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**CREATING A STANDARDIZED FREE-RESPONSE BURDEN SCALE  
FOR SPOUSAL CAREGIVERS OF INDIVIDUALS WITH  
PARKINSON'S DISEASE**

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**CREATING A STANDARDIZED FREE-RESPONSE BURDEN SCALE FOR  
SPOUSAL CAREGIVERS OF INDIVIDUALS WITH PARKINSON'S DISEASE**

(Spine title: Creating a Burden Scale for Spousal Parkinson's Caregivers)

(Thesis format: Integrated-Article)

by

**Kaitlyn P. Roland**

2

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Science

School of Graduate and Postdoctoral Studies  
The University of Western Ontario  
London, Ontario, Canada

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THE UNIVERSITY OF WESTERN ONTARIO  
SCHOOL OF GRADUATE AND POSTDOCTORAL STUDIES

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**Kaitlyn Patricia Roland**

entitled:

**Creating a Standardized Free-Response Burden Scale for Spousal  
Caregivers of Individuals with Parkinson's disease**

is accepted in partial fulfilment of the  
requirements for the degree of  
Master of Science

Date \_\_\_\_\_

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Chair of the Thesis Examination Board

## Abstract

Although some research has focused on the needs of caregivers for individuals with Parkinson's disease, most has focused on the demands associated with the physical needs of the patient, and not on 'mental burden.' The present study utilized the repertory grid method to capture the full range of caregivers' subjective experience, to quantify their perceptions, and to acquire information that might be useful in direction remediation attempts. Results suggest that the main concern of caregivers is spousal safety, as this requires continuous vigilance and constant worry. This demonstrates the strain of mental burden far outweighs the physical. Caregivers also report experiencing "little deaths" as the disease progresses, related to loss of independence for the couple, and the steady diminishment of social networks. Increasing attention on spousal caregivers promises to increase quality of care and quality of life for individuals with Parkinson's disease, by improving quality of life for the caregiver.

**Keywords:** Caregiver Burden, Parkinson's disease, Repertory Grid, Quality of Care, Quality of Life, Assessment Toolkit

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## Chapter 1

## The Burden Experienced by Spousal Caregivers of people with Parkinson's disease

*Parkinson's disease: an introduction*

Parkinson's disease (PD) is a complex neurodegenerative disease, with consequences that include progressive loss of movement control. Individuals with PD have a two to five times higher than average risk of mortality, due to an increased susceptibility to other medical conditions (Guttman, Slaughter, Theriault, DeBoer, & Naylor, 2001).

PD affects nearly 100 000 Canadians, and 6.3 million people worldwide, a number that is small in comparison to other disorders (it has an incidence rate 3.6 times lower than Alzheimer's disease) (Guttman et al., 2001). The associated economic impact is, however, much greater (it is approximately 2.72 times higher than Alzheimer's), due to complications that arise from the patient's increased susceptibility to other medical conditions, which require a disproportionately higher use of resources, and longer hospital stays (Guttman, Slaughter, Theriault, DeBoer, & Naylor, 2003). As the population ages, the number of patients with PD will increase proportionally – it has been estimated that the number of patients with PD will double by the year 2016 (Kontakos & Stokes, 2000).

The uniqueness of this progressive neurological disorder benefits from specialized medical expertise, most notably neurologists and medical movement disorder specialists (Rajput & Rivest, 1998). Despite the patient benefits associated with being under the care of a knowledgeable neurologist, approximately 31% of patients with Parkinson's disease have never received treatment from such a specialist (Guttman, Slaughter,

Theriault, DeBoer, & Naylor, 2002). This number may be expected to increase, given that current trends have suggested that there will be a 20% decrease in the availability of neurologist care over the next five years (Guttman et al., 2002). Consequently, this increases the pressure on family physicians and multidisciplinary health care teams (speech pathologists, occupational therapists, physical therapists, psychologists, etc.), and places additional demands on these professionals to become more knowledgeable in the treatment and management of Parkinson's disease. A 2002 needs assessment done by Parkinson Society Canada demonstrated that 82% of people with PD consider their family physician to be insufficiently knowledgeable about the disease, suggesting that there is a need for increased support for family physicians, in ways that will immediately impact patient care (Parkinson Society Canada, 2002). The foregoing illustrates the need for an increased dialogue regarding education and support. The uniqueness of Parkinson's disease benefits from an individualized approach by a multidisciplinary health care team, in order to provide quality care and effective illness management.

An important, and often forgotten, member of an integrative health care team is, however, the caregiver. In addition to increasing the quality of life in those that they care for, "good" caregivers can decrease morbidity and extend the lives of those that they care for (Cousins, Davies, Turnbull, & Playfer, 2002). Unfortunately, however, the task of care giving places considerable stress on the caregiver, impairing psychosocial functioning, and diminishing the effectiveness of the immune system (Glozman, 2004; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). Furthermore, a caregiver in distress is unable to provide appropriate care to his or her charges. For these reasons, it is important to accurately assess and manage caregiver burden (Cousins et al., 2002).

*Burden and its Impact on Caregivers*

Burden is a psychological concept; it is a subjective interpretation of the extent to which the care giving experience impacts on the health, social life, and financial status of the caregiver (Zarit, Todd, & Zarit, 1986). There is not, however, a clear consensus on the definition of terms such as strain, burden, stress, distress, psychological well-being, depression, health, and cost of care. This makes it difficult to conceptualize and measure burden (Cousins et al., 2002). Burden can be split into three categories: the *physical burden*, which is dependent upon the severity of illness, and the help needed; *mental burden*, which is typically dependent upon the caregiver's relationship with the patient; and finally, caregivers face *social burden* as a result of intrapersonal conflicts and lack of support (Angermeyer, Bull, Bernert, Dietrich, & Kopf, 2006). Given that the principal problem experienced by care receivers is increased physical dependency, caregivers are being called upon to respond to the needs of individuals who were previously independent (McCarron, Gill, Lawlor, & Beagly, 2002). This creates stress for both the care receiver and the caregiver – and the uncertainty and variability within the care giving experience increases the associated stresses (Edwards & Scheetz, 2002). It has been found that patient perception of his or her control over his or her symptoms is inversely related to caregiver burden – presumably due to diminished feelings of self-efficacy, and ultimately an increased reliance on the caregiver.

More specifically, caregiver burden is the extent to which caregivers are suffering because of the care giving experience, and it is often characterized by a decline in psychological and physical health, as well as an increase in the number of physical symptoms and doctor visits. In addition to the stress of performing one's daily activities as a caregiver, the unpredictability and uncertainty that surrounds the caregiver experience exacerbates the negative effects of care giving (Edwards & Scheetz, 2002). The amount of burden experienced by the caregiver is often related to symptom management for the patient, the level of care needed to perform activities of daily living, the perception of control the patient has over his or her illness, perceived support (social and resources), financial situation (especially for informal caregivers), and knowledge (McRae, Sherry, & Roper, 1999). Burden also relates to the sex of the caregiver – it has been found that women are twice as likely to report a burden of care giving, as compared with men (Edwards & Scheetz, 2002). This may be due to the fact that there are more female caregivers, especially informal ones, which may in turn be due to the longer life expectancy of women. Finally, the burden experienced by the caregiver is negatively related to the amount of social support, and positively related to the severity of reported symptoms, and level of support required for activities of daily living (Edwards & Scheetz, 2002).

*Caregiver Burden in Parkinson's disease*

Despite the importance placed on the healthcare team, only a little more than 1% of the published papers concerning Parkinson's disease refer to problems related to caregiving (Pasetti et al., 2003). There is an ongoing shift from institutional care to community care, meaning an increased focus on community-based caregivers, and a focus on the responsibility that rests with families (Thommessen et al., 2002), with much of their long-term care being provided by spouses (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999). Being a caregiver in this position is an extremely demanding task, and is highly likely to result in caregiver burden. In this context, caregiver burden refers to the physical, mental, and socioeconomic problems experienced by the caregivers of chronic patients (Martinez-Martin et al., 2007). This experience impacts on both the patients' and caregivers' health-related quality of life (HRQoL). Burden is mediated by patient characteristics, ability of caregiver to cope in their role, extent of social support, financial resources (Thommessen et al., 2002). Individuals with Parkinson's disease and their caregivers have similar needs: more specifically, there is a need for increased knowledge of the disease to allow adjustments in care to match disease progression. Furthermore, caregivers need recognition of their role as 'caregiver', and require support from friends, family members, and other caregivers to "share and compare" (Pasetti et al., 2003). Additional stressors include the constant adjustments required by the caregiver (i.e. resources, care provision, & maintenance of arrangements) due to functional changes required of the progressive nature of lifelong illness. Furthermore, spousal caregivers of individuals with PD are often elderly themselves, and frequently have their own caring

needs that must be met (Berry & Murphy, 1995). Edwards and Ruettinger (2002) note that families are often ill equipped (emotionally and physically) to care for PD patients.

Providing care to a spouse with a progressive, chronic and debilitating disease affects all aspects of a caregiver's life (Aarsland et al., 1999). Spousal caregivers are less likely than other members of their age cohort to get out of the house at least once per week, and have an almost fivefold worsening of psychological health scores – and not surprisingly, the mental health of the caregiver appears to worsen as the disease progresses (Fernandez, Tabamo, David, & Friedman, 2001; Thommessen et al., 2002). These findings are particularly troublesome when one considers that one of the key predictors of successful care giving is the psychological well-being of the caregivers themselves (Martinez-Martin et al., 2007). Recent research has targeted these psychosocial predictors of caregiver burden, with results suggesting that social support networks tend to be associated with greater satisfaction and less perceived level of burden, while limiting social networks leads to greater chances of burnout. Burdens outside those of the caregiving experience (i.e. family and/or social recreation in case of staff caregivers, and work, social recreation and/or other family members for family caregivers) also increase feelings of being overwhelmed (Edwards & Ruettinger, 2002).

In the early stages of Parkinson's disease, medication enables patients to remain functionally independent; with progression, however, drug treatment becomes less effective, motor symptoms worsen, and dependency increases. This leads to increased demands associated with increased stress and illness, ultimately affecting the patient as well further burdening the caregiver (Edwards & Ruettinger, 2002). The unpredictability of PD means a greater lack of control by the caregiver – the fact that care needed by PD

patients can be irregular may lead to unintentional lack of care. Beyond the overt effects of symptom fluctuations, however, the uncertainty and variability in the caregiving experience increases the associated stresses, and perception of control over symptoms has been found to be negatively correlated with caregiver burden (Edwards & Scheetz, 2002).

Interestingly, however, it is the neuropsychiatric disturbances associated with PD – and not the ubiquitous motoric sequelae – that seem most problematic for caregivers. Secker and Brown (2005) report that psychiatric morbidity of the individual with Parkinson's disease produces a five-fold increase in caregiver anxiety, and also note that the impact of mental disturbances can outweigh the impact of physical symptoms. The highest caregiver distress score was found among caregivers of individuals with delusions, apathy, agitation, depression, and irritability. This was confirmed by Aarsland et al. (2007), who showed that moderate to severe distress was reported by 20% of caregivers for patients without neuropsychiatric symptoms, while 58.6% of caregivers for patients with neuropsychiatric disturbances reported at least moderate distress.

Furthermore, Secker and Brown (2005) found that the mean number of care-related activities performed ranged from 11 in the early stages of PD, to 30 per day in late stages – and this increase in physical and time demands of caring is primarily associated with the increase in non-motoric symptoms that accompany later stage PD. This is not to say, of course, that the increasing motoric disability of PD is not problematic to the caregiver – caregivers report significant distress related to disruption of household routines, difficulties with holiday planning, restriction on the social life of the family, and sleep disturbances (Secker & Brown, 2005; Thommessen et al., 2002).



Healthy and distress-free caregivers facilitate patient care. A healthy caregiver possesses both physical and emotional energy, is motivated and committed, has adequate social support and coping strategies, and retains feelings of accomplishment and personal fulfillment, with a positive outlook on caring (Angermeyer et al., 2006). There is, therefore, a need to achieve some consensus in the conceptualization and measurement of caregiving outcomes in order to identify progress of distress, and to identify suitable resources.

### *Measuring Burden*

Although there is a growing body of information concerning the burden of care, there is a depth of research needed concerning the burden that is shouldered by family members of individuals with Parkinson's disease. There have been few instruments developed that are designed to measure the aforementioned aspects of caregiver burden, among family caregivers - and even fewer that have been expressly developed from the perspective of the caregiver. It should also be noted that none of these measures integrate an assessment of coping mechanisms used with an assessment of burden experienced. Furthermore, there are no existing measures that capture the full range of distress that has been identified among spousal caregivers - and given that all of these measures are quantitative, close-ended questionnaires, we are "locked into" the constructs that are evaluated by the items on the scale. The following measures have been reviewed for their compatibility with assessing the burdens associated with the caregiving experience of Parkinson's disease patients, as well as their ability to meet counseling and measurement goals.

The *Caregiver Distress Scale* is a five-factor distress scale measuring spousal burden in informal caregivers. It consists of 17 items separated into five domains: relationship distress (four items), care receiver demands (three items), emotional burden (four items), social impact (three items), and personal cost (three items). These domains may be arranged in profiles that may be used to monitor progress of the patient and stress levels of the caregiver. The *Caregiver Distress Scale* has high internal consistency with a good test-retest reliability (Cousins et al., 2002). This scale is probably one of the best measures currently available for the assessment of spousal caregiver burden, but has not been validated within neurologically impaired populations (e.g., Parkinson's disease). The content saturation of the measure is also limited by the number of items per scale – for example, it is difficult to capture the range of the emotional sequelae resulting from caregiver burden, with four close-ended questions.

The *Caregiver Activity Survey – Intellectual Disability* measures time spent by family caregivers assisting people with dementia of the Alzheimer's type perform activities of daily living. It identifies and measures care and resource requirements to assist in planning required support and services (McCarron et al., 2002). The measure consists of six domains: communication, transportation, dressing, eating, grooming, and required supervision. The measure is well-validated, demonstrating significant convergent reliability with the *Alzheimer Disease Assessment Scale - Cognitive Subscale* ( $r=0.61$ ), *Mini Mental State Exam* ( $r=-0.57$ ), and the *Physical Self Maintenance Scale* ( $r=0.43$ ). The measure also demonstrates a high test-retest reliability ( $ICC=.88$ ) (McCarron et al., 2002). Given the nature of the validation sample, however, this measure has not been used to assess caregiver burden among caregivers for individuals

with Parkinson's disease. Additionally, there is a need for a finer elicitation of care hours or requirements of care for individuals, as this would enable a look from the care and resource perspective (McCarron et al., 2002). Finally, this measure is largely focused on the needs of the care receiver, not the care giver.

The 42-item *Caregiver Hassle Scale* measures the subjective burden of spousal caregivers. It consists of five subscales, including: assistance with activities of daily living, consequences of cognitive status, behaviors, and support network concerns. The *Caregiver Hassle Scale* has high internal consistency and test-retest reliabilities (.83 to .91), and it relates well to caregivers reports of limitations and well-being (McCallion, McCarron, & Force, 2005). McCallion et al. (2005) report that since the subjective burden may be greater than what this can capture, this test may be limited. It is not enough, however, for a measure to identify burden - it should suggest ways of meeting the needs of the caregiver in order to improve their situation and ease their burden. By using a more open-ended scale geared towards the combined needs of meeting measurement goals (i.e. identifying burden) as well as counseling and education goals (i.e. taking steps to ease burden), we improve our capacity to both identify and manage caregiver burden (McCallion et al., 2005).

To make the items more appropriate for caregivers providing care for individuals with intellectual disability (as occurs in a small percentage of individuals with PD, 22.7%; Aarsland, Tandberg, Larsen, & Cummings, 1996), the *Caregiver Hassle Scale* has been modified to create the *Caregiver Difficulty Scale-Intellectual Disability*. This new scale consists of 38 items and three subscales, with Cronbach's alphas ranging from 0.73 to 0.93. It has limited inter-rater reliability (0.62), but has demonstrated concurrent

validity through correlations with the aforementioned *Caregiver Activity Survey – Intellectual Disability* ( $r=0.45$ ) (McCallion et al., 2005). More exploration of the subscale results is required before the value of *Caregiver Difficulty Scale – Intellectual Disability* can be realized. Additionally, the value of the scale would be increased if it was focused on uniquely measuring subjective appraisal of burden to capture the entire reality of the caregiving experience (McCallion et al., 2005).

The *Care Management Stress* scale consists of 25 items and was designed to gather data about areas of caregiver stress with an emphasis on caring for patients with Alzheimer's disease. Adequate reliability and validity was found (McRae et al., 1999). It is, however, difficult to generalize this scale to Parkinsonian caregivers, as it is geared towards a specific type of dementia in a specific population.

The *Scale of Quality of Life of Caregivers* assesses the quality of life among spousal caregivers, quantifying the impact of the care receivers disease on the professional, social, and leisure activities of the caregiver (Martinez-Martin et al., 2005). It has adequate internal consistency (0.80), significant convergent validity and significant item correlation ( $p<0.001$ ) (Martinez-Martin et al., 2005). The strain placed on the caregiver by the care giving relationship appears to be proportional to disease severity, and the measure was correlated with disease stage, motor complications/disability (clinical rating scales), and patient-reported quality of life (Martinez-Martin et al., 2005). The main predictors of caregiver quality of life were the extent to which the individual was required to support activities of daily living, and the level of disability experienced by the patient. The cross-sectional design of this study limits any potential causal

interpretation of the results. In addition, the size and specificity of the validation sample considerably restricts the utility of this measure.

*Relatives' Stress Scale* (Greene, Smith, Gardiner, & Timbury, 1982) measures the burden on caregivers of people with dementia. It consists of 15 items that are scored between 0-4, with three categories of items, including: personal distress, life upset, and negative feelings (Thommessen et al., 2002). From a measurement perspective, this measure has significant psychometric problems. Only nine of the 15 items demonstrated acceptable item statistics, with the others being demonstrated to have poor prediction of the constructs. Furthermore, the factor analysis performed on the validation sample suggested that only the 'psychosocial burden' scale demonstrated factorial validity. The measure is, therefore, of limited utility in the assessment of spousal caregiver burden – particularly within non-demented populations.

Edwards and Scheetz (2002) used the *Zarit Burden Inventory* to measure the impact of caring on married or cohabiting caregivers. This inventory is a reliable (Cronbach's alpha = 0.93) 22 item, five point scale that measures activities of daily living, social support, psychological well-being, emotional and physical health, financial repercussions and marital satisfaction (Edwards & Scheetz, 2002; Martinez-Martin et al., 2007). All of these indicators are significant predictors of burden. Activities of daily living ( $r = 0.62, p < .01$ ) and social support ( $r = 0.56, p < .01$ ) were found to be the strongest predictor of perceived burden, accounting for 44.3% of the variance (Edwards & Scheetz, 2002). This was also used by Martinez-martin et al. (2007) to determine the distress experienced by caregivers of the elderly or disabled.

*Conclusion*

As suggested by the foregoing, there are limited options for the examination of caregiver burden. The measures that have been validated for use in family caregiver populations are limited by the items developed by clinicians, without any input from the caregivers themselves. Furthermore, many scales are specifically designed to assess the increased burden that results from caring for a population with intellectual disabilities, and so they are not necessarily appropriate for populations that are experiencing motoric disability in the absence of dementia. Measuring burden is not a new area of interest, and the scale-options available demonstrate this; however, these scales are only valid in so far as the clinicians' ability to accurately capture the elements of burden. The caregivers who experience burden as a part of their reality are best able to define burden for us, and we as clinicians should not limit their expression of this by developing our own descriptors of it. This review clearly identifies the need to capture the subjective experience of caregivers; allowing the opportunity for caregivers to voice their specific and varied needs and allowing them to be noticed and addressed. The subjective experience reflects the subjectivity of each caregiver's individual experience. As clinicians, we are only able to define the experiences of caregivers to the best of our limited knowledge; each caregiver sees their experience through a different lens, which our preconceived notions may not be able to capture. By allowing caregivers to further describe what our preconceived elements of burden mean to them, we are better able to capture their experience.

Health care workers should be educated in providing support to caregivers, as well as care to patients. Some ways to address this need include augmenting homecare

during later stages of chronic illness with staff caregivers, as well as having additional interventions coordinated into routines and lifestyles. Partnerships should also be encouraged between health care teams and families (Berry & Murphy, 1995). Clinicians need to be aware of the psychological health of caregivers of patients with Parkinson's disease, particularly in spouses of patients with pronounced mental disturbances and provide appropriate support (Aarsland et al., 1999). Fatigue caused by the caregiving experience can impact the quality of care offered, and continual stress in the caregiver can lead to anger and resentment directed towards the individual with Parkinson's disease (Secker & Brown, 2005). This review demonstrates the importance of this issue to both quality of care and quality of life of both caregiver and care-receiver. There is a noticeable lack of representation in the literature from the viewpoint of the individual reality of spousal caregivers, especially those who care for people with the varying symptoms and severity that accompanies PD. Again, clinicians can only represent burden to the best of our limited knowledge; this validates the data only so far as we as clinician can capture that experience with our preconceived notions. Additionally, there is a gap in accompanying research on managing burden; it is not enough to simply identify it, caregivers should be given the tools to help manage and ease this burden, whether that is individualized coping strategies or directed to support services where they are able to seek counseling or education.

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## Chapter 2

### The Usefulness of Repertory Grid for Assessment in Healthcare Settings

A key problem with quantifying the needs of caregivers is that this typically requires the use of standardized measures that may or may not capture the full range of an individual's experience. Needs analysis should reflect what the best performers actually do, and then use that as a benchmark to see how others measure up. How, then, do we define the term we want to benchmark? A novel approach to this problem may be found in a technique that is not new at all – repertory grid analysis. Repertory grid is a tool that can quantify the unquantifiable, using the subjective insider perspectives of the caregiver (Peters, 1994).

