

Research Article

## The Relationship between Caregiver Stress and Behavioural Changes in Dementia

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### Abstract

**Background:** Clinical studies have shown that caregivers of dementia patients often experience a great deal of stress related to caregiving. This paper examines caregiver stress within the context of behaviour change in dementia using the Kingston Caregiver Stress Scale (KCSS) and the Kingston Standardized Behaviour Scale (Community Form) (KSBA(comm)).

**Methods:** Eighty patients with moderate dementia and their caregivers participated. Each patient was cognitively assessed with the Kingston Standardized Cognitive Assessment-revised (KSCAr) and the MMSE. They were also assessed behaviourally with the KSBA(comm). Each caregiver completed the KCSS.

**Results:** Caregivers reported 13 behaviour changes, on average, as identified by the (KSBA(comm)), with Neuropsychological behaviours outnumbering Neuropsychiatric behaviours (KSBA factors) 3:1. Findings showed a strong correlation ( $r_s = 0.80$ ) between



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caregiver stress and behaviour change, with significant correlations for both the Neuropsychological ( $r_s = 0.69$ ) and Neuropsychiatric ( $r_s = 0.62$ ) factors. Caregiver gender was not significant for level of experienced stress, but caregiver relationship was, where adult child caregivers reported higher levels of family-related stress than did spouses.

**Conclusions:** Caregivers were able to differentiate sources of stress; the strongest relationship emerging between behavioural impairment and stress related to caregiving ( $r_s = 0.80$ ). This supports the hypothesis that behavioural symptoms of dementia play a central role in the experience of caregiver stress.

### **Keywords**

BPSD; behaviour scales; behaviour disturbances; Kingston scales; caregiver stress

## **1. Introduction**

### **1.1 Dementia and Caregiving Stress**

The number of elderly has significantly increased in recent years (and will continue to do so for some time to come), leading to an increasing prevalence of dementia, and a growing health care crisis [1, 2]. Since there is currently no curative pharmacologic treatment for this disorder, compassionate care is the only path available to families. This provision of care requires the ability to constantly handle the resulting daily cognitive challenges and behavioural changes facing those with the disease. Further, caring often falls upon the least able of the population, the elderly themselves, and quite often elderly spouses. This type of “24/7” work is difficult, relentless, and stressful [3]. This paper explores the link between care-related stress and behavioural change in dementia.

### **1.2 Behaviour as a Major Source of Stress**

One aspect of care giving that makes it so potentially stressful, is having to deal with the behavioural changes that are common in dementia [3-8]. While most research into behavioural change in dementia has focused on the most extreme and later-occurring behaviours, i.e., “Neuropsychiatric” such as physical aggression, hallucinations and misidentifications), there is also a large number of earlier emerging and less extreme behaviours that place significant demands on caregivers, as they are primarily responsive to environmental and behavioural interventions, i.e., “Neuropsychological”, that fall to the caregiver to implement, and that can account for up to 90% of the earliest behavioural changes [9]. Behaviour changes can seem unpredictable to the caregiver in their nature, intensity, and timing, often changing the patient into an individual who seems quite different from the one that the caregiver has known most of his or her life. This can easily cause stress, in and of itself. Few caregivers have any training in how to handle altered behaviour, and therefore struggle to provide care amid the changes occurring in their daily lives. Also, in our experience, few caregivers are adequately informed of the changes to come.

It should also be noted that both the introduction of home support services and long term care placement, are almost always triggered by behavioural events, and not cognitive issues [3, 7, 10,

11]. But what is not clear, is the nature of the relationship between such sentinel events and the experience of caregiver stress. Understanding this relationship would provide clinicians (and caregivers) with heightened awareness of the need for specific, timely supports and other transitional events up to, an including placement in Long Term Care.

### **1.3 Kingston Caregiver Stress Scale (KCSS)**

The Kingston Caregiver Stress Scale (KCSS) [12, 13] is a 10-item rating scale, designed to quickly (in fewer than 5 minutes) allow a caregiver to express the amount of stress that he or she is feeling overall, and with respect to caregiving, family and financial areas. The caregiver is defined as the individual who provides care on a day-to-day basis in the home; usually a spouse or relative. For practical purposes, it is the individual who knows the person with the diagnosis best, or spends the most time with him or her. Since more than one person may be involved in an individual's care, each of the caregivers for an individual patient may complete a KCSS separately, and be followed over time.

