



Krawczyk, M. , Wood, J. and Clark, D. (2018) Total pain: origins, current practice, and future directions. *Omsorg: The Norwegian Journal of Palliative Care*, 2018(2)

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/167847/>

Deposited on 01 November 2019

Enlighten – Research publications by members of the University of
Glasgow

<http://eprints.gla.ac.uk>

Total pain: origins, current practice, future directions

Marian Krawczyk, Joseph Wood, David Clark

Marian Krawczyk, PhD is a medical anthropologist and a Lord Kelvin Adam Smith Fellow at the University of Glasgow, School of Interdisciplinary Studies where she works with Joseph Wood and David Clark as part of the Glasgow End of Life Studies Group. Joseph Wood is a PhD candidate in English Literature, and has an interest in medical humanities. David Clark (PhD, FAcSS, OBE) is Professor of Medical Sociology and Wellcome Trust Investigator at the University of Glasgow, Scotland, as well as Adjunct Professor at the University of Southern Denmark. The University Of Glasgow End Of Life Studies Group was founded by Professor David Clark in 2014. We conduct interdisciplinary research on end of life issues, collaborating with communities, policy makers, practitioners and academics worldwide. You can contact any of the authors at: endoflifestudies@glasgow.ac.uk

Abstract

The concept of 'total pain' holds a key place in the history of palliative care. Its origins in the work of Cicely Saunders have been described in some detail, yet there is still much to be learned about and from it. In this article we address some of the intellectual influences on the conceptualization of total pain and explore it as a form of practice. In conclusion, we set out some future directions for thinking about and evaluating total pain - building on the legacy of Cicely Saunders, who first brought it to prominence.

Keywords: total pain, Cicely Saunders, suffering, palliative care practice

Total pain is a well-established part of the lexicon of palliative care, but has not been the subject of extensive research or reflection.

How can total pain be understood and responded to in the pressures of modern healthcare systems?

A bio-ecological approach to total pain may enrich our understanding of the concept, contribute to clinical practice and enable more wide-ranging forms of evaluation.

Cicely Saunders was something of a hybrid. Reading Politics, Philosophy and Economics at Oxford in the late 1930s, she quit her studies to train as a nurse during the Second World War. She then became a medical social worker, before qualifying as a physician in the late 1950s.¹ She was a devout and, for a period, evangelical Christian. A voracious reader and something of an auto-didact, her thinking was shaped from a wide-ranging fusion of philosophical, theological and medical sources as well as influences from literature, poetry, music and the visual arts. All of these contributed to her ground-breaking concept of 'total pain', first articulated in the early 1960s².

Origins and influences

Saunders' concept of total pain has its origins in a post-war reaction to totalitarianism and consumerism. She opposes what she calls the current 'sorry climate of thought' that devalues human relations in favour of individualism and materialism. Unlike the religious and moral culture of pre-1900 Britain, she claims contemporary values have 'no valid answer to the problems of suffering and death' and have established a context in which 'questions must not be asked' because suffering is seen 'as a meaningless burden'.³ To speak of total pain with its inclusive attitude towards a patient's emotional and spiritual needs is therefore part of a rejection of this culture in medicalised modern healthcare systems, which increasingly focus on the disease rather than the patient. It is a view that is strongly influenced by the writing of Holocaust survivor Viktor Frankl, as set out in his popular book *Man's Search for Meaning*.⁴

The belief that meaning can be found, or made, at the end of life also stems from Saunders' own holistic Christianity which emphasises the interconnectedness of body and spirit, and the potential for true meeting between individuals. Although often divided into its constituent parts within the clinical and palliative care literatures, in later life Saunders herself was keen to note that any separation of total pain into physical, mental, social, spiritual and even 'staff' pain represents an artificial division of 'a whole overwhelming experience'. This holistic understanding of total pain is informed by several existential Christian philosophers, such as Martin Buber, Pierre Teilhard de Chardin and John Macmurray, who emphasise that the self does not exist on its own but rather in and through open dialogue with others. Saunders was also in conversation with several members of religious communities who in turn added to her sense of the collective dimensions of suffering, and provided the means to assuage it.⁵ She therefore uses total pain to acknowledge that pain at the end of life, unlike acute pain, 'is a situation rather than an event', one which is experienced through the body but takes place within the meaningful context of the patient's wider life.

