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Title: Cicely Saunders, 'Total Pain' and Emotional Evidence at the End of Life

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ABSTRACT

In this article I explore how Cicely Saunders championed the hospice movement and initiated what became palliative care by representing her emotional connections with others. She became friends (and, once or twice, fell in love) with dying patients and encouraged others to follow her example in listening to patients' descriptions of pain. Her approach was radical at a time when she believed doctors routinely 'deserted' dying patients because it urged them to understand another's embodied pain as inextricably bound up with the emotional impact of a terminal diagnosis. Saunders' attention to how patients expressed their experience is summed up in her term 'total pain', which communicates how an individual's pain is a whole overwhelming experience, not only physical but also emotional, social and spiritual. Previous research frames 'total pain' in terms of narrative, emphasising Saunders' focus on listening to her patients and her use of narratives as evidence in advocating for cultural and institutional change, both of which I understand as engaging with a patient's emotional reality. However, as Saunders' ideals become mainstreamed as palliative care and amid calls for 'narrative palliative care', I use evidence from Saunders' extensive written output alongside archival material to suggest that, just as palliative care is by its nature not a single specific intervention, 'total pain' should not be understood as simply narrative. Building upon existing work in this journal questioning the primacy of conventional understandings of narrative in the medical humanities, I demonstrate how Saunders' prominent use of fragments and soundbites alongside longer case narratives demonstrates the limits of narrative, particularly when someone is dying. Saunders thus offers a case study for considering the implications that questioning the primacy of narrative as emotional evidence might have for our understandings of how empathy or advocacy can function, or be cultivated, in medical settings. (299)

INTRODUCTION

In 1964, Cicely Saunders (1918-2005), now often acknowledged as the founder of the modern hospice movement, introduced her idea of 'total pain', which communicates how a dying individual's pain is a whole overwhelming experience - not only physical but also psychological, social and spiritual. Saunders developed 'total pain' because she noticed how dying patients were, to use her word, 'deserted' by their doctors when no further curative treatment was available.¹ 'Total pain' reflects Saunders' holistic approach to end-of-life care which was informed by her mixed career background as a nurse in the Second World War, then a medical social worker, and finally, from the 1950s, as a physician, as well as her devout Christianity following a conversion experience in 1945. Saunders pioneered what we now know as end-of-life care by combining regular pain relief and symptom management with pastoral care and companionship. After years of campaigning and fundraising, in 1967 she founded St Christopher's Hospice in London as the world's first research-led teaching hospice. The work of Saunders and her colleagues at St Christopher's inspired the international modern hospice movement and led to the acknowledgement of palliative care as a medical specialty.

With 'total pain', Saunders reframed the relationship between medical professionals and dying patients and she continued to use the term throughout her career to advocate for emotionally engaged end-of-life care. Although not as prominent as her near-contemporary Elizabeth Kübler-Ross, Saunders achieved minor celebrity as an important advocate for her cause through frequent public lectures (notably two influential tours of the United States in the early 1960s), occasional media interviews, and a wide range of publications including articles in medical, nursing and religious journals, contributions to textbooks on oncology and thanatology, and foundational edited or co-authored volumes in the field such as *The Management of Terminal Disease* or *Living with Dying*.² In much of this output, Saunders relied on 'total pain' as a means of encapsulating her multidisciplinary approach with the result that 'total pain' is still used today by practitioners and academics within hospice, end-of-life and palliative care. Moreover, even when the term itself is not used, its components have been incorporated into the language of these fields: the current

World Health Organisation definition associates palliative care with the 'assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.³

Previous research tends to frame 'total pain' in terms of narrative, either to emphasise Saunders' focus on listening to her patients, or to demonstrate how she used narratives as evidence in advocating for cultural and institutional change.⁴⁻⁵ Saunders' readiness to be moved by the stories of illness has a legacy in practices like dignity therapy, and her approach is prescient of later ideas of narrative medicine.⁶⁻⁷ Gunaratnam and Oliviere position Saunders' attention to what a patient says within the wider post-war 'turn to narrative', which foregrounds subjectivity within modern biomedical practices that address the disease at the expense of the patient.⁸ Such interpretations coincide with concerns, which echo those Saunders voiced in the 1960s, about the routinisation of hospice practices as they are rolled out to become the wider specialty of palliative care.⁹ In their critique of the current practice of palliative care, Randall and Downie observe that 'care which should be expressed from inside a human relationship is becoming an externally imposed intervention'.¹⁰

In this article I begin by exploring the origins of 'total pain' in Saunders' emotional engagement with her patients. I position existing narrative interpretations as attempts to make Saunders' mid-twentieth-century holism relevant for those now implementing hospice practices in the more complex environments of palliative care today. Following Gunaratnam,¹¹ I question how such interpretations encourage a blanket use of narrative which might misrepresent Saunders' 'total pain'.

