Mental Pain and Suffering: The “Universal Currencies” of the Illness Experience?

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Fava et al. [1] have recently proposed mental pain as a transdiagnostic patient-reported outcome measure. A similar claim has been made for suffering [2]. The main aims of this paper are: (a) to briefly outline the requirements of an optimal person-centred outcome measure; (b) to compare the features characteristic of mental pain and suffering; and (c) to consider mental pain and suffering as candidates for an optimal person-centred outcome measure. The conceptualisation and measurement of mental pain have been reviewed previously [1, 3], and before comparing this with suffering, a brief review will be presented of the conceptualisation and measurement of suffering.

Health and Health Outcomes

The constitution of the World Health Organisation defines health as “a state of complete physical, mental, and social wellbeing” [4]. This definition has been widely criticised for excessively medicalising healthcare, giving clinicians a predominant role in deciding when a person is healthy by confirming the absence of symptoms or of

abnormalities in investigations [5, 6]. Despite such criticisms, the consequences of the WHO definition are deeply ingrained in clinical practice. The ICD classification and the DSM diagnostic manual are based on identifying states of ill health (disorders or diagnoses) based on particular abnormalities (symptoms). This narrowly biomedical, problem-based approach is widely reflected in most of the outcome measures used in healthcare – successful outcomes are measured in terms of removal of problems, that is, symptom reduction.

The main problem with this biomedical approach is that, taken on its own, it fails to consider the values and preferences of the people being treated. Fulford [7] gave a graphic example of an artist whose bipolar disorder was stabilised well with lithium, but who chose to discontinue lithium because taking lithium had caused colours to lose their intensity, interfering with her pursuit of her art. In their seminal book on evidence-based medicine, Sackett et al. [8] noted: “by patient values we mean the unique preferences, concerns and expectations each patient brings to a clinical encounter and which must be integrated into clinical decisions if they are to serve the patient.” They stressed that both an evidence-based ap-

proach and incorporation of the patient's values were essential for optimal healthcare intervention.

The term "patient," in its modern usage, commonly refers to a person receiving, or eligible for, medical treatment. It has been argued that this term is anachronistic, and should be replaced [9]. This use of "patient" also reinforces the problem-based biomedical model. Referring to patients as people is a reminder that healthcare demands more than mere symptom reduction. On the other hand, when people are patients, they have particular roles in clinical encounters and in sharing responsibility for their healthcare. However, the original root of "patient" is from the Latin to suffer or endure. The alleviation of suffering has long been considered one of the principal goals of medicine. It remains a legitimate goal [10], although some have argued that medicine has lost sight of this [11]. Cassell [12] has commented that "the relief of suffering, it would appear, is considered one of the primary ends of medicine by patients and lay persons, but not by the medical profession."

The limitations of the problem-based approach to healthcare implicit in the WHO definition have led to calls for a shift to goal-oriented patient care [13, 14]. Rather than measuring the reduction in symptoms or problems, the goal-oriented approach aims to measure the extent to which people are able to achieve their goals (or conversely the extent to which illness prevents the achievement of goals). Goals are inevitably personal and may be idiosyncratic [15]. For this reason, individual values and preferences have a central role. Mold et al. [13] asserted: "health must ultimately be defined by each individual and therefore will be different for different individuals and at different points in time." Thus, a goal-oriented outcome measure should not only focus on achieving goals rather than reducing problems, but crucially must also take account of the individual's values and preferences. For the same reason, a genuinely goal-oriented approach is also person-centred. Measures which are problem-based do not take account of individual values and preferences, and so do not qualify as person-centred.