Repertory grid can help give a voice to people in a non-threatening way; it can also be used to shape vague ideas as well as provide a means of measuring qualitative non-restrictive representation. Of potentially greater importance, however, the repertory grid technique may be used to acquire information that may be used to guide attempts to remediate the problems quantified within the measure (Peters, 1994). In this way, repertory grid creates something that is more akin to a “toolkit” than a questionnaire...and is thus ideal for the assessment of constructs such as caregiver burden.

### The Repertory Grid Method

#### *Background and Personal Construct Theory*

The repertory grid method elicits constructs from participants in a manner that is reminiscent of a qualitative approach (e.g. a focus group), and then quantitatively examines the relationship between them, within each individual. This method is unusual,

as it places the responsibility for item generation in the hands of the participant. The qualitative/quantitative aspects of this technique allow participants to freely express their views, and allows for a quantitative analysis of this free reporting.

The theoretical foundation for the repertory grid method developed from George Kelly's Personal Construct Theory (PCT) (Kelly, 1955). This method arose as a means of psychological counseling; it stems from the assumption that people are fundamentally interested in looking into all aspects of themselves and their environment (Peters, 1994). In the mid-1950's the repertory grid method was devised as a diagnostic tool based on PCT. According to Kelly's theory, 'reality' does not reveal itself to us directly, but is subject to as many different constructions as we are able to invent, *constructive alternativism*. Any event is open to many different ways of interpretation – different ways of 'construing' the same events (i.e., abstracting future events from past information) can be evaluated in terms of their relative utility, with some interpretations being more useful than others in anticipating events (Ford & Bradshaw, 1993). In short, Kelly's 'personal construct' is the way in which two elements are similar and contrast with a third. The process of construing these constructs leads to personal logic and reasoning. This demonstrates the effort put out by individuals to anticipate and control their environment, and also demonstrates the Kelly's theory of 'persons-as-scientists' (Ford & Bradshaw, 1993). This says that people anticipate and control events by hypothesizing and testing, just like scientists; humans model their environment and scientists model humans through a like process of *simulation*: "Man gets at the truth of things... by erecting constructs to simulate it the best he can... [And scientists] devise machines to simulate—not man directly—but theories about man... the theories, in turn,

are constructed to simulate the human processes they are supposed to explain" (Ford & Bradshaw, 1993). According to Kelly, the goal of this exercise is *anticipation*; by simulating, we improve the "accuracy" of our anticipation of important aspects of the future. Action is a form of active anticipation that seeks to make desirable outcomes more likely (Ford & Bradshaw, 1993).

In general, personal construct theory tends to focus on the viability of a person's unique constructions of reality and helps them find meanings that affirm their own subjective conceptualizations of self, other, and world (Holland, Neimeyer, Currier, & Berman, 2007). More specifically, adherents of personal construct theory view human beings as "scientists" whose primary aim is to make sense of the world and successfully anticipate events. This view dictates that much of human behavior can be conceptualized as living experiments designed to test constructions about the world in an effort to increase our ability to predict the uncertain future (Holland et al., 2007).

#### *A Fundamental Postulate and Eleven Corollaries*

Kelly's fundamental postulate asserts that, "A person's processes are psychologically channelized by the ways in which he anticipates events", thereby making our representation processes anticipatory (Kelly, 1955, p. 46). The implication of this is further discussed in his eleven corollaries (Ford & Bradshaw, 1993):

*Dichotomous.* "A person's construction system is composed of a finite number of dichotomous constructs" (Kelly, 1955, p. 55). The dichotomous structure of personal constructs is essential to the way in which people organize information.

*Construction.* "A person anticipates events by construing their replications" (Kelly, 1955, p. 50). People use constructs to forecast events and evaluate the predictive utility of these

forecasts. Personal constructs are used to organize perceived similarities and differences among events into *schemata*, which are used as *templates* to detect recurrent themes in our experience over time and use these to predict future experiences (Burnard & Morrison, 1989).

*Experience.* "A person's construction system varies as he successively construes the replication of events" (Kelly, 1955, p. 72). Changing perceptions of new events over time comprises an ongoing validation process that is used to confirm or disconfirm anticipations (Adams-Webber, 1979). This results in the *experience cycle*; a process through which people continuously anticipate events and test the efficacy of their constructions, resulting in a continuous progressive change of a person's constructs, generally assumed by Kelly to be the result of predictive failures (Ford & Bradshaw, 1993).

*Range.* "Each construct is convenient for the anticipation of a finite range of events only" (Kelly, 1955, p. 60). Each construct has a *range of convenience*; some degree of differentiation among subsystems of constructs can enhance its overall range of convenience, making it more accommodating to a variety of events within its framework (Adams-Webber, 1979).

*Organization.* "Each person characteristically evolves, for his own convenience in anticipating events, a construction system embracing ordinal relationships between constructs" (Kelly, 1955, p. 56). Related constructs, with some degree of overlap, are usually coordinated in interpreting and predicting events. This overlap, or relatedness, enables an individual to formulate hypotheses. We categorize in terms of one or more constructs in interpreting an event, and review our personal systems of related constructs

to predict inferences (Adams-Webber, 1979). This predictive function provides the logical rationale for the Kellyan view that human beings are characterized by an *anticipatory stance* (Ford & Bradshaw, 1993).

*Individuality.* "people differ from each other in their construction of events" (Kelly, 1955, p. 55). Everyone has different experiences and everyone's construction of reality is different; interpretations of events (i.e., personal reality) are never identical between individuals.

*Communality.* "to the extent one person employs a construction of experience which is similar to that employed by another" (Kelly, 1955, p. 65). If our understanding of reality is similar, so too will be our experiences, behaviours and feelings. Psychological processes are similar to those of other individuals in a similar culture (i.e. social reality).

*Socialty.* "to the extent that one person construes the construction processes of another, he may play a role in a social process involving the other person" (Kelly, 1955, p. 60). In other words, this suggests that you may still relate to another individual, even if you are not similar to him or her. This is an important part of role playing.

*Choice.* "a person chooses for himself that alternative in a dichotomized construct through which he anticipates the greater possibility for extension and definition of his system" (Kelly, 1955, p. 64). People try to improve the usefulness of their system of personal constructs. Kelly says that we will choose to do what we anticipate will most likely improve our understanding and ability to anticipate. Reality places limits on what we can experience or do, but we choose how to interpret that reality, and do so in whatever way we believe will help us the most.



*Modulation.* "variation in the person's construction system is limited by permeability of the constructs within whose range of convenience the variants lie" (Kelly, 1955, p. 77). Some individuals are less willing to change their interpretations based upon new experiences.

*Fragmentation.* "A person may successively employ a variety of construction subsystems which are inferentially incompatible with each other." (Kelly, 1955, p. 65). This says we can be inconsistent within ourselves. Most of us play various roles in our lives and are not quite the same in these various roles.

Repertory grid is a method of eliciting constructs and analyzing the relationship among them. The grid is constructed using columns of elements (alternative events or entities) and rows of constructs (dimensions of similarity and difference between elements) central to the latent trait that is being studied; structurally, it is a rectangular matrix. Each row-column intersect in the grid contains a rating that reflects the value of the construct for the element in question. Either a standardized list of constructs can be given or elicited by the participant, allowing for further insight. Kelly's *method of triads* is a way in which constructs can be elicited; presenting elements three at a time and asking how any two of them are similar to each other and different from the third (Ford & Bradshaw, 1993). This way of framing this task allows for more interesting discriminating dimensions of constructs with practical use. Additionally, it helps lead to discovery on behalf of the participant and tend to generate more robust and permeable constructs (Ford & Bradshaw, 1993).

As with any measurement technique, there are some problems associated with repertory grid. One concern is generating a representative sample set of elements: the selected elements must be sufficient to capture the relevant properties of the domain, and the distinctions amongst them must be sufficient to generate commonalities among the constructs? Another issue is ensuring all the elements are equally represented. By emphasizing distinctions between elements, it may miss important and definitional characteristics of the elements. Finally, the constructs are not all equal, and one must be careful to distinguish those that are truly relevant (Rugg & McGeorge, 1997).

#### The Application of Repertory Grid in Healthcare Settings

Repertory grid is known for its use in eliciting and analyzing knowledge. Firstly, it is applicable to a variety of problems, and secondly allows easy integration into formats applicable for quantitative analysis. Additionally, it allows for easy analysis of knowledge through organization and logic; it amplifies the participant's ability to recognize and offer distinction between the elements, and these relations and correlates can then be identified and described by the tester. Also, ambiguity, redundancy, and incompleteness can be easily identified (Ford & Bradshaw, 1993). Initially (in the 1960's), this was frequently applied to market research, and it was found to be a good way of representing consumer perceptions of products (Peters, 1994).

This method has also been used to study a broad range of subjects within healthcare settings, including: eliciting constructs held by nurses about the attitudes to psychiatry of student general nurses (Wilkinson, 1982); the socialization processes of nurses (Heyman, Shaw, & Harding, 1983); nurse education and training (Davis, 1983, 1985); psychiatric and community psychiatric nursing (Pollock, 1986); community health

students' constructs about persons who have attempted suicide (Costigan, Humphrey, & Murphy, 1987); interpersonally skilled persons (Burnard & Morrison, 1989); nurses as carers (Morrison, 1991); nurses' reactions to patients with specific feeding needs (Barnes, 1990); and similarities and differences between personal constructs of general and psychiatric nurses (Rawlinson, 1995; Retsas & Wilson, 1997).

Repertory grids have been useful in analyzing self-perceptions of nurses, as well as the nature of nurses' expertise and professional roles and research utilization in specialized areas of nursing. Caring attitudes in nursing practices was explored using personal construct theory and the repertory grid interview techniques (Morrison, 1991). These were used to elicit trained nurses' views about caring in relation to the practice of nursing, using a sample of 25 nurses which generated over 200 verbal descriptions (constructs) which were analyzed into seven similar content areas and applied to nursing practices, education and further research (Morrison, 1991).

An exploratory study of the constructs used by nurses to explain the nature of nursing expertise was conducted by Edwards (1998) using Kelly's Repertory Grid Technique. This study enabled seven accident and emergency nurses to come up with a combined total of 55 bi-polar constructs which were clustered under four main headings. These results were deemed applicable to changing nursing practices, and supported team building, and the development of assertive clinical leadership that focused on patient-involvement (Edwards, 1998).

Furthermore, studies have applied the technique to studies of the personal constructs of gerontology nurses (Retsas & Wilson, 1997). Retsas and Wilson (1997) attempted to match these personal constructs with the constructs of 'effective' nurses, to

identify the extent that individuals identify themselves as effective gerontology nurses (Retsas & Wilson, 1997; Wilson & Retsas, 1997). As described in Kelly's PCT, all individuals create their own personal constructs for anticipating and interpreting situations and events, and these constructs influence reactions to professional and educational settings, the tasks they are called upon to perform, and the manner in which they react to others (Retsas & Wilson, 1997; Wilson & Retsas, 1997). This framework suggests, therefore, that personal constructs provide an individual with a frame of reference for understanding their experiences, both current and future, and create a measurement toolkit that is anticipatory and experiential, rather than responsive (Rawlinson, 1995).

Given the extent to which our population is aging, we must commit ourselves to providing quality care, and improving quality of life through in-home care and better long-term care facilities. This is particularly important within the population of spousal caregivers, as it is increasingly difficult to keep up with caregiving stresses while ensuring an optimal level of health, social independence, freedom of choice, privacy, dignity and safety within a home or home-like environment that provides a variety of experiences (Edwards & Scheetz, 2002).

Burden is the extent to which caregivers are suffering because of this demanding caregiving experience (Edwards & Scheetz, 2002). Burden is accompanied by a decline in psychological and physical health and an increase in the number of physical symptoms and doctors visits. The unpredictability/uncertainty that surrounds the caregiver's experience and the difficulty in clarifying expectations, leads to stress, with its perception being a component of burden (Edwards & Scheetz, 2002).

Repertory grid method is the ideal way to assess burden and identify burdensome variables associated with the caregiving experience. It can help meet the increased need to identify community resources and social support to act as a buffer for caregiver burden. It allows caregivers to express the many dimensions of their roles that can be burdensome, as well as allow researchers to analyze these variables quantitatively. Also, the usefulness of repertory grid extends to other healthcare professionals, namely educators and counselors who can use this information to allow for assessment of both the caregiver and patient's needs.

### Assessing Healthcare Burden using Repertory Grid

#### *Methods*

In this context, one of the primary purposes of repertory grid analysis is to simultaneously operationalize and assess caregiver burden. A careful review of the literature suggested that the general domains in which burden is most noteworthy are: number of caregiving hours, caregiving tasks, patient's functional state, and requirements of individuals, care, and resource perspective. These general domains were grouped into three clusters that represent our current knowledge of the predictors of burden: knowledge, support, and personal coping strategies. Knowledge included work-related tasks and skills that required specific knowledge, as well as the confidence to complete these tasks; resources encompassed both personal and work-related opportunities for support, and also included the availability and effectiveness of these resources; and coping strategies included care-related stressors and mechanisms, both personal and professional, that individuals employed to deal with stressors.

*Participants*

As a groundwork demonstration of this for larger application, two healthcare workers completed repertory grids, with the researcher's assistance, in order to measure burden associated with their work; a nurses and a respiratory therapist completed these repertory grids. This small sample is acceptable within a repertory grid analysis, as the technique is designed to elicit clear connections between elements and constructs through a careful attention to an individual's unique experience. This is a potentially important area of inquiry, as there are no published attempts at utilizing repertory grid analysis to understand caregiver burden.

Table 1

*List of Probes Used to Elicit Elements from Healthcare Professionals*

<b>Knowledge</b>
<ul style="list-style-type: none"> <li>A. Describe a task at work that is time consuming.</li> <li>B. Describe a task at work that is physically challenging.</li> <li>C. Describe a task at work that is mentally challenging.</li> <li>D. Describe a task at work that you feel could be done more efficiently.</li> <li>E. Describe a task at work that you rely on help/additional resources to complete.</li> <li>F. Describe a task you feel confident completing.</li> <li>G. Describe a skill that you know to help you complete your daily job tasks.</li> <li>H. Describe a skill that you would like to learn in order to help you complete your daily job tasks.</li> </ul>
<b>Resources</b>
<ul style="list-style-type: none"> <li>I. Describe one personal resource you have available for support.</li> <li>J. Describe one literary resource that you have available for support.</li> <li>K. Describe one resource that you would like to be made available.</li> <li>L. Describe one on-site resource provided to you by your work.</li> <li>M. Describe an available optional off-site resource you found out about at work.</li> </ul>
<b>Stress/Coping</b>
<ul style="list-style-type: none"> <li>N. Describe one example of where your work has your best interests at heart.</li> <li>O. Describe one example of where your work has the patients best interests at heart.</li> <li>P. Describe one stressor that results from your job.</li> <li>Q. Describe one stressor that would not exist with the help of additional resources.</li> <li>R. Describe one mechanism you use for coping with work-related stress while at work.</li> <li>S. Describe one mechanism you use for coping with work-related stress at home.</li> <li>T. Describe one resource provided to you by your work in order to help you effectively deal with work-related stress.</li> </ul>

These cluster definitions were then used to create a series of questions that were designed to elicit relevant elements from participants. These probe questions are listed in Table 1. These probe questions were clustered into three groups: the first probes dealt with knowledge and tasks, the middle probes dealt with the availability of resources and support, and the last probes concerned coping strategies for stressors. Common descriptors of elements of burden were drawn from the literature, and these were expressed as bipolar dimensions to serve as constructs (Table 2). Although a more accurate depiction of burden may come from having participants create their own constructs, using the method of triads, this partial standardization facilitated comparative analysis among individual grids. See Appendix D, which contains a sample of the repertory grid provided to participants.

Quantitative analysis was conducted using city-block distance measures – a quantity that may be defined as the sum of absolute differences between pairs across aligned or unaligned constructs. Many of the clustered elements had large distances; this would indicate further examination of the clustering in order to determine if the elements actually belong together.



Table 2

*Constructs Describing Burden for Healthcare Professionals*

Difficult	Easy
Skilled	No skill
Slow	Fast
Passive	Active
Stressful	Un-stressful
Pleasant	Unpleasant
Independent	Dependent
Structured	Unstructured
Required	Optional
Supportive	Unsupportive
Available	Unavailable
Effective	Ineffective
Onetime	Recurring
Possible	Impossible
Individual	Teamwork
Patient-focus	Productivity
Useful	Useless
Efficient	Inefficient
Costly	Inexpensive

Completed repertory grids were then entered into the web-based repertory grid analysis program *sci:vesco.web* (eac-Leipzig, 2007) and were evaluated within three separate grids: knowledge, availability of support, and coping strategies. *Sci:vesco web* displays principal components analysis results as interactive, three-dimensional, rotating representations that depict the relation of elements and constructs. Quantitative analysis was conducted through an evaluation of the provided distance dimension charts, and the accompanying hierarchical cluster analysis output that accompanies these distances. Data analysis consisted of: (i) a general overview of the PCA of each participant's grid; (ii) an analysis of the cluster distances between the all elements for each participant; (iii) an analysis of the pooled set of constructs from each participant; and finally, a focused analysis of each participant's repertory grid.

*Results*

The study resulted in a few elements that appeared for both participants:

- (1) talking with coworkers when dealing with stress at work
- (2) the provision of on-site counselor debriefing to deal with work related stress
- (3) the use of school texts were used as literary resources

Results of the hierarchical cluster analysis are depicted in Table 3. Values in this table represent the similarity between constructs using city-block measures; therefore, low values indicate greater similarity and relatedness. Values less than 0.30 were deemed related, while those greater than 0.80 were deemed unrelated. It must be taken into consideration that because personal constructs emerged as answers to the pre-determined prompts, the comparative nature of the results are limited; however, this is positive as it allows personal theories to be developed, and personal needs addressed. Full analytical results in table-format are provided in Appendix E.

Table 3

*Summary of Repertory Grid Analysis Results*

Knowledge	Participant A	Participant B
<i>Principal component analysis</i>	All elements are clustered around: <i>slow, recurring, useful, effective</i> *drawing blood & organization slightly closer to: <i>difficult, skilled</i>	Oxygen saturation checks: <i>stressful, fast, unpleasant</i>  Asking for help: <i>slow, stressful, effective, skilled, useful</i>  Changing ETT tapes & Ventilator circuit: <i>slow, stressful, effective, skilled, useful</i>  Memorizing medications, Ventilator rounds, Arterial line certified: <i>slow, stressful, effective, skilled, useful</i>  Chest compressions: <i>slow, stressful, effective, skilled, useful</i>
<i>Element matrix</i>	Drawing blood & Charting (.84) Transferring patients & Organization (.86) Shift work & Drawing blood (.87) Shift work & Administering IV medications (.91) Transferring patients & Administering IV medications (.91) Drawing blood & Medicine administration (.92) Drawing blood & Reporting (.93) Drawing blood & Transfer patients (1)	Changing ventilator circuit & Changing ETT tapes (.18) Oxygen saturation checks & Memorizing meds (.85) Oxygen saturation checks & Changing vent circuit (.87) Oxygen saturation checks & Chest compressions (.88) Oxygen saturation checks & Changing ETT tapes (.89) Oxygen saturation checks & Ventilator rounds (.98) Oxygen saturation checks & Arterial line certified (1)

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

Table 3 (continued)

Knowledge	Participant A	Participant B
<i>Construct matrix</i>	Effective & Useful (.19)	Effective & Useful (.09)
	Easy & Skill (.23)	Skilled & Effective (.12)
	Stressful & Difficult (.26)	Skilled & Useful (.17)
	Pleasant & Stressful (.26)	Patient focus & Recurring (.22)
	Pleasant & Slow (.27)	Skilled & Easy (.28)
	Useful & Ineffective (.87)	Unstressful & Easy (.29)
	Effective & Difficult (.28)	Effective & Unskilled (.81)
		Useless & Patient focus (.82)
	Effective & Onetime (.84)	
	Useless & Effective (.84)	
	Useless & Recurring (.89)	
	Productivity & Recurring (.99)	

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

Table 3 (continued)

Resources	Participant A	Participant B
<i>Principal component analysis</i>	All: <i>skilled, required &amp; available</i> *Computerized charting: <i>fast, easy, active, optional, unavailable</i>	Scattered!
<i>Element matrix</i>	College of nursing & Clinical practice text (.25) Computerized charting & College of nursing (.91) Computerized charting & Charge nurse(.99) Clinical practice text & Computerized charting (1)	Clinical coordinator & Medical sites online (.84) Texts books & Self blood analysis (.92) Text books & Medical sites online (1)
<i>Construct matrix</i>	Optional & No skill (.09) Required & Skilled (.09) Easy & Pleasant (.19) Easy & Supportive (.19) Pleasant & Supportive (.19) Pleasant & Unstressful (.25) Available & Required (.27) Easy & Unstressful (.27) Available & Passive (.27) Available & Skilled (.28) Easy & Passive (.30) Available & No skill (.87) Available & Optional (.91) Required & No skill (.96)	Independent & Structured (.08) Slow & Skilled (.16) Easy & Pleasant (.19) Supportive & Stressful (.21) Pleasant & Fast (.25) Active & Fast (.28) Active & No skill (.28) Independent & Unstructured (.83) Optional & Required (1)

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

Table 3 (continued)

Stress/Coping	Participant A	Participant B
<i>Principal component analysis</i>	All: <i>efficient, useful/possible, supportive, recurring</i> *Not enough nurses: <i>unavailable, inefficient &amp; difficult</i> *Physical activity: <i>available &amp; costly</i>	All: <i>supportive, available, efficient, useful, possible, effective</i> *Talking to employees: <i>slightly more central</i>
<i>Element matrix</i>	Talking with coworkers & Discharge patients home (.22) Not enough nurses & Safe workplace (1) Not enough nurses & Debriefing (.95) Not enough nurses & Discharging (.94) Not enough nurses & Physical activity (1) Not enough nurses & Talk with coworkers (.90) Not enough nurses & Code team(.85)	Transferring patients & Dealing with families (.23) Blood test & Compassionate care (.84) Blood test & Dealing with families (.85) Talking to employees & Relax (.87) Talking to employees & Transferring patients (.87) Talking to employees & Compassionate care (.92) Talking to employees & Debriefing by counselors (.93) Talking to employees & Dealing with families (.94) Talking to employees & Blood test (1)
<i>Construct matrix</i>	Possible & Useful & Effective (0) Effective/Possible/Useful & Efficient (.12) Supportive & Efficient (.23) Supportive & Useful/possible/effective (.25) Supportive & Individual (.83) Supportive & Not useful/impossible/ineffective (.87) Inefficient & Effective/possible/useful (.95)	Effective & Useful (.06) Possible & Useful (.11) Useful & Efficient (.12) Possible & Efficient (.17) Onetime & Possible (.91) Ineffective & Efficient (.92) Useless & Efficient (.92) Onetime & Useful (.95) Possible & Ineffective (.97) Impossible & Useful (.97) Useless & Effective (1)

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

*Knowledge grid*

Note: these are bipolar constructs and for convenience are referred to by a single pole.

i) PCA shows knowledge and skills were clustered around 'slow' and 'useful' but 'effective'. As well, these elements were 'skilled'. 'Shift work' and 'drawing blood' stood out from the rest (more 'difficult'). 'Shift work' requires more organization and physical exhaustion, and drawing blood is a more skilled procedure, requiring accuracy. Additionally, 'Oxygen saturation checks', 'changing ventilator circuits' and 'changing ETT tapes' were more 'stressful' since they can involve high risk situations and require precision and skill.

ii) Specialized skills are often the cause of stress and, therefore, do not lend themselves to being comparable between healthcare workers of differing specialties.

iii) For both participants, redundant constructs include: 'effective' and 'useful', 'easy' and 'skilled', 'stressful' and 'difficult'.