I then evaluate Saunders' use of narrative as a means to advocate for her holistic approach and what this might tell us more broadly about how practitioners might use, deploy, or even access, the feelings of their patients. Following scholars who claim Saunders consciously utilises narratives to communicate 'total pain', I suggest that these narratives go further than the conventional medical case in attempting not only to communicate the diagnostic complexity of her patients'

pain but also to utilise an affective connection to engage practitioners with the reality of each dying patient as a unique individual.

Next, using evidence from Saunders' extensive written output alongside archival material, I show how Saunders just as often illustrates 'total pain' using short forms such as anecdotes or soundbites which invite, rather than offer, narrative interpretation. With this in mind, I explore how Saunders' attention is perhaps more focused on reproducing the specific language and details which her patients use to describe their pain and which Saunders uses as a form of emotional evidence that bears little resemblance to the coherent narratives others assume she prioritises. Building upon existing work in this journal questioning the primacy of conventional understandings of narrative in the medical humanities,¹² I then demonstrate how Saunders' prominent use of fragments and soundbites alongside longer case narratives demonstrates the limits of narrative, particularly when someone is dying.

In doing so, I not only reappraise Saunders and her work, but also consider the broader implications that questioning the primacy of narrative as emotional evidence might have for our understandings of how empathy or advocacy can function, or be cultivated, in medical settings. As the tenets of hospice become 'mainstreamed' as palliative and supportive care and amid calls for 'narrative palliative care',¹³⁻¹⁴ it is important to understand that narrative is one among many ways in which Saunders sought to engage with the emotional reality of her patients' experiences. By using Saunders as a case study, I demonstrate the need to avoid assuming all emotional connections with patients can always be conceived of as narrative.

'ALL OF ME IS WRONG'

As David Clark notes,¹⁵ Saunders first used the phrase 'total pain' in print in 1964 within an article for *The Prescribers' Journal* alongside the reported speech of a patient who said, "it seemed that all of me was wrong".¹⁶ Later in the same year, a similar explanation appeared with a fuller account of the same patient in an article for the Madras Cancer Institute:

When our patients arrive they often tell such a story as this from a woman of 54 with carcinoma of cervix and metastases. "Well doctor, the pain began in my back, but now it seems that all of me is wrong." She described various symptoms, her increasing weakness and incontinence and went on, "It's all round me. I just wanted to cry for the pills and the injections but I knew I mustn't. My husband and son were marvellous but they were having to stay off work and lose their money. No one seemed to understand and I began to feel that all the world was against me". Perhaps her last remark was the most revealing of all, "... but now it is marvellous to begin to feel safe again". Her pain included not only her physical suffering but also her emotional and mental suffering, her social problems and her spiritual need for understanding and security.¹⁷

For the rest of her career, 'total pain' was presented and re-described in similar terms by Saunders, often with a retelling of, or reference to, this patient, later named as Mrs Hinson, and her evocative phrase 'all of me is wrong'. Indeed, Mrs Hinson is used as an example so often by Saunders that she has become 'emblematic' of 'total pain' and Saunders' wider approach.¹⁸

Although she varied its components depending on her audience, when describing 'total pain' Saunders always includes physical, psychological (or mental or emotional), social and spiritual aspects of pain. At the same time, Saunders often makes it clear that this is a 'whole overwhelming experience' indivisible into constituent parts. The term therefore became a rallying cry for Saunders because it articulates how terminal pain, unlike acute pain, 'is a situation rather than an event'.¹⁹ It is always tied to the body but takes place within the patient's wider life. It encourages practitioners to understand that emotions, such as fear, grief or regret, are experienced bodily and so affect how we feel 'conventional' pain, and to understand how such pain is not limited to the dying individual but extends out to affect those around them (as well as family and friends, from the early 1980s onwards Saunders often includes 'staff' pain within her descriptions). Effectively, 'total pain' uses the medically legitimate "pain", to usher in Saunders' own brand of medical holism, informed by her mixed career experience and her religious beliefs. It was radical because it urged doctors to understand another's embodied pain as inextricably bound up with the emotional impact of a terminal diagnosis.

In contrast to the way she believed other doctors 'deserted' their dying patients, Saunders – at least in the received origin story of hospice care which she cultivated – came to the idea of 'total

pain' by allowing herself to be open to emotional connections with others. She became friends with many of her patients and often refers to them by name in her published papers, such as the article devoted entirely to her friend Mrs G.²⁰ Indeed, she once or twice fell in love with certain Polish men who were dying in her care,²¹ encounters in which Saunders' questionable ethical conduct attests to a heightened emotional quality. Such relationships brought home to Saunders the emotional impact on the patient and their family of the processes of dying, an issue routinely repressed in the paternalistic atmosphere of medical practice at the time by what sociologist Richard Titmuss, cited by Saunders, called 'discourtesies of silence' between doctors and patients.²²

