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The Stroke Caregiver Unmet Resource Needs Scale: Development and Psychometric Testing

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Stroke is a major cause of serious long-term disability. Approximately 795,000 strokes occur each year in the United States and over 6 million survivors are living with stroke (Lloyd-Jones et al., 2010). Seventy to eighty percent of survivors are discharged to a community setting, usually in care of a family member (Stineman et al., 2001), whose **life** may be considerably altered by the sudden demands of caregiving (Covinsky et al., 1994). Evidence of the extent of stroke disability is noted in a report of a six-month prevalence of 26% and 35%, respectively, for severe disability and depression among older stroke survivors (Kelly-Hayes et al., 2003). Furthermore, functional levels have been shown to decline annually from six months to five years post-stroke, adding further to the stressors, burden, and needs of caregivers (Dhamoon et al., 2009).

Family members unexpectedly and quickly assume the caregiving role after a stroke often expressing unmet needs and problems related to inadequate information and resources. Among these needs are training on survivor care skills, information and resources on stroke prevention and recovery, survivor and caregiver socio-emotional needs, and financial and

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family issues (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; MacIsaac, Harrison, & Godfrey, 2010). The constellation of problems and needs has been implicated in negative outcomes such as increased stress, burden, injury, anxiety, and depression (Hartke & King, 2002; Hinojosa & Rittman, 2009; King, Ainsworth, Ronen, & Hartke, 2010; Mackenzie et al., 2007; Perry & Middleton, 2011; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998). Identifying and resolving unmet needs can be an important step in promoting positive caregiver (CG) adaptation. Studies focused on assisting CGs with problem-solving and unmet needs have resulted in improvement in one or more adaptive outcomes (Bakas et al., 2009; Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; King, Hartke, & Denby, 2007).

With few exceptions, stroke CG unmet needs, other than information, have been assessed in cross-sectional designs, limiting knowledge of needs over time. Conflicting findings were reported for the few studies of needs over time. A qualitative study examined supportive services for 13 caregiver-survivor dyads 3 weeks and 3 months post-discharge (Ski & O'Connell, 2007). The most frequent unmet needs were delays in home rehabilitation and lack of communication from hospital clinicians. No change was found in unmet service needs over time. Studies comparing needs pre-discharge and two to 6 weeks post-discharge reported contrasting findings, with one indicating a non-significant decrease ($P < .06$) (Mackenzie, et al., 2007) and the other a significant decrease (Mak, Mackenzie, & Lui, 2007). Based on CG recall for the first two years post-discharge, King and Semik (2006) found that needs, such as learning care/skills and managing uncertainty, were limited mainly to the first months caregiving. Other needs extended through two years (financial advice, counseling), or arose post-discharge (King & Semik, 2006).

Reviews of research on caregiving unmet needs indicated needs required tailoring interventions and consensus that unmet needs occur in multiple life domains (Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2010; MacIsaac, et al., 2010). Hafsteinsdottir et al. (2010) reported **that** several studies on information needs **found** change over time. The reviewers concluded that a reliable, valid measure is needed to assess potential needs over time.

Most findings on unmet needs have been based on semi-structured questionnaires or listings of needs (Bakas, et al., 2002; Davis & Grant, 1994; King & Semik, 2006) or did not include domains considered essential for stroke CGs (Kristjanson, Atwood, & Degner, 1995). Other measures were lengthy (Serio, Kreutzer, & Witol, 1997), not subjected to psychometric testing (Houts, Doak, Doak, & Loscalzo, 2006; Mackenzie, Holroyd, & Lui, 1998), or were not translated into English (Shyu, 2000).

A psychometrically sound measure has potential for use clinically and in intervention studies to promote CG and survivor adaptation. Therefore, the purposes of the current study were: 1) to develop a reliable and valid measure of unmet resource needs, and 2) to describe the unmet resource needs of CGs of stroke survivors over time. The hypotheses were that the Unmet Resource Needs (URN) scale will show evidence of structural construct validity, internal consistency reliability, and content and concurrent validity.