### **1.4 Kingston Standardized Behavioural Assessment**

As noted above, behavioural change is believed to be a major source of caregiver stress. A scale that was designed to measure the behaviours changes seen in dementia is the Kingston Standardized Behavioural Assessment (KSBA) [9]. The KSBA is an informant-based behavioural screening tool that assesses 68 behaviours common to neurological disease (particularly Alzheimer's disease). The KSBA comes in two forms, the KSBA(comm) for community living individuals, and the KSBA(LTC) for individuals living in a long term care institution. Only the KSBA(comm) was used in this study.

The KSBA(comm) groups the 68 behaviours into 12 categories, or domains. The domains have been found to fall into two factors that are referred to as neuropsychiatric (NPT) and neuropsychological (NPL). Having these two factors, means that the behaviours assessed by the KSBA(comm) represent a much broader range of behaviour than is typically seen in most behaviour scales (that primarily assess only neuropsychiatric behaviours), providing a more complete and realistic picture of the emergence of behavioural disturbance. From the authors' previously collected scale data (unpublished data) it can be shown that the average KSBA(comm) score for normal individuals with no diagnosis of dementia is less than 2 ( $M = 1.47$ ,  $SD = 1.54$ ). Any scores given to normal individuals usually reflect errors by the rater, or slight behaviour changes for reasons other than dementia.

The purpose of the present study was to explore the relationship between Caregiver stress and Behaviour change associated with progression of dementia by answering the following questions: (1) Is there a significant relationship between overall caregiver stress and degree of behavioural change? (2) Is the level of caregiver stress related to the duration of the illness? (3) Are caregivers able to differentiate between contributors to their experience of stress? (4) Do varying behavioural presentations differentially contribute to caregiver stress? (5) Do male and female caregivers experience different levels of stress? (6) Is there a difference in the level of caregiver stress experienced by spouse vs. adult child caregivers?

## **2. Materials and Methods**

A group of 80 individuals from a geriatric psychiatry outpatient service who met the criteria for dementia according to both DSM-IV [14] and NINCDS-ADRDA [15] criteria as well as their caregivers participated in the study. Behaviour changes in the diagnosed patients were assessed by caregiver completion of the KSBA(comm). Patient cognition was also assessed using the Kingston Standardized Cognitive Assessment - Revised (KSCAr) [16], the mini-Kingston Standardized Cognitive Assessment (mini-KSCAr) [17], where mini-KSCAr scores were calculated simply by extracting the appropriate KSCAr sub-test scores), and by the Mini Mental State Examination (MMSE) [18]. Caregiver stress was measured by caregiver completion of the KCSS.

Dementia patients were recruited from the out-patient pool of individuals referred to our clinic by their primary care physicians for assessment. KSCAr assessments were administered by an experienced neuropsychologist. The MMSE was administered by the case manager (an experienced Registered Nurse or Occupational Therapist). Caregivers, usually spouses or children, completed the KSBA(comm) and the KCSS. Informed consent from the patient was obtained in all cases.

This study, project # 6016786, received Ethics Clearance in 2016 from the REB of Queens University, Kingston, Ontario, Canada.

## **3. Results**

### **3.1 Patient Demographic Variables**

The mean and standard deviation for the age, years of education, reported years of illness, and cognition scores (MMSE, KSCAr and mini-KSCAr) are shown for the total sample of patients in Table 1. Average age was 74.69 ( $SD = 7.72$ ) years. Table 2 shows the same information for males and females separately. Average age for males was 74.06 ( $SD = 7.61$ ) years, and for females it was 75.58 ( $SD = 7.78$ ) years. Patient gender was fairly evenly balanced (males = 53%).

Overall, years of illness ranged from less than 1 year to 5 years, with the overall average less than 2 years ( $SD = 1.29$ ; range: <1 year – 5 years). Using 10 years as the typical duration of dementia, with the first 5 of those typically spent in the community and the latter half in Long Term Care [19], the sample in this study was nearly midway through their tenure in the community. Patient gender was not found to be significant for any of the demographic variables.

### **3.2 Patient Cognitive Status**

The MMSE, KSCAr and mini-KSCAr scores were indicative of cognitive impairment (see Table 1 and Table 2). The mean MMSE score fell below the adjusted age and education cut-off score of 28 [20]. Overall, patients fell into the “Moderate” range of dementia as given by their both their KSCAr and mini-KSCAr scores (i.e. below the 2<sup>nd</sup> and 5<sup>th</sup> percentiles of normal elderly, and at the 78<sup>th</sup> and 75<sup>th</sup> percentiles, for individuals diagnosed with dementia, respectively).

