

THE KINGSTON CAREGIVER STRESS SCALE (KCSS)

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Abstract

The Kingston Caregiver Stress Scale is a scale designed to allow a family caregiver to express the level of stress that he or she is currently feeling around the duties of dementia care. The scale is designed for community living lay caregivers, not institutional care staff. Some caregiver stress scales try to determine how much stress caregivers “should” be experiencing by assigning stress values to caregiving activities. There is evidence that these group scores do not correlate well with how much stress an individual caregiver experiences. Also, the score for one person probably does not mean the same thing as the same score for another. The KCSS takes a more direct approach by asking how much stress the caregiver feels. The scale can also be used to monitor change in an individual caregiver’s stress over time. Evidence suggests that caregivers can attribute their stress to different sources. Accordingly the KCSS consists of a set of ten questions that are grouped into 3 categories: care giving, family, and financial issues. Means and correlations are provided.

Keywords: caregiver stress, Kingston Scales, behaviour scales, dementia care

Introduction

The purpose of the Kingston Caregiver Stress Scale (KCSS) is primarily to allow a family caregiver to express his or her level of perceived stress. The caregiver is the individual who provides care on a day-to-day basis in the home; usually a spouse or other relative. It is unlike “burden scales” in that it does not attempt to measure care load, or suggest how much stress one *should* be experiencing. The KCSS can also be used to monitor changes, in stress levels over time, as the caregiver’s situation changes. The scale is designed for community living lay caregivers, not institutional care staff, as in that case, the scale would require different questions, many pertaining to working conditions.

The Kingston Caregiver Stress Scale (KCSS) was designed to quickly (in fewer than 5 minutes) allow a caregiver to express the amount of stress that he or she is feeling. Caregiver stress has been extensively discussed in the literature, and will not be repeated here. Many stress related scales have been created (e.g. Kaufer, Cummings, Christine, Bray, Castellon, Masterman, MacMillan, Ketchel, & DeKosky, 1998; Greene, Smith, Gardiner, & Timburg, 1982; Zarit, Reever, & Bach-Peterson, 1980), and in the past, a number of “burden scales” have also been created (e.g. Zarit, Reever, & Bach-Peterson, 1980). By determining the type and intensity of stress related factors that an individual caregiver is exposed to, burden scales try to determine how much stress an individual should be experiencing. However, this does not take into account the personality or capabilities (to handle difficult behaviour) of the caregiver, and therefore does not necessarily reflect their true stress levels. The authors favour the more direct approach of simply asking “how much stress do you currently feel”. Instead of asking this in one simple question, the KCSS divides caregiver stress into a more comprehensive set of ten questions that represent different potential sources of stress to the lay caregiver: care related feelings, family matters, and any financial stress. For each question, the degree of stress is rated on a 1 to 5 anchored scale, ranging from (1) Feeling Fine/No stress (Coping fine / no problems), (2) Some stress, (3) Moderate stress, (4) A lot of stress, to (5) Extreme Stress (feeling “at the end of rope”, health at risk). Therefore the total score can potentially range from 10 to 50. The ten KCSS questions are as follows.

Care Group

- 1 Are you having feelings of being overwhelmed, over worked, and/or over burdened?
- 2 Has there been a change in your relationship with your spouse/relative?
- 3 Have you noticed any changes in your social life?
- 4 Are you having any conflicts with your previous daily commitments?
- 5 Do you have feelings of being confined or trapped by the responsibilities?
- 6 Do you ever have feelings related to a lack of confidence in your ability to provide care?
- 7 Do you have concerns regarding the future care needs of your spouse/relative?

Family Group

- 8 Are you having any conflicts within your family over care decisions?
- 9 Are you having any conflicts within your family over the amount of support you are receiving in providing care?

Financial

- 10 Are you having any financial difficulties associated with care giving?

Since perceived stress is a very subjective concept, and there is no evidence to suggest that one person's perceived level of stress is the same as someone else's (i.e. one person's score of 3 does not necessarily represent the same level of stress as another person's 3); the scores are ordinal, with defined anchors.

As noted above, 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 KCSS may be given to the caregiver for completion, or the items can be read to them 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.

Methods

For calculation of the basic KCSS statistics a group of 115 individuals suffering from dementia as defined by the DSM-IV (American Psychiatric Association, 1994) were drawn from archival data from our practise at a regional geriatric psychiatric clinic. Patients were recruited from the out-patient pool of individuals referred to our clinic by their primary care physicians for assessment. Caregivers, usually spouses or children, completed the KCSS. Required ethics approval was obtained and informed consent from the patient was obtained in all cases.

Results

For each of the 10 KCSS questions, and the care groups, Table 1 lists the mean, standard deviation, minimum, and maximum score of the sample.

Table 1 - *KCSS means, standard deviations, and attained minimum and maximum scores.*

Questions	Mean	SD	Min	Max
1	2.28	1.23	1	5
2	2.14	1.16	1	5
3	2.14	1.22	1	5
4	1.55	1.02	1	5
5	1.65	1.04	1	5
6	1.97	1.16	1	5
7	2.25	1.24	1	5
8	1.75	1.20	1	5
9	1.41	0.87	1	5
10	1.69	1.16	1	5
Total Score	18.79	7.80	10	40
Care Group	13.96	5.83	7	35
Family Group	3.15	1.87	2	10
Financial Group	1.69	1.16	1	5
n = 115				

Table 2 - the correlations between the 10 KCSS questions and care groups.