*Resources grid*

i) PCA shows Participant A's resources clustered around 'skilled', 'required' and 'available', while Participant B's demonstrated substantially more variability across elements.

ii) 'Computerized charting' stood out for Participant A due to its inexistence.

Additionally, 'text books' were highly unrelated to 'medical sites online' and 'self blood analysis' for Participant B because though text books were a useful resource, they are not practical in emergency situations. 'Medical sites online' are more easily accessible and available, whereas carting 'text books' around and referencing them is impractical. 'Self blood analysis' was a situation where the hospital had the healthcare workers best

interests at heart; when the worker was in an at-risk situation, the hospital provided unlimited resources to ensure her health and safety were intact.

iii) For Participant A 'required' and 'skilled' (.077), and for Participant B 'independent' and 'structured' (.161) were the most redundant constructs. Additionally, 'easy' and 'pleasant' were related in both participants (.190).

#### *Stress/coping grid*

i) PCA resulted in a cluster around 'efficient', 'useful', 'possible', and 'supportive'. 'Not enough nurses' was a major stressor and, as a result, was clustered around 'unavailable', 'inefficient', and 'difficult'. Additionally, 'talking to employees/coworkers' and 'physical activity' were seen as coping mechanisms and were clustered towards more 'available'.

ii) This divergence was also reiterated in the element distance dimension matrix, as both 'not enough nurses' and 'talking to employees' were highly unrelated to the other elements (distance >0.85).

iii) 'Effective' and 'possible' and 'useful' were all considered redundant constructs.

These three were also highly related to 'efficient' (.120), questioning its use in the same questionnaire as the others.

#### *Discussion*

Health care workers generally tend to be under a lot of stress due to the variable and fast paced work environment. This groundwork study has indicated some key personal constructs that can be used as guides to attitudes of healthcare workers towards burden in general. Both healthcare professionals in this study acknowledge that they are fairly new to the workforce, and therefore may not have years of stress buildup: "*the deeper you get into the job, and the more years you work, burden starts to build up. The*



*longer you work means there's also more work politics involved, burdening you".*

Additionally, both have available coping mechanisms in place to deal with work-related burden, and make the effort to take advantage of these opportunities.

Common stressors included lack of personnel. Participant A explicitly stated 'not enough nurses', while Participant B's answer of 'transferring patient' reflect that when their hospital does not have the resources to handle a patient, it is left up to her and another healthcare worker to transfer the patient to another location. She feels that: "*we are understaffed in this transfer, if something were to go wrong, I'd have to call someone at the hospital for back-up*". Common coping mechanisms used to deal with some stresses of the job include 'physical activity' and 'time out just for me to relax'. Both seem to be able to leave their job-stresses at work, however, they both acknowledge that as their job progresses it will be more and more difficult to dissociate from job-related stressors.

Resources most commonly used to handle difficult tasks are 'talking to colleagues'. Co-workers provide practical advice since they have come across most situations in previous experiences; they are able to share past work experiences. Both participants acknowledged that their workplace provides counselors for debriefing; this is somewhat useful. 'Debriefing by counselor' is more a formal way of seeking advice and talking about experience. However, counselors are hired to help healthcare workers, and both participants would prefer to speak with coworkers who have more patient experience: "*my more experienced co-workers have been there and can tell me things that are more patient-related than a debriefing counselor or sometimes even a supervisor; I trust their advice because they have been through it before*". Additionally, clinical

coordinators and supervisors are available as a resource; however, coworkers provide more practical and understandable advice.

### *Conclusion*

These findings emphasize the importance of improving knowledge and skills through letting people know about resources available and teaching effective coping mechanisms for stress. Noteworthy observations in the context of healthcare setting are that burden is the result of a buildup of years work and it gets harder to separate work-stresses from home-life; it takes initiative and effort to ensure that coping mechanisms are in place and used (e.g., gym memberships). This study provides us with a clearer image of burden faced by healthcare professionals and increases the level of confidence in meeting their needs.

### Further Applications of Repertory Grid

The foregoing example illustrates the ability of the repertory grid method to provide the researcher with a unique synthesis of quantitative and qualitative. As a mixed-methods technique, it allows the investigator an opportunity to evaluate whether or not elements (and constructs) truly "belong" together (i.e., are related in terms of their clustering within the ratings). This is an especially useful adjunct to traditional qualitative research when used in the early stages test construction, as it parallels some of the quantitative techniques used in the item analysis of one's item pool after the administration of a pilot version of the questionnaire. This may serve to improve one's opportunity to devise a psychometrically reliable questionnaire, should this be the end goal of the research project. On a qualitative level, this technique is also useful in the

elicitation of unbiased opinions, and the composition of good items that achieve adequate saturation of the content domain, which avoiding repetitive and irrelevant constructs.

Beyond the capacity of the repertory grid method to produce psychometrically sound questionnaires, however, the technique may serve a more important purpose. In the course of having participants answer probe questions, one is provided with a list of the resources, knowledge sources, and strategies that an individual is currently employing. This information can be evaluated by a manager or counselor in identifying areas that may require attention. For example, if a staff member appears to be unaware of some of the workplace resources that may be available in the remediation of a targeted problem that is increasing his or her burden; the evaluator may direct attention to these resources. In this way, repertory grid analysis serves as a useful foundation for the creation of a toolkit that might help meet our increased need to engage in good knowledge exchange among researchers, administrators, staff caregivers, and spousal caregivers. These features allow for an assessment of improvements within systems of care, provide opportunities to give useful and constructive feedback to staff, and facilitate resource allocation.

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## Chapter 3

Creating a Standardized-Free-Response Scale to Assess the Burden Experienced by  
Parkinson Caregivers

Caregivers, though often forgotten, are integral to the health care team. Caregivers are associated with decreased morbidity and mortality, and increased quality of life in those that they care for. This, however, comes at a cost, and usually results in caregiver stress, diminished immune system, and impaired psychosocial functioning (Glozman, 2004; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). The burden that caregivers bear also makes it difficult to provide appropriate care, thereby putting the individuals' well-being at risk. Furthermore, the multidimensional nature of the burden construct has made it difficult to concretely define. Given the foregoing, there is an immediate need to clearly operationalize 'burden', identify its' causes, and develop techniques to mitigate caregiver distress. This task is further complicated by the variability across caregivers: caregivers may be spouses or staff members, male or female, young or old, and they may come from any ethnic background (McRae, Sherry, & Roper, 1999).

Caregivers are called upon to respond to the needs of individuals who were previously independent, which creates stress for both caregiver and care receiver due to the associated uncertainty and variability (Edwards & Scheetz, 2002; McCarron, Gill, Lawlor, & Beagly, 2002). It has been found that patient perception of control over his or her own symptoms is inversely related to caregiver burden, while the burden experienced by the caregiver is inversely related to the amount of social support available, and positively related to the severity of reported symptoms, and the level of support required for activities of daily living (Edwards & Scheetz, 2002).

Due to the substantive impact of burden on the health and well-being of family caregivers, and the growing proportion of the population in this role, this study is focused on the burden experienced by family caregivers – specifically, spousal caregivers. To ensure that adequate attention is paid to the potential specificity of the care receivers needs within particular ailments, this study will focus on the caregiver burden borne by caregivers of individuals with Parkinson's disease (PD). PD is a complex neurodegenerative disease, with consequences that include progressive loss of movement control. Individuals with PD have a two to five times higher than average risk of mortality, due to an increased susceptibility to other medical conditions (Guttman, Slaughter, Theriault, DeBoer, & Naylor, 2001). More specifically, neuropsychiatric disturbances associated with PD contribute to reduced quality of life, increased risk for admission to nursing home, and burden (Aarsland et al., 2007). In a study by Aarsland, Bronnick et al. (2007), moderate to severe distress was reported by 20% of caregivers for individuals with motoric symptoms in the absence of neuropsychiatric disturbance, as compared to 58.6% of caregivers for individuals with neuropsychiatric symptoms. Although infrequently addressed within this population, the consequences of neuropsychiatric sequelae among individuals with PD is of serious concern – both for individuals and their caregivers.

PD affects nearly 100 000 Canadians, and 6.3 million people worldwide. The associated economic impact is great due to complications that arise from the individual's increased susceptibility to other medical conditions, thus requiring a disproportionately higher use of resources, and longer hospital stays (Guttman et al., 2001). As the population ages, the number of individuals with PD will increase proportionally – it has



been estimated that the number of individuals with PD will double by the year 2016 (Kontakos & Stokes, 2000).

The uniqueness of PD benefits from specialized medical expertise, most notably by neurologists and medical movement disorder specialists (Rajput & Rivest, 1998). The decrease in numbers expected within this specialty over the next few years will consequently increase the pressure on family physicians, and on multidisciplinary health care teams (speech pathologists, occupational therapists, physical therapists, psychologists, etc.). This places additional demands on these professionals to become more knowledgeable in the treatment and management of PD.

The unpredictability of PD means a greater lack of control for caregivers; in addition to the unpredictability, families are often ill equipped (emotionally and physically) to care for their loved ones. It is, therefore, important to understand and meet the needs of caregivers, as this will potentially impact on the quality of care (and quality of life) for both caregiver and care receiver (Edwards & Ruettiger, 2002). Unfortunately, little (if any) qualitative research has been published on the burden experienced by caregivers of individuals with PD. Qualitative research seeks to understand individual perceptions, impact of values, and interpretations of reality; this importance is emphasized through the individualized experiences of spousal caregivers. The nature of the PD-specific caregiver experience lends itself to the combination of incorporating qualitative analysis, which allows for a more complete understanding of this experience through the caregiver's own voice, as well as the usefulness of quantitative measurement. The application of qualitative research principles to the assessment of caregiver burden will not only facilitate the creation of an individualized assessment tool for caregiver

burden, but will create directed communication resources that will help manage and alleviate burden. A useful methodology that bridges the gap between qualitative and quantitative methodologies is the repertory grid method.

The repertory grid method was developed from the theoretical foundations of George Kelly's 1930's Personal Construct Theory (PCT), which was originally conceived as a means of facilitating psychological counseling (Kelly, 1955). It employs a widely used set of techniques in order to study personal and interpersonal systems of meaning. This flexible method was developed with the assumption that people are fundamentally active in their self-reflection, and are interested in looking into all aspects of themselves and their environment (Peters, 1994). In general, PCT tends to focus on the viability of a person's unique constructions of reality, and helps him or her find meanings that affirm subjective conceptualizations of self, other, and world (Holland, Neimeyer, Currier, & Berman, 2007). More specifically, adherents of PCT view human beings as "scientists" whose primary aim is to make sense of the world and successfully anticipate events. In the mid-1950's the repertory grid method was devised as a diagnostic tool based on PCT. According Kelly's theory, 'reality' does not reveal itself to us directly, but is subject to as many different constructions as we are able to invent, in a process known as *constructive alternativism* (Kelly, 1955). Used within clinical setting, grids may be used to assess changes in systems of meanings over a period of time, in different groups of people (Ford & Bradshaw, 1993; Retsas & Wilson, 1997).

Repertory grids may be used to elicit constructs and to identify the relationships among them – and these linkages often provide suggestions of why people remain "stuck" in patterns. These patterns can also be useful in providing clinical information

and useful indications of progress in therapy (Ford & Bradshaw, 1993; Morrison, 1991). The grid is constructed using columns of elements (alternative events or entities), and rows of constructs (dimensions of similarity and difference between elements), central to the latent trait that is being studied; it is basically a rectangular matrix. Each row-column intersect in the grid contains a rating that reflects the value of the construct for the element in question.

The combination of idiographic (self-reports) and nomothetic assessment (measures taken directly by an outside observer) provides both unique dimensions and general patterns. This uniqueness allows the participant to construct his or her own questionnaires (eliciting personal constructs and individualized ranking of elements), while allowing the researcher to retain the ability for comparative analysis (Edwards, 1998; Morrison, 1991).

Repertory grids have been useful in analyzing self-perceptions of nurses, as well as the nature of nurses' expertise and professional roles and research utilization in specialized areas of nursing. Many aspects of caring attitudes in nursing practices have been explored successfully using personal construct theory and repertory grid techniques (Barnes, 1990; Burnard & Morrison, 1989; Costigan, Humphrey, & Murphy, 1987; Davis, 1983, 1985; Heyman, Shaw, & Harding, 1983; Morrison, 1991; Pollock, 1986; Rawlinson, 1995; Wilkinson, 1982). This study will employ repertory grid techniques within a sample of spousal caregivers of individuals with PD, in order to determine: a) the elements of most importance to PD-specific caregiver burden; b) constructs that accurately describe this unique burden; and c) the usefulness of repertory grid as a means of assessing and creating individualized approaches to burden management.

## Methods

### *Participants*

Participants in this project consisted of 5 female spousal caregivers providing in-home care for a family member with PD. Participants were between 49 and 71 years of age, and had been caring for a spouse with PD for two to fourteen years. Participants were recruited through a partnership with Parkinson Society Canada, Southwestern Ontario Region and the *London Partners for Parkinson's Support Group* that meets monthly to offer support to caregivers of people with PD. Purposeful sampling was used to ensure that the sample included participants with a broad range of caregiving knowledge and experience, who would also be sufficiently capable of sharing their experiences. Saturation was defined as the point at which the researcher reached felt capable of communicating the manner in which participants constructed their world, and articulating a theory that illuminates common issues for spousal caregivers.

### *Procedure*

Caregivers were asked to complete three repertory grids during an interview. The probe questions for which were based on previously identified criteria of burden, including: number of caregiving hours, caregiving tasks, patient's functional state, and requirements of individuals, care, and resource perspectives. These criteria were rationally grouped into three categories: knowledge, support, and coping strategies. The probe questions for these repertory grids are presented in Table 4.

Table 4

*List of Probes Used to Elicit Elements from Spousal Caregivers*

Grid	Probes
Knowledge	<p>A. Describe a task done at home to care for your spouse that is time consuming.</p> <p>B. Describe a task done at home to care for your spouse that is physically challenging.</p> <p>C. Describe a task done at home to care for your spouse that is mentally challenging.</p> <p>D. Describe a task done at home to care for your spouse that you feel could be done more efficiently.</p> <p>E. Describe a task done at home to care for your spouse that you rely on help/additional resources to complete.</p> <p>F. Describe a task done at home to care for your spouse that you feel confident completing.</p> <p>G. Describe a skill that you know that helps you complete your daily caregiving tasks.</p> <p>H. Describe a skill that you would like to learn in order to help you complete your daily caregiving tasks.</p>
Resources	<p>I. Name one personal resource you have available for support at home.</p> <p>J. Name one personal resource you have available for support outside of your home.</p> <p>K. Name one resource available to you to use specific to Parkinson's disease.</p> <p>L. Describe one literary resource that you have available to you for support at home.</p> <p>M. Describe one literary resource that you have available to you outside of home.</p> <p>N. Describe one resource that you wish was more available to you at home.</p> <p>O. Describe one available at-home resource that is useful when providing care for your spouse.</p> <p>P. Describe one available out-of-home resource that is useful when providing care for your spouse.</p>

Table 4 (continued)

Grid	Probes
Stress/Coping	<p>Q. Describe one example of where your spouse has your best interests at heart.</p> <p>R. Describe one example of where you have your spouse's best interests at heart.</p> <p>S. Describe one stressor that results from the caregiving experience.</p> <p>T. Describe one stressor that would not exist if you had the help of additional resources.</p> <p>U. Describe one mechanism you use for coping with care-related stress while at home.</p> <p>V. Describe one mechanism you use for coping with care-related stress outside of the home.</p> <p>W. Describe one resource provided to you by an outside source that helps you effectively deal with care-related stress.</p>

The constructs were determined using Kelly's personal construct theory: participants decided whether two elements chosen at random by *sci:vesco.web* (each Leipzig, 2007), are similar or different. Following this, participants generated an adjective (termed a 'construct' within the repertory grid method) that described how the selected elements were either similar or different. Following this, the participant was asked to come up with a construct that represented the opposite pole of a scale that could be used to rate the elements. Due to the difficult nature of construct generation, sample constructs were provided to participants to use if necessary based on constructs previously used among healthcare professionals and common descriptors in general; this list is provided in Table 5. Additionally, a sample repertory grid is presented in Appendix F. The participant then rated all elements on a scale from one to ten, using the constructs that they generated. This process was repeated for all elements, in all three grids.

Table 5

*Sample Constructs Describing Burden given to Spousal Caregivers*

Difficult	Easy
Skilled	Unskilled
Slow	Fast
Efficient	Inefficient
Physical	Mental
Available	Unavailable
Supportive	Unsupportive
Effective	Ineffective
Verbal	Written
Costly	Inexpensive
Onetime	Recurring
Effective	Ineffective
Group	Individual

*Analysis*

Data analysis was done using *sci:vesco.web*, a web-based repertory grid administration and analysis program. This program uses a single-grid, dyadic interview method, and an evaluation scale with no centre point (0) (eac-Leipzig, 2007). Specific element ratings on important constructs are often informative in themselves; however, this program goes further and calculates both a principal component analysis (PCA) and a cluster analysis (with a Bertin-display).

Data analysis consisted of separate grid analysis of: (i) a general overview of the PCA of each participant's grid; (ii) the cluster distances between all elements for each participant; (iii) the pooled set of constructs from each participant; and finally, (iv) a focused analysis of each participant's repertory grid and highlighting common themes. The PCA technique reduces dimensionality while retaining variance, by transforming it into an uncorrelated new set of variables (i.e., the principal components). *Sci:vesco web* displays PCA results as interactive, three-dimensional, rotating representations that depict

the relation of elements and constructs. Correlation matrices, depicting variance-maximizing linear combinations of variables between the elements and constructs, are also provided. This allows a focused analysis of the grids provided by individual participants by locating the elicited elements in multidimensional space. This analysis uses a hierarchical cluster analysis technique to order the constructs according to their spatial relationships (eac-Leipzig, 2007). The repertory grid method expresses inter-relationships among elements and constructs as cluster distances. By examining similarities and differences in the way constructs were rated by the participants with respect to the given elements, a map of each participant's personal construct system was constructed (Costigan et al., 1987).

Cluster analysis was done by measuring distances, which are used to indicate the similarity between a pair of constructs (with respect to their common elements), or a pair of elements (with respect to their common constructs). There are a number of forms of distance: most commonly used in repertory grid analyses are *city-block* or *Euclidean* distances. The city block distance is the sum of the absolute differences between ratings, while Euclidean distance is the straight line between points (the distance 'as the crow flies').

### Results

A summary of the information obtained from participants is presented in Table 6. Values in this table represent the similarity between constructs using city-block measures; therefore, low values indicate greater similarity and relatedness. It must be taken into consideration that because personal constructs emerged as answers to the pre-determined prompts, the comparative nature of the results are limited; however, this is



positive as it allows personal theories to be developed, and personal needs addressed. To facilitate later interpretation, results of each individual repertory grid (knowledge and skills, available support, and coping strategies) will be presented separately. Within each of these sections, we will evaluate the overall information presented by the principal components analysis (PCA), the information contained specifically within the construct matrices, and the information contained specifically within the element matrices. This information will then be evaluated for thematic content. The results of this mixed methods approach may, therefore, be broadly subdivided into 'quantitative repertory grid analyses' and 'qualitative repertory grid analyses.' Full analytical results in raw-data table format are provided in Appendix G.

