivers' perceptions of symptom experience.

Second, this study is based on a convenience sample of patients and family caregivers. This raises the issue of the representativeness of this study's sample of patients and family caregivers. In other words, it might be valuable to know the proportion of patients-family caregivers who were deemed 'eligible' out of all the patients attending the various recruitment settings. Unfortunately, the targeted recruitment sites in the current study did not maintain a profile of or informational base on family caregivers who cared for cancer patients in the home care setting. Fowler, Coppola, and Teno (1999) have noted practical challenges in being able to locate family caregivers who can provide information about illness experiences, which would likely vary among individual patient cases. These authors advised that the selection of family caregiver respondents would have to be done on an individual basis. For example, in some cases there may be one family member who "is fully involved with all phases of the patient's dying experience and who can answer most questions as an informed person" and in other instances, different family members may be involved over the passage of illness. Future feasibility studies are required to evaluate the complexity in developing a profile of family caregivers who can provide reliable information on patient symptom experiences (Fowler et al., 1999).

Nonetheless, it is difficult to determine how well this study's sample of family caregivers reflected key attributes (e.g., age, gender, type of relationship with the patient) of the population of family caregivers who care for advanced

stage cancer patients. Although gender did not appear to play a significant predictor role on levels of agreement on 'lack of energy' and 'worrying', this is likely related to the lack of variability in this study's sample of family caregivers who were primarily female caregivers. However, in light of studies that found a significant gender role on levels of agreement across health related issues, future investigations should not ignore the generality role of gender effects on patterns of response comparability involving male caregivers/female patients and female caregivers/male patients on varied symptom experience events (Bassett et al., 1990; Kristjanson et al., 1998; Kurtz et al., 1996; O'Brien & Francis, 1988).

Regardless, this study's profile of family caregivers is comparable to the characteristics of those included in a number of related study samples where they were primarily older female spouses (i.e., > 60 years of age) who were married to and in long term relationships (an average of 33 years) with the patient, and who stated that they talked openly either "frequently" or "usually" with the patient about his or her symptom experiences, which potentially fostered congruence in perceptions (Bassett et al., 1990; Clipp & George, 1991; Epstein et al., 1989; Hays et al., 1995; Hinton, 1994; 1996; Lobchuk et al., 1997; Kristjanson et al., 1998; Sneeuw, Aaronson, de Haan et al., 1997; Sneeuw et al., 1998; 1999).

Furthermore, this convenience sample was mainly comprised of patients who identified themselves as being Canadian and family caregivers who reported their ethnicity as being either Canadian or no ethnic origin. This prevented an exploration of varying cultural influences on perceptions of patient symptom

experiences. Numerous authors have noted that the palliative care needs of ethnic-minority patients are often overlooked (Hall, Stone, & Fiset, 1998). Others described that, however, the conduct of cross cultural studies would necessitate equivalent symptom measurement and a measure of acculturation into dominant cultures by ethnic-minority patients (Padilla & Kagawa-Singer, 1998).

Nonetheless, the researcher was able to locate two studies by Lawrence, Tennstedt, and Almy (1997) and Sneeuw, Aaronson, Osoba, et al. (1997) that evaluated cultural or ethnic influences on discrepancies between patient and family caregiver ratings. In particular, Lawrence, Tennstedt, and Almy explored differences in response comparability and bias for elderly African American, Puerto Rican, and non-Hispanic Caucasian subjects with some degree of disability and their caregivers. These authors' findings were corroborated by related studies involving Caucasian samples where there was an overall tendency of caregivers relative to elderly persons to overestimate on health status measures. However, there was no difference in a bias to overestimate among the three ethnic groups.

Third, this study's findings were based on the responses of family caregivers who were older and in long-term marital relationships, which may make it difficult to generalize conclusions to non-married and younger caregivers. Other authors have found that in comparison to younger adults, individuals in advanced ages experience a decline in perspective-taking ability that is likely due to compromises older adults experience in working memory capacities (Pratt, Pratt, Diessner, Hunsberger, & Pancer, 1996). Fourth, these findings are

generalizable only to patients who are cognitively stable in light of the fact that this patient sample had a mean MMSE score of 29 (of 30).

Fifth, because this study targeted a specific dyadic perspective-taking situation, it may not be possible to generalize the results to contexts other than where family caregivers currently care for advanced stage cancer patients.

Sixth, any conclusions concerning aspects of perspective-taking will have to be limited to the non-affective empathic outcome of intrapersonal or empathic accuracy. These results cannot be generalized to other modes of empathic outcomes, such as the affective responses of empathic concern or personal distress arising from observing another person's distress.

Seventh, in light of the compromised condition of advanced stage cancer patients who may become quickly tired or disenchanted with lengthy questionnaires, it was important to consider instruments that are relevant and easy to read, understand, and score. Although the MSAS is a 32-item instrument, the completion rate was acceptable in the context of this study that sampled a majority of heterogeneous advanced stage cancer patients. Furthermore, a review of literature on symptoms in advanced stages of cancer confirmed that the MSAS surveys a symptom profile that is relevant to polysymptomatic advanced cancer patients (e.g., Cherny et al., 1994; Donnelly & Walsh, 1995). Most importantly, the MSAS was able to extend current knowledge by promoting the comprehensive measurement of three underlying symptom dimensions experienced by advanced cancer patients, and not just a description of the prevalence and severity of symptoms. This tool's concise

format and clearly worded response items did not confound symptom occurrence with symptom distress items. Consequently, the MSAS offered a clear understanding of what symptom dimensions the family caregiver and the patient were assessing in their respective reports on patient symptom experience.

Sneeuw, Aaronson, Osoba, et al. (1997) speculated on the argument that the use of brief questionnaires might elicit higher levels of agreement between the patient and family caregiver. However, as noted in this study, the levels of agreement on symptom frequency, severity, and distress were consistently good (range between 0.63 to 0.69). These results indicated that family caregivers were able to respond to detailed questionnaires in a fashion that was reasonably similar to patients' responses. Furthermore, the purpose of this study was not to test the MSAS for use in clinical settings, but to provide a comprehensive evaluation of patient and family caregiver reliability across a range of symptoms and symptom dimensions.

Eighth, the patients were asked to provide reports based on recall information related to their MSAS symptoms that may or may not have occurred during the previous week. However, retrospective judgments that are based on recent events (i.e., past week) can be subject to memory biases. This was revealed in previous work that explored patient-family caregiver congruence on pain perceptions (e.g., O'Brien & Francis, 1988). Furthermore, the current study found that even patients with high cognitive abilities exhibited memory deficits that hampered their reliable symptom accounts. Magaziner et al. (1988) similarly found that in cases of mild cognitive impairment, there was lower patient-proxy

concordance on activities of daily living response items.