Conceptual Model

A stress and coping model guided development and testing of the URN (Moos & Schaefer, 1993). The model proposes that stressful events trigger coping processes to restore balance in the individual's life. Contextual factors (background, illness, and social environmental factors) influence the coping process (appraisal [threat], coping [problem-solving], resource needs and use), which in turn, influences physical and socio-emotional adaptation outcomes. Moos and Schaefer emphasized the use of internal and external resources in coping with a health crisis, such as the sudden onset of a severe physical disability.

Methods

Design

We used a longitudinal, exploratory, descriptive design to test the reliability and validity of the URN measure. The study was approved by the institutional review boards for two freestanding rehabilitation hospitals and rehabilitation units in two hospitals.

Procedures

Participants were enrolled in a larger intervention study to improve stroke caregiver adaptation. Subject selection criteria were: 1) planned discharge of survivor to home; 2) primary CG living with the survivor; 3) CG not currently in a support group or therapy; 4) access to a telephone and sufficient hearing to use a phone; 5) survivor and CG age 21 or older, 6) CG depression screening score over 9 on the Center for Epidemiologic Studies-Depression (CES-D) (Radloff, 1977), **which has demonstrated** future depression risk (King, Shade-Zeldow, Carlson, & Roth, 1998). A primary CG was defined as one who supervised, assisted with, or managed care.

Recruiters contacted family members during acute rehabilitation to verify their role as primary CG and to obtain informed consent. Consent of survivors was not necessary for CG participation. Data were collected by research assistants, blind to group assignment, at baseline (acute rehabilitation, Time1); 3 to 4 months post-discharge (Time 2), and 6 (Time 3), and 12 months post-discharge (Time 4). Assessments were read to participants to avoid missing data. Assessments were completed in-person at baseline, when possible, and by telephone post-discharge. The URN measure was part of a compendium of measures administered at each time.

Instruments—A Background and illness form was developed to collect caregiver and stroke survivor background and illness-related factors. Internal consistency reliabilities were adequate (.71 to .95) for all measures at 4 times in the study.

Unmet Resource Needs Scale: Item development for the Unmet Resource Needs measure was guided by the conceptual model, findings from our earlier study on unmet needs of stroke caregivers (King & Semik, 2006), and from a focus group evaluation of a pilot study of a CG intervention (King, Hartke, Iris, Herring, & Alexander, 2003). Unmet needs were defined as the caregiver's desire for more assistance, support or information to manage physical or emotional concerns (Mistiaen, Duijnhouwer, Wijkel, de Bont, & Veeger, 1997).

A search of the literature added further information. To decrease participant burden, we used need categories rather than specific needs. The 13-item unmet resource needs scale (URN) addressed access to CG and survivor resources for managing emotional, physical and behavioral consequences of stroke. Responses (1=strongly disagree to 5=strongly agree) are summed. One item was reverse scored. Higher scores indicated greater unmet needs; the potential range of scores was 13 to 65.

Coping process measures: The Appraisal of Caregiving Scale (ACS-Revised) is a 27-item, 5-point response scale that assessed benefit, benign, and threat appraisals (Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, 1991). The 12-item threat appraisal subscale was used in the current study. Higher mean scale scores reflect higher levels of the scale construct. The possible range of scores was 1 to 5. Validity was supported by significant correlations in the expected directions between the scales and caregiving antecedents and outcomes. Alpha coefficient was .92 (Oberst, 1991).

The Social Problem Solving Short Form-Revised (SPSI-R) was used to assess problem-solving coping (D'Zurilla, 1996; D'Zurilla & Sheedy, 1991). The 25-item scale measures problem-orientation (positive and negative) and problem-solving styles (impulsive/careless, avoidance, rational). Only the positive problem-orientation scale (PPO) was used in the current study. The responses range from (0= not true to 4= extremely true). Possible scale scores range from 0 to 20. Higher scores are desired for the PPO. Validity has been supported by correlations with depression and anxiety in the expected directions (D'Zurilla, 1996). Internal consistency reliability was adequate, ranging from .72 to .85.

Resource Use was assessed using the investigator-generated Intervening Events Questionnaire (IEQ). Caregivers were asked to check the resources used since the prior assessment on listings of 15 resources and to add items not listed. Items used were summed.