Table 6

*Summary of Participant Results of Repertory Grid Analysis*

Knowledge	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
<i>Principal component analysis</i>	All elements: <i>slow, inefficient, difficult, mental</i>  'Shovel': <i>physical, patient, efficient</i>  'Meals': <i>fast, patient, efficient, yet somewhat difficult</i>	All elements: <i>efficient, good, safe, easy, fast</i>	'Walking techniques' & 'Shower seat': <i>physical, good, easy, efficient</i> 'Pill sorting' & 'Organized': <i>mental, good, easy, efficient</i> 'Getting into bed' & 'Walking': <i>inefficient, bad, physical, difficult</i>	'Organized' & 'Daily routine': <i>difficult, mental, efficient &amp; fast</i>  'Patience' & 'Cueing': <i>difficult &amp; mental</i>	Scattered... no real clusters
<i>Element matrices</i>	Efficiency & Patience (.18) Major decisions & Income tax (.22) Shovel & Major decisions (1)	Personal grooming, & Bathing, & Physical aid technique (0) Cooking &: All (1)	Shower seat & Walking techniques (.14) Organized & Walking (.86)	Daily routines & Organized (.17) Dressing & Organized (1)	Internet & Planning meals (.30) Depression & Assistive devices (.95) Turning over in bed & Planning meals (1)

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

Table 6 (continued)

<i>Construct matrices</i>	Efficient & Fast (.30) Physical & Difficult (.85)	Fast & Easy (.04) Efficient & Fast (.13)	Bad & Difficult (.36) Good & Difficult (.84)	Mental & Difficult (.21) Mental & Easy (.84)	Patient & Easy (.12) Easy & Fast (.36)
Resources	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
<i>Principal component analysis</i>	Boys & girls club, Visitor program, Parkwood, Support group : <i>social</i>  PD Binder, PD books, Friends Visiting, Bedrail: <i>personal</i>  All: <i>effective-ness, cost &amp; recurrence</i>	Internet: <i>written, available</i>  Telephone help line & Spouse: <i>oral, caring, supportive</i>  OT & Neurologist <i>supportive, scientific, honest</i>  PD book & PD update: <i>written, realistic, honest, clarity</i>	Homecare & Daughter: <i>effective, supportive, available, individual</i>  Support groups: <i>effective, supportive, available, group</i>  Internet & PD books: <i>written, available &amp; supportive</i>	Exercise books & PD books: <i>available, supportive, written, effective, individual</i>  Family & Neurologist: <i>individual</i>  Family, Neurologist, Carepartners group, Call support group members, Support group facilitator: <i>available, supportive, effective</i>	Children, Homecare & Neurologist: <i>supportive, effective, verbal &amp; recurring &amp; available</i>  PD binder & PD periodical: <i>written, available &amp; recurring *PD periodical: effective &amp; supportive</i>  Assistive device: <i>recurring, slightly effective &amp; supportive</i>

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

Table 6 (continued)

Resources	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
<i>Element matrices</i>	PD book & PD binder (.27) *Bed rail unrelated to <i>Social</i> elements	PD book & PD periodical (.18) Neurologist & OT (.27) Internet & Neurologist (1)	Internet & PD book (.13) Books & Daughter (.81) Support group & Books (1)	Support group facilitator & Carepartners group (.28) Carepartners group & Books (1)	Homecare & Children (.07) Assistive devices & Children (.34) PD binder & Children (.97) PD binder & homecare (1)
<i>Construct matrices</i>	Recurring & Effective (.31) Social & Assistive devices (.92)	Clarity & Honest (.25) Clarity & Caring (.27) Clarity & Scientific (.28)	Available & Supportive (.13) Available & Unsupportive (.92)	Supportive & Effective (.07) Effective & Available (.07) Supportive & Available (.1)	Supportive & Effective (.08) Recurring & Available (.27); Supportive (.22); & Effective (.27) Available & Supportive (.31)

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

Table 6 (continued)

Stress/Coping	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
<i>Principal component analysis</i>	Books: <i>easy, written, at home</i> Shopping, Entertaining him, & Keep him moving: <i>costly</i> For him, Learn to say thank you, Seeing grandkids & Seeing it from his perspective: <i>difficult, verbal, at home, inexpensive</i>	Hockey, Book, Chat with friends, Own private time: <i>frequent, regular, relaxing, helpful, benefit</i> EAP, Fatigue & Financial: <i>useless, unhelpful, irregular, seldom</i>	Support group: <i>inexpensive, helpful, effective, group</i>  Talk to mom, Thank you & Massage feet: <i>inexpensive, recurring, effective, helpful &amp; individual</i>  Not going out: <i>not helpful &amp; ineffective</i>	All: <i>recurring beneficial, effective, inexpensive</i>	All: <i>supportive, effective, frequent</i> * Independence: <i>unavailable</i> * Appreciative: <i>frequent, mental &amp; available</i>
<i>Element matrices</i>	Entertaining him & Keep him moving (.21) Shopping & Learn to say thank you (.94) Shopping & Books (1)	Read a book & Chat with friends (.13) Chat with friends & Watch hockey on TV (.16) Read a book & Financial (.94) Read a book & Fatigue (1)	Talk to mom & Computer (0) Thank you & Talk to mom (.24) Support group & Lonely (9) Not going out & Talk to mom (.99)	Carepartners & Generous (.30) Generous & Fear of falling (.84) Fear of falling & Walk with friends (1)	Invite people to visit & Homecare (.10) Gym & appreciative (.92) In-dependence & appreciative (1)

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

Table 6 (continued)

Stress/Coping	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
<i>Construct matrices</i>	Difficult & Verbal (.31) Inexpensive & For him (.9)	Regular & Frequent (.07), Helpful & Benefit (.05) Frequent & Helpful (.21) Frequent & Benefit (.22) Regular & Useless (.87)	Effective & Inexpensive (.24) Helpful & Effective (.26) Group & Ineffective (.81)	Inexpensive & Effective (.08) Not helpful & Ineffective (.05) Beneficial & Effective (.05) Beneficial & Not helpful (.85)	Effective & Supportive (0) Frequent & Available (.27) Available & Ineffective/Un-supportive (.782)

Note: The column on the left represents the type of statistical analysis done. For Principal Components Analysis, columns on the right indicate the constructs around which the elements clustered for each participant. For hierarchical cluster analysis, the columns on the right represent the most related and unrelated elements/constructs, based on participant's matrix distances.

*Quantitative Repertory Grid Analyses*

Note: These are bipolar constructs and for convenience are referred to by a single pole.

*Knowledge grid*

## i) PCA

When analyzing the results of the PCA, it was clear that obtaining practical information was the main concern. Four out of five participants were concerned about acquiring information about techniques of care, assistive devices, and effective modifications to routine. The PCA also indicated that all participants were concerned about acquiring knowledge that would make care 'easier' and more 'efficient'.

## ii) Element Matrix

Elements of most importance for participants included: learning to incorporate more 'patience' and 'efficiency' in daily care (.18), the stresses of 'major decision making' and 'running errands' (.25), acquiring knowledge to increase efficiency with 'physical aid techniques' (0), more appropriate and efficient uses of 'walking techniques' and 'shower seat' (i.e. assistive devices) (.14), more help planning and increasing speed of 'daily routines' and 'organization' (.17). These are all indicative of the increased concern about acquiring knowledge about techniques of care and daily routine planning that were noted by the PCA.

## iii) Construct Matrix

There were no clear constructs that were redundant for all five participants. Commonly related constructs included: 'fast' and 'easy' (.04), 'patient' and 'easy' (.12), 'mental' and 'difficult' (.21). It is noteworthy that two participants noted the magnitude of the mental component of the caregiving process, as demonstrated by the substantive

relatedness of 'mental' with both 'difficult' and 'inefficient'.

### *Resources grid*

#### i) PCA

This analysis demonstrated three clusters of resources available to spousal caregivers; literary resources (i.e. books and internet), assistive devices (i.e. bed rail, shower seat), and personal resources (i.e. family, friends, healthcare practitioners, support groups). These were also further clustered into social resources (i.e. support groups, day programs) and at-home resources (i.e. family, assistive devices, books). The most important characteristics of a resource is that it be accessible, and clear (i.e. easily understood and thorough) – in other words, caregivers need to be able to easily access and understand a resource in order for it to be supportive. Additionally, it should be 'ongoing' in nature, meaning that it should be available more than once and preferably at the convenience of the caregiver.

#### ii) Element Matrix

Significant resources included: 'assistive devices', 'support group', 'homecare', and 'neurologist'. 'PD-help books' and 'binder from Parkinson Society Canada' were significantly related, (.27), and were construed as being separate from 'support groups' (1), 'family' (.97), and 'homecare' (1).

#### iii) Construct Matrix

Redundant constructs emphasize the important characteristics of elements that make the resources helpful. Most importantly, 'available' and 'supportive' (.10) are related and this indicates that for a resource to aid the caregiver it must be easily accessible. Additionally, the small distance between 'supportive' and 'effective' (.07)



and 'available' and 'effective' (.07) provide more insight to what makes a resource useful. Finally, 'clarity' and 'recurring' indicate that for the resource to be most useful it must provide useable information and have an ongoing nature of support.

### *Stress/coping grid*

#### i) PCA

This analysis demonstrated that in order to cope with stress, participants indicated that mechanisms must be 'frequent', 'regular', 'helpful', 'beneficial', and 'effective'.

#### ii) Element Matrix

Caregivers report a need to cope with 'fatigue', 'financial stresses', 'loneliness', fears for spousal safety (i.e. 'falling'), and report coping mechanisms that include: 'books', 'walking' and/or 'talking to family and/or 'friends', 'social clubs' and physical activity (i.e. 'gym'). Additionally, feeling appreciated by their spouse (i.e. spouse is 'generous', 'appreciative', 'says thank you') is an inexpensive, yet very effective method, of reducing caregiver stress.

#### iii) Construct Matrix

It should be noted in future test construction efforts that the following constructs may be redundant: 'effective' and 'supportive' (0), 'benefit' and 'effective' (.05), 'helpful' and 'benefit' (.05), 'regular' and 'frequent' (.07), and 'helpful' and 'effective' (.26). This also suggests that in order for coping mechanisms to be supportive (and beneficial/effective/helpful) they should also be regular/frequent. This also illustrates the importance of accessibility to spousal caregivers, in determining the effectiveness of a support mechanism.

### *Qualitative Repertory Grid Analysis*

*Education.* One of the themes that resulted from the repertory grid interview was **education**. However, for caregivers, most education currently available deals with what makes people with PD *special*. Caregivers are inundated with information about completing activities of daily living (ADL), feeding schedules and medication provision, etc.. While these are somewhat useful, caregivers do not want to focus on the 'problems' with PD, but rather, the 'interesting aspects' of PD (i.e., it's 'quirks').

In addition, caregivers report having to advocate for both themselves and the person with PD for whom they care, as the individual with PD is often reticent about asking questions – or may not even realize that there are concerns about care, due to an impaired perception of his or her situation. This places additional responsibility on the caregiver, who must be prepared to ask these questions of the healthcare provider.

*Unpredictability.* The **unpredictability** of the disease was also a major concern. Caregivers find that the nature of the disease and the medication schedule requires planning and organization; however, they also have to be able to adapt plans quickly to changing symptoms and moods. Unpredictability of symptoms as well as the strict schedule of the administration of medication and meals can decrease the opportunity to get out of the home. Any attempt at keeping an away-from-home social network is very dependent on one's ability to change plans as the situation demands. Visiting with friends and family occurs more often within the home as this allows the caregivers to better deal with changes in symptoms, and also makes the person with PD feel more comfortable and 'at ease,' which in turn causes the caregiver to experience a sense of relief and comfort. Notably, when visitors come to visit, it serves not only as entertainment for the

individual with PD, but also for the caregiver. Often, these visits provide a distraction from caregiving duties and offer an opportunity to interact in a “normal” social environment. Additionally, it provides the caregiver some relief of worry and the opportunity to complete activities they couldn’t otherwise carry out when they are alone. *“I leave my husband knowing that the company can be my set of eyes and run downstairs and get the laundry done or even run out and get groceries. I feel better leaving him knowing he’s entertained and safe.”*

The unpredictability of the disease extends not only to daily plans and routines, but to ‘lifelong’ plans. Most caregivers addressed the fact that their retirement plans have changed; the nature of the disease makes it impossible, in most cases, to follow through on planned retirement-life, which can be a great loss to both the caregiver and the spouse.

*Independence.* Another common theme is the **loss of independence** for spousal caregivers; as one participant reported: *“your life is based on your spouse’s mood”*. The unpredictability of the disease, and the scheduling required for meals and medications limit the ability for caregivers to make plans outside the home. Homecare is used as a resource to provide some relief to the caregiver, however, this is only relief to the extent the homecare person is educated in PD, as well as the level of comfort the person with PD has with this worker. One participant was very happy with her homecare worker; she provided relief from caregiving duties and increased independence, since she was able to leave the home without worry. However, another participant noted that she was initially unable to depend on her homecare worker to administer medication, meals and washroom duties since her spouse was uncomfortable asking the homecare worker for help. This improved as the person with PD became more comfortable with the situation.

*Social. Support groups* provide an outlet for spousal caregivers. Most caregivers appreciate the opportunity to meet with others in the same situation and share stories, however, some feel guilty about leaving their spouse for that time. This further illustrates the often selfless nature of caregivers. Also, many caregivers appreciate the ability to call a member or facilitator of the support group when they need support. Additionally, many spouses have social outlets (i.e. gym memberships, walking groups, lunch clubs, card clubs, etc.); however, these appear to be more of a 'distraction' than a method for coping with caregiving stresses.

The **loss of social networks** was also a major issue for caregivers. Both caregivers and individuals with PD go through a series of what can be described as "little deaths" in their social life: interactions with people from work begin to decrease; then other social connections become more difficult; and finally, family visits become increasingly infrequent. These "deaths" are due to a combination of factors: the unpredictability of the disease, the interruption of outings due to medication schedule and meals, the increasing discomfort of the person with PD outside the home environment, and the uneasiness of friends and family due to lack of education and lack of familiarity with PD. Additionally, the Parkinson's community is an available social network, and yet is seen as a double-edged-sword: it is a good social environment, since everyone is very understanding and can relate to one another, and yet it can be distressing for participants in the earlier stages of the disease to see the effects of more advanced stages of the disease.

*Family.* **Family** becomes an important social network for caregivers and persons with PD. They are more understanding, apt to continue regular visits, and provide a great outlet for both the caregiver and the person with PD. Grandchildren are especially important for most caregivers; they serve as a great stress-relief and distraction (i.e. something else to focus energies on instead of caregiving tasks), and provide some entertainment and *joie de vivre* for both spouses.

*Safety and Activities of Daily Living.* Participants reported that there is already adequate information on dealing with Activities of Daily Living (ADLs), but more access to assistive devices to aid in ADLs would be very useful. Spousal caregivers expressed that more information on walking strategies designed specifically for their spouse would be helpful. Caregivers all reported the resistance and reluctance put forth by their spouses in the use of assistive devices for mobility.

The main concern addressed by all spousal caregivers was spousal **safety**. Safety is the most frightening and stressful aspect of care for caregivers. Many reported that they are always 'on guard', 'watching and worrying' about their spouse. The person with PD often does not appreciate the safety concerns, and this lack of insight forces the caregiver to constantly be reminding and cueing his or her spouse as to how to safely perform tasks. Understandably, both the caregiver and the person with PD want to hold on to independence for as long as possible, and this constant focus on safety issues draws attention to the fading independence of the person with PD.

## Discussion

The themes revealed through this study are emergent and data driven. Data collection and the analytic process were utilized with the aims of generating a substantive understanding of caregiver burden, and developing a toolkit that can be used to assess and manage caregiver burden. Discussing repertory grid prompts led to clarification of their answers and further discussion of major concerns that caregivers had. Although initial estimates of the time required for data collection was 20 to 30 minutes per participant, most sessions lasted one or two hours. This may reflect a need of the caregiver to obtain emotional support. Additionally, many have limited opportunities to 'get out of the house' and therefore wanted to take full advantage of this opportunity to obtain a change-of-pace in their daily routines.

An unexpected difficulty arose while conducting the repertory grid interviews – the difficulty in eliciting constructs from the participants. As a result, one participant (age 49), completed the grid completely unassisted, while the other four (ages 63-71) used sample constructs provided by the researcher in order to assist them in describing their caregiving experience and the burden they face. This explains why many of the constructs used are similar between participants. A serendipitous benefit of this variation in expected methodology, however, is an improved comparability between participants, especially due to the homogeneity of the sex of the population. Future uses of this grid should take this difficulty into consideration, and provide sample constructs that participants can choose from in order to facilitate their completion of the grids.

The length of time spent caring for spouses with PD also affected the burden measured. The longer time spent caring for a spouse with PD, the more understanding they had of the burden placed on them, but they were also better able to handle the stresses of daily care. Caregivers in the beginning stages of care have more worry about future caregiving tasks and burden, while those caring for spouses starting the advanced stages of the disease experience the most burden. This is when the caregiver's role increases – their independence begins to decrease and the burden in placed on them is increasing. These stages affect the type of support caregivers need, and the different resources that should be made available to them. Attention to these different stages would be brought to light using the repertory grid method of assessing burden, and hence, more appropriate support could be provided to caregivers.

Additionally, another unexpected difficulty arose in the interviews - the 'selflessness' of the spouses. Spousal caregivers of individuals with Parkinson's disease become so attuned to discussing the condition and needs of their spouse that they are not accustomed to discussing their own needs and concerns. This required the researcher to constantly "re-focus" the caregiver on his or her own stresses. For example, spousal caregivers would report: "*the most physically challenging task for my husband is getting into bed*", instead of: "*the most physically challenging thing for me is getting my husband into bed.*" This unexpected methodology difficulty underscores the timeliness of considering the needs of the caregiver.

Selflessness also extends to the health and wellbeing of the caregiver. Most caregivers expressed fears of their own health as they age – but relayed these concerns in terms of their worry for the future care of their spouses. For example, spousal caregivers

were concerned that if they became ill, there would be no one to take care of their spouse. Caregivers had to consider, therefore, the eventual need for long term care facilities as a safe place for their spouse, in the event that they became unable to provide care. This was often a difficult planning step to take, as the individual with PD was typically reluctant to explore this possibility.

One major issue that not often addressed within the literature is the effect of decreased social networks – described by one caregiver as “*little deaths*”. This decrease in work-related, friend, and family social interactions is primarily due to the unpredictability of symptoms and medication regimens, as well as the general discomfort of the individual with PD. This decline in the availability of social outlets affects the ability of the caregiver and the person with PD to engage socially as a couple – which is critical insofar as it represents the main source of support for both. Additionally, this decrease in social networks also impacts on ability to follow through with retirement plans, and many couples have to change the plans they had for retirement, in order to accommodate the increasing symptoms and limitations associated with PD. This often weighs heavily on both the caregiver and the person with PD, increasing stress and creating tensions.

Additionally, the independence of the caregiver is further limited by the amount of assistance available to them in the home. Homecare, as previously mentioned, can be helpful to both the caregiver and the person with PD, providing the caregiver with some independence. If, however, the person with PD is not comfortable with the homecare provider, this may inadvertently add to caregiver’s burden. The discomfort of the person with PD is often a reflection of his or her difficulty in acknowledging his or her declining



independence. It is evident that more education is needed for homecare providers about the uniqueness and unpredictability of PD. This increased understanding would allow individuals with PD to become more comfortable with the homecare provider, who in turn would become better prepared to deal with the challenges associated with the disease. This improved relationship would then allow the spousal caregiver to become more comfortable engaging in independent activities, knowing that his or her spouse is comfortable and safe.

Although ADLs are often the focus of research, and serve as the mainstay of information that is geared towards caregivers, the major concern for most caregivers is the safety of the individual with PD, and this worry is the major contributor to spousal caregiver burden. The constant 'watching and worrying' consumes so much energy that it can exhaust the caregiver. Adding to this concern is the fact that the individual with PD often does not realize that he or she is not performing an ADL safely, given that lack of awareness of deficit is a common cognitive feature of the disease. The person with PD, therefore, often needs to be reminded, or "cued", as to how they can safely complete his or her daily tasks. This safety issue was aptly highlighted by one participant: "*when walking up the stairs sometimes he only puts the tips of his toes on the step, and thinks that since his toes are on the step, he is safe. It is the scariest thing, and I worry about his safety because he needs reminding about common things like that.*" Individuals with PD also require reminders when walking with a filled cup (particularly when it is filled with a hot liquid) or a plate filled with food.

This ongoing caregiver vigilance is a constant reminder to the spouse of his or her increasing loss of independence. Spousal caregivers are very cognizant that their actions

and reminders cause the person with PD to become increasingly aware of their decreasing independence. To spare the feelings of the individual with PD, caregivers often tiptoe around this issue until they are worrying as much about how to be considerate in their cueing, as they are about the spouse's safety.

The foregoing emphasizes the fact that most of the burden associated with caregiving is mental, not physical. While most of the research focuses on how to help the spouse perform ADLs, the results of the present study would suggest that more emphasis needs to be placed on how to deal with worry and mental stress. One caregiver noted: "*I would shovel a hundred driveways if I had to. It is a physical burden, but I'm more stressed about making big decisions on my own that we used to do together, like whether or not to sell the house. That is what is hard!*" This remains the largest gap between identifying and meeting caregiver burden.

At present, most scales for measuring burden are focused on what clinicians think is important to caregivers, instead of asking caregivers to identify their specific burdens. 'Burden' is a subjective concept – there is no one universal burden experienced by all spousal caregivers, especially considering the inter- and intra-individual variability of PD. What is needed is a 'toolkit', rather than an assessment tool. This toolkit would enable clinicians to determine the individual needs of caregivers that are not currently met by available resources. By eliciting specific information about an individual caregiver's burden (i.e., the skills that he or she thinks are important, the resources that are available and trusted, the stressors that exist, and the coping strategies that have been demonstrated to be effective), we are better able to develop ways to more accurately and efficiently manage their burden and meet their needs.