Conceptualisation of Suffering

Cicely Saunders, the founder of the hospice movement, coined the term "total pain" to describe how physical and spiritual suffering shape a single, integrated, multidimensional experience [16]. To illustrate total pain, Saunders quoted a patient who had told her "all of

me is wrong" [17]. Cassell's is probably the most widely cited conceptualisation of suffering, particularly among palliative care specialists. Based on his clinical experience, he defined suffering as occurring "when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner" [12]. Cassell referred to the threat to the individual's personhood to highlight that the threats could involve any aspect of the person. Cassell [18] also commented: "people in pain frequently report suffering from pain when they feel out of control, when the pain is overwhelming, when the source of the pain is unknown, when the meaning of the pain is dire, or when the pain is apparently without end." Krikorian et al. [19] elaborated this, defining suffering as "a multidimensional and dynamic experience of severe stress that occurs when there is a significant threat to the whole person and regulatory processes are insufficient, leading to exhaustion." Loeser and Melzack [20], supporting Cassell's conceptualisation, defined suffering as "a negative response induced by pain and also by fear, anxiety, stress, loss of loved objects, and other psychological states." Based on analysis of patient narratives, Morse and Carter [21] defined suffering as "an emotional response to that which was endured, to the changed present, or to anticipating the altered future," again consistent with Cassell's formulation. However, this last definition differs from the others above in emphasising the primacy of emotion. While suffering inevitably has a strong emotional content, Cassell's conceptualisation and others like it demonstrate that suffering has a prominent cognitive component. Concluding that one's personhood is threatened involves appraisal.

A complication in conceptualising suffering pointed out by Loeser and Melzack [20] is that "the language of pain is used to describe suffering, irrespective of the cause, and thus misleads both the doctor and the patient as to the basis of the suffering." Many publications in the pain literature fail to distinguish between pain and suffering. An added problem is that suffering can take a range of meanings, from the experience of intractable pain in someone who is terminally ill, to having a hangover [22]. Thus, for example, it is unclear whether among people attending the emergency room, waiting longer to be seen genuinely increases suffering as the authors claimed [23], rather than causing greater discomfort. However, these problems can be overcome by asking about suffering in a defined context, for example, by first asking the person about their experience of illness then asking how this ex-

perience contributes to the person's suffering [24, 25]. By putting suffering into context thus, patients understand the term in a consistent way [2, 24].

In their review of suffering in palliative care, Krikorian et al. [19] noted that numerous publications on suffering have lacked a theoretical framework. The same applies to mental pain – numerous publications mention mental pain without defining or explaining their use of the term (e.g., [26–28]).

Assessment of Suffering

Measures used to assess suffering have been summarised in systematic reviews of the relationship of suffering to pain [29] and the assessment of suffering in palliative care [19]. Cassell [30] has advocated asking patients directly about their suffering. This yields valid information provided the question about suffering is put into context, as noted above. Other measures have used Likert scales [31, 32], questionnaires [33, 34], or structured interviews [25]. Some researchers have assumed that the wish to hasten death is a valid proxy for suffering, although such expressed wishes have more complex motives [35–37]. Another approach has been to use clinician-rated questionnaires [38].

A novel approach has been to quantify suffering using a visual metaphor measure, the Pictorial Representation of Illness and Self Measure (PRISM) [2, 39, 40]. Published evidence shows that PRISM measures suffering as expected from Cassell's conceptualisation of suffering. Because the measure is essentially visual with brief and simple instructions, it can easily be used in different languages. A key feature of all metaphors is that people interpret them in a personally salient way, and hence PRISM yields a personal assessment of suffering [2]. The PRISM measure is sensitive to change [40–42]. Systematic reviews have commended PRISM as a measure of suffering in palliative care [19] and in cancer [43]. PRISM has been used clinically [42] as well as in research.

Comparisons between Mental Pain and Suffering

At first glance, the two concepts appear somewhat different. One reason for this apparent difference is that they were developed in different settings and contexts. Early research into mental pain aimed to gain better understanding of suicidality [3]. By contrast, most of the publications on suffering among people who are ill have fo-

cused on palliative care settings [16], or people with cancer [43] or chronic physical illnesses [2]. This may help to explain the different features which have been associated to date with mental pain and with suffering.

On closer inspection, the two concepts are not as dissimilar as they first appear. Crucially, both mental pain and suffering involve distress resulting from the individual's adverse appraisal of their circumstances, and both are features of the whole person. This was stressed by Cassell [12] as a key property of suffering. In addition, both mental pain and suffering are intended to be separate, and different from, physical pain [1, 12], although physical pain, when present, can contribute substantially to each. Mental pain is a transdiagnostic measure [1], a property clearly shared by suffering.

