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Section on Person-centered Health Domains

Suffering

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Suffering—background

Clinicians commonly see the alleviation of their patients' suffering as one of the principal aims of their clinical work. Public health specialists adopt a similar view. For example, the World Health Organisation website includes >10,000 references to 'suffering'.

Crucially, the alleviation of suffering is not the same as alleviation of symptoms. Some interventions may alleviate symptoms while at the same time exacerbating suffering. An added complication is that, as a term, 'suffering' has come to be used imprecisely, and hence also potentially devalued. Thus, we talk of 'suffering from intense pain' or 'suffering from a terminal illness', but also 'suffering a cold' or even 'suffering a hangover'. This is perhaps one reason why clinicians tend not to ask their patients directly about their suffering. However, there are at least three other important reasons why suffering is not mentioned as often as it deserves to be in clinical encounters. First, it is traditionally been considered very difficult to quantify suffering and, in the absence of reliable metric, clinicians perhaps consider that they cannot elicit reliable information from their patients about the patients' suffering. Secondly, clinicians may consider that by relying on an empathic approach to their patients, they can gauge the extent of a patient's suffering. Finally, as will be argued below, suffering is an intensely personal and private experience, and hence enquiring about it might elicit a complex and detailed response for which there is insufficient time available in the clinical encounter, since any individual's suffering needs to be understood in the context of his or her Personhood.

Conceptualisation of suffering

Cassell [1] described suffering as *a state of severe distress associated with events that threaten the intactness of the person and stated that suffering occurs 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*.

A key feature of suffering is that it is a property of the whole person—suffering is not a phenomenon that can be reduced to part of the person. This is a key distinction between suffering and pain. Pain is a common cause of suffering (although there are many others). However, while we may complain that we experience pain in the head or the arm, it is only the whole person who suffers. Suffering is a feature of Personhood [2][1], and hence also of the person-centered approach to health care. This is analogous to the difference between generic measures of health-related quality of life, like the SF-36, and person-specific measures, like the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) [3]. Measures like the SEIQoL focus on those aspects of life most valued by the individual, while generic measures assess features of quality of life likely to be widely shared. In fact, generic quality of life measures are open to wide variation in personal interpretation [4], as are commonly used measures of pain [5], but this is regarded simply as part of the overall variance of such measures, rather than being important in discriminating individual responses.

[1]See the Chapter by Cassell in this volume for a discussion of Personhood.

Because suffering has such a diversity of meanings, clinicians commonly expect these meanings to be reflected in the way the term is used by patients. However, in the context of illness and health, there is evidence that lay people are remarkably consistent in how they understand and use the term. In a qualitative study of people with systemic lupus erythematosus [6], perceived causes of suffering included physical factors due to the illness, constraints in things of high personal value, loss of autonomy, worried about the future, factors in the social environment, and unwanted or unacceptable changes to daily life due to the illness. All of these are features of Personhood. As one person observed: "*Illness is like an unexpected thief that attacks one's life and destroy is one's life expectations. With illness, goals in life fade away and you are convinced that you won't be able to achieve the old goals. One has to painfully reconstruct one's expectations and which goals are important, as energy is lacking to achieve them*". This fits well with Cassell's conceptualisation of Personhood [2], as do the published results of other researchers [7].

Measurement and correlates of suffering

In collaboration with Prof. Stefan Büchi and colleagues at the University of Zürich, we have developed novel and simple visual method of quantifying suffering, using an instrument called the Pictorial Representation of Illness and Self Measure (PRISM). Evidence has been published of the validity and reliability of PRISM [8, 9]. Consistent with suffering being an intensely personal experience, our measure of suffering has, among people with arthritis, shown much stronger correlations with factors likely to influence a personal construct (such as pain, depression, and sense of coherence) than with 'objective' disease variables, such as the SF-36, and disease status. More recent work, as yet unpublished, has indicated that patients who report having been able to make sense of their illness experience showed lower levels of suffering than those who have not been able to make sense of the illness experience. This is consistent not only with Cassell's model but also with Frankl's well-known view that suffering ceases to be suffering when it takes on meaning [10]. In a study of parents whose children had been born prematurely but then died shortly after birth, suffering correlated (as predicted) with the intensity of the parents' grief, but also showed a significant negative correlation with a measure of post-traumatic growth.

Managing suffering

Understanding suffering as a threat to an individual's Personhood also serves to guide clinicians in how to work with their patients to alleviate their suffering. The threat to Personhood can be reduced by removing it (by curing the patient of the illness), by helping the person reappraise the threat to his/her Personhood, or even by reappraising the key features of Personhood itself. Assuming that (as in chronic illnesses in general) complete and effective cure is not possible, people can redefine their Personhood by telling and retelling personal narratives [11]. Therefore, simply giving someone who is suffering the opportunity to review his or her personal narrative has the potential to alleviate suffering. Beyond this, psychological interventions, which can be aided by PRISM [12], can contribute substantially [13].

Future directions

The finding that patients are very consistent in their understanding of suffering should encourage clinicians to focus more specifically on the suffering of their patients, and on how it may be alleviated. Further work is needed to better understand factors likely to moderate suffering, such as spirituality, personal growth and finding meaning. The PRISM measure has shown itself to be very useful in clinical practice as well as research. The challenge remains to develop a practicable way of assessing and managing suffering in everyday clinical practice.

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