

# Current dilemmas in the assessment of suffering in palliative care

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## ABSTRACT

*Objective:* Although relief from suffering is essential in healthcare and palliative care, few efforts have aimed at defining, operationalizing, and developing standards for its detection, assessment, and relief. In order to accurately explore and identify factors that contribute to suffering, more attention needs to be focused on quality assessment and measurement, not only for assessment purposes but also to test the effectiveness of interventions in relieving suffering. The scope of the present paper is to discuss the strategies that aid in the detection and assessment of the suffering experience in patients with chronic illnesses and/or in palliative care settings, and the dilemmas commonly encountered regarding the quality of available assessment measures.

*Method:* A general description of instruments available for suffering assessment is provided. Matters regarding the accuracy of the measures are discussed. Finally, some dilemmas regarding the quality of the measures to screen for and assess suffering are presented.

*Results:* There have been some achievements toward adequate suffering assessment. However, a more robust theoretical background is needed, and empirical evidence aimed at supporting it is required. In addition, further examination of the psychometric characteristics of instruments in different populations and cultural contexts is needed.

*Significance of results:* An interesting number of assessment measures are now available for use in the palliative care setting, employing innovative approaches. However, further examination and validation in different contexts is required to find high-quality tools for detection of suffering and assessment of the results of intervention.

**KEYWORDS:** Suffering, Assessment, Instruments, Measurement, Dilemmas

## INTRODUCTION

Chronic disabling or life-threatening illnesses are becoming more prevalent as the world population grows older and as unhealthy lifestyle habits increase globally (Wagner & Brath, 2012). Noncommunicable diseases (NCDs, including cardiovascular and pulmonary diseases, diabetes, cancer, among others) account for about 60% of all deaths worldwide, while 80% of chronic-disease deaths occur in low- and middle-income countries (Daar et al.,

2007). More than 40 million people with NCDs and other communicable chronic life-limiting diseases (e.g., HIV/AIDS) require complementary palliative care every year in order to alleviate uncontrolled symptoms and problems of a physical, psychosocial, and spiritual nature (World Health Association, 2014). These conditions lead to great suffering, which not only relates to the disease itself but also to a variety of factors, particularly among vulnerable populations, increasing the burden of being ill. Consequently, suffering detection and relief are at the heart of palliative care in this population.

A prior systematic review conducted by Krikorian et al. (2013a) sought to identify, describe, and discuss the psychometric properties of instruments

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developed to assess suffering in palliative care. However, the focus of the present paper is to further describe the content of the strategies that aid in detecting and assessing the suffering experience in patients with chronic illnesses and/or in palliative care settings, as well as the dilemmas commonly encountered regarding the available assessment measures.

## CONCEPTUALIZATION OF SUFFERING

The word “suffering” is commonly used in the health science literature. A quick search in a health literature engine might yield over 100,000 results. However, the scientific study of suffering within the health field is surprisingly recent. While in the 1960s Dame Cicely Saunders introduced the term “total pain,” it was not until the 1980s that Cassell decided to dedicate efforts to the conceptualization and assessment of suffering (Krikorian & Limonero, 2012). Saunders and Baines (1983) described an integrated, multidimensional experience including physical, psychological, social, and spiritual aspects that contrasted with the limited consideration of pain as a physiological response that was held for many at the time. Her work—along with that of Bonica, Melzack, Wall, Fordyce, and others—prepared the ground for a more comprehensive understanding of symptoms and diseases experienced by patients (Krikorian & Limonero, 2012).

Cassell defined suffering as “a specific state of severe distress associated with events that threaten the intactness of a person” (1991, p. 33). It is personal, individual, and subjective in nature, affecting all dimensions of the person. Therefore, it cannot be experienced by the body alone. More recently, in an effort to contribute to our understanding of the experience, suffering was conceptualized as a multidimensional and dynamic experience of severe stress. This experience occurs when there is a significant threat to the whole person and where regulatory processes (biological, psychological, spiritual) that would normally enable adaptation are insufficient, leading to exhaustion (Krikorian & Limonero, 2012).