Nonetheless, the MSAS instructions for participants to provide reports on patient symptom experiences encountered over the past week was realistic. Often health care professionals solicit information from patients and their family members that is based on their retrospective accounts of symptoms which the patient recently experienced. By incorporating the family caregiver's assessment of the patient's symptom experience, this study promoted a more balanced and hopefully more valid account of patient symptom events.

Ninth, this study's convenience sample design provides only a 'snap-shot' of patient-family caregiver response comparability on patients' current experience with symptom events. It was not possible to determine the validity of family caregiver 'monitoring' and 'interpreting' process skills as a function of the patient's changing health status and the family caregiver's increased experience in the management of patient symptoms over time (Sneeuw, Aaronson, Osoba, et al., 1997; Sprangers and Aaronson, 1992). As well, this cross-sectional design focussed on aspects of perspective-taking that were measured on a one time basis only. It was not possible to track the development of empathic accuracy and related perspective-taking processes over an extended time frame.

Tenth, this study was based on the premise that the patient's self-report provided the 'standard' upon which to compare family caregivers' responses. However, because there is no objective measurement of subjective symptom experiences, it is fair to question whether the "true" patient symptom experience is one that is based on patient-derived information. For instance, patients in the

current study may have under-reported their symptoms because of denial, a need to protect their caregiver from emotional anxiety over increasing symptoms, or an experienced adjustment to the symptom situation that is now perceived as normal for the illness. On the other hand, family caregivers may have over-estimated for reasons other than projecting their own 'actual' or 'hypothesized' experiences onto their assessments of the patient symptom situation. For example, they may see the situation as worse than it is due to being over-protective, possessing a negative attitude, or even feeling exhaustion due to caregiver burden (Miaskowski et al., 1997).

Eleventh, this study explored the relationship between perspective-taking and empathic accuracy on only two symptoms: 'lack of energy', as an indicator of physical symptomatology and 'worrying', as an indicator of psychological distress. The purpose was to explore the differential natures of these two symptoms in terms of their potential effects on aspects of perspective-taking and empathic accuracy. It is difficult, however, to generalize these findings to other physical and psychological symptoms that are known to be experienced by end-stage cancer patients (e.g., lack of appetite, pain, feeling drowsy, and sadness).

Conclusions

Conclusions on patient-family caregiver response comparability that may be drawn from this study, based upon testing are as follows:

1. On the prevalence of 32 MSAS symptoms, family caregivers achieved primarily fair to moderate levels of agreement with the patient, depending on the

concreteness or level of visibility of the symptom item.

2. Family caregiver inferences on patients' current total symptom experiences were significantly different from patient self-reports on 12 of 32 MSAS symptoms.

3. On categorical and ordinal level MSAS symptom items, family caregivers tended to over-report on patient symptom experience, at both the global and individual symptom levels.

4. Family caregiver bias to overestimate was modest on a global symptom level basis. At the individual symptom level, the bias to overestimate ranged from small on 'shortness of breath' to moderate on 'feeling sad'.

5. Agreement levels between patients and family caregivers were better at the global versus individual symptom level.

6. Patient and family caregiver agreement levels were substantial on symptom frequency, severity, and distress sub-scales across 32 MSAS symptom items.

7. The lowest amount of bias to overestimate by family caregivers occurred on symptom severity and the highest occurred on symptom distress across 32 symptom items.

8. Patient and family caregiver agreement levels on physical symptoms were good in comparison to psychological symptoms where agreement levels were fair.

9. In the main study group (that included family caregivers who overestimated, underestimated, and were congruent on patient symptom experience), family caregivers appeared to be influenced by an imagine-other (patient oriented) perspective-taking process in order to comprehend patient symptom experience

on physical symptoms like 'lack of energy'.

10. In the main study group, family caregivers appeared to be influenced by a mixture of their own symptom experience and an imagine-other perspective-taking process in order to comprehend patient symptom experience on psychological symptoms like 'worrying'. This finding implies that it was difficult for family caregivers to differentiate between one's self-view and the patient's viewpoint on the symptom experience of 'worrying'.

11. In the respective sub-groups of family caregivers who provided overestimates on 'lack of energy' and 'worrying', there appears to be a notable overlap between caregivers' imagine-other and imagine-self or self-report responses, respectively. This might be attributed to the current study's method that possibly biased family caregiver responses to the imagine-other perspective-taking instructional set. The results remain inconclusive.

12. Depending on whether the symptom is physical or psychological in nature, induced perspective-taking can have differential effects on empathic accuracy. It appears that on physical symptoms like 'lack of energy', more accurate inferences by family caregivers can be achieved by inducing them to embrace the patient's viewpoint on the symptom. However, on psychological symptoms like 'worrying', perspective-taking activities can serve to promote inaccuracy in family caregiver perceptions. A neutral question (i.e., one that does not promote perspective-taking) appears to be more effective in bolstering a more objective account on patient 'worrying' by family caregivers.

13. Of the two perspective-taking instructional sets, imagine-other perspective-

taking appears to promote judgment accuracy more effectively than imagine-self perspective-taking by family caregivers.

14. In general, it appears that family caregivers are capable of engaging in a cognitive endeavour to control their self-view from totally influencing their perceptions on patient symptom experience. However, this becomes more of a challenge when family caregivers are asked to infer patient symptom experience on psychological symptoms like 'worrying'.

15. Family caregiver characteristics (e.g., level of education, length of time caring for the patient, acquaintanceship factors, and dyadic perspective-taking tendencies) do not appear to be predictors of caregiver empathic accuracy on total symptom experience for 'lack of energy' and 'worrying', or on symptom frequency, symptom severity, and symptom distress. The family caregiver's neutral inference and/or the patient's self-report on patient symptom experience served more as descriptive predictors of empathic accuracy on the respective criterion variables.

Recommendations for Future Research

Based upon the findings of the current study, the following suggestions are made for future research:

1. Research related to the status of the family caregiver's level of accurate assessment on patient multidimensional symptom experiences should be pursued in order to continue building a conceptual base on 'family caregiving skills'. Future research should replicate the current study's statistical analysis techniques that employed various parameters of chance-corrected agreement at

both the individual (i.e., correlational analysis) and group (i.e., mean differences) levels of agreement. To promote comparability between studies, researchers should employ common conceptual and operational definitions of patient symptom experience. For triangulation purposes, investigators might employ a multi-method approach (e.g., research diaries, observational field notes, or qualitative interviews) where additional contextual material can provide evidence that further explains patient-family caregiver perceptual differences.

