UPDATED

KINGSTON SCALES

Kingston Caregiver Stress Scale

ADMINISTRATION AND INTERPRETATION MANUAL

The Kingston Scales and Manuals can be freely downloaded from:
www.kingstonscales.org ➜ Caregiver Stress
or email: kscales@queensu.ca

Purpose

The Kingston Caregiver Stress Scale (KCSS) is designed to allow a family member (or other) caregiver to express his/her level of perceived stress, as it relates to caregiving. It 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. The caregiver is the individual who provides care on a day-to-day basis in the home; usually a spouse or other relative, but may be another individual as well. The straightforward structure and plain language used in the KCSS make it applicable to a wide range of disorders and caregiving situations.

Administration and Scoring

The scale may be handed to the caregiver for completion, or one can read the items to the caregiver and ask for a response. Therefore it can be administered over the telephone or internet. Since more than one person may be involved in an individual's care, each person can be interviewed separately and followed over time with the KCSS.

To administer, say to the caregiver **"Some people report feelings of stress surrounding certain aspects of care giving. To what extent, if any, do these apply to you in your role of care giving to your spouse (or relative, etc.)? Using a 5 point rating scale, where 1 indicates no stress and 5 indicates extreme stress, indicate the extent of the stress or frustration you feel surrounding the following issues."**

Scoring the KCSS is easy; the Total score is simply the sum of the indivual's ten responses.

Interpretation

Some caregiver stress scales try to determine how much stress an individual should be experiencing.[1] Other scales use the term "Caregiver Burden" to address the experience of the caregiver. This term has been criticized by caregivers for its negative tone and inherent suggestion that the individual IS a burden. [2,3] In an attempt to avoid these issues, the KCSS takes a more direct approach by asking how much stress the caregiver actually feels. We have observed that caregivers are able to compartmentalize their stress and attribute it independently to various sources. So instead of asking one simple question, "how much stress do you feel", we have derived, from a review of the literature[4], a set of ten questions that represent potential sources of stress to the lay caregiver.

These ten responses can be further divided into 3 categories, namely: "care giving", "family issues", and "financial problems", hence, the three sub-divisions (or domains) of the scale. Parsing out the sources of stress (i.e., examining each of these three domains) provides a clinical opportunity to begin discussions around interventions. Paired with a measure of behavioural change, such as with the Kingston Standardized Behavioural Assessment ($KSBA_{(comm)}$) (see comment below regarding the Relationship Between Caregiver

Stress and Dementia-related Behaviour), a caregiver can determine how the experienced stress can be driven by particular behavioural changes that, in turn, affect the stress domains differentially. This combined set of data can be a way to begin conversations about introducing new supports, or beginning the conversation about placement noting the degree of behavioural change and the resulting effects on stress.

Clinically, the KCSS offers the opportunity for the clinician to identify a starting point for interventions with caregivers. Indeed, each of the 10 KCSS questions suggests a possible strategy to implement or a way to further clarify the experience. For example, Question #3 "Have you noticed any changes in your social life" might begin a conversation about social connections, current/lost friendships, which social connections might be easiest to establish, and which might be most meaningful. Similarly, for question #9: "Are you having any conflicts with your family over the amount of support you are receiving in providing care?" this might lead to a discussion about who in the family is providing the support, who would the caregiver like to have more or different support from, and what is the other family members' understanding of the degree of impairment of the individual being cared for. In this way, the tool becomes not only a way to describe or characterize the stress that the caregiver is experiencing, but also begins to shape practical ways to address the stress.

[1] e.g., The Caregiver Self Assessment questionnaire (American Medical Association. ©2015 Health in Aging Foundation. https://seniorsnetworkcovenant.ca/wp-content/uploads/Screening-for-Stress-and-Burden-in-Caregivers-of-Seniors-Oct-2018.pdf

[2] e.g., Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Gerontologist, 20(6), 649–655.doi:10.1093/geront/20.6.649

[3] e.g.,ttps://www.thecaregiverspace.org/better-term-caregiver-burden/#:~:text=You've%20heard%20the%20term,caring%20for%20is%20a%20burden.

[4] e.g., Lawton, Kleban, Moss, Rovine & Glicksman. (1989) "Measuring caregiving appraisal." Journal of Gerontology, **44**, 61-71.