Similarly, the present study also suggests that the coping mechanisms used by caregivers may be ineffective. All of the caregivers interviewed for this study reported a variety of social outlets (i.e., going to the gym, walking groups, books), but also noted that these activities served more as a 'distraction' than a 'support.' This highlights the fact that the opportunity to share concerns in a safe and non-judgmental setting was among the most effective methods of reducing burden. The support available from fellow caregivers is immeasurable; especially other spousal caregivers of individuals with PD, as these individuals are particularly well-equipped to understand the unpredictability and variability associated with the disease. Support groups provide this companionship, the ability to speak freely to others who understand, but this is often insufficient. Many caregivers expressed the need to have someone to call from home that could help them deal with challenges – not only the physical challenges, but those that simply test their patience – as they arise. Healthcare professionals are, understandably, often busy dealing with other individuals, and so they are unable to lend support to spousal caregivers at all hours. In some circumstances, support group members and coordinators make themselves available to each other, and this provides an invaluable resource, as these individuals represent an understanding ear, and can offer a critical source of reassurance to the caregiver. More emphasis on the development of spousal caregiver support groups, as a means of sharing knowledge, resources, and support, should lead to a reduction in caregiver burden.

### Conclusion

Spousal caregivers play an important role in the care of individuals with PD. They provide selfless and constant care for their spouse, often at the expense of their own wellbeing. Healthcare practitioners should, therefore, include an assessment of spousal caregiver burden within the care plan for an individual with PD – and should consider possible methods for mitigating this burden. Repertory grid technique is a useful way of assessing unique burden profiles, and may inform methods for ameliorating a caregiver's situation as the care receiver's disease progresses.

Healthcare professionals must be provided with information concerning the dimensions of caregiver distress, including appropriate resources, coping mechanisms, skills, and support groups to recommend for caregivers. The simple act of asking how a caregiver is coping, and asking if they need any assistance, would give the caregiver a sense of value within the healthcare team. Ensuring that quality of life of the caregiver does not decrease should be of utmost importance, as they are the main provider of care for the patient. In essence, caregiver quality of life dictates the quality of life for the individual with PD. A creation of communication resources informed by medical and psychological theory would improve the support available to caregivers, and would help in meeting their need to manage care-related burden.

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Final Thoughts on the Use of Repertory Grid  
to Assess Spousal Caregiver Burden

*Burden*

There is increased pressure on family physicians and multidisciplinary health care teams (speech pathologists, occupational therapists, physical therapists, psychologists, etc.) to become more knowledgeable in the treatment and management of Parkinson's disease in order to positively impact patient care. This illustrates the need for increased dialogue regarding education and support. The multifaceted nature of Parkinson's disease lends itself to an individualized approach by a multidisciplinary health care team, in order to provide quality care and effective illness management. The most important member of the integrative health care team is the caregiver, making the accurate assessment and management of their burden important to the quality of care and quality of life of the individual they are caring for. Furthermore, given the expected growth of the population of older adults, community resources are becoming increasingly important.

Burden is a subjective interpretation of the extent to which the care giving experience impacts on the health, social life, and financial status of the caregiver (Zarit, Todd, & Zarit, 1986). There is not, however, a clear consensus on the definition of terms such as strain, burden, stress, distress, psychological well-being, depression, health, and cost of care; this makes it difficult to conceptualize and measure burden (Cousins, Davies, Turnbull, & Playfer, 2002). Nevertheless, any definition of burden must include physical, mental, and social components. *Physical burden* is dependent upon the severity of illness and the help needed; *mental burden* is typically dependent upon the caregiver's

relationship with the patient; and finally, caregivers face *social burden*, which is a result of intrapersonal conflicts and lack of support (Angermeyer, Bull, Bernert, Dietrich, & Kopf, 2006).

*Caregiver knowledge, skills, resources, and coping mechanisms*

Existing burden scales tend to focus on issues deemed important by clinicians and researchers, instead of issues identified by caregivers. Although there is no one universal burden experienced by all spousal caregivers, repertory grid methodology is useful for providing us with greater insight into caregiver experiences and stresses.

Caregivers are hungry for knowledge about PD – but want information on the unique and “special” aspects of the disease, rather than information about the “problems” of the illness. Caregivers emphasized the unpredictability and uniqueness of the disease, and noted that this makes it difficult to make plans, or have an active social life outside the home. This, in turn, contributes to their loss of independence; their life is permanently tied to that of their spouse, and is based on his or her mood.

Caregivers also commented on the inevitable changes in their retirement plans, and the gradual reduction in their social networks. This decrease in social networks was likened to “*little deaths*”: firstly, it becomes more difficult to maintain work relationships and future life plans; secondly, social interactions become more difficult; and finally, family and friend relationships become home-based and less frequent. This decrease in external social interactions can be harmful to the wellbeing of both the caregiver and the individual with PD, as these social interactions allow them to maintain some normalcy. Furthermore, visits from family and friends can provide some relief to the caregiver, as they provide him or her with an opportunity to temporarily surrender care of the

individual with PD. This reduced social contact seems to be an inevitable, albeit unfortunate part of the disease progression. Conceptualizing the gradual reduction of one's social network as a series of social "deaths" may encourage caregivers to grieve them individually, and eventually achieve acceptance.

Much of the current literature on caregiver burden focuses on improving strategies for completing activities of daily living (ADL), and the use of appropriate assistive devices, but from the caregiver's perspective, the most important issue in this regard, is safety. Safety is the most frightening and stressful facet of PD for caregivers, leading them to constantly watch over, and worry about their spouse. This is further exacerbated by the lack of insight that most individuals with PD demonstrate, into their own deficits in the activities of daily living. This forces the caregiver to constantly remind and cue his or her spouse as to how to tasks can be performed safely. Patient safety, therefore, is a key contributor to one of the most ubiquitous aspects of caregiver burden, mental worry. Caregivers were clear in indicating that mental burden overshadows more "practical" considerations, such as walking techniques, meal preparations, or transportation.

Caregivers also indicated that they develop a tendency to be overly sensitive to offending their spouses through their constant reminders (cueing) of their decreasing independence, and this leads caregivers to worry as much about how to be considerate in their cueing, as they are about the spouse's safety. This domain of burden illustrates the thoughtfulness and selflessness of the typical caregiver, which makes it difficult for caregivers to focus on their own needs. In fact, the only domain in which caregivers

consistently express concern for their own health and safety is from the perspective that it is necessary in order for them to provide care for their spouse.

*Repertory grid as a "toolkit" to assess unique burden profiles*

Kelly's repertory grid technique is a useful way to acquire information that reflects the subjective components of caregiver burden. Leaving the responsibility of item generation in the hands of the participant, repertory grid methodology still allows the researcher to quantitatively examine the relationship between the items, and within each individual. This technique thus provides an interesting bridge between qualitative and quantitative techniques: the researcher has the opportunity to elicit unbiased opinions, develop psychometrically robust "items" that achieve adequate saturation of the content domain, and avoid repetitive and irrelevant constructs. Of potentially greater importance, however, repertory grid may be useful in creating a "toolkit," that integrates an assessment of coping mechanisms with an assessment of burden experienced. The nature of the information provided by individual participants is such that the end result is the elicitation of specific resources or information that are used by the caregiver, thereby allowing the researcher to provide feedback to the caregiver as to resources of which he or she may be unaware.

The repertory grid framework suggests that personal constructs provide the individual with a frame of reference for understanding their experiences, both current and future; this enables the repertory grid method to create a measurement toolkit that is anticipatory and experiential, rather than responsive (Rawlinson, 1995). Using repertory grid to assess burden can help meet the increased need to identify community resources and social support that act as a "buffer" for caregivers. Also, the usefulness of repertory

grid may extend to healthcare professionals – namely clinicians, educators, and counselors – who can use this information to assess caregiver and patient needs, and direct them to appropriate support services. The toolkit created in this fashion may serve as a useful foundation for meeting our increased need to engage in good knowledge exchange among researchers, administrators, staff caregivers, and spousal caregivers. These features allow for an assessment of improvements within systems of care, provide opportunities to give useful and constructive feedback to staff, and facilitate resource allocation.

Repertory grid is a targeted approach to remedying situations in which caregiver burden is increased, or domains in which it is under-serviced. By assessing caregivers throughout the disease progression, we might be better able to accurately assess individualized burden dictated by caregiver personality and disease characteristics. Additionally, accurate assessment of burden enables effective management, as it facilitates targeting key areas. Through this approach, caregivers are given a voice, and their needs are heard. The act of simply “paying attention” to their needs tends to make caregivers feel more appreciated. This will require some resource allocation by healthcare professionals, as they will need to ensure that some treatment time is allocated for caregivers, and will need to collaborate in the creation of communication resources that are geared towards specific aspects of caregiver burden. By “caring for the caregiver”, however, they will help ensure that the needs of the individual with PD will be better met as well.

In sum, the variable nature of PD, combined with the individual differences extant among caregivers (and the caregiving experience), makes it difficult to create a

conventional questionnaire that is able to fully and accurately assess these needs. Furthermore, the limited ability of conventional questionnaires to foster open-ended feedback from the respondents makes them poorly suited as a means for initiating discussion between clinician and caregiver. Repertory grid analysis provides an assessment methodology that individualized, and yet standardized, and is an assessment tool that progresses organically from the initial assessment of needs, to the allocation of resources.

### *Looking forward*

The most intuitive and immediate application of these study results is in the creation of an assessment toolkit that may be easily employed within a clinical setting. Results of repertory grid analyses may suggest mechanisms for allotting time and resources to individualized spousal caregiving needs. Combined with a communications package that is customized for use by spouses of individuals with PD, and which contains a compilation of information about community resources and support services, the results of this study may be used to create a method for matching resources with individual caregiver needs (i.e., using elements provided within a repertory grid analysis). Periodic re-assessment, as the disease progresses and as symptoms change, ensures caregivers are able to cope with the increasing burden of care. Although this appears to involve considerably greater demand on healthcare professionals, it should be conceptualized as a "front-loading" of their professional assistance: improvements in the quality of care that result from these interventions will improve quality of care for the individual with PD, and may reduce healthcare demands later in the disease progression.

Beyond these immediate applications, repertory grids may be used to assess the burden of another underevaluated population – staff caregivers (personal support workers) in long-term care facilities. There is a dearth of research concerning the burden that is shouldered by staff members. Decreasing the burden of care among health care professionals may be effective in: (a) improving the care provided; (b) improving morale among health care professionals (thereby reducing absenteeism and illness); and (c) improving recruitment and retention for health care professions.

Additionally, there is a need for health care professional to direct more attention towards increasing the knowledge base of individuals with PD, as well as spouses and community caregivers. This need is particularly important in the areas of symptom management, specific interventions required for daily living, and medical administration and regulation. There is an increased need to identify community resources and social support to act as a mediator for this burden; overall, there is a need to recognize care for the caregiver! Furthermore, this implies that there is an increasing need for education program for caregivers, healthcare professionals and the general public: more education and awareness equals more understanding.

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Appendices

Appendix A  
Initial Ethics Approval



### Office of Research Ethics

The University of Western Ontario  
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### Use of Human Subjects - Ethics Approval Notice

**Principal Investigator:** Dr. A.M. Johnson

**Review Number:** 13361E

**Review Level:** Expedited

**Review Date:** May 25, 2007

**Protocol Title:** Creating a Standardized Free-Response Caregiver Burden Scale for Healthcare Professionals

**Department and Institution:** Faculty of Health Sciences, University of Western Ontario

**Sponsor:**

**Ethics Approval Date:** September 19, 2007

**Expiry Date:** December 31, 2007

**Documents Reviewed and Approved:** UWO Protocol, Letter of Information and Consent, Advertisement

**Documents Received for Information:**

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- all adverse and unexpected experiences or events that are both serious and unexpected;
- new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. John W. McDonald

#### Ethics Officer to Contact for Further Information

Jennifer McEwen (mcewen4@uwo.ca)  Denise Grafton (dgrafton@uwo.ca)  Grace Kelly (gkelly2@uwo.ca)

cc: ORE File

*This is an official document. Please retain the original in your files.*

**Appendix B**  
**Ethics Amendment Approval**



## Office of Research Ethics

The University of Western Ontario  
 Room 00045 Dental Sciences Building, London, ON, Canada N6A 5C1  
 Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca  
 Website: www.uwo.ca/research/ethics

## Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. A.M. Johnson

Review Number: 13361E

Revision Number: 2

Review Date: February 13, 2008

Review Level: Expedited

Protocol Title: Creating a Standardized Free-Response Caregiver Burden Scale

Department and Institution: Faculty of Health Sciences, University of Western Ontario

Sponsor:

Ethics Approval Date: February 12, 2008

Expiry Date: June 30, 2008

Documents Reviewed and Approved: Revised study instruments, participant recruitment, eligibility of subjects and administrative changes. Letter of Information and Consent. Repertory grid.

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. John W. McDonald

## Ethics Officer to Contact for Further Information

<input type="checkbox"/> Janice Sutherland (jsuther@uwo.ca)	<input type="checkbox"/> Jennifer McEwen (jmcewen4@uwo.ca)	<input checked="" type="checkbox"/> Grace Kelly (grace.kelly@uwo.ca)	<input type="checkbox"/> Denise Grafton (dgrafton@uwo.ca)
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This is an official document. Please retain the original in your files.

cc ORE File

Appendix C

Information Letter and Consent Form

## Appendix C

### Information Letter and Consent Form

#### Creating a Standardized Free-Response Caregiver Burden Scale

Lead study investigator: Dr. Andrew Johnson, PhD. Assistant Professor,

Bachelor of Health Sciences Program, The University of Western Ontario (519) 661-2111 x82215

Co-collaborator: Kaitlyn Roland, MSc. (candidate), Health and Rehabilitation Sciences,

You are being invited to participate in a research study looking at caregiver burden. The purpose of this letter is to provide you with information required to make an informed decision about participating in this research.

#### **Purpose of this study:**

This research is being done to complete the test construction of a 'standardized free-response caregiver burden scale' to measure caregiver burden. This study interested in how Parkinson's spousal caregivers caring for their spouse at home view burden and how it affects the quality of their care and, more importantly, the quality of life for both the patient and the caregiver.

#### **Procedure for this study:**

- Data collection will consist of completion of 3 repertory grid tables in the presence of a researcher. Using the repertory grid methods, participants are asked to describe burden-related tasks following prompts and then rate these tasks based on descriptors provided by the participant themselves. This will require approximately thirty (30) minutes of the participants' time and will take place at a location the participant chooses.
- This study will involve a total of 5-10 participants who are spousal caregivers that care for spouses with Parkinson's disease at home in London and the surrounding areas.

#### **Risks and discomforts of participation:**

The risks associated with the proposed research are very minimal. By thoroughly examining care-related stressors, the participants may notice these more on a daily basis, which may lead to the increase in stress-related to these aspects of their caregiving. As well, participants need to take time out of their schedules in order to complete a questionnaire. This may increase the workload on other parts of their day, and potentially be stressful.

#### **Associated benefits of participation:**

As a result of thoroughly examining care-related stressors and accompanying resources, participants will benefit by being more likely to act to decrease any burdens and make more use out of the available resources in order to ease the workload. It will help introduce more stress-related coping strategies to combat care-related stressors. To the society at large, this research will help identify areas of concern in a population that is often ignored. By identifying

their burdens and concerns of spousal caregivers, we will better meet their needs so that they are able to provided better quality of care, and hence better quality of life for both themselves and the patients. As well, Parkinson's disease is an often complication and misunderstood disease; by identifying areas of caregiver burden, we are able to more accurately meet the caregiver's needs for education and resources to ease the workload and burden.

**What to do if you want to withdraw from this study:**

Participation in this study is voluntary. You have the right to refuse to participate, refuse to answer any questions or withdrawal from the study at any time with no effect on your future (care/academic status/employment, etc.).

**Privacy and confidentiality:**

Your confidentiality will be respected. No information that discloses your identity will be released or published without your explicit consent to the disclosure.

*Note:* Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

**Voluntary participation and other pertinent information:**

You have been given all important information regarding your participation in this study. You should only agree to participate if you feel happy that you know enough about these things. If you are participating in another study at this time, please inform the lead study investigator to determine if your participation in this study is appropriate.

If you have any questions about your rights as a research participant or the conduct of the study you may contact Director of the Office of Research Ethics (519) 661-3036, email [ethics@uwo.ca](mailto:ethics@uwo.ca).

Please read and sign one copy of this letter if you agree to participate in this study and return it to the research, while the other copy is to be kept for your personal records.

**I have read the Letter of Information, (have had the nature of the study explained to me) and I agree to participate. All questions have been answered to my satisfaction.**

*Note: You do not wave any legal rights by signing the consent form.*

**Print Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Informed Consent obtained by:** \_\_\_\_\_



Appendix D

Sample Repertory Grid (Healthcare Workers)

## Appendix D

## Sample Repertory Grid (Healthcare Workers)

Repertory Grid Assignment "*burden in healthcare workers*"

1. Please read the following questions and answer them as honestly as possible.
2. Please write the answers in the corresponding box along the top of the page under the heading ELEMENTS.
3. Rate the elements fit to the constructs according the scale provided.
  - A. Describe a task at work that is time consuming.
  - B. Describe a task at work that is physically challenging.
  - C. Describe a task at work that is mentally challenging.
  - D. Describe a task at work that you feel could be done more efficiently.
  - E. Describe a task at work that you rely on help/additional resources to complete.
  - F. Describe a task you feel confident completing.
  - G. Describe a skill that you know to help you complete your daily job tasks.
  - H. Describe a skill that you would like to learn in order to help you complete your daily job tasks.
  
  - I. Describe one personal resource you have available for support.
  - J. Describe one literary resource that you have available for support.
  - K. Describe one resource that you would like to be made available.
  - L. Describe one on-site resource provided to you by your work.
  - M. Describe an available optional off-site resource you found out about at work.
  
  - N. Describe one example of where your work has your best interests at heart.
  - O. Describe one example of where your work has the patients' best interests at heart.
  - P. Describe one stressor that results from your job.
  - Q. Describe one stressor that would not exist with the help of additional resources.
  - R. Describe one mechanism you use for coping with work-related stress while at work.
  - S. Describe one mechanism you use for coping with work-related stress at home.
  - T. Describe one resource provided to you by your work in order to help you effectively deal with work-related stress.

**ELEMENTS**

**CONSTRUCTS**

	A.	B.	C.	D.	E.	F.	G.	H.	I.	J.	K.	L.	M.	N.	O.	P.	Q.	R.	S.	T.
Difficult 1 2 3 4 5 6 7 Easy																				
Skilled 1 2 3 4 5 6 7 No skill																				
Slow 1 2 3 4 5 6 7 Fast																				
Passive 1 2 3 4 5 6 7 Active																				
Stressful 1 2 3 4 5 6 7 Un-stressful																				
Pleasant 1 2 3 4 5 6 7 Unpleasant																				
Independent 1 2 3 4 5 6 7 Dependent																				
Structured 1 2 3 4 5 6 7 Unstructured																				
Required 1 2 3 4 5 6 7 Optional																				
Supportive 1 2 3 4 5 6 7 Unsupportive																				
Available 1 2 3 4 5 6 7 Unavailable																				
Effective 1 2 3 4 5 6 7 Ineffective																				
Onetime 1 2 3 4 5 6 7 Recurring																				
Possible 1 2 3 4 5 6 7 Impossible																				
Individual 1 2 3 4 5 6 7 Teamwork																				
Patient-focus 1 2 3 4 5 6 7 Productivity																				
Useful 1 2 3 4 5 6 7 Useless																				
Efficient 1 2 3 4 5 6 7 Inefficient																				
Costly 1 2 3 4 5 6 7 Inexpensive																				

Spousal Caregiver Burden

Appendix E

Distance Dimensions (Healthcare Professionals)

## Appendix E

## Distance Dimensions (Matrix Dimensions): Knowledge

Table E1

*Participant A: Element / Element (Upper triangle standardized)*

	medical adminis- tration	reporting	administering IV meds	shift work	charting	organization	transfer/ lifting patients	drawing blood for lab work
medical administration	0	0.45	0.60	0.74	0.74	0.74	0.75	0.92
reporting	2.38	0	0.76	0.65	0.61	0.83	0.49	0.93
administering IV meds	3.15	4.03	0	0.91	0.60	0.53	0.95	0.75
shift work	3.89	3.44	4.81	0	0.89	0.72	0.61	0.87
charting	3.91	3.23	3.14	4.72	0	0.72	0.69	0.84
organization	3.91	4.36	2.79	3.82	3.77	0	0.86	0.44
transfer/lifting patients	3.96	2.58	5.00	3.24	3.63	4.55	0	1.00
drawing blood for lab work	4.83	4.91	3.96	4.59	4.43	2.32	5.28	0

Table E2

Participant A: Construct / Construct (Upper triangle standardized)

