

# Measuring Patient's Perception of the Meaning of Suffering<sup>1</sup> : Instrument Reliability and Validity of the Korean Version

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## **Abstract**

When people have experienced a personally life-threatening event, individuals try to find the meaning of suffering. In order to provide nurses with information about how meaning is individually experienced, nurses should assess the degree of suffering and the patient's perceptions of the meaning of suffering. The purpose of this study is to assess the reliability and validity of the Korean version of the MIST (the Meaning of Suffering Test) instrument originally developed by Starck (1983). The MIST consists of PART I and II. In this study, the validity and reliability of MIST I is tested except MIST II consisting of 17 open questions. The translation involved four steps: translation into Korean, checking agreement, translation into English, and arriving at a consensus. Then the Korean version of the MIST, PART I was tested with a sample of 160 patients with cancer who have experienced suffering. The Cronbach's alpha coefficient for internal consistency was .92 for the total 20 items and .91, .89, and .88 for the three dimensions in that order. As a result of the factor analysis using principal component analysis and varimax rotation, three factors with eigenvalue of more than 1.0 were extracted and these factors explained 93.6 percent of the total variance. The items clustered together in this study were almost identical with initial scale and subscales reported by Starck. The instrument for accessing patients' perceptions of the meaning of suffering was identified as a tool with a high degree of reliability and validity. In this sense, this tool can be effectively utilized for assessment in caring for patients with cancer.

Key words : *The meaning of suffering, Reliability, Validity*

## **Introduction**

Suffering is common to all, and part of the overall experience of life. Also the experience of unavoidable suffering offers an opportunity to search for meaning and, at the same time, to extrapolate a teleologic view of its occurrence

(Frankl, 1959). When humans are in severe distress, man's primary concern is not to gain pleasure and avoid pain but rather to see a meaning in life. Frankl (1959) suggests that when the suffering are perceived to challenge the personal meaning systems that people hold, if meaning can be found, individual can find peace

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no matter how severe their illness.

Indeed, if nursing is to meet its philosophical goal of caring for the whole person, an increased understanding of the nature of suffering is crucial. A nursing staff is likely to assume major responsibility for assisting patients when they are hospitalized to cope with suffering, whether acute and temporary, or chronic and permanent. According to Cassell (1982), illness and suffering cannot be understood without taking personal meaning into account. Travelbee (1977) notes that the professional nurse hoping to deal with human responses in the fullest sense of the word "human" must be prepared to assist individuals and families not just in coping with illness and suffering, but in finding meaning in these experiences. Nurses can help to establish and maintain conditions conducive to experiencing meaning. Interventions may include discussions of meaning so that patients and families might be more aware that they may experience such thoughts (Steeves & Kahn, 1987). However, such discussions can only take place if the nurse is a cognizant of the search for meaning and how this search is expressed by people experiencing a life-threatening illness. In order to provide nurses with information about how meaning is individually experienced, nurses should assess the degree of suffering and the patient's perceptions of the meaning of suffering.

There is paucity of research on suffering and on effective nursing strategies to promote adjustment to suffering experiences. The Korean instrument for accessing the degree of suffering in patients who suffer from cancer was developed by Kang (1999). This tool consisted of 38-items on a four-point likert scale and was identified as a tool with a high degree of reliability and validity. However, the degree of the meaning of suffering can not be assessed using the instrument of suffering by Kang. The Meaning in Suffering Test (MIST) was initially developed by Starck (1983). The purpose of MIST is to ascertain the client's perception of the extent to which they found meaning in suffering experiences. However, it is questionable whether the instrument is appropriate for a cross-cultural application.

For assessing the meaning of suffering

comprehensively of the Korean patients who experiences the suffering, it is necessary to translate the MIST into Korean. Thus, the purpose of this study was to examine the validity and reliability of the Korean version of the MIST, Part I in Korean patients who have experienced suffering.