Some of the published definitions of mental pain appear consistent with Cassell's definition of suffering. Bolger [44] described mental pain thus: "emotional pain is the central aspect of the broken self, which is characterised by woundedness or injury, loss of self or wholeness, disconnection within self and from others, and a critical awareness of one's negative attributes." Orbach et al. [45] defined mental pain as a wide range of subjective experiences characterised as an awareness of negative changes in the self and in its functions accompanied by negative feelings. In their review of mental pain, Meerwijk and Weiss [46, 47] concluded: "In sum, our analysis indicated that psychache, psychic pain, emotional pain and suffering essentially refer to the same experience, which we called psychological pain. Based on characteristics that were supported across different conceptual perspectives, we defined psychological pain as 'a lasting, unsustainable and unpleasant feeling resulting from negative appraisal of an inability or deficiency of the self.'"

The extent of the similarities between mental pain and suffering is illustrated by Table 1, which lists characteristics and correlates of each, based on those previously identified for mental pain [1]. There is evidently considerable overlap between the two concepts. Fava et al. [1] made the case that mental pain has a spiritual or religious dimension, and this certainly applies to suffering. The major world religions offer their believers ways of understanding suffering [48]. No study has yet assessed any association between suffering and euthymia. However, numerous studies have reported significant negative correlations between suffering and sense of coherence [2], which shares characteristics with euthymia such as resilience and environmental mastery [49, 50].

Table 1. Mental pain and suffering: comparison of attributes and associations

Feature or correlate	Mental pain	Suffering
Presence of distress	Shneidman [51], 1993 Orbach et al. [52], 2003	Cassell [12], 1982
*Affects whole person rather than localised	Fava et al. [1], 2019	Cassell [12], 1982
*Loss of self/feeling of being broken or wounded	Bolger [44], 1999	Cassell [12], 1982 Büchi et al. [40], 2002 Wittmann et al. [24], 2009
*Hopelessness/helplessness	Bolger [44], 1999 Montemmarano et al. [53], 2018	Krikorian et al. [54], 2013
*Feelings of emptiness	Holden et al. [55], 2001 de Leon et al. [56], 2015	Büchi et al. [40], 2002 Wittmann et al. [24], 2009
*Irreversibility	Orbach et al. [52], 2003	Büchi et al. [40], 2002 Wittmann et al. [24], 2009
Loss of control/autonomy	Baker [57], 1996 Orbach et al. [52], 2003	Wittmann et al. [24], 2009 Krikorian et al. [54], 2013 Taylor et al. [41], 2017
*Loss of meaning	Orbach et al. [45], 2003	Büchi et al. [58], 2009
*Spiritual aspect/dimension	Fava et al. [1], 2019	Breitbart [59], 2002 Best et al. [43], 2015
*Association with suicidal ideation	Shneidman [51], 1993 Orbach et al. [45], 2003 de Leon et al. [56], 2015 Verrocchio et al. [60], 2016 Ducasse et al. [61], 2018 Svicher et al. [62], 2019	Harbauer et al. [63], 2013 Ring et al. [64], 2014
Correlation with depression	Fertuck et al. [65], 2016 Svicher et al. [62], 2019	Büchi et al. [40], 2002 Sensky and Büchi [2], 2016
Negative correlation with post-traumatic growth	–	Büchi et al. [58], 2009 Wittmann et al. [24], 2009
Negative correlation with euthymia	Guidi et al. [66], 2019	–
Negative correlation with sense of coherence	–	Büchi et al. [40], 2002 Sensky and Büchi [2], 2016

* Characteristic features of mental pain listed by Fava et al. [1].

Are Mental Pain and Suffering Suitable as Global Person-Centred Outcome Measures?

Clearly, suffering may be caused other than by illness, but according to Cassell's conceptualisation, it can be argued that alleviation of suffering should be a universal aspiration among people who are ill, with only rare exceptions (e.g., people who present with factitious disorders). The same argument applies to mental pain.

Mental pain and suffering clearly share numerous attributes and correlates (Table 1).

