

Development and Testing of a New Instrument for Measuring Concerns About Dying in Health Care Providers

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A new measure of concerns about dying was investigated in this psychometric study. The Concerns About Dying instrument (CAD) was administered to medical students, nursing students, hospice nurses, and life sciences graduate students (N = 207) on two occasions; on one occasion they also completed three related measures. Analyses included descriptive statistics, factor analysis, Cronbach's alpha, test-retest correlations, t tests, and correlations with other measures. Results suggest the CAD measures three distinct but related areas: general concern about death, spirituality, and patient-related concern about death. Reliability estimates were good, and correlations with related measures were strong. Between-group differences suggest scores are related to actual differences in level of concern and beliefs about death and dying. The CAD has the advantage of being very brief, and of explicitly assessing concerns about working with patients who are dying.

Keywords: attitudes; death and dying; end-of-life care; psychometrics; health care providers

Improving the quality of health care at the end of life has become an important national priority. Experts have called for improvements in the training of health care providers (Billings & Block, 1997; Block, 2002; Block et al., 1998; Weissman & Block, 2002) and current standards for undergraduate medical education explicitly require training in end-of-life care (Liaison Committee on Medicine Education, 2002). The medical education literature contains several recent reports of curriculum efforts in these areas (Binienda, Schwartz, & Gaspar, 2001; Clay, Jonassen,

& Nemitz, 2001; Lewin, Agneberg, & Alexander, 2000; Liao, Amin, & Rucker, 2001; Magnani, Minor, & Aldrich, 2002; Pan, Soriano, & Fischberg, 2002; Ross, Fraser, & Kutner, 2001; Spiegel, Meier, Goldhirsch, Natale, & Morrison, 2002) and national surveys reveal that virtually all U.S. and U.K. medical schools currently have curriculum in this area (Barzansky, Veloski, Miller, & Jonas, 1999; Dickinson, 2002; Field & Wee, 2002).

These efforts to improve end-of-life care have created a need for tools to assess health care providers' concerns

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about dying, and especially about working with patients who are dying. Such instruments also have potential application in research on end-of-life care in efforts to identify provider-level variables that influence quality of care for dying patients and to evaluate the impact of specific educational or training interventions. Results of a number of studies suggest that greater experience with patients who are dying is associated with greater comfort in working with such patients (Bates, Tolle, & Elliot, 1988; Carr & Merriman, 1996; Dickinson & Pearson, 1979; Payne, Dean, & Kalus, 1998), and that greater comfort on the part of the health care provider may, in turn, improve care (Cohrane, Levy, Fryer, & Oglesby, 1990; Dickinson & Pearson, 1979; Vizirani, Slavin, & Feldman, 2000). A better understanding of the relationship between provider concerns about end-of-life and quality of care may suggest specific areas appropriate for targeting of provider-level interventions to improve care. At the same time, maximizing the effectiveness of new educational and training efforts in end-of-life care depends on evaluations of the efficacy of such efforts.

There are existing instruments intended to measure death anxiety and fear of death (see, for instance, Neimeyer, 1994); however most of them do not explicitly address concerns of health care providers, and most are long. A recently published tool by Levetown, Hayslip, and Peel (2000) assessed physicians' end-of-life care attitudes, focusing on communication concerns and anxiety as well as attitudes toward terminal care. The Physicians' End-of-Life Attitude Scale (PEAS) is a relatively long scale (i.e., 64 items), which may reduce its feasibility. There is a need for a very brief, reliable, and valid tool that assesses general concerns about death and concerns specific to health care providers. The current work addresses this need.

The goal of the current study was to develop and test a brief instrument for use with health care providers in research and evaluation studies about end-of-life issues. It was anticipated that such studies would include different groups of health professionals at different stages of training and practice. In addition, although assessment of health professionals was the primary goal, it was anticipated that future research efforts could also include respondents from other groups. This might be desirable, for instance, if the goal were to compare entering medical students to students entering other professions. Therefore, we recruited three cohorts of health care professionals and trainees (medical students, nursing students, and hospice nurses), and one trainee cohort from a nonhealth-care discipline, that is, life sciences graduate students. This resulted in representation of two health care disciplines (nursing and physician), with one subgroup (hospice nurses) having substantial experience with patients who are dying, and presumably greater comfort with death and

dying. The inclusion of the life sciences graduate students allowed for data collection on a nonhealth-care cohort, comparable in age and education level to the medical students. The items referring explicitly to patients who are dying were not included on the version administered to the life sciences graduate students.

