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.

Objective: 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)).

Design: 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 behaviourally assessed with the KSBA(comm). Each caregiver was given 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 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.

Introduction

Dementia and Caring Stress

Due to demographic shifts in the population, the elderly have significantly increased in number over recent years (and will continue to do so for some time to come), leading to dementia becoming an increasingly prevalent disease, and a growing health care problem (Hopkins R, 2010). Since there is currently no effective pharmacologic treatment for this disorder, compassionate care is the only path available to most families. This provision of care necessitates being able to constantly handle the resulting daily cognitive challenges and behavioural changes facing those with the diagnosis. Further, caring often falls upon the least able of the population, the elderly themselves; quite often elderly spouses. This type of "24/7" work is difficult, relentless and stressful (Sadik and Wilcock, 2003). This paper explores the link between care-related stress and behavioural change in dementia.

Behaviour as a Major Source of Stress

One aspect of care giving that makes it so potentially stressful, is having to deal with behavioural changes that are common in dementia (Sadik and Wilcock, 2003; Kilik, Hopkins, Day, Prince, Prince, Rows, 2008; Luxenberg, 2000; Finkel, 2001; Chan, Kasper, Black and Rabins, 2003). These 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. In addition, 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 (Sadik and Wilcock, 2003; Finkel, 2001; Pavlakovic, 2001; Bullock, and Hammond, 2003). 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 and timely types of supports and other transitional events such as placement in Long Term Care.

Kingston Caregiver Stress Scale (KCSS)

The Kingston Caregiver Stress Scale (KCSS) (see accompanying article - Hopkins & Kilik, 2016) was designed to quickly (in fewer than 5 minutes) allow a caregiver to express the amount of stress that he or she is feeling. 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. The items can be read to the caregiver in person, or even over the telephone. Since more than one person may be involved in an individual's care, each person may be assessed with the KCSS separately, and followed over time.

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 abnormal behaviours seen in dementia is the Kingston Standardized Behavioural Assessment (KSBA(comm)) (Hopkins, Kilik, Day, Bradford, & Rose, 2006). The KSBA(comm) 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 scales (that primarily assess only the neuropsychiatric behaviours), providing a more complete and realistic picture of the 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 slight behaviour changes for reasons other than dementia.

Methods

A group of 80 individuals from a geriatric psychiatry outpatient service who met the criteria for Dementia according to both DSM-IV (American Psychiatric Association, 1994) and NINCDS-ADRDA (McKhann, Drachman, Folstein, Katzman, Price, Stadlan, 1984) criteria as well as their caregivers participated in the study. Behaviour changes in the diagnosed patients were assessed through caregiver completion of the KSBA(comm). Patient cognition was also assessed using the Kingston Standardized Cognitive Assessment - Revised (KSCAr) (Hopkins, Kilik, Day, Rows, Hamilton, 2004), the mini-Kingston Standardized Cognitive Assessment (mini-KSCAr) (Hopkins, Kilik, 2013) - simply by extracting the appropriate sub-test scores, and the Mini Mental State Examination (MMSE) (Folstein, Folstein, McHugh, 1975). Caregiver stress was measured through caregiver completion of the KCSS.

Procedures

Dementia patients were recruited from the out-patient pool of individuals referred to our clinic by their primary care physicians for assessment. KSCAr (and mini-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.

Results

Patient Demographic Variables

The mean and standard deviation for the age, years of education, reported years of illness, and also cognition scores (MMSE, KSCAr and mini-KSCAr) are shown for the total sample of patients as well as for males and females separately, in Table 1. Patient gender was fairly evenly balanced (*males = 53%*). Average age was *74.69 (SD = 7.72)* years with no

significant difference between males and females (*range: 53 - 91*). Years of illness averaged nearly 2 years (*SD = 1.29*). Using 10 years as the typical duration of dementia, with the first 5 of those spent in the community and the latter half in Long Term Care (Hopkins, Kilik, Day, Rows, Tseng, 2004), the sample in this study was about midway through their tenure in the community. Patient gender was not found to be significant for any of the demographic variables.