**Table 1** Subject demographics & variable scores (total group).

| Variable   | All Cases |      |     |     |
|--|-----------|------|-----|-----|
|  | Mean      | SD   | Min | Max |
| N  | 80        |      |     |     |
| Years of Age   | 74.69     | 7.72 | 53  | 91  |
| Years of Education   | 13.55     | 3.41 | 6   | 21  |
| Years of Reported Illness  | 1.95      | 1.29 | 0   | 5   |
| Mini Mental State Examination (MMSE)                               | 27.18     | 1.84 | 22  | 30  |
| Kingston Standardized Cognitive Assessment Rev (KSCAr) TOTAL Score | 98.45     | 7.72 | 79  | 115 |
| KSCAr MEMORY Subtotal  | 33.07     | 4.75 | 22  | 45  |
| KSCAr LANGUAGE Subtotal  | 37.76     | 1.46 | 33  | 39  |
| KSCAr VISUAL-MOTOR Subtotal  | 27.62     | 3.72 | 17  | 31  |
| mini-Kingston Standardized Cognitive Assessment (mini-KSCAr)       | 33.41     | 5.14 | 21  | 45  |
| Kingston Standardized Behavioural Assessment (KSBA(comm))          | 12.81     | 9.05 | 1   | 42  |
| Neuropsychiatric Behaviours (NPT)                                  | 3.43      | 3.7  | 0   | 14  |
| Neuropsychological Behaviours (NPL)                                | 9.39      | 6.18 | 1   | 28  |
| Kingston Caregiver Stress Scale (KCSS)                             | 17.45     | 6.82 | 10  | 39  |
| KCSS Care Group (Q1 - Q7)  | 13.59     | 5.71 | 7   | 35  |
| KCSS Family Group (Q8 - Q9)  | 2.6       | 1.38 | 2   | 10  |
| KCSS Financial Group (Q10)   | 1.26      | 0.67 | 1   | 4   |

**Table 2** Subject demographics & variable scores (males versus females).

| Variable  | Males |      |      |       | Females |      |     |     |
|---|-------|------|------|-------|---------|------|-----|-----|
|   | Mean  | SD   | Min  | Max   | Mean    | SD   | Min | Max |
| N   | 47    |      |      |       | 33      |      |     |     |
| Years of Age  | 74.06 | 7.61 | 53   | 87    | 75.58   | 7.78 | 54  | 91  |
| Years of Education  | 14.10 | 3.74 | 6    | 21    | 12.84   | 2.77 | 4   | 18  |
| Years of Reported Illness   | 2.26  | 1.81 | 0    | 10    | 1.80    | 1.19 | 0   | 5   |
| Mini Mental State Examination (MMSE)                                  | 27.23 | 1.94 | 22   | 30    | 27.07   | 1.70 | 22  | 30  |
| Kingston Standardized Cognitive Assessment<br>Rev (KSCAr) TOTAL Score | 99.58 | 7.24 | 82   | 111.5 | 96.88   | 8.1  | 79  | 115 |
| KSCAr MEMORY Subtotal   | 33.60 | 4.12 | 27.5 | 42.5  | 32.33   | 5.44 | 22  | 45  |
| KSCAr LANGUAGE Subtotal   | 37.78 | 1.43 | 34   | 39    | 37.73   | 1.50 | 33  | 39  |
| KSCAr VISUAL-MOTOR Subtotal   | 28.20 | 3.30 | 17   | 31    | 26.82   | 4.10 | 18  | 31  |
| mini-Kingston Standardized Cognitive<br>Assessment (mini-KSCAr)       | 33.59 | 4.42 | 25   | 42.5  | 33.16   | 5.96 | 21  | 45  |
| Kingston Standardized Behavioural<br>Assessment (KSBA(comm))          | 12.23 | 8.76 | 1    | 37    | 13.64   | 9.39 | 2   | 42  |
| Neuropsychiatric Behaviours (NPT)                                     | 3.21  | 3.63 | 0    | 14    | 3.73    | 3.78 | 0   | 14  |
| Neuropsychological Behaviours (NPL)                                   | 9.02  | 5.91 | 1    | 23    | 9.91    | 6.52 | 1   | 28  |
| Kingston Caregiver Stress Scale (KCSS)                                | 16.51 | 6.40 | 10   | 38    | 18.79   | 7.17 | 10  | 38  |
| KCSS Care Group (Q1 - Q7)   | 12.74 | 5.03 | 7    | 27    | 14.79   | 6.36 | 7   | 35  |
| KCSS Family Group (Q8 - Q9)   | 2.51  | 1.51 | 2    | 40    | 2.73    | 1.16 | 2   | 6   |
| KCSS Financial Group (Q10)  | 1.26  | 0.63 | 1    | 4     | 1.27    | 0.71 | 1   | 4   |