Adaptation outcome measures: The Preparedness for Caregiving Scale (PCS) was used to assess perception of preparedness to manage the tasks and stresses of caregiving (Archbold, Stewart, Greenlick, & Harvath, 1990). CG reliability and validity evidence are strong for this 8-item, 5-response option scale (0=not at all prepared to 4=very well prepared). The potential range of scores is 0–4.

Depression was assessed using the Center for Epidemiologic Studies-Depression scale (CES-D)(Radloff, 1977; Shinar et al., 1986), which has extensive evidence of reliability, validity, and sensitivity to change. The 20-item CES-D measures depressive symptom severity during the past week. The possible range of scores is 0 to 60; higher scores reflect greater symptom severity with 16 indicative of depression. Baseline scores were used to identify eligibility for enrollment.

Survivor functional status was measured using the Functional Independence Measure (FIM), which assessed disability severity using an 18 item, 7-point scale; higher scores represent greater independence (Granger, Hamilton, & Sherwin, 1986). The FIM is reliable and valid, sensitive to change, and is used widely to demonstrate functional change. Data were retrieved from the survivors' medical records at baseline and from CGs post-discharge.

Analysis—We assessed the structure of the instrument using principal axis factoring (PAF) and promax rotation on Time 3 data (Tabachnick & Fidell, 2001). We selected Time 3 because that is the point when survivors' progress usually stabilizes, therapy has usually been discontinued, and effective caregiver coping decreases (Van Puymbroeck & Rittman, 2005). Criteria for extraction included: a) loadings of at least .40 and at least .15 difference in cross-loadings, b) use of the scree plot to identify the number of factors, and c) eigenvalues greater than 1.0 (Tabachnick & Fidell, 2001). When low factor loadings (<.40) occurred, one item was deleted and the PAF repeated until all items loaded according to entry criteria. Kaiser-Meyer-Olkin test (KMO) values were examined for sampling adequacy. Cronbach alphas were estimated on the final factors; items with item-total correlations below .30 were deleted and alpha with item deleted was examined.

Concurrent construct validity was assessed by examining the relationship between Time 3 URN and T3 PPO, threat appraisal, depression, preparedness, survivor functional status, and number of resources used. Spearman correlation coefficients were computed because functional status was not normally distributed. Repeated measures ANOVA was computed to assess change in the URN from baseline through one year.

Results

Participants

The sample for the psychometric analysis was 166 participants with complete Time 3 data. Table 1 shows baseline CG and survivor demographic and illness data. CGs **were** well-educated; the majority **was** White and female. The majority of survivors **was** White, male, and hospitalized for a first stroke. The **Time 3** mean FIM score of 96 reflected the need for supervision or cueing for daily living activities. Descriptive statistics for the URN, and outcome and **coping process** variables are in Table 2. Readability of the URN scale items **was** 8.0 grade using the SMOG method, which involves calculating the number of polysyllabic words (McLaughlin, 1969).

Validity

Structural construct validity—The factor analysis loadings yielded a two-factor solution that meets the analytic criteria. PAF was computed on the Time 3 (6 month) 13-item URN scales with no missing data. The initial PAF indicated that all items, except item 9, which **was** reverse scored, **met** the loading criteria of .40. After deletion of item 9, "I usually tried to get a resource or service that I thought we needed", two factors explaining 56% of variance emerged. Factor one explains 43% and factor two 12% of the total variance. Loadings ranged from .46 to .77 for factor 1 and .66 to .89 for factor 2. **No item cross-loaded at the .40 level.** The scree test confirmed a two factor solution. The KMO was .849, supporting sampling adequacy. The Bartlett's test of sphericity was significant ($p = .000$), indicating that the correlation matrix was appropriate for the analysis. Table 3 shows factor loadings, item means and SD, and item-total correlations for the URN items. Factor 1 reflected general resource needs and Factor 2 reflected technology needs.

There is no agreed upon method to test for floor and ceiling effects. Therefore, we examined the proportion of scores with floor and ceiling effects using total scale scores under 24 (strongly disagree) and ≥ 48 (strongly agree), respectively. Ceiling and floor effects were below the acceptable cut-off of 15% (Terwee et al., 2007). Floor effects ranged from 1.2% at baseline to 4.4% at Time 4. Ceiling effects were absent at each time (0%).