2. Continued research about the nature of empathic perspective-taking in patient-family caregiver relationships may contribute more information about how family caregivers derive their inferences on patient's current symptom experiences and achieve judgment accuracy.
3. Continued research relating to the effects of induced perspective-taking on judgment accuracy on a range of physical and psychological symptoms, utilizing a methodology where family caregivers are randomized to receive a counterbalanced sequence of instructional sets.
4. Once evidence exists that specific perspective-taking instructional sets serve as effective heuristic devices on promoting judgment accuracy, time series research is then needed to determine whether training on the use of these devices, and feedback on perceptions can increase the potential for accurate and complete reflection on the target patient's condition by family caregivers.
5. Qualitative research to determine what family caregivers actually do when they are prompted to engage in perspective-taking. This methodology could employ an open-ended questionnaire or interview process to uncover the mental

processes that underlie caregivers' responses to induced perspective-taking activities.

6. Longitudinal research with at least two assessment points to determine the effect of the patient's changing health status on family caregiver judgment accuracy. Rothman et al. (1991) and Sneeuw et al. (1998) employed various statistical methods that are worthy of consideration when attempting to capture caregiver responsiveness to changes over time on patient symptom experience.
7. Research that explores patient and family caregiver 'on-line' interaction in naturally occurring social settings to discover information determinants by patients (e.g., verbal and non-verbal cues) and/or behavioural aspects of social interaction between patients and caregivers (e.g., the use of prompts) that enhance or inhibit family caregiver empathic accuracy on patient symptom experience. However, others have described that an 'on-line' methodology (e.g., videotaping) which embraces empathic accuracy as an emergent product of an interaction process at the dyadic level can be intensive, expensive, and time-consuming (Ickes et al., 1990).
8. Research on the psychological adaptive processes of patients and family caregivers (e.g., worrying, depression, or optimism) may contribute to our understanding of patient-family caregiver discrepancies in symptom perceptions.
9. Research that examines whether congruency levels in patient and family caregiver perceptions on patient symptom experience influence patient and family caregiver outcomes on psychological or emotive states, and quality of life. More specific, future investigative work can determine whether the

consequences for patients and caregivers vary in terms of whether the family caregiver over-estimates, under-estimates, or infers accurately on patient symptom experience.

10. Research that continues to evaluate the psychometric properties of the MSAS and the acceptance of use by family caregivers and cancer patients at all stages of the disease process.

Implications for Practice

The overarching aim of this study was to make more explicit the status of family caregiving skill in regard to the current management of patient symptom experiences within the intimate patient-family carer relationship. More specific, this study assessed the caregiving skill processes of 'monitoring' and 'interpreting' to determine how well caregivers are able to accurately assess the underlying multidimensional symptom experiences of advanced stage cancer patients. The current study has implications for health care professionals on how to provide care not only to advanced stage cancer patients, but also to family caregivers. This knowledge can aid health care professionals to understand how to intervene in order to assist family caregivers to develop their caregiving skills. Specific findings illustrate how family caregivers can be guided to draw on real world cognitive and interpersonal skills to aid them in the provision of optimal symptom assessment and management of patient symptoms.

First, health care professionals need to appreciate that advanced stage cancer is a polysymptomatic, multidimensional symptom experience. Health care professionals commonly assess the more organically-based, physiological

(i.e., symptom location, duration, and onset) and sensory (i.e., severity, quality, and pattern) symptom dimensions. However, symptom distress or the affective, meaning-based dimension is often overlooked. Each element of these dimensions by itself can serve as an indicator for specific intervention by health care professionals. Health care professionals also need to know that patients are able to distinguish each of the dimensions. Patients' reports on symptom distress can vary in relation to their reports on frequency and severity. For example, it was found that patients' reports on levels of symptom distress were not always reported as intense, despite their reports of intense levels of frequency and severity for the same symptoms.

Second, health care professionals need to be aware that by merely asking the family caregiver whether the patient experienced the symptom in the past week, only fair to moderate levels of agreement can result depending on the symptom. On the other hand, more detailed and concrete questioning on the underlying symptom dimensions of frequency, severity, and distress can minimize interpretation and thus, promote improved judgment accuracy by family caregivers. As found in the current study, the degree of discrepancy that can be expected on each of these dimensions is generally less than one response unit.

Third, health care professionals should take note that the current study supports previous trends that describe overestimation by family caregivers. However, their bias to over-report is of only a modest magnitude on a global symptom experience basis. It is also important to know that only a low moderate amount of bias to over-report by family caregivers exists on symptom frequency,

severity, and distress.

Fourth, health care professionals should not engage in a wholesale rejection of family caregivers' input on patient symptom experiences, based on their belief that caregiver assessments are invalid due to projection of their own anxieties in dealing with their loved one's illness. On physical symptoms like 'lack of energy', health care professionals can expect good agreement levels and a scant amount of bias for family caregivers to overestimate. This appears to be related to the ability of family caregivers to respond by inhibiting their own symptom experience from interfering with their consideration of the patient's viewpoint on 'lack of energy'.

On the other hand, a caveat is warranted for psychological symptoms where health care professionals need to carefully interpret the information provided by family caregivers. Since patient-caregiver differences were most pronounced for ratings on psychological symptoms, family caregivers may be less suitable in providing reliable responses on patient symptoms like 'worrying'. Because the cancer experience is likely vicariously shared by family caregivers at a psychological level, it is probable that family caregivers tend to impute some of their own experiences onto their inferences of patient 'worrying'. Therefore, it is advisable that health care professionals verify caregivers' perceptions on psychological or emotional symptoms by eliciting feedback directly from the patients whenever possible.

Fifth, in light of the common practice by health care professionals to elicit patients' retrospective accounts on their recent symptom events, they should be

aware that the investigator found errors in patient symptom reporting despite the patients' high cognitive functioning status. However, by allowing patients and family caregivers an opportunity to share their respective perceptions, health care professionals might obtain a more reliable or balanced account of the patient's actual symptom situation (Sohier, 1995). The current study discovered additional merit in allowing patients and their caregivers to share with each other their discrepant perceptions on patient symptom experiences. Discrepant perceptions often promoted further discussion and clarification between patients and caregivers on the cause of the perceptual divergence. Other authors have described steps that can be taken by health care practitioners to "coach" a dialogue between the patient and family caregiver, which enables the caregiver to see the situation as the patient sees it (e.g., Chaitchik, Kreidler, Rapoport, & Algor, 1992; Sohier, 1995). Furthermore, this type of shared dialogue might serve as a form of reassurance or feedback for caregivers on their 'monitoring' and 'interpreting' caregiving process skills.