As such, total pain includes the suffering of a whole person who is part of a network of relationships that will soon be left behind. In this perspective, Saunders was influenced by the work of Paul Tournier, the Swiss doctor and forefather of person-centred care. Tournier encouraged other medical professionals to practice 'medicine of the person',⁶ a care for the whole being which, like total pain, goes beyond physical symptoms to address the emotional, psychological and spiritual problems in a patient's life, with a commitment to openness and dialogue between patient and medical practitioner.

Other commentators such as the sociologist Yasmin Gunaratnam and the palliative care educator David Oliviere have positioned Saunders' work within the wider 'turn to narrative' in medicine, one which attempts to establish patients as more active participants in their own care by paying attention to their stories.⁷ Total pain is based on Saunders' extensive narrative research: she made countless recordings of interviews with people who were dying and encouraged her staff to make notes on their patients' psychosocial as well as physical progress. For example, Saunders often quotes a particular patient Mrs Hinson ('the pain began in my back, but now it seems that all of me is wrong') when explaining total pain because she somehow articulates an integrated experience, one that is *felt as* pain even if some of its origins lie outside her body in family problems or fear for the future. While some have questioned how it confuses physical pain with other forms of suffering and distress,⁸ total pain therefore echoes the way we narrate the problems of illness and our own figurative use of the word 'pain' in everyday language. Indeed, it follows the influential IASP definition of pain, as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'.⁹

Ultimately, total pain derives from Saunders' conception of how pain functions. She cites William Noordenbos who inspired Melzack and Wall's gate control theory of pain: 'Pain is experienced when stimuli, whatever their nature, exceed certain limits [...] might it not simply be stated that *pain is too much?*'.¹⁰ The 'total' of total pain is therefore not the description of a limit that indicates where professionals should direct their attention but rather a provocation for good care exemplified by Saunders' frequent assertion that it is never true to say 'there is nothing more to be done'.

Contemporary contexts

Addressing total pain today remains a foundational principle within the practice of modern palliative care – wherever it is delivered. Yet its mutable terminology also creates and reflects uncertainty in identifying total pain in people who have advancing life-limiting illnesses. What are the symptoms and signs of total pain? How is it different from other forms of complex pain? Does it continue to have salience in contemporary practice?

For all its centrality within the palliative care narrative, there is little research on total pain that provides clarification or guidance in answering these questions. This may be due to its conceptual 'slipperiness' and be furthered by disciplinary divides. The few clinical publications that focus on total pain do so through individual case studies and practical aspects of treatment, and total pain effectively functions as a diagnostic shorthand for a cluster of intertwined but discrete symptoms recognizable through careful assessment¹¹. Social scientists explore the concept of total pain from a relational viewpoint, examining how it can both generate new ways of knowing one another as well as marking the limits of what can be known about another¹². They also attend to how the concept may reproduce social norms for encouraging specific forms of 'appropriate' conduct¹³⁻¹⁴. Others use an arts-based lens to reflect on the ways that total pain emerges from our inability to fully communicate, or understand in another, the suffering that comes with living near the threshold of one's own death¹⁵. While each of these perspectives offers critical insights about total pain, there is little interdisciplinary "cross-talk" as to how each may inform and enrich the others' understandings.