Concurrent validity—Spearman correlations between the Time 3 URN and Time 3 coping and adaptation outcome variables ranged from $-.11$ for resource use to $-.46$ for preparedness for caregiving (Table 4). Whereas significant positive correlations were found for threat appraisal and depression ($p < .01$), significant negative associations were observed between the URN and preparedness for caregiving and positive problem-solving. Relationships were such that greater threat and depression were associated with higher unmet needs. Lower preparedness and positive problem-solving were associated with greater unmet needs. Resource use and functional independence were not significant.

Reliability

Internal consistency reliability—Cronbach alphas were over .70, for the total scale and general needs subscale at all times in the sample of 166 CGs. The total scale coefficients ranged from .84 to .88 **across four times**. The general needs and technology scale alpha coefficients, respectively, ranged from .84 to .87 and .56 to .85. The alpha coefficients for the 3-item technology needs subscale was inadequate at Time 1, $\alpha = .56$, and was .69 at Time 2.

Description of unmet resource needs

Item statistics are in Table 3. Item means ranged from 2.04 (I wished I could use the internet, but did not have computer access) to 2.61 (I did not know what kind of resources or services would help with a problem). Standard deviations ranged from .91 to 1.10, indicating good variability. Item-total correlations ranged from .42 to .72. The mean scale scores for Time 3 technology (2.29) and general resource needs (2.39) reflected neutral agreement (neither disagreeing nor agreeing) with the resource need item. Each item was endorsed as an unmet need by a minimum of 12% of CGs. Items endorsed as a need by 20% or more were: needed a service to help with caregiving, but did not have it; needed services for my emotional needs, but was reluctant to use them; I did not know what kind of resources would help; *I did not know where to get help finding resources*; and I wanted to use the LIFE center, but did not know how. The LIFE center is a patient-family resource center available to all caregivers in the research study, either in-person or through the internet or telephone. It is similar to services in many rehabilitation hospitals that provide resources and personnel to convey information on resources and other information to aid adaptation to disability.

Unmet needs remained common at one year when 42% of 123 CGs reported one or more unmet resource needs. One CG strongly agreed with needing all 12 resources.

Repeated measures ANOVA indicated that unmet needs decreased significantly ($F(3, 369) = 38.34, p < .0001$). This finding was significant with Bonferroni correction. Results were as follows: a) Time 2, $t(123) = -5.00, p = .000$, b) Time 3, $t(123) = -4.53, p = .000$, and c) Time 4 $t(123) = -6.94, p = .000$. Post-hoc paired t-tests, based on cases with data at 4 times,

indicated a significant reduction between baseline URN and each follow-up score. Table 5 shows the URN scale scores and alpha coefficients at all times for 123 caregivers with data at four times. Alpha coefficients for this sample were similar to the larger sample of 166, ranging from .58 (Time 1 technology scale) to .87 (Time 3 total scale).

Discussion

We developed the URN to meet the need for a psychometrically sound measure of unmet needs of caregivers of stroke survivors. The URN demonstrates construct validity, including structural, content, and concurrent validity and internal consistency reliability during the first year of caregiving.

Although CG literature indicates that unmet needs are related to CG depression, we found no study that provides evidence for this association. However, the difficulty of caregiving problems and problem stress are related to depression (Hartke & King, 2002; King, et al., 2010). Conceptually, problems are similar to unmet needs, but are not the same. Identifying the relationship between depression and unmet needs is an important contribution to clinical practice.

The study hypotheses are supported. Structural construct validity is supported by the PAF findings of two unmet need dimensions (general and technical) that meet all the criteria for retention in the 12-item scale. Evidence for content validity is provided by low floor and ceiling effects and development of the URN using data provided by CGs. Concurrent validity is supported by significant and moderate Time 3 correlations between the URN and PPO, threat appraisal, **depression, and preparedness for caregiving**. The relationships are such that fewer unmet needs are related to healthy **coping and** outcomes, e.g., PPO, greater preparedness, and lower depression and threat appraisal. Our findings did not confirm prior reports that burden or survivor function were related to unmet needs (Hinojosa & Rittman, 2009; Scholte op Reimer, et al., 1998). Functional status, which reflects burden, was marginally significantly related to unmet needs ($p < .06$), and resource use was not significant ($p > .05$). The cross-sectional analyses prohibit determining causality. Future longitudinal or intervention research is needed to clarify the direction of these relationships.