Sixth, health care professionals can take additional steps to facilitate patient-caregiver agreement and to reduce biased reporting by family caregivers. More specifically, they can assist family caregivers to maximize their judgment accuracy simply by the way they ask family caregivers about patient symptom experiences. For example, on physical symptoms like 'lack of energy' health care professionals can utilize a clear, simple, and succinct prompt that evokes the family caregiver to imagine the patient's viewpoint on the symptom situation; such as, "Putting yourself in the patient's shoes, how do you believe the patient

would describe the frequency, severity, and distress he or she experienced this week on lack of energy?" Framing the question in this way can produce in caregivers a more objective, patient-oriented response to the patient's symptom experience. This in turn can promote optimal management of physical symptoms when family caregivers' assessments serve the basis of intervention.

Although family caregivers may follow this instructional set, they may also seize the opportunity to share that their own perception of what the patient experienced varies from what they believe the patient would say about the symptom situation. It is possible that this type of symptom question might serve as a trigger that promotes enhanced communication among health care professionals, patients, and their family caregivers.

On psychological symptoms it is important for health care professionals to be aware that the type of question they ask family caregivers, for example about patient 'worrying', can hazardously promote family caregiver judgment inaccuracy. In other words, it is important for health care professionals to concentrate on how they ask the question. In caregiving literature, it is widely described that family caregivers acutely feel the 'ripple effect' caused by the cancer experience, which often leaves them emotionally affected by their loved one's illness (Yates, 1999). Therefore, health care professionals need to carefully assist caregivers in their provision of accurate judgments on patients' psychological or emotional symptoms by posing questions that promote an objective, unbiased inference by family caregivers. For instance by simply asking, "During the past week, did the patient have any of the following

symptoms? If yes, how often, how severe, and how distressing was the symptom experienced by the patient?”, the family caregiver is not encouraged to draw upon one’s own acutely felt psychological experience that can serve to decrease judgment accuracy on psychological symptoms.

From an ethical perspective, health care professionals also would not want to burden family caregivers with inappropriate perspective-taking questions on psychological symptoms like ‘worrying’; that is, questions that require family caregivers to exert an unwarranted mental effort in an area where they are already experiencing a great deal of angst themselves. Furthermore, family caregivers appear to be inclined to overestimate on psychological symptoms, regardless of the instructional set. However, by posing neutral questions in the manner suggested, the risk of overestimation by family caregivers would be diminished in comparison to the risk that is associated with questions that encourage perspective-taking on psychological symptoms.

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Appendix A**LETTER TO SUBJECTS REQUESTING PERMISSION TO RELEASE NAMES
(PATIENTS AND PRIMARY FAMILY CAREGIVERS)**

Patient Name
Address

Dear

I am mailing you this letter on behalf of Michelle Lobchuk, RN, a doctoral student at the University of Manitoba. She is interested in learning about cancer patients' symptoms and the ways family members view the patients' symptoms. She is also studying how primary family caregivers assess the feelings and thoughts patients may have about their symptoms.

I am writing to obtain your consent to give Michelle Lobchuk your name and the name of the person who is most involved in caring for you in your home (like a family member or friend), as possible participants in the study. If you do not wish your names to be given to Michelle, please call me at _____ by _____ . If I do not hear from you, I will assume that it is alright to give Michelle your names. Michelle will then contact you by telephone and provide further information about the study.

Should you decide to participate, all the information you give will be kept strictly confidential. No information about you or your family will be shared with health professionals caring for you. The care you receive will not be affected by your decision to take part or not take part in this study.

Thank you for considering this request. If you have any questions about the research study Michelle can be reached at 339-0074.

Sincerely,

Name
Home Care Coordinator

Appendix B**LETTER TO SUBJECTS REQUESTING PERMISSION TO RELEASE NAMES
(PATIENTS AND PRIMARY FAMILY CAREGIVERS)**

Patient Name
Address

Dear

I am mailing you this letter on behalf of Michelle Lobchuk, RN, a doctoral student at the University of Manitoba. She is interested in learning about cancer patients' symptoms and the ways family members view the patients' symptoms. She is also studying how primary family caregivers assess the feelings and thoughts patients may have about their symptoms.

I am writing to obtain your consent to give Michelle Lobchuk your name and the name of the person who is most involved in caring for you in your home (like a family member or friend), as possible participants in the study. If you wish your names to be given to Michelle, please call me at _____ by _____ . Michelle will then contact you by telephone and provide further information about the study. If I do not hear from you, I will not give your names to Michelle.

Should you decide to participate, all the information you give will be kept strictly confidential. No information about you or your family will be shared with health professionals caring for you. The care you receive will not be affected by your decision to take part or not take part in this study.

Thank you for considering this request. If you have any questions about the research study Michelle can be reached at 339-0074.

Sincerely,

Name
Liaison Nurse
St. Boniface General Hospital, Palliative Care Unit

Appendix C

INVITATION TO PATIENTS AND FAMILY CAREGIVERS

Michelle Lobchuk is a registered nurse and a doctoral student at the Faculty of Graduate Studies, University of Manitoba. She is doing research here about cancer patients' symptoms and the ways family members view the symptoms. She is also interested in learning about how family members understand the thoughts and feelings patients may have about their symptoms.

The information that you and your family member give will be kept strictly confidential. Whether or not you decide to participate will in no way influence the care that you receive.

Michelle would like to talk to you about the study. Would you be willing to speak to Michelle so that she can explain the study to you? You can let the nurse know about your decision to speak to Michelle. Please indicate your decision on the second page of this invitation and return it to your nurse. You can leave your name and telephone number with the nurse so that Michelle can call you about the study (see second page).

INVITATION TO PATIENTS AND FAMILY CAREGIVERS
(A study by Michelle Lobchuk, R.N., M.N., Faculty of Graduate Studies,
University of Manitoba)

Yes, I agree to speak to Michelle

NAME

TELEPHONE NUMBER

No, I do not agree to speak to Michelle

RETURN THIS PAGE TO THE NURSE

Appendix D**INVITATION TO PATIENTS AND FAMILY CAREGIVERS TO MEET
RESEARCH NURSE**

Michelle Lobchuk is a registered nurse and a doctoral student at the Faculty of Graduate Studies, University of Manitoba. She is doing research here about cancer patients' symptoms and the ways family members view the symptoms. She is also interested in learning about how family members understand the thoughts and feelings patients may have about their symptoms.

The information that you and your family member give will be kept strictly confidential. Whether or not you decide to participate will in no way influence the care that you receive.

Michelle would like to talk to you about the study. Would you be willing to speak to Michelle today so that she can explain the study to you? You can let the nurse know about your decision to speak or not speak to Michelle.