Lack of clarity about what total pain is and how to address it is further challenged by the evolution of health care services and settings in which it is addressed. Some advocates, in the compassionate desire to ameliorate suffering associated with advancing life-limiting illness, continue to campaign for expanding the breadth (appropriate for all diseases) and depth (earlier intervention in the disease trajectory) of palliative care. Yet as palliative care expands, matures and joins the ranks of other mainstream medical specialities, its visibility and relevance depend on practitioners adopting equivalent biomedical evidence-based practices. The increasing focus on early intervention in all life-limiting illnesses, combined with prioritizing the 'determinate' aspects of palliative medicine's technical contributions, have resulted in the privileging of measurable standardized interventions that prioritize physical symptom management. This ensures that non-technical interventions, such as those to address total pain, have been forced to compete for visibility in the same biomedical and institutional language, or become marginalized. Finally, palliative clinicians work within complex health systems organized by institutional needs for organizational efficiency and resource constraints. In this environment clinicians may be forced to privilege task-based care over therapeutic relationship building, and/or see attention to anything other than physical symptom management as outside their scope of practice.

Many palliative clinicians, however, continue to believe that whole person care is a cornerstone of palliative care, and work diligently to attend to patients' and family members' psychological, social, and spiritual distress, either on their own or within multidisciplinary teams. At the same time, clinicians also report struggling to address these aspects of complex end of life pain; an inability that in turn can exacerbate clinician distress¹⁶. In the extreme, challenges to addressing total pain in patients and family members may have severe unintended consequences, including but not limited to the increased need for palliative sedation and/or requests for hastened death^{17 18}. Consequently, we suggest that, in spite of the challenges in visibility and resources for addressing it, total pain continues to have significant salience in contemporary palliative care.

A new way forward?

Cicely Saunders' original conception of suffering at the end of life simultaneously conjoined and distinguished between physical, psychological, social and spiritual aspects of pain. Even with Saunders' caution against doing so, this framing has lent itself to over-simplified representations which often separate total pain into its constituent parts in ways that negate a sense of integration. We therefore believe that Saunders' original conception of total pain, along with the definitional and practical challenges outlined here, can benefit from new interdisciplinary approaches. One such way is through use of a generalized bio-ecological approach. It is a perspective that combines ecological, biological, and system theories to understand human physiological development as resulting from the bi-directional relationships between individuals and their environments, across the lifespan¹⁹. In this framing, who we are - the combined physical, emotional, and social aspects of being human - emerges as an embodied consequence of existing within, and being able to act on, dynamic individual (micro), community (meso), and structural (macro) environments that together make up a complex and always changing ecosystem. While the bio-ecological approach originated within childhood development considerations, it has since been applied to a range of experiential processes across the lifespan, although not yet to end of life. Using this lens to examine total pain enables us to understand the experience simultaneously as negative affect *and* the effect of the diminished capacity to strive within the world as we know it as end of life nears²⁰.

We believe that this approach synthesizes different disciplinary perspectives on total pain without prioritizing any one viewpoint, while at the same time attending to the contexts of contemporary care provision. We offer some opportunities that may emerge for policy makers, researchers, and clinicians when exploring total pain through a bio-ecological lens.

First, much end of life care policy implicitly references the concept of total pain, yet often does so without questioning how structuring total pain as an individual experience may unintentionally limit public debates about the role of palliative care and assisted dying in the relief of suffering. In attending to the diverse 'levels' that constitute an individual's overall ecosystem, a bio-ecological approach can provide a conceptual framework to explore how and why the needs and priorities of individuals expressing total pain, the clinicians caring for them, and the larger health system may not always match.

Second, this perspective constructs us as bio-social beings, enabling new research questions to be asked about how the relationships between biology, culture, and environment shape human experience – even at the very end of life.

Third, through its consideration of life course and context, a bio-ecological approach may help clinicians to 'see' total pain as more than a form of psychopathology. Total pain, for some patients, is a lived consequence of making the transition into the last phase of life. Clinicians using a bio-ecological approach to understand total pain might then openly acknowledge and validate the differences that characterize the last part of patient's life span, whilst at the same time seeking to maintain continuity with what has gone before. A bio-ecological approach can also help clinicians approach total pain as a dynamic experience with external dimensions, rather than as a constant, static event located only within the body of an individual.