Others offer broader definitions in which suffering is considered a subjective experience nested in social and cultural contexts of an event interpreted as painful or damaging (Le Breton, 1999), and where suffering is conceived as a social experience resulting from such power imbalances as inequality, poverty, and insecurity related to political, economic, and institutional reciprocal forces and influences (Darby, 2006). In this sense, members of a group or community agree to perceive certain phenomena as painful or damaging to their integrity (Vargas et al., 2008). Anderson, in order to account for experiences of

suffering beyond healthcare settings, provides a more simple definition: “distress resulting from threat, major loss, or damage to one’s body and/or self-identity” (Anderson, 2014).

Although relief from suffering is essential in healthcare and palliative care, particularly regarding patients with chronic, deteriorating conditions such as NTDs, little research has been directly aimed at defining, operationalizing, and developing standards for suffering detection, assessment, and relief. In order to enhance the efforts to explore and identify factors that contribute to suffering (Kahn & Steeves, 1995; Dildy, 1996; Sherman, 1998; Black & Rubinstein, 2004; Wilson et al., 2007; Blume et al., 2014), more attention needs to be paid on studying the means to assess and measure it in palliative care and other health settings (Krikorian et al., 2013a).

## ASSESSMENT OF SUFFERING

Making a diagnosis of suffering means first of all maintaining a high index of suspicion in the presence of serious disease and obviously distressing symptoms. As a start, it means asking whether the patient is suffering and why. Even though patients often do not know that they are suffering, they must be questioned directly: “Are you suffering?” (Cassell, 1991, p. 532)

Assessing suffering is a challenging task—not only because it is a complex experience in itself, but also because it is not always obvious to the health professional that the patient *is* suffering. Regarding patients, those who are gravely ill may have conditions that affect verbal communication; denial might hamper their expression of emotions or concerns; uncontrolled symptoms in a determined dimension may block the identification or expression of problems in other dimensions; the mere recognition of suffering may be energy consuming for patients in a frail condition. Barriers associated with health system procedures also exist: time limitations, referrals from one professional to another, and fragmentation of care, among others. These factors may impose difficulties when establishing a therapeutic relationship, when conducting follow-ups, or when communicating with patients and families about sensitive matters.

Suffering is a dynamic experience in which contributing factors may lightly or radically change over time. Continued follow-up and assessment of the experience is thus essential. As well, many factors may interact to shape a single, integrated experience. Thus, rather than going over a list of possible contributing factors with each patient (a time- and effort-consuming task), suffering

assessments should be directed at understanding the specific contributors of suffering in each patient and what weight they bring to bear in this comprehensive experience. Furthermore, given that the objective of palliative care and other types of interventions is directed at relief from suffering, it should follow that their effectiveness should be measured in terms of actual alleviation of suffering.

## SUFFERING ASSESSMENT MEASURES

Over the past decades, a number of suffering assessment measures have been developed in healthcare or palliative care settings in order to aid in the difficult task of detecting when a patient is suffering and identifying why this is occurring. Krikorian et al. (2013a) conducted a systematic review of suffering-assessment instruments employed in the context of palliative care and found 10 different strategies (see Table 1); their psychometric quality was also examined and described. A further discussion regarding their content is provided herein.

Most of the instruments identified consist of a series of questions examining factors associated with suffering in different dimensions. Their presence and frequency are evaluated using Likert-type scales or 0-to-10 numeric scales, either in a self-administrated format or a structured interview. Common physical symptoms are examined (e.g., pain, weakness, loss of appetite) as well as psychological or emotional (e.g., feeling depressed or anxious) and spiritual aspects (e.g., hopelessness, loneliness, worthlessness). For some, family, social, and environmental matters are also included (e.g., feeling a burden to others, financial strains). Table 2 lists the common factors included in the instruments for more detailed examination.