In recognition of this, Saunders urged clinicians to engage with the emotional complexity of terminal pain by attending to what a patient says. While history-taking establishes a chronology of medical events in a patient's life, Saunders encouraged staff to be open to problems which might seem irrelevant to medical intervention but may ultimately reveal new ways to help treat their pain. She claims the question should not be 'what do you tell you patients but what do you let your patients tell you?'.²³ Moreover, she argued that the resultant conversation with a patient is often intrinsically therapeutic, breaking down perceived barriers between patient and staff and encouraging open dialogue in a manner which Marian Krawczyk asserts was designed to be cathartic.²⁴ Saunders frequently describes how patients report experiencing less pain and needing lower doses of morphine after voicing pent-up feelings, citing one patient who said, 'And then I came here and *you listened*. It seems as if the pain went with me talking'.²⁵ Saunders made recordings of hundreds of interviews with dying patients and encouraged her staff to record patients' psychosocial progress on separate pink sheets in their clinical notes, in which patients described their non-physical suffering in terms of pain: 'It was all pain',²⁶ 'the pain was all round me'.²⁷ 'Total pain' therefore reflects how Saunders' patients used the word pain to articulate their complex suffering and encourages medical professionals to engage in the emotional reality of their patients' experiences.

TOTAL PAIN AS NARRATIVE HOLISM

In current practice and research, however, the holism of 'total pain' (almost out of necessity) remains ill-defined²⁸ and Saunders' vision of attending to the whole person risks becoming either a reductive checklist²⁹ or an unattainable ideal.³⁰ Furthermore, the term now applies within the complexity-rich resource-poor environments of contemporary healthcare systems quite unlike the relative ideological containment of independent institutions like St Christopher's.³¹ Amid growing economic and staffing pressures, and an increasing emphasis on evidence-based medicine, the emotionally engaged practices that were self-evident under Saunders' charismatic leadership, or those of other hospice pioneers such as Florence Wald or Eric Wilkes, risk being abandoned. Moreover, 'total pain' is unpopular among some scholars because it is predicated on a spiritual understanding of each individual and on Saunders' refusal to give up on a patient, both of which are difficult to standardise as interventions and, worse, lay the term open to accusations of totalisation.³² As a result, while bringing together much of hospice care, 'total pain' appears to be conceptually resistant to the evidence-based thrust of much current palliative and end-of-life care research, and is not often the direct focus of study.

Existing conceptual research appears to frame 'total pain' in terms of narrative as a means of rehabilitating Saunders' holistic approach for a new professionalised generation of hospice and palliative care staff. Associating 'total pain' with narrative is an obvious link to make since Saunders' vision of hospice in 'total pain' is in some ways prescient of later ideas of narrative medicine.³³ David Barnard argues that palliative care and the medical humanities – he implies but does not name narrative medicine within this – developed in tandem during the 1950s and 1960s as existing cultures of care were undermined by increasing medical technologization and the atomisation of family units.³⁴ We can therefore understand both narrative approaches to medicine and the hospice ideals expressed in 'total pain' as concurrently attempting to seek out a new form of medical holism through attention to what patients say.

With such shared objectives and methods, it is not surprising that narrative approaches have currency within the palliative care literature, with some advocating the meaning-making benefits

of personal reflective writing as 'narrative palliative care'.³⁵ Recent discussions of 'total pain' similarly emphasise how it is best appreciated through open-ended patient interviews or taught using literary accounts of dying.³⁶ 'Total pain' is also referenced, but not discussed, in broader assessments of narrative in palliative care,³⁷ and, conversely, lengthy case descriptions and attention to narrative are prominent in the few clinical articles which foreground the term.³⁸

However, narrative is a contested term and overemphasising the narrative aspect of 'total pain' risks perpetuating some of the ethical problems noted by Angela Woods and others when linking narrative and medicine.³⁹ By positioning the patient's whole life within the remit of medical care, 'total pain' echoes a wider discourse observed by David Armstrong in which medical professionals who aspire to undermine a cultural silence on death and dying monopolise the power to define when and how it is appropriate to speak with and as dying patients.⁴⁰ In publishing narratives of a peaceful and resolved death, such as that of Mrs Hinson, Saunders might therefore be presenting an implicit hierarchy of utterances in which only those able to demonstrate a narratively conceived 'total pain' are deemed valid. Such a hierarchy is implicit in several more recent articulations of the need for narrative in work with dying patients which illustrate their ideas using interviews with patients who are already published writers.⁴¹ As Woods observes, the corollary of over-emphasising narrative in this way is to question the psychological health or even humanity of those who cannot or do not narrate.⁴² Furthermore, David Clark, who has written widely on Saunders and elsewhere asserts 'total pain' was always 'tied to a sense of narrative and biography',⁴³ suggests that Saunders' reliance on personal stories as evidence may simply be due to the initial absence of an existing body of relevant pain research.⁴⁴

For these reasons, although Saunders occasionally gestures towards ideas of laying down the story of one's life, Gunaratnam specifically links narrative medicine to the research practices which led Saunders to 'total pain',⁴⁵ suggesting they prefigure Rita Charon's 'narrative competence'.⁴⁶ As Gunaratnam implies, the conversations Saunders had with patients provided a kind of emotional evidence which indicated to her the depth and complexity of their pain. Rather than requiring narrative coherence, we can therefore understand 'total pain' as prefiguring Charon's 'narrative

competence' in eliciting a form of medical empathy based on a capacity to understand, and be moved by, the emotional impact of illness on an individual's wider life.