	Q 1	Q 2	Q 3	Q 4	Q 5	Q 6	Q 7	Q 8	Q 9	Q 10
Question 2	0.73									
Question 3	0.67	0.68								
Question 4	0.49	0.31	0.32							
Question 5	0.4	0.28	0.37	0.71						
Question 6	0.59	0.51	0.53	0.46	0.37					
Question 7	0.2	0.29	0.20	0.30	0.37	0.32				
Question 8	0.65	0.65	0.63	0.11	0.04	0.59	0.01			
Question 9	0.49	0.44	0.48	0.23	0.18	0.29	0.25	0.53		
Question 10	0.47	0.54	0.53	0.17	0.07	0.37	-0.02	0.76	0.46	
Total Score	0.83	0.8	0.8	0.59	0.54	0.75	0.43	0.74	0.63	0.65
Groups	Family	Financial	Total							
Care	0.62	0.41	0.96							
Family		0.65	0.8							
Financial			0.61							

Discussion

The purpose of this paper is to introduce the Kingston Caregiver Stress Scale as a tool to help describe the experience of someone caring for a person with dementia. As can be seen from the data, even though the range on all 10 questions is from 1 to 5, the question means vary from 1.41 (Q9) to 2.28 (Q1). This level of stress is what one might expect of caregivers of patients with mild to moderate dementia, living in the community. Even though the question range was 1 to the maximum 5, the Total Score range was 10 to 40, as no caregiver indicated a 5 for all 10 questions.

This data 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 8 out the 115 response sets had the same numerical answer to all 10 KCSS questions. In these eight cases, it was always a score of 1; presumably, in these caregivers were expressing minimal, or no, perceived stress. 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.

Validity and Reliability

Inter-rater and Retest Reliability

Rating scales are usually described in terms of their validity (does the scale measure what it claims to measure) and reliability (does it do this consistently). For scales that measure such concepts as cognitive abilities or personality traits, inter-rater (a measure of the agreement between two or more raters) and test-retest reliability (the stability of a set of test scores over a defined period of time) are often described. For a scale like the KCSS that encourages an individual to express his or her personal perceived stress levels, which is a measure of one's personal feelings, these types of reliability are both difficult to measure or not even appropriate.

Internal Reliability

Internal reliability (internal consistency) is concerned with the extent to which items of a scale are correlated with each other. Coefficient alpha (Cronbach, 1951) is an index of the average intercorrelation of a set of scores (Nunnally, 1978). This calculation was made based on 115 administrations of the KCSS to outpatients referred to our geriatric psychiatry programme and yielded a value of $\alpha = 0.88$ suggesting a high degree of internal reliability.

Since it was hypothesized that specific subgroups of items might differ with respect to their degree of internal reliability. The sub-scales of the KCSS as defined above in terms of item content, were also examined. For example, the Care sub-scale is comprised of items believed to be relevant to the care responsibilities of caregivers. Coefficient alpha was calculated for each of the sub-scales, and are: Care group $\alpha = 0.85$, Family group $\alpha = 0.75$. The Financial group consisting of a single question does not allow for such a calculation.

Content or Face Validity

Content or face validity is a non-statistical type of validity that involves "the systematic examination of the test content to determine whether it covers a representative sample of the behavior domain to be measured" (Anastasi & Urbina, 1997 p. 114). A simple examination of the questions reveals that ten facets of caregiver stress are covered, allowing one to conclude that the KCSS has content validity.

Criterion-related Validity

Criterion-related validity concerns the relationship between two measures. One of the major factors that leads to caregiver stress is the behavioural load that one is caring for (Luxenberg, 2000; Finkel, 2001; Chan, Kasper, Black and Rabins, 2003; Sadik and Wilcock, 2003; Kilik, Hopkins, Day, Prince, Prince, Rows, 2008). Therefore, the stress reflected in the KCSS is most likely produced by the deterioration of the patient's behavioural state. This behavioural change has been measured by various authors, e.g. Hooker, Bowman, Padgett-Coehlo, Lim, Kaye, Guariglia, Li, 2002; Pinquart, and Sørensen, 2003. Kilik and Hopkins (2016) also studied the relationship between caregiver stress and behaviour change, and found the correlation between the KCSS and the Kingston Standardized Behaviour Scale (Community Form) [KSBA_(comm)] (Hopkins, Kilik, Day, Bradford, Rows C. 2006), a measure of behavioural change, was quite high i.e. $\rho = 0.80$ (Spearman's ρ). This suggests that caregiver stress rises as behavioural changes in patients with dementia increases. (see accompanying article "The Relationship Between Caregiver Stress and Behavioural Changes in Dementia" - Kilik & Hopkins, 2016).

Predictive validity

Predictive validity refers to the degree to which a measure predicts a relationship between what is measured and something else; predicting whether or not the other thing will happen in the future. This type of validity is somewhat difficult to assess in terms of caregiver stress, but as noted above by the very high KCSS KSBA_(comm) correlation, increases in caregiver stress would predict increases behaviour changes in the individual being cared for, or conversely, increases behaviour changes would predict increases in caregiver stress.

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 KCSS may be used in research projects where an indication a caregiver well being is considered a factor (e.g. Pitsikali, Galanakis, Varvogli, & Darviri, 2015). 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.

The KCSS is available in several languages in addition to English (e.g. French, Hebrew, Chinese, Greek - see www.kingstonscales.org/scales-in-other-languages.html) and like all of the Kingston Scales, the KCSS may be used free of charge, but may not be altered without the permission of the authors.

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