METHOD

Participants and Procedures

The CAD was administered twice for this study, to participants from four different cohorts (medical students, nursing students, hospice nurses, and life sciences graduate students). All participants were volunteers, who received a \$20 gift certificate for completing both sets of questionnaires. The first administration involved the new measure and additional established measures (described below under Measures) selected for a validity study of the instrument. The second administration, approximately 1 to 3 weeks later, involved the CAD only and was conducted to estimate the test-retest reliability of the instrument. All analyses that involved data from two occasions (Time 1 and Time 2) were based on responses from participants who completed the two measures at least 7 days but no more than 21 days apart.

Respondent Characteristics

A total of 207 respondents participated in this study, including 62 medical students, 47 nursing students, 48 life sciences graduate students, and 50 hospice nurses. Of all participants, 80% were women; this high percentage is largely because of the inclusion of nursing students and hospice nurses, of whom 93% were women. Of the participants, 83% were White. The mean age was 36 years ($SD = 11$), with a range from ages 22 to 60 years.

Measures

The Concerns About Dying Instrument. The CAD consists of 10 descriptive statements intended to elicit concerns and beliefs about death and dying (see Table 1 for item content). The items were written following discussions with clinicians and review of the literature in this area. Our intent was to create a brief measure that directly assessed providers' comfort level in working with patients who are dying, as well as general concerns about death. The patient-related items were written to assess concerns identified through provider interviews and the literature review as directly related to comfort in working with patients who are dying. For the general items, we sought

TABLE 1
Item Content, Factor Loadings, and Eigenvalues

Item (Original Item Number)	Factor Loadings		
	General	Spiritual	Patient
I get anxious or uncomfortable when I think about my own death. (1)	.84	.11	-.01
I sometimes worry that I will die young. (2)	.88	-.03	-.09
I get anxious or uncomfortable when I think about someone I care about dying. (4)	.54	-.14	.17
I am worried that my own death may be painful. (6)	.37	-.06	.02
I think that when its time for me to die, I will be able to let go. (7R)	.27	.22	.14
I believe that my soul or spirit will continue after death. (3R)	.08	.70	-.02
My religious and/or spiritual beliefs and practices help me think about death. (5R)	-.09	.88	.02
I am worried about how I will react emotionally to dying patients. (8)	.09	-.10	.85
I think that I will feel powerless with dying patients. (9)	-.02	.02	.75
I think I will find it hard to work with dying patients. (10)	-.03	.09	.80
Initial eigenvalue	3.998	1.146	1.468

NOTE: For hospice nurses, Items 8, 9 and 10 were worded in the present tense as follows: 8. I am worried about how I react emotionally to dying patients; 9. I feel powerless with dying patients; 10. I find it hard to work with dying patients.

Item scoring was as follows: Items 1 through 4, 6, 8 through 10 *disagree completely* (1); *disagree somewhat* (2); *neutral* (3); *agree somewhat* (4); *agree completely* (5).

Items 3, 5, 7: *disagree completely* (5); *disagree somewhat* (4); *neutral* (3); *agree somewhat* (2); *agree completely* (1).

to write items that focused on normal rather than pathological feelings and beliefs about death, with wording that would be understandable and acceptable to laypeople and medical professionals. We also sought to word these general items so that they would be applicable to respondents with considerable experience with death and dying, as well as to those without such experience. The items were written by a psychometrician with experience in item writing (KM) and refined in discussions with clinicians and social scientists involved in end-of-life care research. Pilot testing was conducted with one cohort of medical students prior to the current study. Initial psychometric statistics based on the pilot administration were good, with the exception of one item; that item was therefore removed from subsequent administrations. Each item is followed by five response options: *disagree completely*, *disagree somewhat*, *neutral*, *agree somewhat* and *agree completely*. Item scoring was done such that greater agreement reflected greater anxiety or concern about death or dying (scoring is indicated in Table 1).