Surprisingly, only a few instruments include items that directly ask about the suffering experience—State of Suffering (SOS–5) and the Structured Interview of Symptoms and Concerns (SISC):

### SOS–5:

- How severe is your suffering overall?
- How unbearable is your suffering overall?
- How hopeless is your suffering overall?

### SISC:

- In an overall, general sense, do you feel that you are suffering?
- How bad does it get?
- Is it a problem for you?

The single-item numeric rating is also an example of direct exploration of level of suffering, consisting, however, of a one-dimensional assessment strategy.

Other single-item instruments that employ nondirective strategies are: the Perception of Time (POT) (Bayés et al., 1997) and the Pictorial Representation of Illness and Self-Measure (PRISM) (Büchi et al., 1998). While the POT employs a verbal cue to indirectly assess suffering (how long has the patient perceived the passage of time), the PRISM uses a graphic, nonverbal strategy where the patient points out how much the illness (or aspects of it) have had an impact on the self.

Some of the instruments also include the caregiver's perceptions of a patient's suffering. For example, the Suffering Scales (Schulz et al., 2010) include a separate scale for caregivers where they are asked questions about whether the patient they are caring for is suffering, how easy it is for them realize this, and if they feel they can help lessen this suffering, among others. Two items of the Mini-Suffering State Examination (MSSE) (Aminoff et al., 2004) rely on the caregiver's and health professional's perceptions of a patient's suffering.

Although social aspects are relevant to suffering assessment, few instruments take them into account. The SISC, SOS–5, and the Suffering Scales include such interpersonal matters as social connection, communication, and sense of burden (e.g., SISC: "Are you feeling left out or abandoned?" "Are you able to talk openly to your family and friends?" "Do you feel that you have become a physical or emotional burden for your family?"; SOS–5: "Unsatisfactory contact with family, friends, and those who are nearby"; Suffering Scales: "Feeling abandoned," "Feeling rejected").

The interpersonal and social consequences of suffering are usually considered in a linear mode: the suffering of the patient and the caregiver are assessed and considered separately. However, the bidirectional influences of suffering and how both the patient's and caregiver's suffering can be mutually amplified should be considered. Sherman (1998) proposed a dyadic perspective on suffering and introduced the concept of reciprocal suffering, referring to the inextricable interrelatedness of the suffering experience in patients and caregivers, a type of social suffering that is not currently considered in assessment instruments.

## QUALITY OF THE MEASURES

Assessment measures are designed to accurately measure behaviors that reflect attitudes, emotions, beliefs, and experiences in a standardized manner. They should also be able to measure subjective elements or concepts in a consistent and valid manner during a specified period of time (Gregory, 2012). Regarding validity, an instrument should reflect the

**Table 1.** Available instruments to assess suffering

Instrument	Author/year	Language	Country	No. Items/ Dimensions	Dimensions Evaluated	Administration/Measurement Scale
Initial assessment of suffering	MacAdam & Smith, 1987	English	Australia	20/Unknown	Unknown	Structured interview/5-point Likert-type scale
Perception of time	Bayés et al., 1995	Spanish	Spain	2/1	Subjective perception of time	Semistructured interview/ordinal scale
Pictorial Representation of Illness and Self-Measure (PRISM)	Büchi et al., 1998	English/ German (mostly nonverbal)	Switzerland	1/1	Total suffering	Structured interview or self-administered/numeric scale
Mini-Suffering State Examination (MSSE)	Aminoff et al., 2004	English	Israel	10/1	Physical	Administered to healthcare professionals and caregivers. Yes/no questions for a total of 1 to 10 points
Suffering assessment tool	Baines & Norlander, 2000	English	United States	10/3	Physical, spiritual, emotional/personal and familial	Structured interview. 0-to-10 numeric scale
Structured Interview of Symptoms and Concerns in Palliative Care (SISC)	Wilson et al., 2004	English	Canada	13/No specified	Physical, emotional, social, spiritual aspects, and coping	Structured interview. 7-point Likert-type scale
SOS-5	Ruijs et al., 2009	English/ Dutch	Netherlands	69/5	Functionality, medical, personal, social, and illness-related aspects.	Semistructured interview. 5-point Likert-type scales
Suffering Scale	Chaban et al., 2009	English	United States	10/3	Not reported	Unknown. 10-point numeric scale
The Suffering Scales	Schulz et al., 2010	English	United States	33/3	Physical, psychological, and existential.	Self-administered (by patients and caregivers) or within an interview. 4- and 5-point Likert-type scales
Single-item numeric rating	Benedict, 1989	Any language	Different countries	1/1	Total suffering	Used within a structured or semistructured interview. 5-, 6-, or 7-point Likert-type scales