Because they have much in common, questions arise about their relationship. Are they fundamentally different concepts, or similar, or the same? It is possible, though unlikely, that two concepts, each referring to personally salient negative and global appraisals about illness, are measuring fundamentally different things. Other possibilities are that one concept incorporates and subsumes

the other, or that they essentially tap the same underlying concept, with the apparent differences caused by the different settings in which the two were developed. Further work is needed to distinguish between these possibilities.

Fava et al. [1] recommended measurement of mental pain in clinical practice and in treatment outcome studies. A bolder claim can be made, that mental pain and suffering should be marked out as potential global health outcome measures. Three key shared features support such a claim.

First, among those who are ill, both mental pain and suffering are integral to the illness experience, and as already noted, being free from mental pain and suffering are likely to be aspirations of the overwhelming majority of people who are ill.

Second, when applied appropriately in clinical encounters or in research, both concepts are readily and consistently understood by lay people. Fava et al. [1] noted that from clinical experience, patients are unlikely to refer spontaneously to mental pain, but when asked about this explicitly, their sometimes very vivid descriptions indicate their understanding of the term. When people with illness are asked about suffering in an appropriate context, research as well as clinical experience indicates that they understand the concept in a very consistent way [2, 24]. Despite this, clinicians seldom ask their patients about their suffering, for a number of reasons [22]. One factor is highlighted by a comment from Thomas Lee [67]: “We avoid the word ‘suffering’ even though we know it is real for our patients because the idea of taking responsibility for it overwhelms us as individuals – and we are already overwhelmed by our other duties and obligations.”

The third key factor supporting mental pain and suffering as person-centred outcome measures is that neither is localised in a part of the body [1, 12]. Cassell [12] stressed that suffering was a feature of the whole person. As such, both mental pain and suffering should yield, for each individual, a global appraisal of their illness experience, which will be influenced by multiple factors [40]. Not only will these factors differ between individuals, but so will their appraisals. Personal appraisals incorporate the person’s values and preferences, and thus these will also be reflected in measurements of mental pain and suffering. There is evidence that this applies in suffering, as Cassell’s conceptualisation requires, both from research [2, 40] and clinical practice [42].

Despite the points above, there are at least two potential problems in using either mental pain or suffering as outcome measures. The first problem is that mental pain

and suffering have possible ceiling effects. Not all patients will experience suffering all the time, even in life-threatening illnesses like advanced cancer [25]. Kleinman (quoted by Frank [68]) added to Cassell’s conceptualisation that for suffering to occur, the threats to personhood have to be resisted. Where the threats are accepted, for example in instances where the person is successful in finding strong and consistent meaning in their illness experience, suffering will be reduced [37]. The extreme expression of this is Frank’s assertion that suffering ceases to be suffering when it takes on meaning [69]. Another reason why suffering might be minimal or even absent is that the person is attempting to cope by denying their illness and/or its threats [70]. However, especially in clinical practice, the failure to identify suffering is more likely due to the clinician avoiding sufficient exploration of the patient’s experience, as Lee’s quotation above warns.

The second problem is more complex. Although mental pain and suffering each provide a comprehensive measure of the person’s illness experience, clinicians are understandably most interested in how the illness experience responds to their interventions. However, each person’s illness experience may be affected by interpersonal and cultural factors which are outside the clinician’s influence [71–73]. Pain can be a powerful way to communicate distress [74], and anthropologists have gone as far as to describe sickness as a “cultural performance” [75]. Somatic presentations of distress are well recognised in some non-Western cultures (e.g., [76]), but are most likely more widespread than is usually assumed [77]. It has been suggested that people who somatise are “distress-prone” [78], just as Engel [79] described some people as “pain-prone,” whose pain is heavily influenced by their circumstances. Thus the outcome of healthcare interventions should be reflected by reductions in suffering and mental pain, but there will be instances where these are not eliminated completely or may even worsen, even when healthcare interventions have been optimal. It may be helpful here to draw a distinction between measuring mental pain or suffering in a sample of people, and measuring changes, for example with interventions. In a group of patients, cultural and other “non-illness” factors will vary between people and will therefore increase the variance of measures of mental pain or suffering. However, this should have less effect on changes to mental pain or suffering, where each person’s before and after measurements both incorporate that person’s “non-illness” factors.