### 3.3 Patient Behavioural Status

Table 1 and Table 2 also shows the means and standard deviations of the KSBA(comm) and its two factors, Neuropsychological (NPL) and Neuropsychiatric (NPT) behaviour. Caregivers (in the total sample) identified an average of 12.81 (*SD* = 9.05) changed behaviours in their family members using the KSBA(comm), falling in the middle portion of the “consult/concern” range on the KSBA(comm) score analysis page. As with the obtained cognitive patterns, male and female patients showed equivalent levels of overall behavioural impairment as given by the KSBA(comm) total score and also for each of the two factor scores (NPL, NPT). Consistent with other research with patients who had similar levels of behavioural change identified with the KSBA(comm) [5], a majority (but not all) of the endorsed behaviours came from the neuropsychological domains at a ratio of roughly 3:1.

### 3.4 Caregiver Stress and Patient Behaviour

Table 3 shows the means and standard deviations for each of the 10 KCSS questions, the KCSS Total Score, and the three question groupings (i.e., Care, Family, and Financial). Caregivers reported a mean KCSS total of 17.45 (*SD* = 6.82). Shown in Table 4 are the correlations (Spearman’s rho [ $r_s$ ]) between caregiver stress (KCSS) and the degree of behavioural impairment (KSBA(comm)). Owing to the large number of computed correlations, Bonferroni corrections were used for interpretation. The KCSS total score, question groupings and 10 KCSS individual questions were correlated with the KSBA(comm) total score, as well as its two factor components (NPL and NPT).

**Table 3** Kingston Caregiver Stress Scale (KCSS)\* question and group scores.

| Question | Mean  | SD   | Min | Max |
|----------|-------|------|-----|-----|
| 1        | 2.01  | 1.09 | 1   | 5   |
| 2        | 2.00  | 1.04 | 1   | 5   |
| 3        | 1.90  | 1.14 | 1   | 5   |
| 4        | 1.58  | 0.96 | 1   | 5   |
| 5        | 1.78  | 1.06 | 1   | 5   |
| 6        | 1.75  | 1.03 | 1   | 5   |
| 7        | 2.60  | 1.18 | 1   | 5   |
| 8        | 1.29  | 0.67 | 1   | 5   |
| 9        | 1.31  | 0.78 | 1   | 5   |
| 10       | 1.26  | 0.67 | 1   | 4   |
| Total    | 17.43 | 6.86 | 10  | 39  |

\* The KCSS has a potential Total minimum score of 10 (when all 10 questions are scored 1), and Total maximum score of 50 (all questions scored 5). No reported stress would be 10.

**Table 4** Correlations with Kingston Standardized Behavioural Assessment (community form) (Plus NPT and NPL factors) with the Kingston Caregiver Stress Scale (Spearman's rho) and demographic and cognitive variables (Pearson's r).

| KCSS Question          | KSBA(comm) |           |           |
|------------------------|------------|-----------|-----------|
|                        | TOTAL      | NPT       | NPL       |
| 1                      | 0.683 *    | 0.550 *   | 0.589 *   |
| 2                      | 0.701 *    | 0.556 *   | 0.594 *   |
| 3                      | 0.600 *    | 0.508 *   | 0.532 *   |
| 4                      | 0.546 *    | 0.416 *   | 0.444 *   |
| 5                      | 0.523 *    | 0.512 *   | 0.463 *   |
| 6                      | 0.438 *    | 0.407 *   | 0.375 *   |
| 7                      | 0.582 *    | 0.483 *   | 0.460 *   |
| 8                      | 0.421 *    | 0.230 ns  | 0.438 *   |
| 9                      | 0.427 *    | 0.294 ns  | 0.402 *   |
| 10                     | 0.306 ns   | 0.176 ns  | 0.323 ns  |
| Care Group (1-7)       | 0.801 *    | 0.669 *   | 0.671 *   |
| Family Group (8-9)     | 0.444 *    | 0.270 ns  | 0.448 *   |
| Financial (10)         | 0.306 ns   | 0.176 ns  | 0.323 ns  |
| Total Score            | 0.802 *    | 0.645 *   | 0.691 *   |
| KSCAr Total Score      | -0.034 ns  | 0.019 ns  | -0.061 ns |
| mini-KSCAr Total Score | 0.120 ns   | 0.109 ns  | 0.111 ns  |
| MMSE Total Score       | 0.252 ns   | 0.344 ns  | 0.157 ns  |
| Age                    | -0.249 ns  | -0.211 ns | -0.238 ns |
| Years of Education     | 0.009 ns   | 0.091 ns  | -0.041 ns |
| Years of Illness       | 0.582 *    | 0.545 *   | 0.530 *   |

NPT: Neuropsychiatric Behaviour Factor; NPL: Neuropsychological Behaviour Factor;

\* Correlation Significance (2-tailed)  $p < 0.000$  with Bonferroni correction; Ns: Not Significant.