CASE NARRATIVES, MEDICAL ANECDOTES, AND THE 'REAL'

My interest is in how this emotionally engaged practice, which can clearly be understood in narrative terms, is conveyed by Saunders in her published output and what this tells us about the ways, narrative or not, in which practitioners might use or deploy, or even access, the feelings of their patients. Both Clark and Devery observe Saunders' awareness of the power of narratives for establishing an emotional connection with others as a means of broadcasting her ideas about 'total pain' and reframing the culture of end-of-life care.⁴⁷ They foreground how, in descriptions like that of Mrs Hinson, Saunders places the patient and Saunders' interaction with her at the narrative's centre, letting her describe her own emotions and relationships and so articulate what her illness means to her. In a manner, as Clark notes, similar to the work of Elizabeth Kübler-Ross, doing so has the effect of transforming Saunders' patients 'into active subjects'.⁴⁸

However, there is little sense of the sorts of narratives which Saunders is using to convey 'total pain' in this way or how far Saunders herself might be mediating her emotional relation to her patients. (In contrast, Clark is clear that Saunders creates a 'self-conscious' foundation story for herself and St Christopher's).⁴⁹ For example, while Saunders sometimes uses the formal medical case narrative, most prominently at the beginning of her career,⁵⁰ her patient narratives are perhaps notable for the way they often depart from this conventional mode of medical narration, both in terms of function and length.

Rather than presenting a series of interventions reproducible for similar cases in the future and so functioning as what Gianna Pomata has called an 'epistemic genre',⁵¹ Saunders' narratives encourage a sense that each individual's experience of pain at the end of life is different by highlighting the uniqueness of a single individual case. To use terms applied by others to published patient narratives more generally,⁵² while Saunders' interviews and narratives clearly have an epistemological 'forensic' aim of exploring the complexities of 'total pain' and discovering

aspects of her patients' pain which remain untreated, they are more importantly 'epideictic' (from Ancient Greek *δεικνύναι*, meaning to show or point) in the way they celebrate the uniqueness of each patient's experience. While it can be understood as a conservative 'rhetoric of orthodoxies',⁵³ the epideictic can equally perform the more radical function of inspiring its audience to enact change by identifying situations which have not been at the forefront of cultural consciousness.⁵⁴

Clark and Devery are therefore right to argue that Saunders uses patient narratives like Mrs Hinson's to represent the complex interrelational network constituting an individual's 'total pain' but I would add that she appears to intend this most prominently as a means of fostering respect for dying patients by highlighting the uniqueness of each individual patient. As such, Saunders' published narratives function differently to the narrative methods of the medical case or to some of the claims of narrative medicine because they do not use narrative to diagnose. Instead, they pre-empt later demands from within narrative medicine for the personal to be reintroduced into case writing as a means of encouraging wider attention to patient care beyond the diagnosis.⁵⁵ Saunders herself was aware of this and asserts that it is precisely 'because of this personal aspect that I am talking from the stories of individual patients. Each one, as it were, illustrates a whole group'.⁵⁶

In presenting what she calls 'stories', Saunders' diction moves away from the formal medical case towards the tradition of medical anecdotes. 'Total pain' is often conveyed in passing, either through paragraphs, such as the account of Mrs Hinson, or in far shorter vignettes, perhaps betraying their origin as asides in Saunders' many public lectures. For example, in a talk given in the US in 1967 and later published, Saunders presents a series of short accounts of patients such as:

I recall a girl newly admitted. When I went in to talk to her she just burst into tears because she expected to be hurt so much the moment anybody came near her. She had chronic pain that went on the whole time but also was exacerbated by movement. The situation held her, as it were in a vise [*sic*]. As she described it, "The pain was all around me."⁵⁷

Although containing less contextual information than a longer case narrative, the recounting of anecdotes is integral to medical practice and education because their brief first-hand observation

has a convincing sense of the real not found in large datasets or trials.⁵⁸ Indeed, unlike the closed narration of the case, the anecdote's brevity contributes to its effectiveness. Joel Fineman claims the anecdote 'as a narration of a singular event is the literary form or genre that uniquely refers to the real'. An anecdote gestures towards a wider story and set of circumstances, yet, unlike a fuller narration, does not delimit the implied wider narrative that it comes from. As such, 'by establishing an event as an event within and yet without the framing context of historical successivity', an anecdote reinforces its origin within the amorphous whole of real life.⁵⁹ This sense of the real is perhaps behind Kathryn Montgomery Hunter's suggestion that the medical anecdote, freed from the anonymising rigours of peer-reviewed publication, functions to critique current therapies and direct research attention.⁶⁰ In this way, Saunders' use of anecdote reinforces the consciousness-raising enacted by her epideictic rhetoric, both of which I argue serve primarily to communicate how the experiences of dying patients are real to a medical audience which Saunders believed was ignoring them.