Existing instruments. Construct validity in the current study was addressed by examining patterns of associations with scores from three established scales that would be expected to correlate with scores from the new measure. The first scale, the Death Attitude Profile–Revised (DAP-R; Wong, Reker, & Gesser, 1994), is a 32-item measure that includes subscales addressing death acceptance and avoidance. Within the death acceptance subscales, neutral acceptance reflects a view of death as a reality that is neither feared nor welcomed; approach acceptance refers to a view of death as a gateway to a happy afterlife; and escape

acceptance connotes a view of death as an escape from a painful existence. Within the avoidance subscales, the Fear of Death subscale measures negative thoughts and feelings about the state of death and the process of dying, whereas death avoidance assesses the extent to which a person avoids thinking or talking about death to reduce death anxiety. Items are rated on a 7-point Likert-type scale ranging from *strongly agree* to *strongly disagree*. The measure has demonstrated reliability and validity, and there are established gender- and age-related norms (Wong et al., 1994). It was predicted that the scores from the CAD would be correlated with, but not redundant with, subscores of the DAP-R.

The second scale, the Tension-Anxiety subscale of the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1971), is a 9-item adjective checklist with Likert-type scaled items that asks respondents to indicate how much they have experienced these feelings in the past week: *not at all* (1) to *extremely* (5). We predicted low to zero correlations between scores from the CAD and the POMS subscore, as the latter purportedly measures mood, and the former was intended to measure relatively stable rather than transitory feelings.

Two subscales from the Systems of Beliefs Inventory (SBI-15R; Holland et al., 1998) were selected for the current study as measures of spiritual well-being. The first subscale was the Beliefs and Practices subscale, which assesses religious beliefs and practices and belief in a supreme being. The second was the Social Support From the Religious Community subscale, which assesses the extent to which one perceives social support from one's

religious or spiritual community. One additional item, "How important is your spiritual practice to your sense of well-being?" was written for the current study. This item was on a 4-point scale, *not at all* (1) to *a great deal* (4). It was predicted that people who scored high on these measures would report less concern about death and dying.

Additional Validity Assessment

It was predicted that nurses involved in hospice care would have less anxiety or concern about death and dying, and about working with patients who are dying compared to the other provider cohorts in the current study, because as noted above, greater contact with patients who are dying appears to be associated with greater comfort in working with such patients (Bates et al., 1988; Carr & Merriman, 1996; Dickinson & Pearson, 1979; Payne et al., 1998). In addition, it is reasonable to assume that hospice nurses would be unlikely to work in this setting if they were not comfortable with such extensive contact with patients who are dying. Thus, our approach to assessing the validity of the scores for differentiating those with high and low levels of concern or anxiety about death and dying was to compare scores for hospice nurses to scores for all other participants. We did not analyze scores for medical students, nursing students, and life sciences students separately because we did not predict differences (or the absence of differences) between these groups.

Statistical Analyses

Item frequency distributions were examined to ascertain whether item responses were distributed across the full range of response options. Corrected item-total correlations (within subscales and for the full 10-item scale) were examined to check that reverse scoring for the 3 items was appropriate. Maximum likelihood factor analysis with promax rotation was performed on responses to the CAD items (using responses to the first administration). Because the life sciences graduate students did not complete the patient-related items, these respondents were not included in the factor analysis. Hence, the sample size for the factor analysis was 154 (5 respondents had at least one missing value). To examine the reliability of the scores, we computed Cronbach's alpha for each subscale and for the combined scale. We also estimated test-retest stability using Pearson correlations between scores from the two occasions. Differences between mean scores for hospice nurses and all other respondents were assessed using *t* tests. Patterns of association between the CAD scores and other measures were evaluated using Pearson correlation coefficients.

RESULTS

Item Frequency Distributions

An examination of the item frequency distributions, means, and standard deviations showed that for all items of the CAD measure, all response options were endorsed by at least some respondents.