[4] e.g., https://www.sciencedirect.com/science/article/abs/pii/S0020748912003367

[4] e.g., https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7644552/pdf/main.pdf

[4] e.g., https://seniorsnetworkcovenant.ca/wp-content/uploads/Screening-for-Stress-and-Burden-In-Caregivers-of-Seniors-Oct-2018.pdf

Why There Is No “0” or “NA” on the KCSS

It should be noted that the lowest value on the scale (Feeling NO Stress) is “1” and not “0”. This is done to aid in mathematical calculations, as a value of zero can be problematic if, for example, division is required. Being a Likert scale, the data are ordinal, and zero has no absolute meaning.

It should also be noted that the KCSS has no "n/a " (not applicable) option on the form. The reason for this is, for example, on the family questions (numbers 8 and 9), there could be no stress due to reasons such as "all relatives dead", "closest relative is living on another continent ", "estranged from family", or "have not talked to family in years". Such caregivers might be experiencing no stress, but for different reasons, and if "n/a" was available, all might choose it. On the other hand, you may have individuals with very active and supportive families who really do not produce stress for the caregiver. In fact, in many cases, they may help relieve it. There are obviously differences between these caregivers and their exact sources of stress.

Ultimately, there may be many reasons that an item does not completely apply, with many gradations of relevance. These gradations are best accounted for, or studied, in experiments where appropriate collateral information is collected along with the KCSS, to make analysis more meaningful. A simple "n/a" would not really be adequate to cover all possibilities. But, for the scale's purpose, it does not matter. While there are always some sources of error, the current configuration would seem to provide the least.

A Note of Caution

As we are assessing a subjective condition, i.e. perceived stress, a score for one person probably does not mean exactly the same thing as a similar score for another. What do the differences between “no stress”, “some stress” and “moderate stress” on a Likert scale really mean? One cannot assume that the differences between responses are equidistant even though the numbers assigned to those responses are. For example, what exactly is the meaning of an average of say “3.2", or a standard deviation of “1.9". Therefore, the following tables, containing data applicable to the KCSS, should be interpreted with some caution, and are only provided as a guide as to what might be expected with the average dementia caregiver.

While the KCSS was designed for caregivers of seniors with dementia, it has reportedly been used with a variety of caregiver groups, and has consistently been found to be sufficiently robust to speak to the issues relevant to caregiving more generally. This is undoubtedly partly due to the scale’s use of neutral language, making it applicable to a variety of situations. Some of these other areas include caregivers of adults and children with disabilities, pediatric cancers, and a variety of other neurological conditions.

As mentioned above, the KCSS has been used in diverse caregiving situations, and in a few cases we have been asked whether slight wording changes could be made to the scale. Such as in the case where the person being cared for is not a “spouse” or “relative” but maybe a “ward” or some other non relative, and it has been requested that

"spouse/relative" be changed accordingly. Additional minor changes of this fashion might be acceptable. We would request that before such changes are made that one contacts the authors to discuss such changes. Major changes to the scale are not permitted. The current version incorporates some of the changes that have been suggested over the years, to accommodate the broad range of users who have expressed an interest outside the field of dementia.

It should also be noted that the data shown below, and the subjective classification of stress levels shown in Table 6, are based on Kingston area residents caring for dementia (mostly Alzheimer's) patients. Caregivers in **other parts of the world** and/or caregivers of **other conditions** may vary considerably.

The Relationship Between Caregiver Stress and Dementia-related Behaviour

(see Kilik & Hopkins, 2019)

An important relationship that has emerged in working with the KCSS is that of caregiver stress and the behavioural changes associated with dementia. These changes as measured by the Kingston Standardized Behavioural Assessment ($KSBA_{(comm)}$) are outlined in Table 3. (See KCSS references below)

Some Abbreviations Used Below

KCSS = Kingston Caregiver Stress Scale
$KSCAr^{+Drive}$ = Kingston Standardized Cognitive Assessment - Revised +Drive Score
*Brief*KSCAr = *Brief* Kingston Standardized Cognitive Assessment - Revised
mini-KSCAr = mini-Kingston Standardized Cognitive Assessment - Revised
$KSBA_{(comm)}$ = Kingston Standardized Behavioural Assessment - Community Form
$KSBA_{(ltc)}$ = Kingston Standardized Behavioural Assessment - Long Term Care Form
MMSE = Mini Mental State Examination
Age = Current age of subject
Education = Years of education
NPT = Neuropsychiatric Behaviours
NPL = Neuropsychological Behaviours
Min = Minimum Observed Score
Max = Maximum Observed Score