The hypothesis on internal consistency reliability is supported by alpha coefficients equal to or exceeding .70 for all but the Time 1 three-item technology subscale. The technology needs scale is not recommended for use as a separate scale during the pre-discharge phase because of questionable reliability pre-discharge. At that time, it is likely that caregivers are less aware of post-discharge resource needs and the usefulness of technology, such as internet web sites targeted to caregivers. Nevertheless, both the 12 item and 9-item general scales showed high internal consistency reliability for the pre-discharge assessment time.

The scale covers a wide range of needs and as a clinical tool could serve as a precursor to discussion with CGs to either meet needs directly or point the way to resources. Our finding that unmet resource needs decrease quickly is similar to one report (Mak, et al., 2007), but differs from others (Mackenzie, et al., 2007; Ski & O'Connell, 2007). However, Mackenzie's finding is marginally significant ($p < .06$). We found the reduction in unmet needs between

pre-discharge and 3 months post-discharge is sustained during the year. However, 42% of CGs continued to report an unmet need at one year. Hinojosa & Rittman (2007) reported that 22% to 29% of chronic CGs reported unmet needs, related to managing behavior, safety issues, protecting the survivor, and managing the survivor's emotions (Hinojosa & Rittman, 2007). Similarly, finding services for the survivor's emotional response is a common need in our study. At Time 3, 19% and 13% of CGs reported unmet needs for patient emotional and behavioral concerns, respectively. Resources for managing the CG's own emotions, reluctance to use resources for self, and not knowing which resources would help **were common** needs in our study.

Limitations

Several limitations exist in our study, including a modest sample size with a ratio of 12:1 participants to items. Recommendations for sample size for factor analysis vary considerably. Recommendations for ratios of participants to items range from 5:1 to 20:1, or alternatively, recruit a sample of 300 or more participants (Henson & Roberts, 2006; Tabachnick & Fidell, 2001). Although our findings are promising, this is the first step in development of the URN scale. The next steps should be confirmatory factor analysis to confirm the factor structure and reliability in a larger sample, and to examine predictive validity. Also, temporal stability should be assessed with no more than two weeks between assessments to add support for scale reliability. Further refinement of the scale could include the addition of an item on information needs related to stroke symptoms and prevention (Bakas, et al., 2002). Additionally, the current scale does not allow caregivers to add unmet needs, which could provide important information. The high drop-out rate is a limitation because we cannot determine how CGs who dropped out would have responded about resource needs over time.

Implications For Practice

Identifying the resource needs of family CGs can help to define interventions to reduce negative outcomes after stroke. **Despite the limitations noted**, the URN holds promise to help clinicians quickly assess if an intervention for unmet needs is indicated. This brief, structured measure can be used in clinical settings and in research studies. The brevity of the scale and its 8th grade readability level support its use as a self-report measure. Strengths of the study include guidance by a conceptual model and findings of preliminary studies, as well as using a prospective design that allowed assessment of change over one year.

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Table 1

Time 3 Caregiver and Survivor Demographics

	Caregiver n = 166			Survivor n = 153 – 166 ^a		
	Range	Mean (SD)	N (%)	Range	Mean (SD)	N (%)
Sex (female)	---	---	134(80.7)	---	---	65(39.2)
Race (white)	---	---	116(69.9)	---	---	129(78.2)
Relation (spouse)	---	---	111(66.9)	---	---	---
Employment (Full/Part time)	---	---	81(48.8)	---	---	81(49.4)
Education H S	---	---	154(92.7)	---	---	138(84.7)
Aphasia (yes)			N/A			69(45.1)
First Stroke (yes)			N/A			130(78.3)
Age	21 – 84	55.34(13.38)	---	22 – 93	61.49(15.35)	---
Survivor Function			N/A	18 – 126	96.66(25.64)	