Factor Analyses

Results of the factor analysis suggest that the CAD measures three distinct, but correlated domains. The three-factor solution provided a significantly better fit than either a two-factor or four-factor solution as determined by evaluating the improvement in the chi-square goodness-of-fit statistic from two to three factors (significant improvement) and from three to four factors (improvement was not significant). The three factors together explained approximately 66% of the variance in the data. The first factor contained five items (see Table 1). The items loading highest on this factor were those referring directly to worries or anxiety about one's own death, or the death of someone close; therefore this set of items is referred to as General Concern About Death (CD-General). The second factor, which will be referred to as Spirituality, was made up of only two items. The first item in this set referred to the importance of spiritual beliefs in thinking about death, and the second to a belief in the continuance of the soul after death. The third factor, which will be referred to as Patient-Related Concern About Death (CD-Patient), consisted of three items. These items explicitly addressed actual (hospice nurses) or expected (medical/nursing students) concerns or worry about working with patients who are dying. As noted above, these items were not administered to the life sciences graduate students.

The correlations between scores for the three subscales were as follows: CD-General With Spirituality, $r = .22$ ($p = .001$, $N = 207$); CD-General and CD-Patient, $r = .55$ ($p < .001$, $N = 159$); Spirituality and CD-Patient, $r = .28$ ($p < .001$, $N = 159$). These correlations, together with the results of the factor analysis, suggest that the three sets of items measure three related but distinct domains. Of note, however, is the relatively high correlation between the CD-General and the CD-Patient subscale, which could be considered evidence that these two sets of items could be combined. We therefore computed a combined score, based on items from both of these subscales. However, to allow comparisons between health care providers and others, we report results for each subscale separately as well. Those conducting research or evaluation studies with health care professionals only may choose to use com-

TABLE 2
Means and Standard Deviations by Group

Item Set	Group					Statistics		
	Medical Students (n = 62)	Nursing Students (n = 47)	Life Sciences Graduate Students (n = 48)	Hospice Nurses (n = 50)	Medical Students, Nursing Students, and Life Sciences Students Combined	t Statistic	p Value	Cohen's d
General	3.48 (0.80)	3.22 (0.78)	3.07 (0.75)	2.77 (0.83)	3.28 (0.79)	3.88	< .001	0.54
Spiritual	2.59 (1.0)	2.05 (1.0)	2.78 (1.17)	1.48 (0.68)	2.49 (1.1)	7.74	< .001	1.32
Patient	2.95 (0.92)	2.07 (1.1)	—	1.39 (0.58)	2.57 (1.1)	9.02	< .001	1.46
Combined (general and patient)	3.28 (0.72)	2.79 (0.77)	—	2.25 (0.65)	3.07 (0.78)	6.48	< .001	1.03

combined scores only, while those including lay respondents may prefer to consider subscale scores, as the CD-Patient items are not applicable to those not involved in caring for patients. We report results for the three subscales and the combined score for all remaining analyses.

Reliability

Estimates of Cronbach's alpha were all moderate to good: for CD-General, alpha was .73 ($N = 203$); for Spirituality, alpha was .76 ($N = 207$), for CD-Patient alpha was .85 ($N = 156$), and for the combined scale, alpha was .83 ($N = 154$).

Correlations between scores at Time 1 and Time 2 were based on responses from participants who completed the two measures at least 7 days but no more than 21 days apart. For the CD-General scale, the test-retest correlation was .84 ($N = 143$); for the Spirituality scale, the correlation was .89 ($N = 143$); for the CD-Patient scale, the correlation was .83 ($N = 116$), and for the combined score, the correlation was .89 ($N = 116$).

Comparison of Hospice Nurses' Scores With All Others' Scores

The means and standard deviations on the three subscales and the combined scale for each group of respondents are presented in Table 2. The most striking finding from this table is that ratings for the hospice nurses are substantially lower than ratings from all other groups, reflecting less concern or worry about the death of self or someone close, greater influence of spiritual beliefs, and greater comfort working with dying patients. Results of the four t tests, (comparing mean scores for hospice nurses to mean scores for the three other cohorts combined on CD-General and Spirituality, and comparing hospice nurses to medical students and nursing students together for CD-Patients and combined) were all statistically sig-

nificant at the .001 level. However, inspection of the mean scores suggests that hospice nurses are clearly comfortable working with patients who are dying. Nursing students also report relatively high comfort in this area, however medical students' scores were closer to neutral. It is also noteworthy that the standard deviations associated with nursing students and medical students suggest that members of these groups are more varied in their views than hospice nurses. With respect to spirituality, again the hospice nurses had the most extreme mean score, with the nursing students being most similar to the hospice nurse, but less extreme. The life sciences students were least likely to endorse spiritual views. Again, the standard deviation of the hospice nurses' scores suggests this group is relatively more homogeneous than the other three groups.