Devery suggests the most significant aspect of Saunders' early advocacy for the hospice movement is the specificity of her narrative examples, highlighting the inclusion of verbatim speech as confirming that the dying patient is 'a feeling person'.⁶¹ Although Devery focuses on Saunders' use of patient voice, I suggest that Saunders also utilises unusual everyday details as a means of engaging a sense of the inner lives of her dying patients. She often emphasises the everyday physical experience of a situation, noting the rituals of sitting up for hot water bottles and the social importance of tea or alcohol. At other times, her descriptions are rich in idiosyncratic detail: the dying man who 'could scarcely think of anything but a creased sheet beneath him', a woman bringing strawberries and jellied eels for her husband,⁶² or Paula replacing the cross in her room with a 'horny little red devil'.⁶³ Such details achieve what Roland Barthes calls a 'reality effect': they are present within the text but have no purpose other than to make it feel real.⁶⁴ While the reality effect produces realism in a novel, it is incongruous in conventional medical discourse.

In these instances, Saunders is utilising a sense of the everyday as a method of meaning-making to legitimise the needs of dying patients but also as a means of normalising the emotional

complexity of ordinary people going through a difficult experience. For Ben Highmore, the everyday describes 'a form of attention that attempts to animate the heterogeneity of social life, [...] the name for an activity of finding meaning in an impossible diversity'.⁶⁵ By noticing and describing the significance of painful details she believes are often overlooked, Saunders articulates their unique meaning at the same time as demonstrating that similar meaning can be found in such details all the time. Palliative care physician Adrian Tookman observes that the 'secret' of 'total pain' is 'attention to detail',⁶⁶ as does Saunders' first biographer.⁶⁷ The everyday details in Saunders' accounts of 'total pain' allow space for the affective importance to the individual of unique details which might otherwise be ignored by medical professionals.

Saunders' narratives consequently appear to be descriptive in a documentary sense but also have a prescriptive force in demonstrating her closeness to her subjects. I suggest her reported speech and evocative idiosyncratic details provide what sociolinguist Deborah Tannen, after Labov,⁶⁸ calls 'story-internal evidence' that convinces more than the external evaluation of a narrator,⁶⁹ which I would argue is clearly more common in clinical academic writing. Such evidence not only boosts authenticity but indicates the speaker's involvement within the events of the story by establishing what Tannen terms a 'metamessage' of intimacy.⁷⁰ Saunders uses the details of her patients' lives as evidence of her attention to detail and consequently of how much she cares for them. I suggest these details therefore communicate Saunders' own presence as an emotionally invested participant in a situation in which the patient is her equal, demonstrating, as Devery observes, that it is possible for a doctor in her position to be 'both expert and human'.⁷¹

By communicating the reality of her accounts and the significance to be found in everyday details, Saunders utilises the epideictic mode to demonstrate the specificity of a patient's 'total pain' and the possibility of engaging with dying people in a way that affirms the emotional reality of their experience. 'Feelings are facts in this house', she often says, and 'they are often the most powerful facts in a whole situation'.⁷² As well as highlighting the complexity of end-of-life pain, Saunders appears consciously to use her medical authority as a clinician to present narratives which affirm feelings as a form of evidence that rivals the dominant clinical facts.

NARRATIVES, QUOTATIONS, AND SOUNDBITES

Having said that, it is disingenuous to claim that such details or Saunders' references to Mrs Hinson and other patients always constitute narrative retellings of her patients' situations. Her articles which most heavily foreground narratives are often published in nursing rather than medical journals, which display different attitudes towards clinical detachment. When addressing an audience of surgeons, rather than nurses, in a 1967 article for the house journal of the Royal College of Surgeons of England, Saunders seems less willing to use either the term 'total pain' or anecdotes of specific patients. She emphasises how terminal pain 'can fill the whole consciousness of a patient and be a most complex and interwoven problem' but focuses on the impact of other aspects on physical pain:

Those who have known these patients will have seen how often mental distress is linked with their physical problems. The fear so commonly caused by dyspnoea, the depression that accompanies anorexia and nausea and the feelings of guilt aroused by incontinence are all eased by treatment of the physical cause.⁷³