## Literature Review

No human being can escape suffering, for it is a part of the human condition. There are many faces in human suffering. Suffering is subjective and, therefore, unique to each of us. Suffering never affects just one part, but always affects the whole of the being (Starck & McGovern, 1992). In addition, it varies in intensity and duration, but it may constitute an unforgettable experience. This viewpoint is inclusive with respect to any one or all types of causative conditions: self-inflicted, other person inflicted, societally inflicted, and/or by chance happenings in nature. In any case, there is interaction among the dimensions, and suffering, no matter how great or small, fills the entire human soul (Kang, 1996; Brallier, 1992; Cassell, 1992, Starck & McGovern, 1992; Copp, 1974).

Since it is common to all, and part of the overall experience of life, the experience of unavoidable suffering offers an opportunity to search for meaning and, at the same time, to extrapolate a teleologic view of its occurrence (Frankl, 1959). When humans are in severe distress, man's primary concern is not to gain pleasure and avoid pain but rather to see a meaning in life. Bown and Williams (1993) contend that this search for meaning is at the core of the individual's being and is the driving force behind intellect and emotion. Antonovsky (1979) and Kobassa (1979) also identified the ability to find meaning as an influencing factor in a person's ability to cope with stress. Autton (1980) suggests that the need for meaning is a universal trait, essential to life itself, and that a lack of meaning can lead to spiritual distress, feelings of emptiness and despair and all domains of life may be affected. Therefore, if meaning can be found, and individual can find peace no matter

how severe their illness (Dickinson, 1975).

On the other hand, suffering is not easy to talk about or write about. Doubtless there are many reasons for this, but three reasons merit special consideration in relation to suffering and nursing care. First, as Copp (1974) pointed out, suffering, like death is personally threatening when acknowledged. The existence of suffering challenges the meaningfulness of life and confronts each of us with our own vulnerability. Thus, it is very easy for a nurse confronted by suffering to avoid discussion about the suffering of patients and family members. Yet, returning to Copp's analogy of suffering with death, in our own practice as hospice nurses, opening up the topic of death was often extremely therapeutic for patients and families.

Second, Starck and McGovern (1992) pointed out that often suffering cannot be seen on the surface because we humans hide our suffering as we attempt to disguise our vulnerability. After all we live in a society that does not encourage weakness or the admission of weakness, one that prefers that the ugliness of suffering remain invisible.

Eric Cassell has written about a third reason discourse in suffering has been slow to advance in the health science literature (Cassell, 1992: 1991: 1982). Cassell pointed out that the biomedical view of reality is that body and mind are separate; that distress of the body is viewed as more objective, real, and important than other kinds of distress; and that the reductive methods of normal science inevitably obscure understanding of suffering because it is an experience not of just the body but of the whole person.

Other aspects of this complex relation are clarified by explicating eight aphorisms of suffering (Kahn & Steeves, 1995).

1. Suffering is a privately lived experience of a whole person, unique to each individual.
2. Suffering results when the most important aspects of a person's identity are threatened or lost.
3. Because suffering is dependent on the meaning of an event or loss for the individual. It can not be assumed to be present or absent in any given clinical condition.
4. Possible sources of suffering are countless.
5. The expression of suffering is more accessible to nurses than the experience.
6. As a fundamental human experience, suffering has a basic structure.
7. The experience of suffering involves the person in a larger process that includes the person's own coping with suffering and the caring of others.
8. The caring environment in which the processes of suffering occurs can influence a person's suffering either positively or negatively. When considering all aspects of suffering, responses to suffering are highly individualistic.