Appendix E

PATIENT CONSENT TO PARTICIPATE

I am inviting you to take part in a study about patients' symptoms and the ways family members view patients' symptoms. The results of the study may be helpful to health professionals (like nurses) who want to know how to improve the care they give to patients and family members. Your signature below indicates only that you agree to participate in the study and allow the investigator access to your chart for medical information, such as the type of cancer you are diagnosed with, the stage of your disease, and the type of treatment you may be receiving.

The medical information from your chart will be collected in accordance with the Personal Health Information Act. Depending on the health care program(s) you are enrolled with as a cancer patient, you are giving the investigator permission to access your chart(s) that may be held at either the: CancerCare Manitoba facility (formerly known as the Manitoba Cancer Treatment and Research Foundation), Winnipeg Regional Health Authority facilities at Riverview Health Centre or St. Boniface General Hospital, or the Grace General Hospital.

As part of the normal routine for all patients in this study, I will first ask you eleven short questions that relate to your thinking, memory, and concentration abilities. I will ask you questions like, "Can you tell me what day it is today?" and "Can you tell me what season we are in?". I will also ask you simple questions as to your age, marital status, occupation, etc. I will then ask you to complete a questionnaire in a room where your verbal responses to questions cannot be heard by your family member. This questionnaire will have questions about how you have been feeling in regard to symptoms you may be having. The last questionnaire will ask you how your partner behaves and acts towards you to help him or her understand how you are feeling. The four questionnaires will take about twenty minutes to complete.

Your participation is voluntary and you may withdraw from the study at any time by simply telling the researcher. Your specific responses on the questionnaires will be kept confidential. Your name will not be used in any reports about the study or in any future publications. Only myself and my dissertation committee members (listed below) will have access to questionnaire information. During and after the research, all questionnaires will be securely locked up, and kept for seven to ten years and then destroyed. Your decision to take part or not take part in this study will not affect your care.

There are no known risks involved with participating in the study. This study offers no direct benefits to you. You will receive answers to any questions

you may have about the study at any time.

This study is being conducted as part of my course work for the Faculty of Graduate Studies, Interdisciplinary Doctoral Program. The following agencies and committees have given approval for the study: Ethical Review Committee, Faculty of Nursing at the University of Manitoba; Winnipeg Regional Health Authority, Access Committees at St. Boniface General Hospital, Riverview Health Centre, Grace General Hospital, and CancerCare Manitoba. If you choose to take part, your assistance is appreciated. If you choose to withdraw from the study, your decision will be respected.

The researcher, Michelle Lobchuk, can be reached at 339-0074. The researcher's advisor is Dr. Lesley Degner (235-3481), University of Manitoba, Faculty of Nursing.

Michelle M. Lobchuk, R.N., B.N., M.N.
Interdisciplinary Doctoral Student
Faculty of Graduate Studies
University of Manitoba
Winnipeg, Manitoba

I agree to participate in this project.

Your signature _____ Date _____

Interviewer signature _____ Date _____

Dissertation Committee:

Dr. Lesley Degner
Professor
Faculty of Nursing
University of
Manitoba

Dr. T. Hassard
Professor
Department of
Community Health
Sciences
University of
Manitoba

Dr. P. Kirk
Professor and
Head
Department of
Family Medicine
Faculty of Medicine
University of
Manitoba

Dr. J. Vorauer
Assistant
Professor
Faculty of Arts:
Psychology
University of
Manitoba

Please send me a copy of the summary of the research report.

Send to: _____ (name)
_____ (address)

Appendix F

FAMILY CAREGIVER DISCLAIMER

I am inviting you to take part in a study about patients' symptoms and the ways family members view patients' symptoms. You have been identified by the patient as the person most involved in caring for him or her in his or her home. The results of the study may be helpful to health professionals (like nurses) who want to know how to improve the care they give to patients and family members. You will be giving your consent to participate when you respond to items on the questionnaires.

I will ask you to complete four questionnaires in the patient's home at the same time the patient completes his or her questionnaires. The first questionnaire is a short form that will ask you simple questions as to your age, marital status, occupation, etc. The second form is a questionnaire that asks you to rate how the patient is experiencing symptoms that you think the patient has. You will also be asked to complete a simple questionnaire that asks you to describe how you behave and act towards the patient that might help you to understand how the patient is feeling and what the patient is thinking. The last set of three short questions asks you to rate two symptoms in terms of your own viewpoint, as well as other viewpoints. The survey questionnaires can be completed within twenty to thirty minutes. You will be asked to not discuss the symptoms you believe the patient to be feeling while completing the questionnaires.

Your participation is voluntary and you may withdraw from the study at any time by simply telling the researcher. Your decision to take part or not take part in this study will not affect the patient's care. Your name will not be revealed and your confidentiality will be maintained in all reports about the study or in any publications. Your specific responses to the questionnaires will be kept confidential. During and after the research, all questionnaires will be securely locked up, and kept for seven to ten years and then destroyed. Only myself and my dissertation committee members (listed below) will have access to questionnaire information.

There are no known risks involved with your participation in this study. This study offers no direct benefits to you. You will receive answers to any questions you may have about the study at any time.

This study is being conducted as part of my course work for the Faculty of Graduate Studies, Interdisciplinary Doctoral Program. The following agencies and committees have given approval for the study: Ethical Review Committee, Faculty of Nursing at the University of Manitoba; Winnipeg Regional Health Authority; Access Committees at St. Boniface General Hospital, Riverview Health

Centre, Grace General Hospital, and CancerCare Manitoba (formerly known as the Manitoba Cancer Treatment and Research Foundation). If you choose to participate, your assistance is appreciated. If you choose to withdraw from the study, your decision will be respected.

The researcher, Michelle Lobchuk, can be reached at 339-0074. The researcher's advisor is Dr. Lesley Degner (235-3481), University of Manitoba, Faculty of Nursing.

Michelle M. Lobchuk, R.N., B.N., M.N.
Interdisciplinary Doctoral Student
Faculty of Graduate Studies
University of Manitoba
Winnipeg, Manitoba

Dissertation Committee:

Dr. Lesley Degner
Professor
Faculty of Nursing
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Dr. T. Hassard
Professor
Department of
Community Health
Sciences
University of
Manitoba

Dr. P. Kirk
Professor and
Head
Department of
Family Medicine
Faculty of Medicine
University of
Manitoba

Dr. J. Vorauer
Assistant
Professor
Faculty of Arts:
Psychology
University of
Manitoba

Please send me a copy of the summary of the research report.

Send to: _____ (name)
_____ (address)

APPENDIX G

Patient-Family Dyad No. _____

MINI-MENTAL STATE

Maxi-
mum

score

Score

Orientation

5 () What is the (year)(season)(date)(day)(month)?