Table 1 - Questions, Subsection Score Means and Standard Deviations

KCSS Questions (n = 115)

	1	2	3	4	5	6	7	8	9	10	Total
Mean	2.28	2.14	2.14	1.55	1.65	1.97	2.25	1.75	1.41	1.69	18.79
sd	1.23	1.16	1.22	1.02	1.04	1.16	1.24	1.20	0.87	1.16	7.80
Min	1	1	1	1	1	1	1	1	1	1	10
Max	5	5	5	5	5	5	5	5	5	5	40

KCSS Subsections

	Mean	sd	Min	Max
Care Factor 1-7	13.96	5.83	7	35
Family Factor 8-9	3.15	1.87	2	10
Financial Factor	1.69	1.16	1	5

Table 2 - Demographics

Variable (n = 80)	Mean	sd
Males = 46 Females = 34		
Age	74.69	7.72
Years of Education	13.55	3.41
Years of Reported Illness	2.16	1.87
MMSE	27.18	1.84
KSCAr^{+Drive} Total	98.45	7.72
Memory	33.07	4.75
Language	37.76	1.46
Visual-Motor	27.62	3.72
***Brief*KSCAr**	39.23	5.78
mini-KSCAr	33.41	5.14
KSBA$_{(comm)}$	12.81	9.05
NPT Behaviours	3.43	3.70
NPL Behaviours	9.39	6.18
KCSS	17.45	6.82

Table 3 - KCSS x KSBA$_{(comm)}$ Correlations (Spearman's rho)

KSBA Domains	KCSS Total	Care Total	Family Total	Financial Total
Daily Activities	0.77	0.83	0.43	0.24
Atten/Conc/mem	0.44	0.28	0.06	0.13
Emotional	0.49	0.59	0.34	0.03
Aggressive	0.48	0.45	-0.06	0.04
Misperceptions	0.27	0.28	0.28	0.39
Paranoid	0.62	0.53	0.20	0.15
Judgement	0.71	0.72	0.33	0.34
Perseveration	0.12	-0.03	-0.14	-0.15
Motor Rest	0.52	0.57	0.45	0.25
Sleep	0.63	0.60	0.38	0.22
Motor Spatial	0.51	0.55	0.27	0.17
Language	0.62	0.56	0.37	0.26
TOTAL	**0.80**	**0.80**	**0.44**	**0.31**
NPT	0.65	0.67	0.27	0.18
NPL	0.69	0.67	0.45	0.32

Table 4 - KCSS Internal Correlations (Spearman's rho)

	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	0.40	0.28	0.37	0.71						
Question 6	0.59	0.51	0.53	0.46	0.37					
Question 7	0.20	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	0.00	0.76	0.46	
Total	0.83	0.80	0.80	0.59	0.54	0.75	0.43	0.74	0.63	0.65
Care	0.81	0.80	0.67	0.66	0.79	0.62	0.71	0.47	0.53	0.27
Family	0.47	0.48	0.42	0.45	0.38	0.41	0.46	0.94	0.90	0.47
Financial	0.27	0.32	0.18	0.17	0.25	0.13	0.12	0.48	0.52	

	Total	Care	Family
Care	0.99		
Family	0.62	0.55	
Financial	0.39	0.27	0.55

Table 5 - Internal Consistency

	Full Scale	Care Group	Family Group
Coefficient alpha (Cronbach)	*α = 0.89*	*α = 0.88*	*α = 0.88*

Note: The Financial group consisting of a single question does not allow for *α* calculation.

Table 6 - KCSS Subjective Level of Stress *

	Mild	Moderate	Severe
Score	10 - 14	15 - 23	24 - 50

* Approximately +/- ½ sd

Profile

The caregiver circles the number corresponding to the stress level associated with each item. The circles can also be connected with a line for additional visual emphasis. See Figure 1.

KCSS References

Kilik LA, & Hopkins RW. (2019) "The Relationship between Caregiver Stress and Behavioural Changes in Dementia." OBM Geriatrics, **3**(2):1-16 doi:10.21926/obm.geriatr.1902052.

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Figure 1 - KCSS Scored Example