	Difficult	Easy	Skill	No skill	Slow	Fast	Stressful	Unstressful	Pleasant	Unpleasant	Effective	Ineffective	Recurring	Onetime	Teamwork	Individual	Patient focus	Productivity	Useful	Useless
Difficult	0	0.66	0.67	0.23	0.43	0.43	0.26	0.57	0.33	0.42	0.28	0.71	0.43	0.62	0.68	0.51	0.56	0.57	0.42	0.69
Easy	3.67	0	0.23	0.67	0.43	0.43	0.57	0.26	0.42	0.33	0.71	0.28	0.62	0.43	0.51	0.68	0.57	0.56	0.69	0.42
Skill	3.71	1.28	0	0.76	0.37	0.54	0.57	0.36	0.40	0.44	0.60	0.40	0.59	0.53	0.46	0.76	0.57	0.61	0.69	0.49
No skill	1.28	3.71	4.0	0	0.54	0.37	0.57	0.44	0.40	0.40	0.40	0.70	0.53	0.59	0.76	0.46	0.61	0.57	0.49	0.69
Slow	2.33	2.38	2.05	3.00	0	0.54	0.31	0.47	0.27	0.38	0.37	0.60	0.40	0.57	0.48	0.64	0.48	0.57	0.36	0.68
Fast	2.38	2.33	2.00	2.05	2.99	0	0.47	0.31	0.27	0.38	0.60	0.37	0.40	0.57	0.48	0.64	0.48	0.57	0.68	0.36
Stressful	1.43	1.14	3.16	1.98	1.73	2.59	0	0.58	0.26	0.41	0.34	0.65	0.36	0.69	0.50	0.65	0.57	0.51	0.39	0.68
Unstressful	3.14	3.43	1.16	3.98	2.73	1.59	3.0	0	0.41	0.26	0.34	0.65	0.36	0.69	0.50	0.65	0.57	0.51	0.39	0.68
Pleasant	1.83	2.33	2.22	2.43	1.47	2.10	1.43	2.29	0	0.37	0.40	0.52	0.38	0.52	0.53	0.54	0.54	0.43	0.46	0.54
Unpleasant	2.83	2.33	2.22	2.43	1.47	2.10	1.43	2.29	0	0.37	0.40	0.52	0.38	0.52	0.53	0.54	0.54	0.43	0.46	0.54
Effective	1.56	3.90	3.86	2.19	2.07	3.34	1.86	3.57	2.18	2.88	0	0.85	0.37	0.75	0.73	0.57	0.56	0.68	0.19	0.87
Ineffective	3.56	3.90	3.86	2.19	2.07	3.34	1.86	3.57	2.18	2.88	0	0.85	0.37	0.75	0.73	0.57	0.56	0.68	0.19	0.87
Recurring	2.36	3.41	3.25	2.94	2.22	3.17	2.00	4.42	2.11	2.85	2.04	4.16	0	0.83	0.55	0.74	0.50	0.71	0.40	0.79
Onetime	3.41	3.36	3.25	2.94	2.22	3.17	2.00	4.42	2.11	2.85	2.04	4.16	0	0.83	0.55	0.74	0.50	0.71	0.40	0.79
Teamwork	3.76	3.2	2.56	4.18	2.68	3.55	2.76	5.93	2.93	2.96	0.04	1.15	2.20	0.08	0	0.00	0.63	0.72	0.72	0.65
Individual	2.81	3.76	4.18	2.56	3.55	2.68	3.76	5.93	2.93	2.96	0.04	1.15	2.20	0.08	0	0	0.63	0.72	0.72	0.65
Patient focus	3.81	3.76	4.18	2.56	3.55	2.68	3.76	5.93	2.93	2.96	0.04	1.15	2.20	0.08	0	0	0.63	0.72	0.72	0.65
Productivity	3.10	3.12	3.17	3.37	3.67	3.16	3.17	3.80	3.01	3.38	0.07	0.77	0.75	0.95	0.46	0.00	0	0.91	0.52	0.76
Useful	2.12	3.10	3.37	3.17	3.67	3.16	3.17	3.80	3.01	3.38	0.07	0.77	0.75	0.95	0.46	0.00	0	0.91	0.52	0.76
Useless	3.32	3.83	4.84	3.71	4.84	3.74	3.73	5.99	2.55	2.99	0.06	0.82	0.36	0.19	0.57	0.99	0.21	0.88	0.17	0

Table E3

*Participant B: Element / Element (Upper triangle standardized)*

	ventilator rounds	memorizing meds	arterial line certified	changing ventilator circuit	changing ETT tapes	chest compressions	Asking For help	oxygen saturation checks
ventilator rounds	0	0.43	0.57	0.60	0.65	0.65	0.68	0.98
memorizing meds	2.50	0	0.35	0.50	0.51	0.38	0.59	0.85
Arterial line certified	3.32	2.04	0	0.63	0.62	0.53	0.66	1.00
changing ventilator circuit	3.48	2.90	3.66	0	0.18	0.42	0.44	0.87
changing ETT tapes	3.78	2.98	3.61	1.06	0	0.51	0.46	0.89
chest compressions	3.78	2.21	3.09	2.43	2.94	0	0.54	0.88
asking for help	3.96	3.39	3.84	2.55	2.67	3.14	0	0.70
oxygen saturation checks	5.66	4.90	5.80	5.04	5.16	5.12	4.06	0

Table E4

Participant B: Construct / Construct (Upper triangle standardized).

	difficult	easy	skilled	no skill	slow	fast	unstress	stressful	pleasant	unpleasant	effective	ineffective	recurring	onetime	individual	teamwork	patient	productiv	useful	useless
Difficult	0	0.71	0.68	0.28	0.54	0.37	0.56	0.29	0.44	0.50	0.69	0.33	0.69	0.52	0.47	0.58	0.60	0.56	0.69	0.39
Easy	4.00	0	0.28	0.68	0.37	0.54	0.29	0.56	0.44	0.50	0.69	0.33	0.69	0.52	0.47	0.58	0.60	0.56	0.69	0.39
Skill ed	3.85	1.59	0	0.77	0.31	0.61	0.30	0.58	0.47	0.52	0.78	0.37	0.81	0.37	0.60	0.49	0.60	0.41	0.74	0.17
No skill	1.59	3.86	4.33	0	0.61	0.31	0.58	0.30	0.52	0.47	0.78	0.37	0.81	0.37	0.60	0.49	0.60	0.41	0.74	0.17
Slow	3.03	2.09	1.74	3.44	0	0.59	0.35	0.43	0.48	0.38	0.60	0.38	0.52	0.63	0.43	0.54	0.53	0.56	0.41	0.61
Fast	2.09	3.03	3.44	1.74	3.32	0	0.43	0.35	0.38	0.48	0.60	0.38	0.52	0.63	0.43	0.54	0.53	0.56	0.41	0.61
Un stress	3.14	1.63	1.71	3.31	1.99	2.46	0	0.53	0.32	0.48	0.60	0.38	0.50	0.63	0.37	0.55	0.52	0.54	0.37	0.62
Stress ful	1.14	3.63	3.71	1.13	2.99	1.46	2.0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Stress ful	1.63	1.14	3.31	1.71	2.46	1.99	2.0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Pleasant	2.51	2.84	2.67	2.93	2.70	1.14	1.82	2.74	0	0.63	0.46	0.56	0.43	0.72	0.48	0.52	0.44	0.65	0.45	0.61
Unpleas	2.84	2.51	2.93	2.67	2.70	1.14	1.82	2.74	0	0.63	0.46	0.56	0.43	0.72	0.48	0.52	0.44	0.65	0.45	0.61
Effect ant	3.90	1.87	0.69	4.42	2.15	3.39	1.89	4.40	2.62	3.18	0	0.82	0.36	0.84	0.52	0.61	0.38	0.78	0.09	0.84
Effective	1.90	3.87	0.69	4.42	2.15	3.39	1.89	4.40	2.62	3.18	0	0.82	0.36	0.84	0.52	0.61	0.38	0.78	0.09	0.84
In effect	1.87	1.90	4.42	0.69	3.39	1.15	4.0	1.89	1.18	2.62	1.13	0	0.84	0.36	0.61	0.52	0.78	0.38	0.84	0.09
Ive effect	3.90	2.87	2.07	4.59	2.96	3.57	2.80	3.56	2.44	2.03	4.75	0	1.00	0.61	0.65	0.22	0.93	0.30	0.89	0.89
Re-curing	3.90	2.87	2.07	4.59	2.96	3.57	2.80	3.56	2.44	2.03	4.75	0	1.00	0.61	0.65	0.22	0.93	0.30	0.89	0.89
ring	2.97	3.90	4.59	2.07	3.57	2.96	2.80	3.56	2.44	2.03	4.75	0	1.00	0.61	0.65	0.22	0.93	0.30	0.89	0.89
One time	2.97	3.90	4.59	2.07	3.57	2.96	2.80	3.56	2.44	2.03	4.75	0	1.00	0.61	0.65	0.22	0.93	0.30	0.89	0.89
Indiv idual	2.64	3.29	2.78	3.38	2.46	3.04	2.12	3.74	2.93	2.95	4.42	3.48	0	0.67	0.78	0.55	0.65	0.55	0.62	0.62
Team work	3.29	2.64	3.38	2.78	2.46	3.04	2.12	3.74	2.93	2.95	4.42	3.48	0	0.67	0.78	0.55	0.65	0.55	0.62	0.62
Patie nt	3.38	3.16	3.33	2.16	2.99	1.15	2.92	0.05	2.48	3.68	1.15	4.40	1.22	1.28	1.11	0.67	0	0.91	0.35	0.82
focus	3.16	3.38	3.33	2.16	2.99	1.15	2.92	0.05	2.48	3.68	1.15	4.40	1.22	1.28	1.11	0.67	0	0.91	0.35	0.82
Produc tiv	3.16	3.38	3.33	2.16	2.99	1.15	2.92	0.05	2.48	3.68	1.15	4.40	1.22	1.28	1.11	0.67	0	0.91	0.35	0.82
Use ful	3.90	2.23	0.96	4.54	3.32	5.0	2.12	4.49	3.53	4.47	5.3	0.75	1.70	0.03	1.11	0.50	0.97	0.65	0	0.87
Use less	2.23	3.90	0.96	4.54	3.32	5.0	2.12	4.49	3.53	4.47	5.3	0.75	1.70	0.03	1.11	0.50	0.97	0.65	0	0.87



## Distance Dimensions (Matrix Dimensions): Resources

Table E5

*Participant A: Element / Element (Upper triangle standardized)*

	Computerized charting	Pharmacy	College of nurses	Charge nurse	Clinical practice text
Computerized charting	0	0.85	0.91	0.99	1.00
Pharmacy	4.86	0	0.48	0.68	0.46
College of nurses	5.25	2.74	0	0.43	0.25
Charge nurse	5.68	3.88	2.47	0	0.50
Clinical practice text	5.75	2.65	1.44	2.86	0

Table E6

Participant A: Construct / Construct (Upper triangle standardized)

	Easy	Difficult	No skill	Skilled	Fast	Slow	Active	Passive	Unstressful	Stressful	Pleasant	Unpleasant	Independent	Dependent	Optional	Required	Supportive	Unsupportive	Unavailable	Available
Easy	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Difficult	51	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
No skill	41	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Skilled	63	41	63	41	37	41	37	41	30	45	59	27	62	19	46	34	46	48	63	19
Fast	41	37	41	37	41	30	45	59	27	62	19	46	34	46	34	63	48	62	19	55
Slow	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Active	45	30	42	65	48	70	48	70	48	70	37	77	55	58	09	96	37	77	28	87
Passive	30	45	59	27	62	19	46	34	46	34	63	48	62	19	55	48	0	0	0	0
Unstressful	27	62	19	46	34	46	34	63	48	62	19	55	48	0	0	0	0	0	0	0
Stressful	59	27	62	19	46	34	46	34	63	48	62	19	55	48	0	0	0	0	0	0
Pleasant	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Unpleasant	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Independent	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Dependent	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Optional	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Required	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Supportive	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Unsupportive	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Unavailable	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Available	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Difficult	26	0	63	41	37	41	30	45	59	27	62	19	46	34	63	48	62	19	55	48
No skill	84	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Skilled	81	84	18	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Fast	84	66	33	25	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Slow	66	84	25	33	68	0	54	22	51	47	52	45	52	51	34	28	78	45	52	32
Active	00	33	89	89	00	41	0	57	54	41	54	40	42	43	41	70	54	40	40	27
Passive	33	00	89	89	41	00	53	0	41	54	40	54	43	42	70	41	40	54	70	27
Unstressful	22	63	15	15	08	63	39	82	76	25	73	73	57	41	54	70	38	67	59	59
Stressful	63	22	15	15	26	08	82	39	42	0	73	25	41	57	70	54	67	38	59	59
Pleasant	85	79	64	46	03	32	43	79	11	24	0	0	47	52	45	77	19	75	52	66
Unpleasant	79	85	46	64	32	03	79	43	24	11	44	0	52	47	77	45	75	19	66	52
Independent	52	06	46	59	29	54	86	94	54	84	12	33	0	63	59	59	43	56	45	63
Dependent	06	52	59	46	54	29	94	86	84	54	33	12	83	0	59	59	56	43	63	45
Optional	16	81	40	32	27	46	84	13	43	15	99	46	65	65	00	45	45	77	27	91
Required	81	16	31	40	46	27	13	84	15	43	46	3	65	65	47	0	0	0	0	0
Supportive	85	79	64	46	03	32	43	79	71	97	85	34	94	48	99	46	0	0	0	0
Unsupportive	79	85	46	64	32	03	79	43	71	97	34	85	48	94	46	99	44	0	0	0
Unavailable	44	16	27	90	44	10	13	22	62	65	32	93	03	82	20	08	32	93	0	90
Available	2	2	3	1	3	1	3	1	2	2	2	2	2	2	1	1	2	2	4	0

Table E7

*Participant B: Element / Element (Upper triangle standardized)*

	Self blood gas analysis	Medical sites online	Medical library	My clinical coordinator	Text books from school
Self blood gas analysis	0	0.51	0.58	0.79	0.92
Medical sites online	2.95	0	0.53	0.84	1.00
Medical library	3.36	3.07	0	0.72	0.64
My clinical coordinator	4.59	4.88	4.20	0	0.68
Text books from school	5.36	5.82	3.71	3.94	0

Table E8

Participant B: Construct / Construct (Upper triangle standardized)

	Easy	Difficult	No skill	Skilled	Fast	Slow	Active	Passive	Stressful	Unstressful	Pleasant	Unpleasant	Independent	Dependent	Structured	Unstructured	Optional	Required	Supportive	Unsupportive
Easy	0	0.66	0.36	0.52	0.30	0.60	0.47	0.49	0.38	0.52	0.19	0.69	0.47	0.63	0.41	0.59	0.55	0.65	0.51	0.40
Difficult	2.97	0	0.52	0.36	0.60	0.30	0.49	0.47	0.52	0.38	0.68	0.19	0.63	0.47	0.59	0.41	0.65	0.55	0.40	0.51
No skill	1.61	2.34	0	0.61	0.16	0.63	0.28	0.59	0.28	0.55	0.36	0.59	0.56	0.52	0.51	0.47	0.32	0.76	0.32	0.53
Skilled	2.34	1.61	2.0	0	0.63	0.16	0.28	0.59	0.28	0.55	0.36	0.59	0.56	0.52	0.51	0.47	0.32	0.76	0.32	0.53
Fast	1.36	2.70	0.72	0.81	2.0	0.69	0.28	0.63	0.40	0.52	0.25	0.68	0.52	0.61	0.46	0.56	0.33	0.79	0.45	0.48
Slow	2.70	1.36	2.81	0.72	0.3	0	0.28	0.63	0.40	0.52	0.25	0.68	0.52	0.61	0.46	0.56	0.33	0.79	0.45	0.48
Active	2.10	2.17	2.25	2.62	2.23	2.81	2.0	0.69	0.49	0.45	0.47	0.55	0.41	0.69	0.37	0.63	0.33	0.79	0.48	0.45
Passive	2.17	2.10	2.25	2.1	2.81	2.23	3.07	0	0.45	0.49	0.47	0.55	0.41	0.69	0.37	0.63	0.33	0.79	0.48	0.45
Stressful	1.71	2.34	2.27	2.47	2.80	2.34	2.18	2.99	0	0.63	0.47	0.51	0.63	0.45	0.58	0.32	0.52	0.66	0.21	0.60
Unstressful	2.34	1.71	2.47	2.1	2.80	2.1	2.99	2.2	0	0.63	0.47	0.51	0.63	0.45	0.58	0.32	0.52	0.66	0.21	0.60
Pleasant	0.85	0.06	0.59	0.62	1.10	0.03	0.08	0.47	0.11	0.29	0	0.75	0.54	0.62	0.47	0.59	0.50	0.73	0.55	0.43
Unpleasant	3.06	3.85	3.62	3.59	3.03	3.10	3.47	3.08	3.29	3.11	3.37	0	0.62	0.54	0.59	0.47	0.73	0.50	0.43	0.55
Independent	2.09	2.84	2.51	2.32	2.71	2.82	2.07	2.81	2.02	2.43	2.79	2	0	0.89	0.08	0.83	0.57	0.76	0.67	0.39
Dependent	2.84	2.09	2.32	2.51	2.71	2.82	2.07	2.81	2.02	2.43	2.79	2	0	0.89	0.08	0.83	0.57	0.76	0.67	0.39
Structured	1.81	2.64	2.27	2.09	2.66	2.51	2.65	2.80	2.76	2.12	2.65	2.35	3.35	3.70	0	0.76	0.54	0.70	0.62	0.32
Unstructured	2.81	1.64	2.27	2.09	2.66	2.51	2.65	2.80	2.76	2.12	2.65	2.35	3.35	3.70	0	0.76	0.54	0.70	0.62	0.32
Optional	2.45	2.90	2.43	2.41	2.47	2.54	2.47	2.54	2.32	2.93	2.25	2.26	2.57	2.38	2.43	2.15	0	0.00	0.48	0.69
Required	2.90	2.45	2.41	2.43	2.54	2.47	2.54	2.47	2.32	2.93	2.25	2.26	2.57	2.38	2.43	2.15	0	0	0.69	0.48
Supportive	2.29	2.78	2.41	2.38	2.03	2.15	2.03	2.15	2.03	2.94	2.67	2.46	2.91	2.72	2.79	2.43	2.15	2.07	0	0.63
Unsupportive	1.78	2.29	2.38	2.41	2.15	2.03	2.15	2.03	2.03	2.94	2.67	2.46	2.91	2.72	2.79	2.43	2.15	2.07	2.83	0

## Distance Dimensions (Matrix Dimensions): Stress and Coping Strategies

Table E9

*Participant A: Element / Element (Upper triangle standardized)*

	Safe/ protected workplace	Debriefing with a counselor	Discharging patient home	Talk with coworkers	Physical activity	Code team	Not enough nurses
Safe/protected workplace	0	0.36	0.45	0.47	0.49	0.56	1.00
Debriefing with a counselor	2.48	0	0.47	0.48	0.55	0.42	0.95
Discharging patient home	3.11	3.23	0	0.22	0.63	0.44	0.94
Talk with coworkers	3.24	3.30	1.50	0	0.59	0.55	0.90
Physical activity	3.36	3.82	4.35	4.08	0	0.70	1.00
Code team	3.86	2.90	3.03	3.81	4.79	0	0.85
Not enough nurses	6.88	6.53	6.48	6.18	6.86	5.84	0

Table E10

Participant A: Construct / Construct (Upper triangle standardized)

	Costly	Inexpensive	Efficient	Inefficient	Useful	Useless	Teamwork	Individual	Possible	Impossible	Recurring	Onetime	Effective	Ineffective	Available	Unavailable	Supportive	Unsupportiv	Easy	Difficult
Costly	0	0.79	0.54	0.68	0.58	0.67	0.63	0.65	0.58	0.67	0.52	0.68	0.58	0.67	0.52	0.64	0.55	0.60	0.60	0.44
In	4.18	0	0.68	0.54	0.67	0.58	0.65	0.63	0.67	0.58	0.68	0.52	0.67	0.58	0.64	0.52	0.60	0.55	0.60	0.44
Expen- sive	2.85	3.59	0	0.94	0.12	0.95	0.55	0.80	0.12	0.95	0.41	0.83	0.12	0.95	0.44	0.79	0.23	0.86	0.54	0.63
Effi- cient	85	59	0	94	12	95	55	80	12	95	41	83	12	95	44	79	23	86	54	63
Ineffi- cient	3.59	2.85	4.97	0	0.12	0.80	0.55	0.55	0.12	0.83	0.41	0.41	0.12	0.79	0.44	0.86	0.23	0.86	0.54	0.63
Useful	09	53	3.63	02	5.0	97	51	85	00	97	36	87	00	97	46	80	25	87	55	65
Useless	3.53	3.09	5.02	63	15	0	85	51	00	0	87	36	97	00	80	46	87	25	65	55
Team	3.31	3.43	2.89	2.24	2.69	4.48	0	1.00	0.51	0.85	0.40	0.87	0.51	0.85	0.70	0.62	0.39	0.83	0.69	0.52
Indiv- idual	43	31	3.24	4.89	4.47	2.69	5.29	0	85	51	88	40	85	51	62	71	83	40	52	69
Possible	3.09	3.53	5.63	02	5.00	15	69	4.48	0	97	36	87	00	97	46	80	25	87	55	65
Im	3.53	3.09	5.63	0.0	5.00	15	4.48	2.5	0	0	87	36	97	00	80	46	87	25	65	55
possible	53	09	02	63	15	00	48	69	15	0	87	36	97	00	80	46	87	25	65	55
Recur- ring	2.74	3.58	2.18	4.38	1.91	4.61	2.10	4.60	1.61	4.82	0	91	36	87	58	67	44	75	57	58
One- time	3.58	2.74	4.38	2.18	1.91	4.61	2.10	2.61	1.61	4.82	0	91	36	87	58	67	44	75	57	58
Effect- ive	3.09	3.53	5.63	02	5.00	15	69	4.48	0	97	36	87	00	97	46	80	25	87	55	65
In	3.53	3.09	5.63	0.0	5.00	15	4.48	2.5	0	0	87	36	97	00	80	46	87	25	65	55
Effect- ive	53	09	02	63	15	00	48	69	15	00	61	91	15	0	80	46	87	25	65	55
Availa- ble	2.76	3.39	2.33	4.16	2.42	4.22	3.72	3.26	2.42	4.22	3.07	3.55	2.42	4.22	0	86	50	69	38	69
Un	3.39	2.76	4.33	2.16	2.42	2.26	3.72	3.26	2.42	2.22	3.07	3.55	2.42	2.22	4.0	0	0	0	0	0
Availa- ble	39	76	16	33	22	42	26	72	22	42	55	07	22	42	56		69	50	69	38
Support ive	2.91	3.15	1.22	4.53	1.34	4.60	2.41	4.34	1.60	4.33	2.98	3.34	1.60	4.33	2.63	3.63	0	83	54	55
Unsupp ortive	3.15	2.91	4.53	1.22	1.34	4.60	2.41	2.60	1.60	4.33	2.98	3.34	1.60	4.33	2.63	3.63	4.40	0	55	54
Easy	3.18	2.33	2.84	3.33	2.89	4.42	2.76	2.89	3.42	2.01	3.06	3.89	2.42	01	63	83	91	2.0	70	0
Diffi- cult	2.33	3.18	3.84	3.33	2.89	4.42	2.76	2.89	3.42	2.01	3.06	3.89	2.42	01	63	83	91	2.0	70	0