On the other hands, there are many research results about suffering phenomena and characteristics like the above literatures. However, there is a paucity of research on suffering assessment and on effective nursing strategies to promote adjustment to suffering experiences. The Korean instrument for accessing the degree of suffering in patients who suffer from cancer was developed by Kang (1999). This tool consisted of 38-items on a four-point likert scale and was identified as a tool with a high degree of reliability and validity. The Cronbach's alpha coefficient for internal consistency was .92 for the total 38 items and .79, .82, .85, for the three dimensions (the intrapersonal dimension, the significant-other and context related dimension, the transcendental dimension) in that order. The Meaning in Suffering Test (MIST) was initially developed by Starck (1983). A synthesis of Frankl's idea and theory has been adapted and given the title of "Meaning of Suffering" by Starck. and developed this tool. "Suffering," in this report, is understood to mean "unavoidable suffering." The purpose of MIST is to ascertain the client's perception of the extent to which they found meaning in suffering experiences. The MIST, Part I scale was tested for reliability and validity in 99 American patients in six different hospitals.

## Methods

### 1. Sample and Procedure

The sample consisted of 160 clients who had a medical diagnosis describing type and degree of cancer and were inpatients or outpatients of three university hospitals and one general hospital in Seoul. The reason for selecting cancer patients as a sample was because the sample which showed all attributes of suffering was the patients with cancer, based on the research results of Kang(1996) who had done research about concept analysis of suffering. Criteria for participation in the study included being mentally clear and able to communicate, and currently undergoing a suffering experience as perceived by the client. The sample of 160 met the criteria for an adequate sample size for a factor analysis (at least five cases for each observed item) as suggested by Tabachnick and Fidell (1989).

The period of data collection was from september 10, to November 7, 1999. The participants were given a description of the study and asked if they were interested in participating. Those who wished to participate were met in a patient's room in a cancer ward or in a waiting room while waiting to be seen by the physician or while waiting for the administration of chemotherapy or radiation therapy. During the contact, the purpose of the study and the nature of participation were outlined. Individuals were then invited to read and check a questionnaire. In cases in which the clients could not do it by themselves, the researcher's aid assisted them with reading and checking.

## 2. Instruments

Three instruments were used to collect data. These instruments completed by the participants included a demographic profile, a medical data form, and the MIST, Part I translated into Korean.

The demographic information form was used to obtain information on age, sex, religion, education level, marital status, and number of children. The medical data form was used to obtain information on the period after diagnosis.

The meaning of suffering was measured by MIST Part I which was translated into Korean using a back translation technique in the study. MIST consisted of Part I and Part II. MIST, Part

I was 20-items which reported the client's perception of the frequency of feelings toward suffering on a seven-point likert scale. The scale consists of a total of 20 items, including three subscales : Personal Responses to Suffering (12 items), Subjective Characteristics of Suffering (4 items), and Meaning of Suffering (4 items). Each item of MIST, Part I was scored from 1 to 7. A high score indicates a higher perception level of the meaning of suffering. The Cronbach's alpha coefficient for the total items was .95. MIST, Part II asked for client verbalization to describe the suffering experience, coping mechanism, and experience of others known to the client. For developing the Korean version of the MIST I, first, items were translated into Korean by two bilingual koreans. Next, seven bilingual Korean professors checked a translated scale into Korean for identifying the accuracy of translation. And then, it was translated into English again by five bilingual Koreans. Finally, the researcher along with professors in the English department reviewed and reached consensus on the final Korean version of the MIST I.

## 3. Data Analysis

The SAS (Statistical Analysis System) was used to analyze the data.

- 1) Descriptive statistics were calculated to describe the demographic and medical characteristics of the sample.
- 2) For testing the construct validity, factor analysis was used applying a varimax rotation. Loading criterion was set at .40 (Nunnally, 1978).
- 3) Cronbach's alpha internal consistencies were estimated for the total scale and for the meaningful factors that emerged.

## Results

### 1. Demographic and medical characteristics

Demographic analysis revealed that the ages of the clients ranged from 21 to 72 years; the mean was 53.6 years. The percentage (51.9%) of males and of females (48.1%) were almost the same.

Most of the participants had at least a middle school degree or above (71.3%). In religion, 31.3% were Protestant and 38.7% had no religion. The participants were predominantly married (75.0%) and had children (86.3%). The period after diagnosis of most of the subjects was under 1 year (75.6%). A summary of the demographic and medical characteristics is presented in Table 1.