**Table 2.** Aspects generally included in the instruments used to assess suffering

Physical Dimension	Psychological/ Cognitive Dimension	Spiritual Dimension	Social Dimension	Others
Pain	Confusion	Hopelessness	Feeling dependent on others	Financial concerns
General discomfort/ malaise	Memory or concentration loss	Worthlessness	Feeling a burden to others	Perceived passage of time
Tiredness/ weakness	Depression		Feeling not being important to others	Suffering according to medical opinion
Lack of energy	Sadness	Loss of meaning/ purpose	Feeling abandoned	Suffering according to family opinion
Dry mouth	Loss of interest	Loss of faith	Feeling rejected	Suffering (intensity)
Nausea/vomiting	Tension	Not feeling the same person	Insufficient availability of care	Unbearable suffering
Constipation/ diarrhea	Anxiety	Feeling like a failure in life	Insufficient support	Hopeless suffering
Sleep problems	Worry	Tired of living	Communication problems	
Appetite loss	Fear	Dissatisfaction with life	Feeling isolated (lack of social connection)	
Shortness of breath	Guilt	Desire for death		
Dizziness	Shame	Being peaceful		
Impaired physical functioning	Feeling embarrassed	Having peace of mind		
Loss of function	Irritability	Being in harmony		
Thirst	Being angry	Having a reason to live		
Smelling unpleasant	Acceptance problems	Enjoying life		
Changed appearance	Adaptation problems	Spiritual well-being		
Screams	Negative thoughts	Able to maintain dignity and self-respect		
Ulcers	Loss of control			
Not being calmed	Feeling confident			
Invasive actions	Feeling cheerful			
	Being resilient (feeling able to cope)			
Unstable medical condition				

theoretical construct of what it intends to measure. The items of the instrument are supposed to be comprehensive and include all aspects of the domain (content validity). The results of an assessment must also relate to measures of similar constructs and differ from opposing ones (construct validity) (Bot et al, 2003).

When it comes to assessing suffering, an initial dilemma is encountered. Even though several definitions of suffering have been offered (Fordyce, 1988; Cassell, 1991; 1999; Bayés et al., 1996; Loeser & Melzack, 1999; Chapman & Gavrin, 1999; van Hooft, 2000; Krikorian & Limonero, 2012), few attempts at developing theoretical models exist (Kahn & Steeves, 1995; Dildy; 1996; Bayés et al., 1996; Reeve et al., 2009; Krikorian & Limonero, 2012). To date, only one proposed model has undergone empirical valida-

tion (Krikorian et al., 2013b). Thus, suffering is still a construct under development, and ongoing efforts toward clarifying this concept are required. Moreover, when developing a suffering assessment measure or using one already developed, a coherent theoretical background should be presented.

Concerning administration issues, measures should be not only easy to administer and understandable for the patient in his/her cultural context, but also simple and fast. These aspects are crucial when assessing suffering due to the particular conditions patients are experiencing. Patients with life-limiting conditions are usually polysymptomatic, feel weak, and have little time on their hands. Consequently, assessment of suffering should not constitute an additional burden but a means to lessen it. It should as well be a practical tool for the clinician.