Table 1 - *Subject Demographics & Variable Scores*

	All		Males		Females	
N	80		47		33	
Variable	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**
Years of Age	74.69	7.72	74.06	7.61	75.58	7.78
Years of Education	13.55	3.41	14.10	3.74	12.84	2.77
Years of Reported Illness	1.95	1.29	2.26	1.81	1.80	1.19
Mini Mental State Examination (MMSE)	27.18	1.84	27.23	1.94	27.07	1.70
Kingston Standardized Cognitive Assessment Rev TOTAL Score	98.45	7.72	99.58	7.24	96.88	8.10
KSCAr MEMORY Subtotal	33.07	4.75	33.60	4.12	32.33	5.44
KSCAr LANGUAGE Subtotal	37.76	1.46	37.78	1.43	37.73	1.50
KSCAr VISUAL-MOTOR Subtotal	27.62	3.72	28.20	3.30	26.82	4.10
mini-Kingston Standardized Cognitive Assessment (mini-KSCAr)	33.41	5.14	33.59	4.42	33.16	5.96
Kingston Standardized Behavioural Assessment (comm)	12.81	9.05	12.23	8.76	13.64	9.39
Neuropsychiatric Behaviours (NPT)	3.43	3.70	3.21	3.63	3.73	3.78
Neuropsychological Behaviours (NPL)	9.39	6.18	9.02	5.91	9.91	6.52
Kingston Caregiver Stress Scale (KCSS)	17.45	6.82	16.51	6.40	18.79	7.17
KCSS Care Group (Q1 - Q7)	13.59	5.71	12.74	5.03	14.79	6.36
KCSS Family Group (Q8 - Q9)	2.60	1.38	2.51	1.51	2.73	1.16
KCSS Financial Group (Q10)	1.26	0.67	1.26	0.63	1.27	0.71

No Male versus Female means are significant at p<0.05

Patient Cognitive Status

The MMSE, KSCAr and miniKSCAr scores were indicative of cognitive impairment (see Table 1). The MMSE mean fell below the adjusted age and education cut-off score of 28 (Crum, Anthony, Bassett, Folstein, 1993). Overall, patients fell into the "Moderate" range of dementia as given by their both their KSCAr and miniKSCAr scores (i.e. below the 2nd and 5th percentiles, of normal elderly, and at the 78th and 75th percentiles, for individuals diagnosed with dementia, respectively.

Patient Behavioural Status

Table 1 also shows the means and standard deviations of the KSBA(comm) and its two factors, Neuropsychological (NPL) and Neuropsychiatric (NPT) behaviour.   Caregivers 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 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) (Kilik et al., 2008), a majority (but not all) of the endorsed behaviours came from the neuropsychological domains at a ratio of roughly 3:1.

Caregiver Stress and Patient Behaviour

Table 2 shows the means and standard deviations for each of the 10 KCSS questions, the total score, and the three question groupings (i.e., Care, Family, Financial). Caregivers reported a mean KCSS total of *17.45* (*SD = 6.82*). Shown in Table 3 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). 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 (Cohen, 1988), significant, large, positive correlations were obtained between the KCSS total score and overall behaviour change (KSBA(comm) total score) (i.e. $r_s=.80$), as well as, between each of the NPL ($r_s=.69$) and NPT ($r_s=.65$) factor scores. In terms of the differentiation of specific areas of potential stress, a large correlation ($r_s=.80$) was also 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). *

Table 2 - *Kingston Caregiver Stress Scale (KCSS) Question and Group Scores*

Question	Mean	SD
1	2.01	1.09
2	2.00	1.04
3	1.90	1.14
4	1.58	0.96
5	1.78	1.06
6	1.75	1.03
7	2.60	1.18
8	1.29	0.67
9	1.31	0.78
10	1.26	0.67
Total	17.45	6.82
Care Group	13.59	5.71
Family Group	2.60	1.38
Financial Group	1.26	0.67

*According to Cohen (1988), correlation coefficients in the order of .10 are "small," those of .30 are "medium," and those of .50 are "large" in terms of magnitude of effect sizes).