Finally, we believe that a bio-ecological lens offers clinicians a way to value the work they already do. Whether or not they are able to resolve a patient's suffering within the constraints of current care environments, the willingness to be present – to bear witness and not turn away – becomes a meaningful part of that person's ecosystem at the end of life. This interdisciplinary approach offers a new way to understand the continuing importance of Saunders' injunction that, when all else fails, the imperative is not to explain or even understand total pain, but rather to 'watch with me'.

Funding

The contribution of Joseph Wood was supported by an Arts and Humanities Research Council Doctoral Studentship. The contribution of David Clark was supported by a Wellcome Trust Investigator Award (grant number 103319/Z/13/Z).

¹ Clark, D. *Cicely Saunders: A life and legacy*. Oxford: Oxford University Press, 2018.

² Saunders, C. The symptomatic treatment of incurable malignant disease. *Prescribers' Journal*. 4(4) October 1964: 68-73

³ Saunders, C. 'And From Sudden Death...'. *Frontier*. Winter 1961: 1-3.

⁴ Frankl, V. *Man's Search for Meaning*. London: Rider 2011.

⁵ Such as the theologian Dr Olive Wyon; Sr. Penelope of Wantage, England; Sr. Genéviève of the Sisters of Commaunaté at Grandchamp, Switzerland. See Saunders, C. *Cicely Saunders: Founder of the Modern Hospice Movement: Selected Letters 1959-1999*. ed. D. Clark. Oxford: Oxford University Press, 2002.

⁶ Tournier, P. *The Meaning of Persons*. London: SCM Press, 1957.

-
- ⁷ Gunaratnam, Y. and D. Oliviere. 'Introduction'. *Narrative and Stories in Health Care: Illness, Dying, and Bereavement*. In. Y. Gunaratnam and D. Oliviere (eds) . Oxford: Oxford University Press, 2009.
- ⁸ Lawton, J. *The Dying Process: Patients' experiences of palliative care*. London: Routledge, 2002.
- ⁹ Merskey, H. and N. Bogduk (eds.) *Classification of Chronic Pain, second edition*. Seattle: IASP Press, 2002.
- ¹⁰ Saunders, C. The depths and the possible heights. *Medical News*. 10 July: 16-17, 1964.
- ¹¹ Mehta, A., & Chan, L. S. Understanding of the concept of "total pain": a prerequisite for pain control. *Journal of Hospice & Palliative Nursing*, 10(1), 26-32, 2008.
- ¹² Gunaratnam, Y. Learning to be affected: social suffering and total pain at life's borders. , 60(1_suppl), 108-123, 2012.
- ¹³ Clark, D. Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Social Science and Medicine*, 49(6), 727-736, 1999.
- ¹⁴ Krawczyk, M. "I'm here to help with pain": Diagnosing and resolving total pain in hospital palliative care. In Nissan, N. & M. Risor (Eds.) *Diagnostic Fluidity: Working with Uncertainty and Mutability*. Tarragona, Spain: Universidad de Tarragona, 2018.
- ¹⁵ Lucas, V. The Death of Ivan Ilyich and the concept of 'total pain'. *Clinical Medicine*, 12(6), 601-602, 2012.
- ¹⁶ Rushton, C. H., Kaszniak, A. W., & Halifax, J. S. A framework for understanding moral distress among palliative care clinicians. *Journal of Palliative Medicine*, 16(9), 1074-1079, 2013.
- ¹⁷ George, R. Suffering and healing—our core business. *Palliative Medicine*. 23, 385–387, 2009.
- ¹⁸ Cassell, E. J., & Rich, B. A. Intractable end-of-life suffering and the ethics of palliative sedation. *Pain Medicine*, 11(3), 435-438, 2010.
- ¹⁹ Bronfenbrenner, U., & Morris, P. A. The bioecological model of human development. In R. Lerner (Ed.) *Handbook of Child Psychology: Theoretical models of human development*, Vol. 1. New Jersey, USA: Wiley & Sons, 2006.
- ²⁰ Spinoza B, Curley E. *Ethics. The Collected Writings of Spinoza*. Trans. Edwin Curley. Princeton: Princeton University Press. 1985.