In this sense, assessment strategies that have a therapeutic impact or guide clinical decisions are preferred. Early detection and assessment of suffering is supposed to be followed by implementation of particular standards of care intended at relieving suffering. Strategies designed to prevent suffering in a particular patient and in others need to be developed. Furthermore, follow-up assessments should be implemented in order to provide feedback on the effectiveness of interventions.

The use of multisource information is recommended: for example, objective data from clinical charts and the perception of formal and informal caregivers beyond the patient's perception. It not only offers a more global view of the patient's context, but increases the validity of the measure and provides a more accurate means for assessing suffering.

The conceptualization, assessment, and management of pain may serve as an example of the former. The International Association for the Study of Pain (Merskey & Bogduk, 1994) provided a clear definition of pain coherent with current models to explain the pain experience (see Melzack, 2000). Visual analog and numeric rating scales have been developed for pain assessment, and their psychometric quality in different patient populations has been examined (Flaherty, 1996). The World Health Organization (1986) developed a model for pain relief known as the "analgesic ladder," which has been implemented as part of patient care (e.g., the "Toward a Pain-Free Hospital" initiative, Besner & Rapin, 1993). This efficacy of this model has been investigated (see Azevedo São Leão Ferreira et al., 2006).

A second dilemma in relation to suffering assessment deals with the coherence between the conceptual framework and the measure used to assess suffering. In some cases, the measure is coherent with the available theoretical framework. For instance, the PRISM (Büchi & Sensky, 1999) is a nondirective, nonverbal, and integrated assessment of the suffering experience. It utilizes a graphic representation of the patient's illness in relation to the self in order to quantitatively measure a person's perception of the intrusiveness of an illness. This is consistent with the conceptualization of suffering as a personal experience of threat to integrity and has been shown to correlate with factors likely to influence personal constructs (Sensky, 2010).

Other measures, on the other hand, lack a sound theoretical background or show inconsistencies between the theoretical construct and how they are assessed. As an example of the first case, Bayés et al. (1997) developed an instrument they called the "Perception of Time," according to which time is perceived as passing more slowly when the patient suffers. In order to screen for suffering, they

developed an instrument where patients were asked such questions as "How long did yesterday seemed to you? What would you say? Short, long, neither?" Most of their patients who reported feeling very bad, bad, or fair indicated perceiving time as passing more slowly. However, judgments on perceived passage of time have also been found to be influenced by such external factors as segmentation of events into discrete units and consumption of alcohol (Ogden et al., 2011; Liverence & Scholl, 2012), not specifically related to suffering.

In the second case, some measures show inconsistencies in terms of theoretical background. Suffering is generally conceived as a subjective experience of severe stress and threat to a person's integrity. As such, it must be assessed using the subjective perception of the individual and not only attending to the objective aspects of the experience. Aminoff and colleagues (2004) developed the Mini-Suffering State Examination (MSSE) in order to assess suffering in patients with advanced dementia incapable of verbal communication. It consists of a 10-item scale including the patient's characteristics and the perception of their condition by the medical staff and family. According to this instrument, the presence of agitation, screaming, facial expressions of pain, ulcers, malnutrition, and other objective signs, as well as the perception of the family and the healthcare professionals of the patient's suffering, are considered indicative of a patient's actual suffering. Although it is a useful tool for assessing the condition of a patient and his/her deteriorating health status and to identify potential sources of suffering, it is not actually aimed at examining a subjective construct that requires the personal expression of a private experience.