KCSS total scores were significantly correlated with years of illness ( $r_s=.58$ ). Using Cohen’s guidelines to interpret the strength of correlations in the social sciences [21], significant, large, positive correlations were obtained between the KCSS total score and overall behaviour change (i.e. KSBA(comm) total score) ( $r_s=.80$ ), as well as, between each of the NPL ( $r_s=.69$ ) and NPT ( $r_s=.65$ ) factor scores with the KSBA(comm) total score. In terms of the differentiation of specific areas of potential stress, a large correlation ( $r_s=.80$ ) was found between the KSBA(comm) total score and the KCSS Care-related activities score; moderate correlations were obtained between the KSBA(comm) total score and the other two KCSS groups (Family and Financial) [21].

To examine whether particular behavioural presentations differentially contributed to caregiver stress, correlations (Spearman’s rho) between the 12 KSBA(comm) domains and the KCSS total score were computed (Table 5). All but Misperceptions/Misinterpretations and Perseverations domain correlations were found to be significant ( $p < 0.05$ ), indicating a wide range of behaviour, rather than a few specific areas, were related to caregivers’ experience of stress.

**Table 5** Spearman rho correlations between the Kingston Standardized Behavioural Assessment (community form) domains and Kingston Caregiver Stress Scale scores.

| KSBA Domain      | KCSS Scores |            |           |           |
|------------------|-------------|------------|-----------|-----------|
|                  | Total       | Caregiving | Family    | Financial |
| Daily Activities | 0.768 *     | 0.758 *    | 0.470 *   | 0.305 ns  |
| Atten/Conc/mem   | 0.435 *     | 0.426 *    | 0.178 ns  | 0.260 ns  |
| Emotional        | 0.487 *     | 0.513 *    | 0.315 ns  | 0.079 ns  |
| Aggressive       | 0.478 *     | 0.509 *    | 0.211 ns  | 0.078 ns  |
| Misperceptions   | 0.272 ns    | 0.287 ns   | 0.139 ns  | 0.173 ns  |
| Paranoid         | 0.617 *     | 0.539 *    | 0.316 ns  | 0.144 ns  |
| Judgement        | 0.714 *     | 0.519 *    | 0.357 *   | 0.367 *   |
| Perseveration    | 0.123 ns    | 0.131 ns   | -0.060 ns | -0.070 ns |
| Motor Rest       | 0.518 *     | 0.388 *    | 0.294 ns  | 0.053 ns  |
| Sleep            | 0.631 *     | 0.512 *    | 0.260 ns  | 0.173 ns  |
| Motor Spatial    | 0.510 *     | 0.415 *    | 0.317 ns  | 0.148 ns  |
| Language         | 0.619 *     | 0.479 *    | 0.234 ns  | 0.058 ns  |

\* Correlation (Spearman’s rho) Significance (2-tailed)  $p < 0.000$  with Bonferroni correction; Ns: Not Significant.

### 3.5 Caregiver Variables and Caregiver Stress

As is commonly reported in the literature, the majority of the caregivers in this study were female (72%) and spouses (74%), with the remainder being adult children. In one case, the primary caregiver was a male, adult child (i.e., son). In a small number of cases the relationship to the patient was not known.

Caregiver gender was not found to be significantly different for KCSS total score or any of its three component scores. The relationship between caregiver connection to patient was more complex: spouse and child caregivers did not differ in terms of the level of overall stress reported; however there was a significant difference (Mann Whitney U test 2 tailed  $p < .004$ ) between stress levels in the Family Issues grouping where adult child caregivers reported significantly more stress than did spouses (See Table 6 and Table 7).