5 () Where are we? (country)(province)(city)(street)
(street number)**Registration**3 () Name 3 objects: 1 second to say each. Then ask the
patient all 3 after you have said them. Give 1
point for each correct answer. Then repeat them until
he/she learns all 3. Count trials and record.

Trials _____

Attention5 () Serial 7's. 1 point for each correct. Stop after 5
answers.

Alternatively spell "world" backwards.

Recall3 () Ask for the 3 objects repeated above. Give 1 point for
each correct.

- 2 -

Language

9 ()

Name a pencil, and watch (2 points)**Repeat the following "No ifs, ands or buts." (1 point)****Follow a 3-stage command:****"Take a paper in your right hand, fold it in half,
and put it on the floor" (3 points)****Read and obey the following:****CLOSE YOUR EYES (1 point)****Write a sentence (1 point)****Copy design (1 point)**

TOTAL SCORE**ASSESS level of consciousness along a continuum.**

Alert Drowsy Stupor Coma

Appendix H

Patient-Family Dyad No. _____

PATIENT DEMOGRAPHIC DATA FORM

1. Age: _____

2. Marital status (please check one):

- Single/Never Married
 Married
 How long? _____ yrs. _____ mos.
 Divorced/separated
 How long? _____ yrs. _____ mos.
 Widowed
 How long? _____ yrs. _____ mos.
 Other (SPECIFY) _____
 How long? _____ yrs. _____ mos.

3. Gender: _____ female _____ male

4. Primary diagnosis of cancer:

5. Time since diagnosis (MONTHS):

- 0 - 9
 10 - 18
 19-36
 > 36

6. What is the actual date of your diagnosis?

7. Current treatment:

- None
 Chemotherapy
 Radiotherapy
 Other

8. Past treatment:

- None
 Chemotherapy
 Radiotherapy
 Other
-

9. Are you currently receiving nursing care in your home?

- Yes
 No

10. How long have you been receiving nursing care in your home?

11. Ethnic background:

a) Do you consider yourself a member of a particular ethnic, cultural, or racial group?

- No (GO TO QUESTION 12)
 Yes

b) If yes, which major ethnic group? _____

- 01 Canadian
- 02 British (ISLES) English/Scottish/ Welsh
- 03 U.S.A.
- 04 French
- 05 German
- 06 Norwegian/Danish/Swedish/Icelandic
- 07 Dutch/Belgian
- 08 Polish
- 09 Russian/Ukrainian
- 10 Other European-Middle East
(Italian, Spanish, Portuguese, Greek, Slavic, etc.)
- 11 Asia Oceanic (Chinese, Japanese, Polynesian, East Indian, etc.)
- 12 Aboriginal/First Nations/Inuit
- 13 Jewish
- 14 Other (SPECIFY) _____

12. What is your occupational status?

- 01 full-time
- 02 part-time
- 03 retired
- 04 unemployed
- 05 medical leave

13. What is/was your major occupation in life?

- 01 Professional (self-employed or employed)
- 02 High level management, semi-professional
- 03 Low level management, skill crafts, trades, technical
- 04 Semi-skilled or unskilled
- 05 Farm labourer
- 06 Homemaker
- 07 Other (SPECIFY) _____

14. What is your annual family income?

- 01 Below \$10,000
- 02 \$10,000 - \$20,000
- 03 \$21,000 - \$30,000
- 04 \$31,000 - \$40,000
- 05 \$41,000 - \$50,000
- 06 \$51,000 - \$60,000
- 07 \$61,000 - \$70,000
- 08 Over \$71,000 / year

15. What is the highest level of schooling or education you completed?

- 01 No formal schooling
- 02 Some elementary school
- 03 Finished elementary school
- 04 Some secondary/high school
- 05 Completed secondary/high school
- 06 Some community or technical college
- 07 Completed community or technical college
- 08 Some university
- 09 Bachelor's degree
- 10 Master's degree
- 11 PhD
- 12 Other (SPECIFY) _____
- 13 Don't know

16. What is your religion, if any?

- 01 No preference
- 02 Anglican
- 03 Baptist
- 04 Greek Orthodox
- 05 Jehovah's Witness
- 06 Jewish
- 07 Lutheran
- 08 Mennonite
- 09 Pentecostal
- 10 Presbyterian
- 11 Roman Catholic
- 12 United Church
- 13 Other (SPECIFY) _____

Appendix I

Patient-Family Dyad No. _____

**MEMORIAL SYMPTOM ASSESSMENT SCALE -
PATIENT****INSTRUCTIONS:**

We have listed 32 symptoms below. Read each question carefully.

If you had the symptom during this past week, please let us know

how OFTEN you had it, how SEVERE it was usually, and how much

it DISTRESSED OR BOTHERED you by circling the appropriate

number. If you DID NOT HAVE the symptom, make an "X" in the box

marked "DID NOT HAVE".

DURING THE PAST WEEK, Did you have any of the following symptoms?	D I D N O T H A V E	IF YES, How OFTEN did you have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER you?				
		Rarely	Occas- ionally	Frequ- - ently	Almost Const- antly	Slight	Moder- ate	Severe	Very Severe	Not At All	A Little Bit	Some- what	Quite A Bit	Very Much
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness / tingling in hands / feet		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4

Continued on the next page

DURING THE PAST WEEK, Did you have any of the following symptoms?	D I D N O T H A V E	IF YES, How OFTEN did you have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER you?				
		Rarely	Occas- ionally	Frequ- - ently	Almost Const- antly	Slight	Moder- ate	Severe	Very Severe	Not At All	A Little Bit	Some- what	Quite A Bit	Very Much
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4

Continued on the next page

OTHER:	0	1	2	3	4
OTHER:	0	1	2	3	4
OTHER:	0	1	2	3	4

.. IF YOU HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND INDICATE HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOTHERED YOU.

DURING THE PAST WEEK, Did you have any of the following symptoms?	D I D	T O N	E V A L	IF YES,				How SEVERE was it usually?	How much did it DISTRESS or BOTHER you?			
				Very Severe	Severe	Moder-ate	Slight					
Mouth sores				1	2	3	4	0	1	2	3	4
Change in the way food tastes				1	2	3	4	0	1	2	3	4
Weight loss				1	2	3	4	0	1	2	3	4
Hair loss				1	2	3	4	0	1	2	3	4
Constipation				1	2	3	4	0	1	2	3	4
Swelling of arms or legs				1	2	3	4	0	1	2	3	4
"I don't look like myself?"				1	2	3	4	0	1	2	3	4
Changes in skin				1	2	3	4	0	1	2	3	4

Appendix J

OTHER DYADIC PERSPECTIVE-TAKING SCALE

How does your partner act towards you on a scale from 0 to 4, where 0 does not describe your partner very well, and 4 describes your partner very well. For each question circle the number that is the best description of your partner's actions towards you.