With respect to the magnitude of the effects, the effect size for CD-General was the smallest (however the difference was still statistically significant). Again, the hospice nurses had the lowest score, reflecting greatest comfort with death, however in this case, the mean score for the life science graduate students was most similar to the hospice nurses' mean.

Finally, considering the hospice nurses, nursing students, and medical students, it appears that all three groups report greater level of concern about their own death or the death of someone they care about compared to their concern about working with patients who are dying.

Patterns of Associations

Table 3 presents the correlations between scores from the CAD and scores from the established measures included for comparison purposes. Considering the CD-General scale, the highest correlation with another measure was on the Fear of Death subscale of the DAP-R ($r = .75$). The Fear of Death subscale measures negative thoughts and feelings about the state of death and the process of dying and thus would be expected to correlate

TABLE 3
Correlations Between Scores from New and Established Measures

	<i>Death Anxiety Profile-Revised</i>					<i>Systems of Belief Inventory</i>		<i>Profile of Mood States</i>	<i>Importance of Spiritual Practice to Well-Being</i>
	<i>Fear of Death</i>	<i>Death Avoidance</i>	<i>Approach Acceptance</i>	<i>Escape Acceptance</i>	<i>Neutral Acceptance</i>	<i>Beliefs and Practices</i>	<i>Social Support from Religious Community</i>	<i>Tension Anxiety</i>	
General	.75	.39	-.29	-.10	-.39	-.23	-.19	.26	-.21
Spiritual	.32	.20	-.78	-.20	-.20	-.82	-.66	.20	-.72
Patient	.57	.47	-.40	-.25	-.33	-.27	-.27	.31	-.24
Combined	.77	.51	-.44	-.18	-.41	-.32	-.29	.34	-.29

NOTE: All correlations in this table are statistically significant ($p < .01$) except the correlation between CD-General (General Concern About Death) and Escape Acceptance ($p = .14$).

highly with the CD-General measure, which also measures negative feelings about death and dying. Of the correlations between the DAP-R and the CD-Patient scale, the highest correlation was between the CD-Patient and the DAP-R Fear of Death scale. The magnitude of the correlation is less than the corresponding correlation for the CD-General scale, again suggesting that concerns about working with patients who are dying are distinct from concerns about one's own death, or the death of a loved one. Finally, the highest correlations for the Spirituality scale were with the DAP-R Approach-Acceptance subscale ($r = -.78$), the SBI-15R Beliefs subscale ($r = -.82$), and the importance of spiritual beliefs item ($r = -.72$), all of which are also intended to measure the importance of spirituality. These correlations are negative because of reverse scoring of the CAD spirituality items, however the magnitude of the correlations is consistent with the assertion that the CAD Spirituality measure is strongly related to other measures of spirituality. Correlations between each of the CAD subscales and the Tension-Anxiety subscale of the POMS were low, consistent with the assertion that the concerns measured by the CAD subscales are distinct from mood states. With respect to the correlations between the combined CAD score and the other measures, the highest correlation is with the Fear of Death subscale ($r = .77$), and the lowest is with the Escape Acceptance subscale ($r = -.18$).

DISCUSSION

Findings obtained in the current study suggest that the CAD measures three related but distinct underlying constructs. Scores from the first set of items, the CD-General, appear to be related to concerns and worries about one's own death, or the death of someone close; higher scores on this scale are indicative of greater worry or concern in this area. Not surprisingly, scores on this scale are positively

related to fear of death and death avoidance (as measured by DAP-R), and negatively related to measures of death acceptance and spiritual beliefs. Scores on the CD-Patient subscale, which explicitly address concerns about working with patients who are dying, appear to be related to, but not completely redundant with, scores on items addressing concerns about one's own death or the death of someone close. Scores on this scale are also positively related to fear of death and death avoidance, and negatively related to death acceptance and spirituality. Finally, scores on the Spirituality subscale are strongly related to other established measures of the importance of spiritual beliefs.