Saunders is still willing to place consideration of a patient's emotions at the heart of treatment but uses stand-alone quotations, among them Mrs Hinson's 'all of me is wrong', rather than specific narratives to suggest that such phrases sum up 'all the anxiety, the loneliness and the despair of long pain as well as the galaxy of physical symptoms common to this phase of illness'.⁷⁴

The affective heft of Saunders' article for surgeons perhaps demonstrates my main point about Saunders' use of specific details as emotional evidence in support of better care for dying patients. As I have indicated, most scholars who attend to 'total pain' on a conceptual level ally it with narrative and Saunders is clearly interested in her patients' narratives in as much as 'total pain' assumes a holistic context-driven understanding of each patient. However, if you examine her written output as a whole, she is more likely to demonstrate a situation using a short soundbite or detail with limited personal context. Mrs Hinson is often reduced to 'all of me is wrong', others to 'it was all pain', "Will you turn me out if I cannot get better?",⁷⁵ "The whole house is full of her

pain"⁷⁶ – quotations which retain the authority of documentary but go further than Fineman's account of anecdotes in implying a set of circumstances without defining them at all.

In fact, suggestions that Saunders' collected 'patient narratives'⁷⁷ or indeed 'over 1000 patient narratives'⁷⁸ are misleading. Saunders certainly kept medical records of over 1000 patients as part of her pain research while at St Mary's Hospital, Paddington and made hundreds of recordings of conversations she had with patients at St Joseph's in the early 1960s. She also continued to record her own reactions to patients at St Christopher's and to encourage patients to express themselves in diaries, poetry and drawings. While many of these use narrative methods and all inform the patient narratives Saunders publishes in later articles, they do not constitute a formal collection of narratives.

Moreover, the archived transcripts of Saunders' recorded conversations at St Joseph's, made in the years immediately prior to her first use of 'total pain' in publication, show two things. Firstly, for every Mrs Hinson there are dozens of patients who are more interested in talking about their next meal or their bedpan and who offer up no cathartic narrative unburdening to Saunders. Secondly, Saunders' transcripts more often read like fairly patrician interviews, with Saunders appearing to be active in leading the conversation. For example:

Dr. S.: How do you feel, Mrs. [B]?

Mrs. B.: Very well, indeed, thank you.

Dr. S.: All right in yourself?

Mrs. B.: Yes, thank you.

[...]

Dr. S.: Any pain?

Mrs. B.: No pain whatever.

Dr. S.: Not anywhere?

Mrs. B.: No.

[...]

Dr. S.: Did you have a lot [of visitors] yesterday?

Mrs. B.: Oh I had four I think.

Dr. S.: Did you? And you talked away with them

Mrs. B.: Yes.

Dr. S.: Well done. Well you're not too badly are you?⁷⁹

Some have very limited narrative qualities, for example, one transcript is barely a few lines long and records Saunders asking a patient whether having a daily sherry has helped him begin eating again.⁸⁰

We can quibble over whether these brief or fragmented transcripts are narrative, for example in inviting narrative interpretation in Claire McKechnie's understanding of the term,⁸¹ but they certainly provide little in the way of cathartic narration or cumulative causal detail. It is unsurprising then that Clark and Gunaratnam imply a massed contribution of narratives to the conception of 'total pain' but evidence their claims with examples from the select group of Saunders' patients, such as Mrs Hinson, David Tasma (the oft-cited 'founding patient' of St Christopher's who died in 1948) or the early formal case narratives, which Saunders handpicked for publication. The implication that all Saunders' interviews are lengthy rich accounts of an individual's illness is perpetuated by those advocating narrative approaches to palliative care who describe Saunders' transcribed collection of 'stories' and written 'illness experiences'.⁸² Through a chain of misinterpretation, Brittany Pladek even claims Saunders used her collection of over 1000 patient stories to 'measure' her patients' 'total pain'.⁸³ Encouraged by Clark and Gunaratnam, who are using narrative to frame their re-evaluations of Saunders, these scholars assume that the primary purpose of Saunders' recordings was to collect stories from her patients in a manner that I suggest retrospectively affords a primacy to long-form narrative that Saunders does not display herself.

There are several reasons why Saunders' exchanges might not all constitute 'narratives', such as a mid-century 'doctor knows best' deference to authority or a reticence when presented with an intimidatingly large early-1960s tape recorder. However, I suggest that so few of the archived transcripts represent the types of narratives they are implied to because Saunders is less interested in eliciting narrative accounts from her patients than with documenting the language and metaphors which her patients use to describe their pain and which she can utilise as a form of emotional evidence for her practices of regular pain relief and attention to the whole person.