Despite these limitations, mental pain and suffering meet the criteria proposed by Mold et al. [13] for goal-

oriented healthcare outcomes. Health must be defined by each individual, and will differ between people and at different times. The PRISM measure of suffering has been shown to be responsive to change [40]. Also, health-related goals require an assessment of the individual's personal values and preferences. Mold et al. [13] also noted that a person's health goals can best be determined by collaboration between the patient and the clinician, each of whom has expertise to contribute, as recognised by shared decision-making [80]. Given their qualities, mental pain and suffering should be crucial elements in shared decision-making. Paradoxically, the only criterion which neither of these concepts meets is that they should be outcome measures. Strictly speaking, mental pain and suffering are still problems. However, a strong case can be made that both are fundamentally different from other problem measures like symptoms or diagnoses, notably because they are measures of the whole person. For this reason, and because they incorporate the person's values and preferences, it can be argued that they are proxy measures of individually appraised (and therefore person-centred) global outcomes.

Implications for Clinical Practice and Research

Focussing on mental pain or suffering has clear implications for interventions. Most importantly, a shared understanding of these as concepts by clinician and patient facilitates the exploration and choice of interventions. As the quotation by Lee above illustrates, if suffering is seen as nebulous and predominantly emotional, recognising it does not alone suggest particular interventions. However, following Cassell's formulation, opportunities can be explored to reduce suffering by working with the person to reappraise their personhood and/or the perceived threats to personhood [22, 37]. For example, a man devastated that worsening arthritis has prevented him from playing football with his young sons might have lost sight of all the other positive qualities he possessed as a father. Such reappraisals can sometimes be achieved quite rapidly when the person's suffering is explored. The PRISM tool can be used clinically to aid such discussions [42].

More generally, as Fava et al. [1] have noted, well-being therapy might be expected to reduce mental pain, because it focuses on enhancing the individual's strengths rather than on reducing symptoms [81, 82]. Also, as Arthur Frank [68] has observed, serious illness and suffering can lead to the person becoming a "narrative wreck," and merely acknowledging the person's suffering or mental

pain and allowing them the opportunity to talk can allow them to revise their personal narrative. Such interventions are likely to be more productive when clinicians approach discussions with people who consult them having in mind a clear conceptualisation of suffering or mental pain.

Suffering and mental pain, as has been stressed, are features of the whole person. However, a person's suffering is made up of contributions from different aspects of that person's illness experience. For example, a grandmother who cannot knit clothes for her grandchildren might appraise impaired manual dexterity as much more threatening to her personhood (and therefore as causing greater suffering) than impaired mobility. These threats to personhood can be explored clinically and ranked or even quantified, in collaborative discussions between patient and clinician. Such discussions can be aided by PRISM [42]. They can contribute to decision-making about priorities for intervention, and to measuring the success of interventions by the reduction in suffering.

Research priorities include evaluating the Mental Pain Questionnaire more widely [81, 82]. It is possible that data from people with different illnesses and in different settings might lead to refining of the key elements currently attributed to mental pain [1]. If this does happen, it will be of interest to review whether mental pain and suffering diverge or converge. Direct comparisons between the concepts would be helpful.

While the person-centred approach outlined above can be readily applied with individual patients in clinical practice, it is more challenging to apply in research. Pilot work has demonstrated the feasibility, in a research context, of eliciting for individual research participants salient aspects of their personhood which have been affected by illness and measuring how these contribute to their suffering [41]. People with substance misuse frequently have comorbid post-traumatic stress disorder (PTSD), and a study of people with both diagnoses established that those in the selected sample appraised PTSD as causing them greater suffering than their substance misuse [83]. Such data can help to inform intervention priorities, particularly in those with multiple diagnoses [84]. It would be very difficult, if not impossible, to make such comparisons between a person's experience of comorbidities, or different aspects of the same illness, without using a measure like suffering or mental pain, valid for disparate aspects of the illness experience. It should be possible to extend the same methodology to a wide range of research and healthcare policy questions. Being able to apportion levels of mental pain or suffering to different and dispa-

rate aspects of a person's illness experience offers the prospect of these being used as "universal currencies" of the illness experience.

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Statement of Ethics

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Conflict of Interest Statement

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