**Table 6** Subject demographics & variable scores by caregiver gender.

| Variable   | Male        |           |            |            | Female      |           |            |            |
|--|-------------|-----------|------------|------------|-------------|-----------|------------|------------|
| N  | 18          |           |            |            | 47          |           |            |            |
| Patient Gender: Male   | 1           |           |            |            | 34          |           |            |            |
| Female   | 17          |           |            |            | 13          |           |            |            |
|  | <b>Mean</b> | <b>SD</b> | <b>Min</b> | <b>Max</b> | <b>Mean</b> | <b>SD</b> | <b>Min</b> | <b>Max</b> |
| Years of Age   | 75.56       | 7.64      | 61         | 91         | 74.77       | 7.09      | 53         | 85         |
| Years of Education   | 14.11       | 2.26      | 11         | 18         | 13.18       | 3.84      | 6          | 21         |
| Years of Reported Illness  | 1.81        | 1.27      | 1          | 5          | 1.96        | 1.3       | 0          | 5          |
| Mini Mental State Examination (MMSE)                               | 27.38       | 1.54      | 24         | 30         | 27.35       | 1.7       | 22         | 30         |
| Kingston Standardized Cognitive Assessment Rev (KSCAr) TOTAL Score | 98.03       | 7.89      | 79         | 109.5      | 98.66       | 6.79      | 82.5       | 111.5      |
| KSCAr MEMORY Subtotal  | 32.58       | 5.68      | 22         | 43.5       | 33.06       | 3.9       | 24         | 41.5       |
| KSCAr LANGUAGE Subtotal  | 37.83       | 1.42      | 34         | 39         | 37.89       | 1.31      | 34         | 39         |
| KSCAr VISUAL-MOTOR Subtotal  | 27.61       | 3.87      | 18         | 31         | 27.7        | 3.4       | 17         | 31         |
| mini-Kingston Standardized Cognitive Assessment (mini-KSCAr)       | 33.53       | 5.77      | 24         | 30         | 33.13       | 4.37      | 25         | 41.5       |
| Kingston Standardized Behavioural Assessment (KSBA(comm))          | 14.28       | 11.07     | 2          | 42         | 13.38       | 8.38      | 1          | 37         |
| Neuropsychiatric Behaviours (NPT)                                  | 3.67        | 4.15      | 0          | 14         | 3.89        | 3.77      | 0          | 14         |
| Neuropsychological Behaviours (NPL)                                | 10.61       | 7.65      | 2          | 28         | 9.49        | 5.52      | 1          | 23         |
| Kingston Caregiver Stress Scale (KCSS)                             | 17.83       | 6.46      | 10         | 39         | 17.83       | 7.16      | 10         | 38         |
| KCSS Care Group (Q1 - Q7)  | 14.28       | 6.76      | 7          | 35         | 13.64       | 5.49      | 7          | 27         |
| KCSS Family Group (Q8 - Q9)  | 2.44        | 0.83      | 2          | 5          | 2.81        | 1.67      | 2          | 10         |
| KCSS Financial Group (Q10)   | 1.11        | 0.46      | 1          | 3          | 1.38        | 0.79      | 1          | 4          |

**Table 7** Subject demographics & variable scores by caregiver relationship to patient.

| Variable   | Spouse |      |      |       | Child |      |      |      |
|--|--------|------|------|-------|-------|------|------|------|
|  | Mean   | SD   | Min  | Max   | Mean  | SD   | Min  | Max  |
| N  | 46     |      |      |       | 16    |      |      |      |
| Patient Gender: Male   | 32     |      |      |       | 1     |      |      |      |
| Female   | 14     |      |      |       | 15    |      |      |      |
| Years of Age   | 74.91  | 6.61 | 61   | 91    | 78    | 6.62 | 68   | 85   |
| Years of Education †   | 14.23  | 3.6  | 6    | 21    | 11.13 | 2.09 | 8    | 15   |
| Years of Reported Illness  | 1.86   | 1.34 | 0.5  | 5     | 1.87  | 0.96 | 1    | 4    |
| Mini Mental State Examination (MMSE)                               | 27.62  | 1.51 | 24   | 30    | 26.56 | 1.8  | 22   | 30   |
| Kingston Standardized Cognitive Assessment Rev (KSCAr) TOTAL Score | 98.92  | 7.24 | 79.0 | 111.5 | 96.59 | 6.9  | 81.0 | 107. |
| KSCAr MEMORY Subtotal  | 32.97  | 4.38 | 22   | 44    | 32.03 | 4.47 | 23   | 38   |
| KSCAr LANGUAGE Subtotal  | 37.87  | 1.31 | 34   | 39    | 37.69 | 1.45 | 34   | 39   |
| KSCAr VISUAL-MOTOR Subtotal  | 28.09  | 3.22 | 17   | 31    | 26.88 | 3.69 | 19   | 31   |
| mini-Kingston Standardized Cognitive Assessment (mini-KSCAr)       | 33.27  | 4.58 | 22.0 | 42.5  | 32.41 | 5.29 | 21.0 | 41.0 |
| Kingston Standardized Behavioural Assessment (KSBA(comm))          | 13.5   | 9.19 | 1    | 42    | 11.44 | 6.83 | 2    | 24   |
| Neuropsychiatric Behaviours (NPT)                                  | 3.76   | 3.91 | 0    | 14    | 3.25  | 3.46 | 0    | 12   |
| Neuropsychological Behaviours (NPL)                                | 9.74   | 6.16 | 1    | 28    | 8.19  | 4.43 | 1    | 16   |
| Kingston Caregiver Stress Scale (KCSS)                             | 16.78  | 6.34 | 10   | 38    | 19.13 | 7.12 | 10   | 36   |
| KCSS Care Group (Q1 - Q7)  | 13.15  | 5.17 | 7    | 27    | 14.25 | 5.65 | 7    | 27   |
| KCSS Family Group (Q8 - Q9) ‡                                      | 2.46   | 1.44 | 2    | 10    | 3.25  | 1.39 | 2    | 6    |
| KCSS Financial Group (Q10)   | 1.17   | 0.56 | 1    | 4     | 1.63  | 0.93 | 1    | 4    |