Many transcripts begin with Saunders encouraging a patient to repeat what they have just said to her, or otherwise to verbalise their experience of pain. One has 'a sort of jumping', another a 'harsh stiffness',⁸⁴ or 'a sort of squeal of pain, sort of thready pain, but nothing to speak of [...] more a soreness, an acute soreness I should say, than a pain'.⁸⁵ Saunders is often careful to use the patient's own metaphor, such as of wires running up and down the patient's leg, when she refers back to the pain in a conversation in subsequent months.⁸⁶ Few permit a wider narrative of any detail to be constructed around their words and yet, as a whole, the recordings are suggestive of Saunders' conceptualisation of 'total pain': they give a sense that an individual's physical pain often blocks out other thoughts or is bound up with a range of other factors from blocked bowels and bad sleeping to orphaned children or absent partners, all of which are articulated by the patients when asked to describe their pain.

As such, I would argue Saunders' prominent use in publication of very short narrative fragments or quotations to communicate 'total pain' testifies to a way of working that prioritises linguistic fidelity to her patients over individual narrative coherence. Some may be narrative but it is more important that they are idiosyncratic expressions of pain given as reported speech. Indeed, Saunders as often utilises photos or descriptions of body language – gripped hands, lack of eye contact – to communicate 'total pain' instead. Like Saunders' anecdotes, these function epideictically in appealing to a sense that the experiences they articulate were real.

(IN)ARTICULACY AT THE END OF LIFE

Not only does Saunders' use of quotations and soundbites perform the realness of the experiences she depicts, it also recognises how a purely narrative understanding of 'total pain' ignores the limits of narrative when someone is dying. At times, Saunders implies as much, indicating Mrs Hinson's account represents a problem just as much as a compelling expression of 'total pain'. Saunders uses her words to demonstrate how some patients are 'much less articulate or tell us stories'⁸⁷ or, in an oncology textbook, exhibit 'problems of language'.⁸⁸ Elsewhere, she encourages those interested in terminal pain to read the articulate descriptions of surgeon-writer

René Leriche or else find the same thing summed up 'with simplicity' in 'it was all pain' or 'all of me was wrong'.⁸⁹ While it may sound condescending (elsewhere in the archives Saunders' occasional transliteration of her patients' working-class accents is certainly that), Saunders' association of Mrs Hinson's words with 'simplicity' or inarticulacy does not necessarily mean she dismisses them. In fact, there is a sense that Mrs Hinson is a key patient precisely because she is not good at articulating her experience of 'total pain'. In one article, Saunders emphasises how Mrs Hinson is 'trying' but finding it difficult to describe her pain and so ends up talking 'simply', a struggle Saunders directly allies to the inseparability of the elements of 'total pain'.⁹⁰

In this way, we might understand Saunders to be practising something like the 'episodic reading' offered by Sara Wasson in which 'fragments, episodes and moments' are often better at communicating the complex affective experiences of chronic pain that tend to be marginalised by conventional understandings of narrative.⁹¹ Rather than aspiring to teleological coherence, 'episodic reading' assumes painful experiences may resist such narrative structures. Wasson uses the phrase the 'temporality of thwarted connection' to articulate how fragments can communicate:

the experience of a present in which one reaches for connection – for diagnosis, medical care, emotional support or companionship amid acute suffering – while aware of the (justified) anticipation of imminent failure and future pain, the recollection of past failures and past pain, acute self-awareness of one's present performativity in the clinical encounter, and one's ongoing somatic and emotional distress.⁹²

Although Wasson attends to chronic pain which is not necessarily terminal, her description echoes Saunders' account of 'total pain' as 'a crisis situation, with the joys and regrets of the past, the demands of the present and the fears of the future all brought into stark focus'.⁹³

Saunders' use of shorter forms and quotations is thereby contextualised by Wasson's foregrounding of the fragment as a genre that articulates temporal experiences resistant to conventional narrative frameworks. While it may prompt narrative retrospection for some, dying can also challenge a person's capacity to narrate by frustrating an idealised conception of life as

a past-to-future narrative or limiting agency for decision-making and by implication self-authorship.⁹⁴⁻⁹⁵ In an embodied sense, people's narratives at the end of their lives are likely to halt or disintegrate since that is exactly what their bodies are doing. Like Wasson, Saunders' fidelity to her patients' expressions of pain, which only sometimes constitute coherent narratives, testifies to the difficulty of articulating the experience of a provisional temporality enacted by something like 'total pain'.

Furthermore, Wasson's 'temporality of thwarted connection' chimes with Gunaratnam's qualification of her initial narrative interpretation of 'total pain'. Gunaratnam recognises that 'total pain' refuses to finalise our perception of another person by allowing for aspects of suffering that resist communication and remain mute because they are 'ontologically and temporally insecure and/or withdrawn'.⁹⁶ After Waddell,⁹⁷ Gunaratnam thus likens 'total pain' to Keats' 'negative capability',⁹⁸ in which an individual is 'capable of being in uncertainties, Mysteries, doubts, without any irritable reaching after fact & reason'.⁹⁹ By implication, 'total pain' acknowledges the co-presence of the disparate and conflicting feelings that come with dying or bereavement and acknowledges recalcitrant, perhaps traumatic, elements in a person's life which are suppressed or inexpressible.