As stated above, suffering-assessment instruments are intended to help relieve suffering and thus should not constitute a burden for the patient. The third dilemma deals with practical issues such as the length of the measure, its potential intrusiveness, and the need to rely on verbal expression (oral or written). Time-consuming instruments may be difficult to complete when patients have debilitating conditions. In such a case, the assessment procedure in itself may become an additional source of suffering. Consequently, the length of the instrument should conform to the needs of gravely ill populations. In the context of requests to hasten death, the SOS-5 instrument was developed specifically to detect unbearable suffering (Ruijs et al., 2009). The authors dedicated their efforts to first define the concept of unbearable suffering and then describe a framework in which items were to be identified and selected. The framework consisted of five domains: medical signs and symptoms; loss of function; personal aspects; aspects of environment and

nature; and disease prognosis. Sources of suffering in each domain were selected using a prior literature search, and the instrument was designed to measure not only the presence of the problem but also how unbearable it was for the patient. Moreover, open questions were included at the end of the interview that addressed the capacity to bear suffering, the role of spirituality, the influence of previous experiences, and any unexpected positive consequences of the disease. The instrument examined 69 aspects, and the time required to complete the interview was between 60 and 75 minutes. The instrument showed adequate content and construct validity and was psychometrically sound in many respects. However, the length of the interview constituted its major limitation, bearing in mind that its focus is on detection of unbearable suffering. Most people who consider hastening their death have uncontrolled symptoms, depression, and hopelessness (Breitbart et al., 2000), so that an instrument capable of detecting suffering and its sources in a practical, sensitive, and timely fashion would be ideal for both the patient and the health team.

Single-item measures have become increasingly popular in healthcare settings, particularly for screening purposes or when multiple-item instruments are not suitable due to time and resources limitations. Chochinov et al. (1997) compared the performance of different measures to screen for depression in the terminally ill and found that a single measure asking “Are you depressed?” was more valid than multiitem instruments and visual analog scales. The Distress Thermometer is another example of a valid and reliable single-item tool to measure distress in cancer settings (Snowden et al., 2011). Regarding quality-of-life measures, Cunny and Perri (1991) found that a single item extracted from the short-form General Health Survey of the Medical Outcomes Study positively and significantly correlated with overall score. Finally, single-item measures may be useful for research in palliative care, where small sample sizes are more common.

Finally, a fourth dilemma deals with the psychometric adequacy of instruments. Not only should an instrument measure what it is intended to be measured, but it should do so in a valid and reliable manner in order to be useful for both clinical and research purposes. The Scientific Advisory Committee of the Medical Outcomes Trust (1994) developed a list of attributes necessary for an instrument to be considered of high quality:

1. conceptual and measurement model
2. reliability
3. validity

4. responsiveness
5. interpretability
6. respondent and administrative burden
7. alternative forms
8. cultural and language adaptations

Following these recommendations and the report by Lohr et al. (1996), a checklist to test for psychometric quality was developed in order to examine the quality of assessment instruments (see Bot et al., 2003). The quality and usefulness of some suffering-assessment instruments have been examined (for a complete review of the psychometric quality of suffering-assessment instruments, see Krikorian et al., 2013a). When suffering-assessment instruments were tested against these criteria, two instruments were found to have the strongest psychometric quality: the PRISM and the SISC. Both tested positive for 9 of 12 items included in the checklist: ease of scoring, readability and comprehensibility, content and construct validity, floor and ceiling effects, test–retest reliability, agreement, responsiveness, and interpretability. For many, however, there was insufficient or no information available on such aspects as content validity, internal consistency, test–retest reliability, floor and ceiling effects, and agreement and responsiveness; and for none was a statistically significant difference calculated.

Although a number of assessment measures are now available for use in the palliative care setting that employ different and innovative approaches to assessment, many are yet to be examined and validated in different contexts, so that they cannot be considered high-quality tools for suffering detection and assessment of intervention results.

## CONCLUSIONS

Though we have made much progress, there is still a great deal of work to be done toward optimal suffering detection, assessment, and relief in patients with both communicable and noncommunicable chronic life-limiting diseases. A more robust theoretical background is needed, as well as supporting empirical evidence. Further examination of the psychometric characteristics of most suffering-assessment instruments is still to be done. Testing these instruments in different patient populations and cultural contexts is recommended as a means to identify sensitive and practical ways for early detection and assessment of the suffering experience and a way to determine the effectiveness of the means provided to alleviate it.

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