	0	1	2	3	4
DOES NOT DESCRIBE MY PARTNER VERY WELL					DOES DESCRIBE MY PARTNER VERY WELL
1. When involved in an argument with me, my partner is the type of person who will consider and take into account my point of view and compare that with his/her own.	0	1	2	3	4
2. My partner is not good at understanding my problems.	0	1	2	3	4
3. My partner not only listens to what I am saying but really understands and seems to know where I am coming from.	0	1	2	3	4
4. My partner does not seem to know how I feel.	0	1	2	3	4
5. My partner is able to accurately compare his/her point of view with mine.	0	1	2	3	4
6. My partner evaluates my motivation for doing something before he/she makes judgments about a situation.	0	1	2	3	4
7. My partner easily becomes impatient with me.	0	1	2	3	4
8. My partner is not able to put him/herself into my shoes.	0	1	2	3	4

- 2 -

	0	1	2	3	4
DOES NOT DESCRIBE MY PARTNER VERY WELL					DOES DESCRIBE MY PARTNER VERY WELL
9. My partner nearly always knows exactly what I mean.	0	1	2	3	4
10. My partner does not sense or realize what I am feeling.	0	1	2	3	4
11. My partner realizes what I mean even when I have difficulty saying it.	0	1	2	3	4
12. My partner does not usually understand the whole meaning of what I say to him/her.	0	1	2	3	4
13. My partner appreciates how the things I experience, feel to me.	0	1	2	3	4
14. Before criticizing me, my partner tries to imagine how I feel.	0	1	2	3	4
15. If my partner thinks he/she is right about something he/she doesn't waste much time in listening to my arguments.	0	1	2	3	4
16. My partner tries to understand me better by imagining how things look from my perspective.	0	1	2	3	4
17. My partner believes that there are two sides to every argument and tries to look at both sides.	0	1	2	3	4
18. My partner sometimes finds it difficult to see things from my perspective.	0	1	2	3	4
19. My partner tries to look at my perspective before making a decision.	0	1	2	3	4
20. When my partner is upset with me he/she tries to put him/herself in my shoes for a while.	0	1	2	3	4

Appendix K

Patient-Family Dyad No. _____

FAMILY CAREGIVER DEMOGRAPHIC DATA FORM

1. Age: _____

2. Marital status (please check one):

_____ Single/Never Married

_____ Married
How long? _____ yrs. _____ mos.

_____ Divorced/separated
How long? _____ yrs. _____ mos.

_____ Widowed
How long? _____ yrs. _____ mos.

_____ Other (SPECIFY) _____
How long? _____ yrs. _____ mos.

3. Gender: _____ female _____ male

4. Ethnic background:

a) Do you consider yourself a member of a particular ethnic, cultural, or racial group?

_____ No (GO TO QUESTION 5)

_____ Yes

b) If yes, which major ethnic group? _____

- 01 Canadian
- 02 British (ISLES) English/Scottish/ Welsh
- 03 U.S.A.
- 04 French
- 05 German
- 06 Norwegian/Danish/Swedish/Icelandic
- 07 Dutch/Belgian
- 08 Polish
- 09 Russian/Ukrainian
- 10 Other European-Middle East
(Italian, Spanish, Portuguese, Greek, Slavic, etc.)
- 11 Asia Oceanic (Chinese, Japanese, Polynesian, East Indian, etc.)
Aboriginal/First Nations/Inuit
- 12 Jewish
- 13 Other (SPECIFY) _____
- 14

5. What is your occupational status?

- 01 full-time
- 02 part-time
- 03 retired
- 04 unemployed
- 05 medical leave

6. What is/was your major occupation in life?

- 01 Professional (self-employed or employed)
- 02 High level management, semi-professional
- 03 Low level management, skill crafts, trades, technical
- 04 Semi-skilled or unskilled
- 05 Farm labourer
- 06 Homemaker
- 07 Other (SPECIFY) _____

- 3 -

7. How long have you been caring for the patient? **(MONTHS)**

- _____ 0 - 9
- _____ 10 - 18
- _____ 19-36
- _____ > 36

8. What is the extent to which you assist the patient in coping with his/her medical condition and symptoms?

- 1 Never assist the patient
- 2 Rarely
- 3 Sometimes
- 4 Frequently
- 5 Always assist the patient

9. Do you and the patient talk openly about what the patient's thoughts and feelings are in regard to the patient's symptoms?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Frequently
- 5 Usually

10. How well do you think you know 'how the patient thinks and feels' about his or her symptoms?

- 1 Totally not at all
- 2 Not very well
- 3 Have some knowledge
- 4 Adequate
- 5 Very well

11. How much contact do you have with the patient?

- 1 Daily, I live with the patient
- 2 Daily but I don't live with the patient
- 3 More than weekly, I don't live with the patient
- 4 Weekly, I don't live with the patient
- 5 Less than weekly, I don't live with the patient

12. What is your relationship to the patient?

- 1 Wife
- 2 Husband
- 3 Parent
- 4 Daughter
- 5 Son
- 6 Sister
- 7 Brother
- 8 Friend
- 9 Other (SPECIFY) _____

13. What is your religion, if any?

- 01 No preference
- 02 Anglican
- 03 Baptist
- 04 Greek Orthodox
- 05 Jehovah's Witness
- 06 Jewish
- 07 Lutheran
- 08 Mennonite
- 09 Pentecostal
- 10 Presbyterian
- 11 Roman Catholic
- 12 United Church
- 13 Other (SPECIFY) _____

14. What is the highest level of schooling or education you completed?

- 01 No formal schooling
- 02 Some elementary school
- 03 Finished elementary school
- 04 Some secondary/high school
- 05 Completed secondary/high school
- 06 Some community or technical college
- 07 Completed community or technical college
- 08 Some university
- 09 Bachelor's degree
- 10 Master's degree
- 11 PhD
- 12 Other (SPECIFY) _____
- 13 Don't know

Appendix L

Patient-Family Dyad No. _____

MEMORIAL SYMPTOM ASSESSMENT SCALE - FAMILY CAREGIVER

INSTRUCTIONS:

We have listed 32 symptoms below. Read each question carefully. If you believe the patient had the symptom during this past week, please let us know how OFTEN the patient had it, how SEVERE it was usually, and how much it DISTRESSED OR BOTHERED the patient by circling the appropriate number. If the patient DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE".