^a Survivor function, aphasia: N = 153, age: N = 159, education: N = 163, employment: N = 164

Table 2

Measures: Time 3 Descriptive Statistics and Alpha Coefficients

Measure	Number	Mean	SD	Min	Max	α
Unmet Resource Needs Time 3	166	28.25	7.91	12.00	47.00	.88
Number Resources Used	166	5.09	2.35	0.0	12.00	N/A
Caregiver Preparedness	166	2.88	.67	.63	4.00	.87
Functional status	153	96.66	25.64	18.00	126.00	.94
Threat appraisal	165	2.81	.70	1.06	4.75	.87
Positive Problem Orientation	165	12.78	3.62	2.00	20.00	.76
Center for Epidemiologic Studies Depression	165	15.16	10.62	.00	45.00	.82

Note, α = coefficient alpha.

Table 3

Revised Unmet Resource Needs Scales: Factor analysis statistics and Alpha coefficients (N = 166)

Item	Factor 1 loading	Factor 2 loading	Mean/SD	Item-total Correlation
4. We needed services to help with the patient's emotions, but did not have them.	.77	-.06	2.37/.97	.67
8. I did not know where to get help finding resources and/or services that we needed.	.74	.002	2.42/1.03	.68
5. We needed services to help with the patient's behavioral response, but did not have them.	.73	-.03	2.24/.91	.64
1. I needed a resource/service to help with caregiving, but did not have it.	.72	.02	2.46/1.08	.69
2. I needed services to help with my own emotional response to caregiving, but did not have them	.67	.04	2.44/.99	.65
7. I did not know what kind of resources and/or services would help with a problem.	.66	.009	2.61/1.05	.62
6. We needed services to help with the patient's physical recovery, but did not have them/.	.63	.06	2.16/1.04	.55
13. Our financial situation prevented us from getting resources/services that we needed.	.46	.17	2.33/1.10	.52
3. I needed services to help with my emotional response to caregiving, but was reluctant to use them.	.46	-.003	2.49/.95	.42
11. I wished I could use the internet for help with resources, but I did not know how.	.02	.89	2.27/1.05	.72
12. I wished I could use the internet for help with resources, but I did not have access to a computer.	-.14	.72	2.04/.99	.56
10. I wanted to use the LIFE Center or its website, but did not because I was not sure what to do.	.16	.66	2.42/.98	.64

Note. Variance Explained: Total Scale = 56%; Factor 1 Scale = 43%; Factor 2 Scale = 12%.

Table 4

Spearman Correlations between Time 3 Unmet Resource Needs and Time 3 Outcomes and Coping Process Variables (N = 154)

Measures	1	2	3	4	5	6	7
1. Unmet Resource Needs	---						
2. Resource Use	-.11	---					
3. Threat Appraisal	.34**	.16	---				
4. CES-D	.37**	.18*	.62**	---			
5. Preparedness for Caregiving	-.46**	-.02	-.47**	-.42**	---		
6. Functional Independence Measure	-.16	-.04	-.15	-.29**	.14	---	
7. Positive Problem-Solving	-.34**	-.03	-.38**	-.38**	.35**	.15	---

Table 5

Unmet Resource Needs Scale: Scores and Internal Consistency Values During One Year (n=123)

Data Collection Times	Total Scale Mean(SD)	α	General Mean(SD)	α	Technology Mean(SD)	α
Time 1 (predischarge)	30.28(7.02)	.83	23.02(5.71)	.83	7.26(2.30)	.58
Time 2 (3 months)	27.47(7.08)	.86	20.74(5.66)	.84	6.74(2.36)	.70
Time 3 (6 months)	27.46(7.55)	.87	20.83(5.85)	.87	6.64(2.61)	.81
Time 4 (12 months)	26.26(6.77)	.85	20.05(5.36)	.84	6.21(2.49)	.86

Note. Total scale = 12 items; General Needs scale = 9 items; Technology Needs scale = 3 items

Note. The sample includes 123 caregivers who completed 4 assessments.