Table 3 - *Correlations with Kingston Standardized Behavioural Assessment (Community Form) (Plus NPT and NPL Factors) with the Kingston Caregiver Stress Scale (KCSS) (Spearman's rho) and Demographic and Cognitive Variables (Pearson's r).*

KCSS Question	KSBA$_{(comm)}$		
	TOTAL	NPT	NPL
Q1	0.683 ‡	0.550 ‡	0.589 ‡
Q2	0.701 ‡	0.556 ‡	0.594 ‡
Q3	0.600 ‡	0.508 ‡	0.532 ‡
Q4	0.546 ‡	0.416 ‡	0.444 ‡
Q5	0.523 ‡	0.512 ‡	0.463 ‡
Q6	0.438 ‡	0.407 ‡	0.375 ‡
Q7	0.582 ‡	0.483 ‡	0.460 ‡
Q8	0.421 ‡	0.230 ¤	0.438 ‡
Q9	0.427 ‡	0.294 ¤	0.402 ‡
Q10	0.306 ¤	0.176 ¤	0.323 ¤
Care Group (Q1-Q7)	0.801 ‡	0.669 ‡	0.671 ‡
Family Group (Q8-Q9)	0.444 ‡	0.270 ¤	0.448 ‡
Financial (Q10)	0.306 ¤	0.176 ¤	0.323 ¤
KCSS TOTAL	0.802 ‡	0.645 ‡	0.691 ‡
KSCAr Total Score	-0.034 ¤	0.019 ¤	-0.061 ¤
mini-KSCAr Total Score	0.120 ¤	0.109 ¤	0.111 ¤
MMSE	0.252 ¤	0.344 ¤	0.157 ¤
Age	-0.249 ¤	-0.211 ¤	-0.238 ¤
Years of Education	0.009 ¤	0.091 ¤	-0.041 ¤
Years of Illness	0.582 ‡	0.545 ‡	0.530 ‡

MMSE *Mini Mental State Examination*
NPT   *Neuropsychiatric Behaviour Factor*
NPL   *Neuropsychological Behaviour Factor*
‡   *Correlation Significance (2-tailed) p< 0.000 with Bonferroni correction*
¤   *Not Significant*

Table 4 - *Kingston Caregiver Stress Scale (KCSS) Total Score Correlation (Spearman's rho) with Kingston Standardized Behavioural Assessment (Community Form) Domains*

KSBA Domains	Correlation with KCSS Total Score (Spearman's rho)
Daily Activities	0.768 ‡
Atten/Conc/Mem §	0.435 ‡
Emotional	0.487 ‡
Aggressive	0.478 ‡
Misperceptions/ Misidentifications	0.272 ¤
Paranoid	0.617 ‡
Judgement/Insight	0.714 ‡
Perseveration	0.123 ¤
Motor Restlessness	0.518 ‡
Sleep §§	0.631 ‡
Motor Spatial	0.510 ‡
Language	0.619 ‡

‡   *Correlation Significance (2-tailed) p< 0.000 with Bonferroni correction*
¤   *Not Significant*
§   *Attention/Concentration/Memory*
§§   *Sleep/Activity/Sundowning*

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 4).   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.

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.

Table 5 - *Subject Demographics & Variable Scores by Caregiver Gender*

Caregiver Gender	Male		Female	
N**	18		47	
Patient Gender: Male	1		34	
Female	17		13	
Variable	Mean	SD	Mean	SD
Years of Age	75.56	7.64	74.77	7.09
Years of Education	14.11	2.26	13.18	3.84
Years of Reported Illness	1.81	1.27	1.96	1.30
Mini Mental State Examination (MMSE)	27.38	1.54	27.35	1.70
Kingston Standardized Cognitive Assessment Rev TOTAL Score	98.03	7.89	98.66	6.79
KSCAr MEMORY Subtotal	32.58	5.68	33.06	3.90
KSCAr LANGUAGE Subtotal	37.83	1.42	37.89	1.31
KSCAr VISUAL-MOTOR Subtotal	27.61	3.87	27.7	3.40
mini-Kingston Standardized Cognitive Assessment (mini-KSCAr)	33.53	5.77	33.13	4.37
Kingston Standardized Behavioural Assessment (comm)	14.28	11.07	13.38	8.38
Neuropsychiatric Behaviours (NPT)	3.67	4.15	3.89	3.77
Neuropsychological Behaviours (NPL)	10.61	7.65	9.49	5.52
Kingston Caregiver Stress Scale (KCSS)	17.83	6.46	17.83	7.16
KCSS Care Group (Q1 - Q7)	14.28	6.76	13.64	5.49
KCSS Family Group (Q8 - Q9)	2.44	0.83	2.81	1.67
KCSS Financial Group (Q10)	1.11	0.46	1.38	0.79