#### 4. Discussion

The purpose of this paper was to explore caregiver stress associated with behavioural change in a dementia group, in order to offer a context into which caregiver stress might be at least partially understood. The clinical sample used in this study was judged to be typical of that reported in much of the caregiver stress literature: primarily (female) spouses (the remainder being adult

children), caring for an individual in their mid-seventies, living at home with significant cognitive and behavioural change associated with dementia of moderate severity.

The main finding of this study indicates that perceived stress in caregivers as identified by the KCSS is very highly correlated with the number of altered behaviours that one has to manage ( $r_s = 0.80$ ). This very strong correlation between the KCSS and the KSBA(comm) suggests an important relationship between the behaviour changes in dementia and caregiver stress. It could be said that the KSBA(comm) predicts stress in caregivers, or that high caregiver stress scores on the KCSS suggest that there will very likely be significant behavioural changes in the individual being cared for. Further, the findings show that the level of stress is greater for those who have been managing the changes for longer periods of time.

The relationship found in this study between patient behaviour change and caregiver stress seems to be the strongest reported so far in the literature. In a study by Hooker and colleagues [22] the authors used a number measures to assess dementia patients and their caregivers, including a modified version of the NPI [23] and the Perceived Stress Scale (PSS) [24], which is a general, non-dementia related stress scale. The correlation between the two scales was  $r = 0.37$ . In a meta-analysis of studies looking at patient disabilities and caregiver issues including burden, Pinquart and Sörensen [25] also report a  $0.37$  correlation between caregiver burden and patient problem behaviours. Despite the limitations of meta-analysis, the authors were able to say that “we conclude that caregivers are most burdened by care recipients’ behavior problems”.

We posit that the stronger relationship found in our study, is probably due to the fact that the KSBA(comm) detects a wider range of behaviour change than is assessed by the NPI (i.e. NPI as well as NPT behaviours), and that the KCSS is specifically tuned to the problems faced by caregivers of dementia patients, presented in a straightforward, simple fashion [13]. Indeed, one might consider that the high correlations between behaviour change and caregiver stress suggest the possibility of some third, latent construct, underlying both of these factors. However, we see that breaking down the behaviour changes into the NPI and NPT factors and then also into the 12 KSBA domains and separately relating these to each of the three components of caregiver stress (i.e., Caregiving, Financial, Family), yielded considerable variability in the strength of the obtained correlations ( $r_s = 0.13$  to  $0.76$  for Caregiving,  $r_s = -0.06$  to  $0.47$  for Family and  $r_s = -0.07$  to  $0.37$  for Finances), and demonstrated different aspects of behavioural change had varying effects on the distinct components of caregiver stress. The differentiation amongst components of caregiver stress reported here is consistent the conceptualizations used in enduring models of stress and coping reported in the literature, including that of Pearlin [26, 27].

The behavioural changes caregivers in the present study reported seeing in their family members included both the traditional neuropsychiatric behaviours as well as neuropsychological behaviours. That both types of behaviours were identified is a finding the authors have reported in previous research with the KSBA [5] and is noteworthy as it speaks to the contribution of behaviours for which pharmacologic interventions are typically used (Neuropsychiatric) as well as behaviours for which behavioural and environmental interventions are most appropriate (Neuropsychological). Thus, both classes of behaviour change contribute significantly to the overall experience of caregiver stress. Further, behaviour change in these patients tended to cover many areas (often 10 or more of the 12 KSBA domains Median = 5), reflecting the complexity of behaviour challenges that a caregiver must manage on a daily basis.