Table E11

*Participant B: Element / Element (Upper triangle standardized)*

	Compassionate care	Debriefing by counselors	Dealing with families	Some time out just for me to relax	Transferring patients	Blood test after secretion contact	Talking to employees
Compassionate care	0	0.54	0.54	0.55	0.59	0.84	0.92
Debriefing by counselors	2.56	0	0.60	0.71	0.54	0.52	0.93
Dealing with families	2.58	2.84	0	0.77	0.23	0.85	0.94
Some time out just for me to relax	2.64	3.41	3.67	0	0.76	0.70	0.87
Transferring patients	2.83	2.59	1.10	3.63	0	0.78	0.87
Blood test after secretion contact	3.99	2.48	4.08	3.35	3.70	0	1.00
Talking to employees	4.40	4.42	4.48	4.13	4.16	4.78	0

Table E12

Participant B: Construct / Construct (Upper triangle standardized)

	Inexpensive	Costly	Efficient	Inefficient	Useful	Useless	Individual	Teamwork	Possible	Impossible	Recurring	Onetime	Effective	Ineffective	Available	Unavailable	Supportive	Unsupportive	Difficult	Easy	
Inexpensive	0	0.95	0.53	0.73	0.60	0.77	0.61	0.66	0.62	0.72	0.40	0.89	0.61	0.76	0.55	0.80	0.55	0.78	0.51	0.74	
Costly	4.38	0	0.73	0.53	0.77	0.60	0.66	0.61	0.72	0.62	0.89	0.40	0.76	0.61	0.80	0.55	0.78	0.55	0.74	0.51	
Efficient	2.43	3.35	0	0.84	0.12	0.92	0.58	0.61	0.17	0.88	0.28	0.88	0.12	0.92	0.17	0.90	0.17	0.88	0.17	0.50	
Inefficient	3.35	2.43	3.35	0	0.12	0.92	0.58	0.61	0.17	0.88	0.28	0.88	0.12	0.92	0.17	0.90	0.17	0.88	0.17	0.50	
Useful	2.76	3.55	0.53	2.23	0	1.00	0.63	0.68	0.11	0.97	0.31	0.95	0.06	0.00	0.14	0.98	0.15	0.97	0.56	0.73	
Useless	3.55	2.76	2.43	2.23	4.0	0	0.63	0.68	0.11	0.97	0.31	0.95	0.06	0.00	0.14	0.98	0.15	0.97	0.56	0.73	
Individual	2.81	3.03	2.67	2.81	2.91	3.12	0	0.84	0.59	0.68	0.64	0.67	0.66	0.65	0.65	0.65	0.65	0.65	0.62	0.70	0.47
Teamwork	3.03	2.81	2.2.2.	2.2.2.	2.3.2.	2.2.2.	3.0	0.84	0.59	0.68	0.64	0.67	0.66	0.65	0.65	0.65	0.65	0.65	0.62	0.70	0.47
Possible	2.85	3.34	3.78	0.07	4.49	4.48	2.74	12	0	95	35	91	14	97	19	95	18	94	54	51	0.69
Impossible	3.34	2.85	0.07	4.49	4.48	4.48	2.74	4.40	0	0.95	0.35	0.91	0.14	0.97	0.19	0.95	0.18	0.94	0.54	0.51	0.69
Recurring	1.84	4.10	1.31	4.06	1.41	4.39	2.07	1.60	4.21	0	1.00	0.31	0.95	0.29	0.95	0.29	0.95	0.29	0.93	0.51	0.77
Onetime	4.10	1.84	4.06	1.31	4.41	4.39	2.07	1.60	4.21	0	1.00	0.31	0.95	0.29	0.95	0.29	0.95	0.29	0.93	0.51	0.77
Effective	2.81	3.3.3.	0.53	2.23	0.28	0.60	0.04	0.99	0.63	0.46	0.41	0.39	0	0.00	0.14	0.98	0.14	0.97	0.54	0.75	0.0.0.
Ineffective	3.3.3.	2.81	2.4.4.	2.23	4.28	4.60	2.04	0.99	0.63	0.46	0.41	0.39	0	0.00	0.14	0.98	0.14	0.97	0.54	0.75	0.0.0.
Available	2.53	3.69	0.80	4.16	0.66	4.54	2.98	0.01	0.87	0.40	0.34	0.39	0.66	0.54	0	0.99	0.04	0.97	0.49	0.77	0.0.0.
Unavailable	3.69	2.53	4.16	0.80	4.66	4.54	2.98	0.01	0.87	0.40	0.34	0.39	0.66	0.54	0	0.99	0.04	0.97	0.49	0.77	0.0.0.
Supportive	2.54	3.58	0.78	4.07	0.69	4.45	2.88	0.85	0.32	0.36	0.30	0.30	0.63	0.46	0.20	0.48	0	0.95	0.46	0.77	0.0.0.
Unsupportive	3.58	2.54	4.07	0.78	4.45	4.45	2.88	0.85	0.32	0.36	0.30	0.30	0.63	0.46	0.20	0.48	0	0.95	0.46	0.77	0.0.0.
Difficult	2.33	3.39	2.32	3.09	2.60	3.35	2.20	15	49	29	36	53	49	44	28	54	13	54	3.0	0.83	0.0.
Easy	3.39	2.33	3.09	3.32	3.35	2.60	15	20	29	29	49	53	49	44	28	54	13	54	3.0	0.83	0.0.



Appendix F

Sample Repertory Grid (Spousal Caregivers)

## Appendix F

## Sample Repertory Grid (Spousal Caregivers)

Repertory Grid "burden, as experienced by spousal caregivers"

1. Please read the following questions and answer them as honestly as possible in the corresponding box along the top of the page under the heading ELEMENTS
2. Describe the element in column A and add the term to the right hand side of the numbers under the heading CONSTRUCTS
3. Write the polar opposite of this term on the left hand side of the numbers under the heading CONSTRUCTS.  
Repeat for all elements.
4. Rate all the elements fit according to the constructs you provided on the scale.

## KNOWLEDGE TO COMPLETE TASKS

- A. Describe a task done at home to care for your spouse that is time consuming.
- B. Describe a task done at home to care for your spouse that is physically challenging.
- C. Describe a task done at home to care for your spouse that is mentally challenging.
- D. Describe a task done at home to care for your spouse that you feel could be done more efficiently.
- E. Describe a task done at home to care for your spouse that you rely on help/additional resources to complete.
- F. Describe a task done at home to care for your spouse that you feel confident completing.
- G. Describe a skill that you know that helps you complete your daily caregiving tasks.
- H. Describe a skill that you would like to learn in order to help you complete your daily caregiving tasks.

## AVAILABLE RESOURCES/SUPPORT

- I. Name one personal resource you have available for support at home.
- J. Name one personal resource you have available for support outside of your home.
- K. Name one resource available to you to use specific to Parkinson's disease.
- L. Describe one literary resource that you have available to you for support at home.
- M. Describe one literary resource that you have available to you outside of home.
- N. Describe one resource that you wish was more available to you at home.
- O. Describe one available at-home resource that is useful when providing care for your spouse.
- P. Describe one available out-of-home resource that is useful when providing care for your spouse.

## STRESSORS AND COPING STRATEGIES

- Q. Describe one example of where your spouse has your best interests at heart.
- R. Describe one example of where you have your spouses best interests at heart.
- S. Describe one stressor that results from the caregiving experience.
- T. Describe one stressor that would not exist if you had the help of additional resources.
- U. Describe one mechanism you use for coping with care-related stress while at home.
- V. Describe one mechanism you use for coping with care-related stress outside of the home.
- W. Describe one resource provided to you by an outside source that helps you effectively deal with care-related stress.



Appendix G

Distance Dimensions (Spousal Caregivers)

## Appendix G

## Distance Dimensions (Matrix dimensions): Knowledge

Table G1

*Participant 1: Element / Element (Upper triangle standardized)*

	Major decisions - research	Income tax	Running errands, Dressing	Personal visitors / companionship	Patience	Efficiency	Meals	Shovel
Major decisions-research	0	0.22	0.29	0.41	0.45	0.46	0.70	1.00
Income tax	0.75	0	0.25	0.26	0.44	0.40	0.68	0.92
Running errands, Dressing	0.98	0.85	0	0.46	0.63	0.55	0.68	0.89
Personal visitors/companionship	1.41	0.89	1.58	0	0.34	0.26	0.58	0.80
Patience	1.55	1.52	2.15	1.17	0	0.18	0.63	0.89
Efficiency	1.58	1.39	1.90	0.89	0.63	0	0.50	0.72
Meals	2.38	2.33	2.32	2.00	2.17	1.70	0	0.44
Shovel	3.43	3.15	3.06	2.74	3.06	2.47	1.50	0

Table G2

*Participant 1: Construct / Construct (Upper triangle standardized)*

	Difficult	Easy	Slow	Fast	Inefficient	Efficient	Impatient	Patient	Mental	Physical
Difficult	0	0.85	0.39	0.59	0.45	0.61	0.55	0.48	0.37	0.85
Easy	3.30	0	0.59	0.39	0.61	0.45	0.48	0.55	0.85	0.37
Slow	1.54	2.29	0	0.53	0.30	0.52	0.34	0.45	0.52	0.61
Fast	2.29	1.54	2.08	0	0.52	0.30	0.45	0.34	0.61	0.52
Inefficient	1.76	2.38	1.17	2.02	0	0.66	0.22	0.59	0.42	0.74
Efficient	2.38	1.76	2.02	1.17	2.56	0	0.59	0.22	0.74	0.42
Impatient	2.15	1.89	1.34	1.76	0.87	2.29	0	0.60	0.50	0.66
Patient	1.88	2.15	1.76	1.34	2.29	0.87	2.33	0	0.66	0.50
Mental	1.43	3.32	2.02	2.38	1.63	2.87	1.95	2.55	0	1.00
Physical	3.32	1.43	2.38	2.02	2.87	1.63	2.55	1.95	3.90	0

Table G3

*Participant 2: Element / Element (Upper triangle standardized)*

	Bathing	Personal grooming	Personal grooming	Physical aid technique	Organized	Communi-cation	Cooking	Proper physical aid technique
Bathing	0	0.00	0.00	0.00	0.29	0.32	1.00	1.00
Personal grooming	0.00	0	0.00	0.00	0.29	0.32	1.00	1.00
Personal grooming	0.00	0.00	0	0.00	0.29	0.32	1.00	1.00
Physical aid technique	0.00	0.00	0.00	0	0.29	0.32	1.00	1.00
Organized	0.89	0.89	0.89	0.89	0	0.34	0.79	0.82
Communication	0.98	0.98	0.98	0.98	1.06	0	0.96	0.81
Cooking	3.10	3.10	3.10	3.10	2.43	2.97	0	0.78
Proper physical aid technique	3.10	3.10	3.10	3.10	2.53	2.50	2.40	0

Table G4

*Participant 2: Construct / Construct (Upper triangle standardized)*

	Fast	Slow	Easy	Difficult	Oral	Written	Efficient	Inefficient	Peaceful	Scary	Good	Bad	Safe	Unsafe
Fast	0	1.00	0.04	0.99	0.40	0.91	0.13	0.98	0.14	0.93	0.17	0.96	0.17	0.98
Slow	5.15	0	1.00	0.04	0.91	0.40	0.98	0.13	0.93	0.14	0.96	0.17	0.98	0.17
Easy	0.20	5.10	0	0.98	0.41	0.89	0.13	0.97	0.15	0.92	0.17	0.95	0.17	0.97
Difficult	5.10	0.20	5.04	0	0.89	0.41	0.97	0.13	0.92	0.15	0.95	0.17	0.97	0.17
Oral	2.06	4.67	2.09	4.60	0	0.98	0.39	0.90	0.28	0.89	0.33	0.90	0.40	0.90
Written	4.67	2.06	4.60	2.09	5.06	0	0.90	0.39	0.89	0.28	0.90	0.33	0.90	0.40
Efficient	0.66	5.04	0.69	4.98	1.99	4.63	0	0.97	0.15	0.92	0.10	0.95	0.04	0.98
In Efficient	5.04	0.66	4.98	0.69	4.63	1.99	5.01	0	0.92	0.15	0.95	0.10	0.98	0.04
Peaceful	0.72	4.80	0.75	4.74	1.43	4.59	0.75	4.72	0	0.88	0.15	0.90	0.18	0.92
Scary	4.80	0.72	4.74	0.75	4.59	1.43	4.72	0.75	4.54	0	0.90	0.15	0.92	0.18
Good	0.87	4.93	0.85	4.87	1.71	4.65	0.49	4.91	0.75	4.64	0	0.94	0.10	0.96
Bad	4.93	0.87	4.87	0.85	4.65	1.71	4.91	0.49	4.64	0.75	4.85	0	0.96	0.10
Safe	0.85	5.07	0.87	5.01	2.08	4.65	0.20	5.06	0.92	4.75	0.53	4.96	0	0.99
Unsafe	5.07	0.85	5.01	0.87	4.65	2.08	5.06	0.20	4.75	0.92	4.96	0.53	5.12	0

Table G5

*Participant 3: Element / Element (Upper triangle standardized)*

	Walking	Getting in to bed	Yardwork	Common sense tasks	Walking techniques	Shower seat	Organized	Pill sorting
Walking	0	0.45	0.55	0.62	0.83	0.84	0.86	1.00
Getting into bed	2.38	0	0.44	0.56	0.59	0.56	0.56	0.62
Yardwork	2.90	2.33	0	0.50	0.48	0.48	0.56	0.66
Common sense tasks	3.31	2.97	2.68	0	0.68	0.75	0.53	0.85
Walking techniques	4.42	3.14	2.58	3.61	0	0.14	0.74	0.56
Shower seat	4.45	2.97	2.56	3.98	0.75	0	0.73	0.48
Organized	4.58	2.93	2.98	2.84	3.96	3.89	0	0.55
Pill sorting	5.32	3.31	3.52	4.50	2.99	2.55	2.94	0

Table G6

*Participant 3: Construct / Construct (Upper triangle standardized)*

	Difficult	Easy	Slow	Fast	Physical	Mental	Inefficient	Efficient	Bad	Good
Difficult	0	0.95	0.58	0.74	0.57	0.75	0.57	0.79	0.36	0.87
Easy	4.33	0	0.74	0.58	0.75	0.57	0.79	0.57	0.87	0.36
Slow	2.65	3.39	0	0.94	0.80	0.50	0.72	0.65	0.56	0.74
Fast	3.39	2.65	4.27	0	0.50	0.80	0.65	0.72	0.74	0.56
Physical	2.62	3.44	3.63	2.28	0	0.95	0.67	0.70	0.57	0.74
Mental	3.44	2.62	2.28	3.63	4.31	0	0.70	0.67	0.74	0.57
Inefficient	2.60	3.61	3.30	2.94	3.07	3.20	0	1.00	0.39	0.88
Efficient	3.61	2.60	2.94	3.30	3.20	3.07	4.56	0	0.88	0.39
Bad	1.63	3.95	2.55	3.39	2.62	3.37	1.78	4.02	0	0.92
Good	3.95	1.63	3.39	2.55	3.37	2.62	4.02	1.78	4.21	0



Table G7

*Participant 4: Element / Element (Upper triangle standardized)*

	Dressing	Dressing	Transport	Patience	Cueing	Daily routine	Organized
Dressing	0	0.00	0.56	0.77	0.83	0.95	1.00
Dressing	0.00	0	0.56	0.77	0.83	0.95	1.00
Transport	2.81	2.81	0	0.77	0.74	0.79	0.77
Patience	3.85	3.85	3.86	0	0.37	0.38	0.42
Cueing	4.13	4.13	3.69	1.83	0	0.60	0.59
Daily routine	4.72	4.72	3.95	1.90	2.98	0	0.17
Organized	4.99	4.99	3.86	2.08	2.94	0.85	0

Table G8

*Participant 4: Construct / Construct (Upper triangle standardized)*

	Easy	Difficult	Unskilled	Skilled	Slow	Fast	Physical	Mental	Inefficient	Efficient
Easy	0	0.71	0.33	0.56	0.36	0.61	0.21	0.84	0.36	0.60
Difficult	3.73	0	0.56	0.33	0.61	0.36	0.84	0.21	0.60	0.36
Unskilled	1.77	2.95	0	0.59	0.29	0.58	0.42	0.70	0.39	0.51
Skilled	2.95	1.77	3.12	0	0.58	0.29	0.70	0.42	0.51	0.39
Slow	1.88	3.20	1.52	3.06	0	0.70	0.49	0.71	0.32	0.61
Fast	3.20	1.88	3.06	1.52	3.69	0	0.71	0.49	0.61	0.32
Physical	1.13	4.44	2.25	3.72	2.61	3.74	0	1.00	0.41	0.75
Mental	4.44	1.13	3.72	2.25	3.74	2.61	5.29	0	0.75	0.41
Inefficient	1.89	3.16	2.50	2.69	1.69	3.24	2.16	3.99	0	0.69
Efficient	3.16	1.89	2.69	2.05	3.24	1.69	3.99	2.16	3.62	0

Table G9

*Participant 5: Element / Element (Upper triangle standardized)*

	Planning meals	Internet	Assistive Devices	Moving him when freezing	Transporting	Depression	Turning over in bed (moving)
Planning meals	0	0.30	0.56	0.61	0.67	0.83	1.00
Internet	1.63	0	0.59	0.44	0.57	0.56	0.78
Assistive Devices	3.05	3.16	0	0.46	0.27	0.95	0.79
Moving him when freezing	3.31	2.40	2.48	0	0.32	0.57	0.48
Transporting	3.64	3.06	1.44	1.72	0	0.79	0.57
Depression	4.47	3.01	5.11	3.06	4.25	0	0.54
Turning over in bed (moving)	5.40	4.20	4.24	2.59	3.06	2.90	0

Table G10

*Participant 5: Construct / Construct (Upper triangle standardized)*

	Easy	Difficult	Fast	Slow	Mental	Physical	Efficient	Inefficient	Patient	Frustrating
Easy	0	0.84	0.36	0.60	0.64	0.67	0.37	0.73	0.12	0.85
Difficult	4.12	0	0.60	0.36	0.67	0.64	0.73	0.37	0.85	0.12
Fast	1.74	2.97	0	0.53	0.70	0.38	0.41	0.53	0.36	0.64
Slow	2.97	1.74	2.59	0	0.38	0.70	0.53	0.41	0.64	0.36
Mental	3.13	3.28	3.45	1.89	0	1.00	0.61	0.66	0.67	0.67
Physical	3.28	3.13	1.89	3.45	4.92	0	0.66	0.61	0.67	0.67
Efficient	1.81	3.57	2.00	2.62	3.00	3.26	0	0.79	0.40	0.74
Inefficient	3.57	1.81	2.62	2.00	3.26	3.00	3.88	0	0.74	0.40
Patient	0.60	4.20	1.76	3.13	3.30	3.27	1.97	3.63	0	0.89
Frustrating	4.20	0.60	3.13	1.76	3.27	3.30	3.63	1.97	4.37	0

## Distance Dimensions (Matrix dimensions): Resources

Table G11

*Participant 1: Element / Element (Upper triangle standardized)*

	Bed rail	PD binder (From office)	PD book	friend	Parkwood 10week course	Visitor program	Boys and Girls club	Support group coordinator
Bed rail	0	0.49	0.60	0.77	0.90	0.98	0.98	1.00
PD binder (From office)	2.08	0	0.27	0.54	0.84	0.80	0.90	0.76
PD book	2.58	1.17	0	0.60	0.87	0.76	0.83	0.82
Friend	3.29	2.32	2.56	0	0.72	0.66	0.77	0.60
Parkwood 10week course	3.87	3.61	3.73	3.10	0	0.47	0.40	0.41
Visitor program	4.18	3.44	3.26	2.81	2.02	0	0.30	0.43
Boys and Girls club	4.19	3.87	3.53	3.27	1.70	1.30	0	0.59
Support group coordinator	4.28	3.24	3.51	2.56	1.74	1.86	2.53	0

Table G12

*Participant 1: Construct / Construct (Upper triangle standardized)*

	At-Home	Social	Effective	Ineffective	Assistive Device	Personal	Recurring	Onetime	Costly	Inexpensive
At-home	0	1.00	0.67	0.57	0.38	0.92	0.64	0.55	0.73	0.53
Social	4.75	0	0.57	0.67	0.92	0.38	0.55	0.64	0.53	0.73
Effective	3.16	2.73	0	0.74	0.60	0.64	0.31	0.62	0.37	0.67
Ineffective	2.73	3.16	3.51	0	0.64	0.60	0.62	0.31	0.67	0.37
Assistive Device	1.81	4.39	2.86	3.05	0	1.00	0.60	0.60	0.63	0.64
Personal	4.39	1.81	3.05	2.86	4.75	0	0.60	0.60	0.64	0.63
Recurring	3.04	2.62	1.48	2.96	2.84	2.84	0	0.65	0.45	0.57
Onetime	2.62	3.04	2.96	1.48	2.84	2.84	3.10	0	0.57	0.45