**Table 1.** Sociodemographic and Medical

Characteristics		(n=160)	
Categories	n	%	
Age			
21-30	21	13.1	
31-40	26	16.3	
41-50	29	18.1	
51-60	52	32.5	
greater than 60	32	20.0	
Sex			
male	83	51.9	
female	77	48.1	
Religion			
Buddhist	34	21.3	
Protestant	50	31.3	
Roman Catholic	13	8.1	
None	62	38.7	
Missing data	1	0.6	
Education			
Elementary school	45	28.1	
Middle school	30	18.7	
High school	50	31.3	
greater than Baccalaureate	34	21.3	
missing data	1	0.6	
Marital Status			
Married	120	75.0	
Never married	13	8.1	
Divorced	20	12.5	
Widowed	7	4.4	
Numbers of Children			
None	22	13.7	
1	42	26.3	
2	67	41.9	
3 or more	29	18.1	
Period after diagnosis			
less than 1 year	121	75.6	
1 - 5	22	13.8	
greater than 5 years	17	10.6	

## 2. Validity and Reliability

In analyzing the results of MIST I, it was found that the mean score was 98.24, the standard deviation 15.81, and the range was 58 to 140.

One common approach to testing construct validity is factor analysis. As a result of the initial factor analysis using principal component analysis and varimax rotation of orthogonal rotation method, 3 factors with eigenvalue of more than 1.0 were extracted and these factors explained 93.6 percent of the total variance. After orthogonal rotation, eigenvalue, variance, factor loading, and communality are shown in Table 2, 3. A total of twenty items loaded significantly on one of the three factors. Each factor loading was completely above the level of high significance  $\pm .50$  (Lee, Lim, & Park, 1998). All items of the three factors were corresponded to ones of subscales of MIST, Part I.

**Table 2.** Eigenvalue, Proportion, and Cumulative Proportion

Factor	Eigen value	Proportion of total sample variance	Cumulative proportion of total sample variance
1	11.5724	57.8	57.8
2	5.5181	27.6	85.5
3	1.6191	8.1	93.6

The internal consistency of the Korean version of the MIST I was high. Cronbach's alpha coefficient for the total scale was .95 (Table 4). All the reliabilities of subscales were highly satisfactory (Subjective Characteristics .91; Personal Responses .89; Meaning of Suffering .88). Cronbach's alpha for the total scale and three subscales that emerged were all above the minimum of .70, as recommended by Nunnally (1978).

## Discussion

In this study, the instrument, the Korean version of the MIST, PART I, for accessing the

**Table 3.** Factor Loading and Commuality

Subscale/Item	Factor Loading	Cummuality
Personal Responses to Suffering (Factor 1)		
16. I believe people are not given more suffering than they can bear.	.9759	.9659
5. I believe suffering limits a person's opportunities for true fulfillment.	.9626	.9654
3. I believe I understand life better because of the suffering I have experienced.	.9499	.9978
13. I believe my suffering experience has given me a chance to complete my mission in life	.9484	.9715
12. I believe suffering is a punishment for sin.	.9473	.9719
11. I believe my suffering is part of a grand design even though I may not always understand it.	.9454	.9720
10. I believe my suffering experiences have a pattern which recurs despite my efforts to change my life.	.9445	.9725
8. I believe there is always hope in suffering.	.9411	.9730
19. I believe suffering is part of the human condition and comes to everyone sooner or later.	.9362	.9989
20. I believe suffering tests the strength of a person's character.	.9361	.9990
15. I believe people differ in the amount of suffering that they can bear.	.8222	.7678
17. I believe my suffering has given my loved ones a chance to become more fulfilled.	.8040	.9177
Subjective Characteristics of Suffering(Factor 2)		
1. I believe I have the spiritual help(not necessarily religious) to overcome the burdens of my suffering.	.9497	.9978
18. I believe suffering occurs if a person is unlucky and fate has been unkind.	.9361	.9990
4. I believe success in dealing with suffering depends upon a person's attitude about the situation.	.7674	.9215
6. I believe everyone has a purpose in life: a reason for being on earth.	.6559	.8799
Meaning of Suffering(Factor 3)		
2. I believe suffering causes a person to find new and more worthwhile life goals.	.9498	.9978
14. I believe some good things have occurred as a result of my suffering.	.8227	.7714
7. I believe life has been unfair to me because I am a victim of fate.	.6728	.7940
9. I believe suffering can teach valuable lessons about life.	.5943	.8740