No means are significant at p<0.05
*** Note that N's do not all add to 80 as in some cases gender &/or relationship were not reported.*

Table 6 - *Subject Demographics & Variable Scores by Caregiver Relationship to Patient*

Relationship of Caregiver to Patient	Spouse		Child	
N	46		16	
Patient Gender: Male	32		1	
Female	14		15	
Patient Variables	**Mean**	**SD**	**Mean**	**SD**
Years of Age	74.91	6.61	78.00	5.62
Years of Education ***	14.23	3.60	11.13	2.09
Years of Reported Illness	1.86	1.34	1.87	0.96
Mini Mental State Examination (MMSE)	27.62	1.51	26.56	1.80
Kingston Standardized Cognitive Assessment Rev Total	98.92	7.24	96.59	6.9
KSCAr MEMORY Subtotal	32.97	4.38	32.03	4.47
KSCAr LANGUAGE Subtotal	37.87	1.31	37.69	1.45
KSCAr VISUAL-MOTOR Subtotal	28.09	3.22	26.88	3.69
mini-Kingston Standardized Cognitive Assessment	33.27	4.58	32.41	5.29
Kingston Standardized Behavioural Assessment (comm)	13.5	9.19	11.44	6.83
Neuropsychiatric Behaviours (NPT)	3.76	3.91	3.25	3.46
Neuropsychological Behaviours (NPL)	9.74	6.16	8.19	4.43
Kingston Caregiver Stress Scale (KCSS)	16.78	6.34	19.13	7.12
KCSS Care Group (Q1 - Q7)	13.15	5.17	14.25	5.65
KCSS Family Group (Q8 - Q9) ****	2.46	1.44	3.25	1.39
KCSS Financial Group (Q10)	1.17	0.56	1.63	0.93

***   *Years of Education significant t-test (2 tailed) p < 0.05*
****   *KCSS Family Group significant Mann-Whitney U test (2 tailed) p < 0.004*

Discussion

The purpose of this paper was to explore caregiver stress associated 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 likely be significant behavioural changes in the individual being cared for.

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 (Hooker, Bowman, Padgett-Coehlo, Lim, Kaye, Guariglia, Li, 2002) the authors used a number measures to assess dementia patients and their caregivers, including a modified version of the NPI (Cummings, 1997) and the Perceived Stress Scale (PSS) (Cohen, Kamarck, Mermelstein, 1983), 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 (Pinquart, and Sörensen, 2003) 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. NPL 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.

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 (Kilik et al., 2008) 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 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. This compartmentalization of stress is useful to the clinician since it gives one 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 relationships the caregiver has with other family members is altered. It might also identify differential support needs depending on the type of caregiver.

Clinical Applications

The KCSS is primarily a scale that allows a family caregiver 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 follow the effects of the care giving process on the family caregivers. The three components of the KCSS also provide a means of targeting 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, (Cummings, 1997). 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 authors' previously collected scale data (unpublished) it was 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 *31.50 (SD = 5.68)*, compared to a mean of *16.67 (SD = 6.33)* for those with a score of less than 30.

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. It did not examine the role of community supports available, usage patterns, and access. Further work to both replicate the finding reported here and evaluate the role of community supports would further advance the understanding of caregiver stress and give 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 (Hopkins, David, Kilik, 2014). The authors have been approached in regards to use of the KCSS for caregivers of other physical and mental diseases (e.g. cancer, mental retardation).

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.

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