DURING THE PAST WEEK, Did the patient have any of the following symptoms?	D I D N O T H A V E	IF YES, How OFTEN did the patient have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER the patient?				
		Rarely	Occas- ionally	Frequ- - ently	Almost Const- antly	Slight	Moder- ate	Severe	Very Severe	Not At All	A Little Bit	Some- what	Quite A Bit	Very Much
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness / tingling in hands / feet		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4

Continued on the next page

DURING THE PAST WEEK, Did the patient have any of the following symptoms?	D I D N O T H A V E	IF YES, How OFTEN did the patient have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER the patient?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Some-what	Quite A Bit	Very Much
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4

Continued on the next page

OTHER:	0	1	2	3	4
OTHER:	0	1	2	3	4
OTHER:	0	1	2	3	4

IF THE PATIENT HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND INDICATE HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOTHERED HIM OR HER.

DURING THE PAST WEEK, Did the patient have any of the following symptoms?	D I D D I O N E V A L U A T I O N	IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER the patient?				
		Very Severe	Severe	Moderate	Slight	Very Much	Quite A Bit	Some-what	A Little Bit	Not At All
Mouth sores		4	3	2	1	0	1	2	3	4
Change in the way food tastes		4	3	2	1	0	1	2	3	4
Weight loss		4	3	2	1	0	1	2	3	4
Hair loss		4	3	2	1	0	1	2	3	4
Constipation		4	3	2	1	0	1	2	3	4
Swelling of arms or legs		4	3	2	1	0	1	2	3	4
"I don't look like myself?"		4	3	2	1	0	1	2	3	4
Changes in skin		4	3	2	1	0	1	2	3	4

Appendix M

SELF DYADIC PERSPECTIVE-TAKING SCALE

How well do the following questions describe your behaviour and actions with your partner on a scale from 0 to 4, where 0 does not describe you very well and 4 describes you very well. Circle the number that is the best description of yourself.

	0	1	2	3	4
DOES NOT DESCRIBE MY PARTNER VERY WELL					DOES DESCRIBE MY PARTNER VERY WELL
1. I am good at understanding my partner's problems.	0	1	2	3	4
2. I not only listen to my partner, but I understand what he/she is saying, and seem to know where he/she is coming from.	0	1	2	3	4
3. I very often seem to know how my partner feels.	0	1	2	3	4
4. I always know exactly what my partner means.	0	1	2	3	4
5. I am able to sense or realize what my partner is feeling.	0	1	2	3	4
6. Before criticizing my partner, I try to imagine how I would feel in his/her place.	0	1	2	3	4
7. I sometimes try to understand my partner by imagining how things look from his/her perspective.	0	1	2	3	4
8. In my relationship with my partner I believe there are two sides to every question, and I try to look and think about both sides.	0	1	2	3	4

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	0	1	2	3	4
DOES NOT DESCRIBE MY PARTNER VERY WELL					DOES DESCRIBE MY PARTNER VERY WELL
9. I try to look at my partner's side of a disagreement before I make a decision.	0	1	2	3	4
10. When I'm upset with my partner, I usually try to put myself in her/his shoes for a while.	0	1	2	3	4
11. Even if my partner has difficulty in saying something, I usually understand what he/she means.	0	1	2	3	4
12. I usually do not understand the full meaning of what my partner is saying to me.	0	1	2	3	4
13. I am able to appreciate exactly how the things my partner experiences, feel to him/her.	0	1	2	3	4

Appendix N

Patient-Family Dyad No. _____

**FAMILY CAREGIVER
SELF-REPORT****INSTRUCTIONS:**

We have listed 2 symptoms below. Read each question carefully. If you have the symptom, please tell us how OFTEN you have it, how SEVERE it is usually, and how much it DISTRESSES OR BOTHERS you by circling the appropriate number. If you have not had the symptom, make an "X" in the box marked "DO NOT HAVE".

AT PRESENT Do YOU have any of the following symptoms?	D O N O T H A V E	IF YES, How OFTEN do you have it?				IF YES, How SEVERE is it usually?				IF YES, How much does it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Somewhat	Quite A Bit	Very Much
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4

Appendix O

Patient-Family Dyad No. _____

**"IMAGINE-SELF"
INSTRUCTIONAL SET****INSTRUCTIONS:**

Sometimes when people try to understand what the other person is feeling or thinking, they imagine how they themselves would feel in the person's situation. We would like you to try the same for the 2 symptoms listed below. Read each question carefully. While you are doing so, please try to imagine how YOU would feel if you had the patient's diagnosis and how this would affect your life. In your mind's eye, try to picture how you yourself would feel if you were experiencing the same symptoms. Focus on yourself. AS YOU IMAGINE HOW YOU WOULD FEEL IF YOU WERE DIAGNOSED WITH THE PATIENT'S DISEASE, please tell us how OFTEN you would have the symptom, how SEVERE the symptom would be, and how much it would DISTRESS OR BOTHER you by circling the appropriate number. If you do not believe you would have the symptom, make an "X" in the box marked "WOULD NOT HAVE".

If you were diagnosed with the patient's disease and in your own life situation, would YOU have any of the following symptoms?	W O U L D N O T H A V E	IF YES, How OFTEN would you have it?				IF YES, How SEVERE would it be usually?				IF YES, How much would it DISTRESS or BOTHER you?				
		Rarely	Occas- ionally	Frequ- - ently	Almost Const- antly	Slight	Moder- ate	Severe	Very Severe	Not At All	A Little Bit	Some- what	Quite A Bit	Very Much
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4

Appendix P

Patient-Family Dyad No. _____

**"IMAGINE-OTHER"
INSTRUCTIONAL SET****INSTRUCTIONS:**

We have listed 2 symptoms below. Read each question carefully.

While you are doing so, please try to imagine how the patient feels

and how the two symptoms are affecting him or her. In your mind's

eye, put yourself in the patient's shoes. Forget yourself. Try to

picture how the symptom felt to the patient. Answer the questions as

you believe the patient would. Please tell us how OFTEN the patient

would say he or she had the symptom, how SEVERE the patient

would say the symptom was usually, and how much DISTRESS OR

BOTHER the patient would say the symptom caused him or her by

circling the appropriate number. If the patient would say he or she

did not have the symptom, make an "X" in the box marked "DID NOT

HAVE".

DURING THE PAST WEEK Putting yourself in the patient's shoes, do you believe the patient would say that he or she had any of the following symptoms?	D I D N O T H A V E	IF YES, How OFTEN would the patient say he or she had it?				IF YES, How SEVERE would he or she say it was usually?				IF YES, How much would the patient say it DISTRESSED or BOTHERED him or her?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Somewhat	Quite A Bit	Very Much
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4