**Table 4.** Cronbach's Alpha for the Internal consistency of 20-item Korean Version of the MIST, Part I

Factors	Number of Items	Cronbach's Alpha
Personal Responses to Suffering	12	.91
Subjective Characteristics of Suffering	4	.89
Meaning of Suffering	4	.88
Total scale	20	.95

meaning of suffering of patients was identified as a tool with a high degree of reliability and validity. Also is identified that this translated instrument can be recommended for use in cross-cultural studies of describing and accessing

the perception of the meaning of suffering in patients who are suffering. In this sense, this tool can be effectively utilized for assessment in caring for patients with suffering, especially those patients with cancer.

Translation of the MIST into a different language and validation of this instrument are important for international understanding of a significant psychological experience that influences an individual's health. However only MIST, PART I was tested in this study. In further studies, the MIST, PART II needs to be tested. The first question in MIST II ask the client to choose a number 1 to 10 which best represents the degree of the client's suffering (1=minimum, 10=maximum). The responses to MIST II questions 2 through 16 (open question naming 3 if possible or at least 3 things) are transferred to a master sheet and reviewed for patterns. Answers are categorized according to Frankl's (1959) three ways of experiencing meaning in life events : (a) task or missions values, (b) experiential values, and (c) attitudinal values (Starck, 1983).

The items clustered together in the present study were almost identical with initial scale and subscales reported by Starck (1983) in 99 American patients who were admitted to six different hospitals. These subscales were identified as : (a)subjective characteristics of suffering (b) personal responses to suffering and (c) meaning of suffering. The findings according to subjective characteristics of suffering indicate that individuals do perceive suffering differently. These results are accorded with the opinion of Kahn and Steeves (1995) that suffering is a privately lived experience of a whole person, unique to each individual. By dimension of personal responses to suffering, the majority of the subjects' responses were more indicative of " the human condition" than " a punishment for sin". Also participants responded that they believed " unavoidable suffering was beneficial" and "helped them understand life better". They also thought that "individuals varied in the amount of suffering that each could tolerate". In the last dimension, most of the individuals believed that "suffering had meaning". Few were willing to admit that they were victims of fate. Most subjects believed that "some good things came from their suffering" and "they had learned valuable lessons".

Cronbach's alpha for the total scale in this study was high enough (.95). Nunnally (1978)

suggested that an instrument reliability of .70 or higher will suffice in preliminary research, thus the reliability of subscales in this study was within the acceptable range (personal responses to suffering .91; subjective characteristics of suffering .89; meaning of suffering .88).

## Conclusion and Suggestions

In this study, the high reliability and validity of the Korean version of MIST, PART I were identified by applying factor analysis for construct validity and Cronbach's Alpha for internal consistency. However, further study is needed to provide more information with respect to other analysis (known-group technique, multitrait-multimethod method) for construct validity and to conduct in other kinds of subjects who are suffering to gain more credibility for the scale.

For further research, since the meaning of a situation is personal, awareness of the patient's experience may be limited. By acknowledging and legitimizing an individual's search for meaning, the nurse can help the patient understand the meaning of a person's suffering experience. The findings of this study suggest the need to continue exploring ways for helping professionals to dialog with clients about their suffering experiences. A recommendation is made for further research to refine and improve the knowledge base of suffering within a conceptual framework of caring and compassion.

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