Each of the three subscores showed adequate reliability in this sample. This is especially encouraging given the relatively small number of items on each subscale. Cronbach's alpha was highest for the CD-Patient subscale, followed by the Spirituality subscale, and then the CD-General subscale; test-retest correlations were 0.83 or greater for all subscales, and 0.89 for the total score. The high test-retest correlations are particularly important for researchers and evaluators who might choose to administer this instrument at multiple time points to assess change.

Perhaps the strongest evidence that this measure may be valuable in future research and evaluation efforts is the finding that the CAD was sensitive to between-group differences. Hospice nurses were included in the current study because we believed a priori that nurses who worked closely with patients who are dying would be more comfortable with death and dying and would have stronger spiritual beliefs about death. Therefore, the fact that scores for this group were substantially lower than scores for other respondents is evidence that this new measure is measuring concerns about death and dying, and that it is sensitive to between-group differences at least of the magnitude studied here.

The finding that correlations with the established measures were in the predicted directions is further support

that scores from this instrument are indicative of concerns about death and dying. Of particular interest is the fact that the CD-Patient subscale does appear to be measuring concerns that are not redundant with general concerns, death anxiety, or spiritual beliefs. Although scores on this measure were correlated with other measures, the highest correlation (.57 with fear of death) suggests that only 32% of the variance in CD-Patient scores can be explained by this factor. In contrast, 56% of the variability in CD-General scores could be explained by this same factor, and 67% of the variability in the Spirituality subscale could be explained by the established Beliefs and Practices subscale of the SBI-15R. The PEAS was not published at the time that this research was initiated, however research into the relationship between the PEAS and the CAD (especially the CD-Patient subscale) should be conducted. It is, however, noteworthy that the alpha estimate for the CD-Patient subscale (.85) compares very favorably with the alphas reported for the two subscales of the PEAS (.81 and .79), and that the CD-Patient subscale is substantially shorter. The CAD has the advantage of being very brief (only 10 items total) and has taken most respondents less than 2 minutes to complete. This is an advantage in the medical education setting, where curriculum time is often limited, and evaluation time even more so. In addition, the wording of the items on the new measure is straightforward. Although we have not investigated this directly, we believe that the CAD items are less emotionally laden than items from some of the established measures of death anxiety and fear of death, which may be attractive to potential users and respondents.

The current study does have limitations. First, we developed the items after reviewing numerous articles on end-of-life care and medical education, and in informal consultation with practicing clinicians, however we did not submit the items to a formal review by a panel of experts. Our approach was primarily empirical, and we believe that the results of the analyses presented here provide evidence of the usefulness of the scale. The items are not exhaustive, and there are areas of concern or belief that are untapped. However most instruments consist of samples of items, rather than exhaustive listings of items; and our results, particularly the reliability coefficients, suggest that our sampling yields internally consistent, stable, and valid items. Although a greater number of items would result in broader representation across the domains of interest, one of our primary goals was to keep the instrument short. We note further that although we sought to develop items that would directly assess health care providers' comfort with working with patients who are dying, as well as general concerns about death, we have not yet assessed whether scores on this measure are related to quality of care.

Because we used a convenience sample in the current study, we were not able to assess whether our sample is representative in terms of gender. Another limitation of the current study is that we did not address the divergent validity of the measure; specifically, we did not determine whether or to what extent scores on the CAD are related to general anxiety. We did find, however, that scores were not highly related to anxious mood. Future research efforts should investigate whether the CAD scores correlate highly with trait anxiety.

It must also be noted that this measure, similar to other scales that attempt to measure feelings, beliefs, attitudes, emotional states, or other internal states using direct self-report, may be limited by the extent to which people are aware of their own internal states and willing to report on them. Again, the fact that we found substantial differences between hospice nurses and other respondents suggests that respondents were willing and able to report on their actual feelings and beliefs.

In conclusion, we believe that the instrument presented here, the Concerns About Dying instrument, is a potentially useful contribution to the current set of tools available for researchers and evaluators involved in efforts to better understand and improve end-of-life care. Developed explicitly for use with health care providers, the instrument can be completed in less than 2 minutes, and scores show good psychometric properties. This instrument is not intended to replace other measures of death anxiety, fear of death, or end-of-life care attitudes, but instead to provide a very brief, targeted assessment that can be used with health care providers in curriculum evaluation efforts, and in descriptive studies of provider-level correlates of end-of-life care.

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