Table G12 (continued)

	At-Home	Social	Effective	Ineffective	Assistive Device	Personal	Recurring	Onetime	Costly	Inexpensive
Costly	3.47	2.51	1.73	3.19	3.00	3.05	2.15	2.68	0	0.79
In Expensive	2.51	3.47	3.19	1.73	3.05	3.00	2.68	2.15	3.75	0

Table G13

*Participant 2: Element / Element (Upper triangle standardized)*

	Neurologist	OT*	Spouse	Book-Parkinson's the first years	Periodical Parkinson's Update	Spouse	Telephone help line	Internet
Neurologist	0	0.273	0.632	0.699	0.702	0.710	0.870	1.000
OT*	1.265	0	0.638	0.756	0.712	0.704	0.704	1.000
Spouse	2.926	2.953	0	0.846	0.817	0.414	0.829	0.936
Book-Parkinson's the first years	3.237	3.499	3.919	0	0.183	0.810	0.981	0.570
Periodical Parkinson's Update	3.250	3.298	3.784	0.849	0	0.775	0.904	0.580
Spouse	3.286	3.262	1.918	3.752	3.589	0	0.611	0.715
Telephone help line	4.030	3.262	3.837	4.543	4.186	2.828	0	0.924
Internet	4.630	4.630	4.336	2.638	2.683	3.311	4.280	0

Note: \* OT= Occupational Therapist

Table G14

Participant 2: Construct / Construct (Upper triangle standardized)

	Caring	Uncaring	Supportive	Unsupportive	Honest	Dishonest	Oral	Written	Scientific	Unscientific	Available	Unavailable	Clarity	Confusing	Realistic	Unrealistic
Caring	0	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.
		7	43	58	39	58	35	79	48	51	48	61	27	56	37	48
Uncaring	3.	0	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.
	67		58	43	58	39	79	35	51	48	61	48	56	27	48	37
Supportive	2.	2.	0	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.
	18	99		73	36	61	50	72	44	55	51	59	39	50	40	47
Unsupportive	2.	2.	3.	0	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.
	99	18	73		61	36	72	50	55	44	59	51	50	39	47	40
Honest	2.	2.	1.	3.	0	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.
	02	98	84	13		69	58	64	28	63	47	60	25	56	26	54
Dishonest	2.	2.	3.	1.	3.	0	0.	0.	0.	0.	0.	0.	0.	0.	0.	0.
	98	02	13	84	53		64	58	63	28	60	47	56	25	54	26
Oral	1.	4.	2.	3.	2.	3.	0	1.	0.	0.	0.	0.	0.	0.	0.	0.
	81	07	54	69	95	26		00	60	61	77	49	54	59	57	54
Written	4.	1.	3.	2.	3.	2.	5.	0	0.	0.	0.	0.	0.	0.	0.	0.
	07	81	69	54	26	95	12		61	60	49	77	59	54	54	57
Scientific	2.	2.	2.	2.	1.	3.	3.	3.	0	0.	0.	0.	0.	0.	0.	0.
	46	62	26	83	43	22	09	12		69	53	55	28	54	17	57
Unscientific	2.	2.	2.	2.	3.	1.	3.	3.	3.	0	0.	0.	0.	0.	0.	0.
	62	46	83	26	22	43	12	09	51		55	53	54	28	57	17
Available	2.	3.	2.	3.	2.	3.	3.	2.	2.	2.	0	0.	0.	0.	0.	0.
	43	12	60	03	38	09	96	53	71	79		83	33	61	39	56
Unavailable	3.	2.	3.	2.	3.	2.	2.	3.	2.	2.	4.	0	0.	0.	0.	0.
	12	43	03	60	09	38	53	96	79	71	23		61	33	56	39
Clarity	1.	2.	2.	2.	1.	2.	2.	3.	1.	2.	1.	3.	0	0.	0.	0.
	39	88	01	54	27	86	74	02	43	76	70	10		52	17	47
Confusing	2.	1.	2.	2.	2.	1.	3.	2.	2.	1.	3.	1.	2.	0	0.	0.
	88	39	54	01	86	27	02	74	76	43	10	70	65		47	17
Realistic	1.	2.	2.	2.	1.	2.	2.	2.	0.	2.	1.	2.	0.	2.	0	0.
	92	47	00	39	33	74	91	77	87	91	98	84	85	42		48
Unrealistic	2.	1.	2.	2.	2.	1.	2.	2.	2.	0.	2.	1.	2.	0.	2.	0
	47	92	39	07	74	33	77	91	91	87	84	98	42	85	47	

Table G15

*Participant 3: Element / Element (Upper triangle standardized)*

	Daughter	Inhome care	Internet	Support Group	PD specific Book	Books
Daughter	0	0.34	0.64	0.64	0.67	0.81
Inhome care	1.52	0	0.71	0.58	0.70	0.77
Internet	2.86	3.16	0	0.90	0.13	0.44
Support Group	2.86	2.61	4.00	0	0.91	1.00
PD specific Book	2.97	3.11	0.57	4.04	0	0.32
Books	3.63	3.42	1.98	4.46	1.41	0

Table G16

*Participant 3: Construct / Construct (Upper triangle standardized)*

	Available	Unavailable	Supportive	UnSupportive	Verbal	Written	Effective	Ineffective	Individual	Group
Available	0	0.92	0.13	0.92	0.73	0.63	0.36	0.74	0.42	0.83
Unavailable	4.49	0	0.92	0.13	0.63	0.73	0.74	0.36	0.83	0.42
Supportive	0.63	4.50	0	0.94	0.71	0.66	0.37	0.74	0.41	0.85
Unsupportive	4.50	0.63	4.60	0	0.66	0.71	0.74	0.37	0.85	0.41
Verbal	3.56	3.07	3.48	3.24	0	1.00	0.49	0.71	0.82	0.52
Written	3.07	3.56	3.24	3.48	4.90	0	0.71	0.49	0.52	0.82
Effective	1.74	3.60	1.79	3.64	2.40	3.49	0	0.70	0.51	0.66
Ineffective	3.60	1.74	3.64	1.79	3.49	2.40	3.44	0	0.66	0.51
Individual	2.04	4.08	2.02	4.15	4.02	2.56	2.50	3.23	0	0.95
Group	4.08	2.04	4.15	2.02	2.56	4.02	3.23	2.50	4.63	0

Table G17

*Participant 4: Element / Element (Upper triangle standardized)*

	Care Partners group	Support group facilitator	Call support group members	Neurologist	PD office books	Family	Books	Exercise books
CarePartners group	0	0.28	0.32	0.71	0.76	0.86	1.00	1.00
Support group facilitator	1.13	0	0.14	0.44	0.71	0.65	0.83	0.83
Call support group members	1.27	0.57	0	0.44	0.72	0.60	0.84	0.84
Neurologist	2.86	1.74	1.74	0	0.83	0.41	0.72	0.72
PD office books	3.06	2.84	2.90	3.34	0	0.94	0.42	0.42
Family	3.44	2.59	2.40	1.65	3.76	0	0.84	0.84
Books	4.01	3.31	3.36	2.87	1.70	3.36	0	0.00
Exercise books	4.01	3.31	3.36	2.87	1.70	3.36	0.00	0

Table G18

*Participant 4: Construct / Construct (Upper triangle standardized)*

	Group	Individual	Available	Unavailable	Supportive	UnSupportive	Verbal	Written	Effective	InEffective
Group	0	0.80	0.51	0.66	0.53	0.68	0.70	0.58	0.52	0.65
Individual	4.53	0	0.66	0.51	0.68	0.53	0.58	0.70	0.65	0.52
Available	2.86	3.76	0	0.87	0.07	0.89	0.63	0.69	0.10	0.86
Unavailable	3.76	2.86	4.92	0	0.89	0.07	0.69	0.63	0.86	0.10
Supportive	3.00	3.82	0.40	5.03	0	0.91	0.63	0.72	0.07	0.89
Unsupportive	3.82	3.00	5.03	0.40	5.17	0	0.72	0.63	0.89	0.07
Verbal	3.94	3.27	3.58	3.90	3.56	4.08	0	1.00	0.57	0.74
Written	3.27	3.94	3.90	3.58	4.08	3.56	5.66	0	0.74	0.57
Effective	2.93	3.68	0.57	4.87	0.40	5.01	3.22	4.19	0	0.86
Ineffective	3.68	2.93	4.87	0.57	5.01	0.40	4.19	3.22	4.88	0

Table G19

*Participant 5: Element / Element (Upper triangle standardized)*

	Homecare	Homecare	Children	Assistive Device	Neurologist	Periodical - Parkinson's Update	PD binder
Homecare	0	0.00	0.07	0.34	0.44	0.70	1.00
Homecare	0.00	0	0.07	0.34	0.44	0.70	1.00
Children	0.28	0.28	0	0.34	0.43	0.69	0.97
Assistive Device	1.47	1.47	1.50	0	0.52	0.41	0.80
Neurologist	1.90	1.90	1.88	2.26	0	0.78	0.87
Periodical-Parkinson's Update	3.07	3.07	3.01	1.77	3.41	0	0.53
PD binder	4.36	4.36	4.22	3.48	3.78	2.30	0

Table G20

*Participant 5: Construct / Construct (Upper triangle standardized)*

	Available	Unavailable	Supportive	UnSupportive	Effective	Ineffective	Verbal	Written	Recurring	Onetime
Available	0	1.00	0.31	0.87	0.36	0.88	0.61	0.80	0.27	0.92
Unavailable	4.90	0	0.87	0.31	0.88	0.36	0.80	0.61	0.92	0.27
Supportive	1.52	4.28	0	0.85	0.08	0.87	0.36	0.85	0.22	0.85
Unsupportive	4.28	1.52	4.16	0	0.87	0.08	0.85	0.36	0.85	0.22
Effective	1.74	4.31	0.40	4.25	0	0.89	0.37	0.88	0.27	0.86
Ineffective	4.31	1.74	4.25	0.40	4.38	0	0.88	0.37	0.86	0.27
Verbal	2.97	3.90	1.77	4.19	1.79	4.29	0	1.00	0.56	0.78
Written	3.90	2.97	4.19	1.77	4.29	1.79	4.90	0	0.78	0.56
Recurring	1.30	4.52	1.10	4.19	1.33	4.23	2.73	3.83	0	0.92
Onetime	4.52	1.30	4.19	1.10	4.23	1.33	3.83	2.73	4.49	0



## Distance Dimensions (Matrix dimensions): Stress &amp; Coping Strategies

Table G21

*Participant 1: Element / Element (Upper triangle standardized)*

	Shopping	Entertaining him	Keep him moving	Seeing it from his perspective	Seeing grandkids	Learn to say Thank You	Books
Shopping	0	0.26	0.40	0.59	0.77	0.94	1.00
Entertaining him	1.30	0	0.21	0.54	0.63	0.73	0.84
Keep him moving	2.02	1.06	0	0.59	0.72	0.76	0.88
Seeing it from his perspective	3.01	2.74	2.99	0	0.50	0.64	0.87
Seeing grandkids	3.90	3.19	3.63	2.55	0	0.38	0.65
Learn to say Thank You	4.76	3.71	3.86	3.25	1.94	0	0.66
Books	5.08	4.24	4.46	4.41	3.30	3.38	0

Table G22

*Participant 1: Construct / Construct (Upper triangle standardized)*

	Verbal	Written	For him	For me	Difficult	Easy	Social	At-home	Costly	Inexpensive
Verbal	0	1.00	0.59	0.81	0.31	0.85	0.51	0.73	0.72	0.68
Written	4.47	0	0.81	0.59	0.85	0.31	0.73	0.51	0.68	0.72
For him	2.62	3.62	0	1.00	0.40	0.81	0.40	0.79	0.41	0.90
For me	3.62	2.62	4.47	0	0.81	0.40	0.79	0.40	0.90	0.41
Difficult	1.40	3.78	1.80	3.61	0	0.79	0.45	0.63	0.49	0.74
Easy	3.78	1.40	3.61	1.80	3.53	0	0.63	0.45	0.74	0.49
Social	2.27	3.26	1.80	3.54	2.00	2.83	0	0.76	0.51	0.71
At-home	3.26	2.27	3.54	1.80	2.83	2.00	3.39	0	0.71	0.51
Costly	3.22	3.04	1.84	4.03	2.21	3.31	2.28	3.19	0	0.98
Inexpensive	3.04	3.22	4.03	1.84	3.31	2.21	3.19	2.28	4.38	0

Table G23

*Participant 2: Element / Element (Upper triangle standardized)*

	Read a book	Chat with friend(s)	Favorite TV show	Own private time	EAP professional counselling	Financial	Fatigue
Read a book	0	0.13	0.25	0.29	0.75	0.94	1.00
Chat with friend(s)	0.75	0	0.16	0.21	0.64	0.82	0.87
Favorite TV show	1.41	0.89	0	0.27	0.55	0.79	0.80
Own private time	1.63	1.20	1.55	0	0.65	0.71	0.80
EAP professional counselling	4.26	3.62	3.12	3.69	0	0.51	0.45
Financial	5.34	4.66	4.50	4.01	2.87	0	0.33
Fatigue	5.69	4.96	4.53	4.55	2.58	1.88	0

Table G24

*Participant 2: Construct / Construct (Upper triangle standardized)*

	Peaceful	Chaotic	Frequent	Seldom	Regular	Irregular	Unlimited	Limited	Relaxing	Disruptive	Helpful	Unhelpful	Benefit	Useless
Peaceful	0	0.77	0.36	0.78	0.37	0.81	0.50	0.63	0.20	0.61	0.18	0.74	0.19	0.75
Chaotic	3.30	0	0.78	0.36	0.81	0.37	0.63	0.50	0.61	0.20	0.74	0.18	0.75	0.19
Frequent	1.55	3.37	0	0.95	0.07	0.97	0.37	0.81	0.27	0.71	0.21	0.83	0.22	0.84
Seldom	3.37	1.55	4.08	0	0.97	0.07	0.81	0.37	0.71	0.27	0.83	0.21	0.84	0.22
Regular	1.60	3.49	0.28	4.19	0	1.00	0.40	0.83	0.30	0.73	0.23	0.85	0.23	0.87
Irregular	3.49	1.60	4.19	0.28	4.31	0	0.83	0.40	0.73	0.30	0.85	0.23	0.87	0.23
Unlimited	2.13	2.70	1.58	3.50	1.72	3.57	0	0.83	0.38	0.57	0.38	0.69	0.38	0.72
Limited	2.70	2.14	3.50	1.58	3.57	1.72	3.58	0	0.57	0.38	0.69	0.38	0.72	0.38
Relaxing	0.87	2.65	1.15	3.05	1.28	3.16	1.64	2.46	0	0.50	0.16	0.62	0.19	0.63
Disruptive	2.65	0.87	3.05	1.15	3.16	1.28	2.46	1.64	2.15	0	0.62	0.16	0.63	0.19
Helpful	0.78	3.17	0.92	3.56	1.00	3.67	1.64	2.99	0.69	2.65	0	0.75	0.05	0.77
Unhelpful	3.17	0.78	3.56	0.92	3.67	1.00	2.99	1.64	2.65	0.69	3.23	0	0.77	0.05

Table G24 (continued)

	Peaceful	Chaotic	Frequent	Seldom	Regular	Irregular	Unlimited	Limited	Relaxing	Disruptive	Helpful	Unhelpful	Benefit	Useless
Benefit	0.80	3.25	0.94	3.63	0.98	3.75	1.63	3.09	0.83	2.72	0.20	3.31	0	0.79
Useless	3.25	0.80	3.63	0.94	3.75	0.98	3.09	1.63	2.72	0.83	3.31	0.20	3.39	0

Table G25

*Participant 3: Element / Element (Upper triangle standardized)*

	Talk to mom	Computer	Thank you-appreciative	Massage feet, apply lotion	Support group	Lonely	Not going out
Talk to mom	0	0.00	0.24	0.42	0.68	0.72	0.99
Computer	0.00	0	0.24	0.42	0.68	0.72	0.99
Thank you-appreciative	1.13	1.13	0	0.48	0.63	0.74	1.00
Massage feet, apply lotion	2.04	2.04	2.33	0	0.72	0.39	0.76
Support group	3.25	3.25	3.05	3.49	0	0.90	0.68
Lonely	3.48	3.48	3.57	1.86	4.34	0	0.65
Not going out	4.75	4.75	4.82	3.64	3.27	3.11	0

Table G26

Participant 3: Construct / Construct (Upper triangle standardized)

	Inexpensive	Costly	Recurring	Infrequent	Effective	Ineffective	Individual	Group	Helpful	Not helpful
Inexpensive	0	0.85	0.32	0.75	0.24	0.75	0.45	0.81	0.31	0.81
Costly	4.49	0	0.75	0.32	0.75	0.24	0.81	0.45	0.81	0.31
Recurring	1.71	3.99	0	0.79	0.40	0.65	0.44	0.79	0.53	0.64
Infrequent	3.99	1.71	4.18	0	0.65	0.40	0.79	0.44	0.64	0.53
Effective	1.28	3.99	2.12	3.42	0	0.73	0.33	0.81	0.26	0.77
Ineffective	3.99	1.28	3.42	2.12	3.86	0	0.81	0.33	0.77	0.26
Individual	2.38	4.29	2.32	4.17	1.77	4.28	0	1.00	0.59	0.74
Group	4.29	2.38	4.17	2.32	4.28	1.77	5.29	0	0.74	0.59
Helpful	1.61	4.28	2.81	3.41	1.36	4.05	3.10	3.90	0	0.88
Not helpful	4.28	1.61	3.41	2.81	4.05	1.36	3.90	3.10	4.65	0

Table G27

Participant 4: Element / Element (Upper triangle standardized)

	Generous (knows when caregiver is tired)	CarePartners group	Reading	Watch movies/ news together	Fear of falling	Walk with friends
Generous (knows when caregiver is tired)	0	0.30	0.61	0.63	0.84	0.89
CarePartners group	1.10	0	0.33	0.48	0.56	0.82
Reading	2.21	1.20	0	0.42	0.43	0.82
Watch movies & news together	2.28	1.74	1.50	0	0.76	0.51
Fear of falling	3.01	2.00	1.55	2.74	0	1.00
Walk with friends	3.19	2.94	2.97	1.83	3.60	0

Table G28

Participant 4: Construct / Construct (Upper triangle standardized)

	Infrequent	Recurring	Effective	Ineffective	Inexpensive	Costly	Mental	Physical	Beneficial	Not Helpful
Infrequent	0	0.80	0.40	0.72	0.41	0.72	0.54	0.73	0.38	0.74
Recurring	3.58	0	0.72	0.40	0.72	0.41	0.73	0.54	0.74	0.38
Effective	1.78	3.24	0	0.85	0.08	0.85	0.50	0.78	0.05	0.85
Ineffective	3.24	1.78	3.82	0	0.85	0.08	0.78	0.50	0.85	0.05
Inexpensive	1.86	3.24	0.35	3.83	0	0.86	0.56	0.75	0.11	0.85
Costly	3.24	1.86	3.83	0.35	3.88	0	0.75	0.56	0.85	0.11
Mental	2.42	3.26	2.25	3.50	2.53	3.35	0	1.00	0.48	0.79
Physical	3.26	2.42	3.50	2.25	3.35	2.53	4.49	0	0.79	0.48
Beneficial	1.70	3.30	0.20	3.82	0.49	3.83	2.17	3.57	0	0.85
Not Helpful	3.30	1.70	3.82	0.20	3.83	0.49	3.57	2.17	3.84	0

Table G29

Participant 5: Element / Element (Upper triangle standardized)

	Appreciative, grateful	Homecare	Homecare (to increase independence)	Invite people to visit	Social clubs	Gym	In dependence
Appreciative, grateful	0	0.54	0.54	0.56	0.74	0.92	1.00
Homecare	1.92	0	0.000	0.08	0.40	0.47	0.79
Homecare (to increase independence)	1.92	0.00	0	0.08	0.40	0.47	0.79
Invite people to visit	1.98	0.28	0.28	0	0.33	0.40	0.74
Social clubs	2.65	1.44	1.44	1.17	0	0.24	0.59
Gym	3.26	1.67	1.67	1.44	0.85	0	0.63
Independence	3.57	2.81	2.81	2.62	2.10	2.26	0

Table G30

*Participant 5: Construct / Construct (Upper triangle standardized)*

	Supportive	Unsupportive	Effective	Ineffective	Frequent	Infrequent	Mental	Physical	Available	Unavailable
Supportive	0	1.00	0.00	1.00	0.32	0.73	0.53	0.61	0.38	0.78
Unsupportive	4.90	0	1.00	0.00	0.73	0.32	0.61	0.53	0.78	0.38
Effective	0.00	4.90	0	1.00	0.32	0.73	0.53	0.61	0.38	0.78
Ineffective	4.90	0.00	4.90	0	0.73	0.32	0.61	0.53	0.78	0.38
Frequent	1.59	3.59	1.59	3.59	0	0.54	0.43	0.33	0.27	0.57
Infrequent	3.59	1.59	3.59	1.59	2.62	0	0.33	0.43	0.57	0.27
Mental	2.58	3.01	2.58	3.01	2.13	1.61	0	0.55	0.53	0.36
Physical	3.01	2.58	3.01	2.58	1.61	2.13	2.71	0	0.36	0.53
Available	1.87	3.83	1.87	3.83	1.30	2.81	2.59	1.78	0	0.72
Unavailable	3.83	1.87	3.83	1.87	2.81	1.30	1.78	2.59	3.51	0