This study also reveals that people do distinguish between sources of stress and that they can assign a relative value to each. This is demonstrated by the fact that only 5 out the 80 response sets had the same numerical answers to all 10 KCSS questions. When this did occur, it was always a score of 1; presumably, in these cases the caregiver was expressing minimal, or no, perceived stress for all questions. The study also found that of the three broad sources of caregiver stress, the area related to specific caregiving tasks was associated with greater stress than family issues or financial issues. This compartmentalization of stress is useful to the clinician since it affords a clue as to where to start to deal with the problems facing a caregiver.

It is also noteworthy, that while gender of caregiver did not differentiate perceived level of stress, the nature of the caregiver relationship did differentiate the degree of stress experienced in the area of Family Issues, where adult children reported higher levels of family related stress than did spouses. This finding speaks to the need for more research into the reasons for this difference, such as: how care decisions are made / shared, and how the relationship the caregiver has with other family members is altered. It might also identify differential support needs depending on the type of caregiver.

## **5. Conclusions**

The KCSS is primarily a scale that allows family caregivers to express their level of stress in a relevant and easy format. It can also be used to monitor changes in stress levels over time, as the situation changes. This allows a clinician to not only follow the condition of the patient, but also to follow the effects of the care giving process on the family caregivers. The three components of the KCSS also provide a means of targeting those specific areas in most need of support and intervention.

The KSBA(comm) is particularly useful in providing clinicians a comprehensive and standardized behavioural analysis in only a few minutes. It is a simple and efficient way of collecting behavioural data that is broader in coverage than other currently available behaviour scales (e.g. the NPI) [23]. Indeed, there were differences in the patterns of the relationship of NPL and NPT factors with the different components of caregiver stress that supports the need for inclusion of a broader sample of dementia-related behaviours. Specifically, NPL behaviours were significantly correlated to both Care-related and Family Stress but not to the Finance Component, while NPT behaviours were only related to Care-related stress. Exclusion of the NPL behaviours would have resulted in missing the driver of family-related stress.

In this study, it was shown that knowledge of a patient's behavioural status is germane to understanding the caregiver experience. For example, where items related to the KCSS care giving issues are a salient source of caregiver stress, the KSBA(comm) provides a context into which behavioural / pharmacologic interventions can be targeted in a systematic fashion and the reasons for the stress can be more easily articulated and understood by the caregiver.

From the data it can also be shown that the average KCSS score for individuals with a KSBA(comm) score of 30 or more (the range where caregivers anecdotally declare that they are ready to place their family member in long term care) is 32.50 ( $SD = 4.27$ ), compared to a mean of 16.66 ( $SD = 5.96$ ) for those with a score of less than 30. This speaks to the considerable increase in stress that occurs around the time at which placement is being considered.

The results of this study underline the central role of behavioural symptoms in the stress load on caregivers. Therefore, any efforts to relieve the effects of these behaviour changes would be most welcome in the lives of caregivers, and also allow them to better care for their spouse or relative with dementia.

#### *Limitations of this Study and Future Research Directions:*

This study explored the relationship between dementia related behaviour change and caregiver stress. While the study addressed several important issues in clarifying this relationship, it also raises several interesting questions for future study: It did not examine the role of community supports available, usage patterns, and access. Further work to both replicate the findings reported here, and evaluate the role of community supports, would further advance the understanding of caregiver stress and provide direction to funding agencies providing services to persons with dementia and their caregivers.

Another goal for future research would be to explore the usefulness of the KSBA(comm) in other neurological disease groups. For example, the authors have evidence to suggest that the KSBA(comm) may be an effective tool for uncovering behavioural disturbances in depression [28]. The authors have been approached in regards to use of the KCSS for caregivers of other physical and mental diseases (e.g. cancer, intellectual disability).

The effectiveness of behavioural/pharmacologic interventions on stress could also be assessed to monitor or identify any resulting changes (increase or decrease) in stress over time.

It should be noted that all of the Kingston Scales can be downloaded free of charge from [www.kingstonscales.org](http://www.kingstonscales.org).

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### **Author Contributions**

Both authors were involved in the conceptualization of the project, data collection and each author completed portions of the data analysis; the first author had a primary role in the development of the manuscript while the second author contributed to the written revisions.

### **Competing Interests**

The authors have declared that no competing interests exist.

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