To build on Gunaratnam's point, Keats described 'negative capability' in 1817 at the same time as the fragment was an object of particular aesthetic attention during the Romantic period. Fragments encourage the reader to imagine a whole from a part and so permit a vague idealised version of the whole truth by holding multiple possibilities of its totality in suspension. Linking this to palliative care, Pladek opposes the dominant Romantic holism – which she argues led directly to narrative medicine's claims that literature can heal through restoring integrity – to the parallel idealism of the fragment in the same period, one which she claims is maintained within current hospice and palliative care practice in the assumption that the 'whole' of whole-person care affirms the complexity of the individual rather than represents something lost in illness and aspired to in healing.¹⁰⁰ The 'total' of 'total pain' might therefore not be something which requires

an emplotted narrative but which acknowledges a level of complexity that can only be appreciated obliquely through one or more of its parts.

In light of this, while Devery suggests Saunders uses narrative to communicate the complexity of another's 'total pain', I would argue shorter forms that leave details unsaid and so rely more heavily on a sense of 'negative capability' might more accurately represent the emotional complexity of end-of-life experiences by acknowledging that a professional is unlikely to understand the whole of another's experience. At one point, Saunders introduces Mrs Hinson's account with the idea that 'total pain' *'and much more, is often conveyed by the patient, sometimes in the simplest language'*.¹⁰¹ She goes on to ally Mrs Hinson with the suggestion in T. S. Eliot's 'East Coker' that language is 'a raid on the inarticulate',¹⁰² suggesting both the limits of narrative at the end of life but also associating her patient's inarticulacy with the poetic force of an esteemed literary figure.

As a means of demonstrating Saunders' holistic case-based approach, fragments like 'all of me is wrong' therefore engage the emotions by having what Laurence Kirmayer calls 'the evocative force of a single image or metaphor' which rivals the emplotted patient narrative often deemed more important.¹⁰³ Such fragments are a means of 'speaking loosely' in order to optimise communication,¹⁰⁴ but they also honour the authority of Saunders' patients as experts of their own experience in much the same way that Charon and others suggest narrative does. In this way, Mrs Hinson's apparently simple words have perhaps inspired the aspects of Saunders' approach which have been identified as narrative without necessarily constituting an ideal narrative in themselves.

CONCLUSION

Saunders' publications and archives challenge the monopoly that longer, more coherent narratives might have if we follow too rigidly demands for 'narrative palliative care'. To take a narrative view of 'total pain' might be to stress too far its origins in Saunders' interest in how her patients disclose themselves in moments of authenticity when in fact she appears more interested

in how complex experiences of pain and suffering resist communication and so require a different approach by medical professionals. Just as palliative care is by its nature not a single specific intervention, 'total pain' should not be understood as simply narrative

Saunders' use of more fragmented forms therefore suggests 'total pain' might represent a way of approaching medical knowledge about whole-person care that differs even to received conceptions of narrative medicine. Rather than encouraging a lengthy unburdening that catalogues all the interlocking factors contributing to a patient's pain, her reliance on the evocative force of fragments and telling details recognises that such a feat may be impossible, particularly given the limited time available to dying patients. One patient, in fact Antoni Michniewicz who Saunders fell in love with in 1960, told Saunders all he wanted was for 'someone to look as if they are trying to understand me'.¹⁰⁵ Interventions that utilise narrative such as life review, dignity therapy, or meaning centred group psychotherapy should be understood in just this context: as a single attempt to communicate rather than a finalising of the self. Unlike some later models of medical empathy, Saunders implies that acknowledging the emotional difficulties experienced by a dying patient at that moment might be all the medical professional can do. Although it is possible to do this through exchanging narratives, the emotional tenor of Saunders' evidence, narrative or not, appears to be more important.

At the same time, throughout her career Saunders celebrates the ascendance within the field of 'objective' data over 'anecdotal' evidence.¹⁰⁶ While palliative treatment such as pain relief or symptom management requires an 'objective' evidence base, Saunders' apparent dismissal of anecdotal evidence and the routinisation such a dismissal potentially endorses represents a tension in her work and in the wider aims of hospice and palliative care. Even at the end of her career, Saunders' papers that address 'total pain' still rely on the kinds of evidence I have been describing to promote an engagement with the uniqueness of each patient. The most effective way to foreground the whole separate subjectivity of her dying patients seems for Saunders still to have been anecdotal.

Moreover, while narrative approaches with dying patients are clearly beneficial to many, not least in mitigating the forces of routinization, they potentially replace the redemption that Saunders found in God with the redemption Bourke suggests some find in speech and writing.¹⁰⁷ Cleaving too closely to traditional coherent narratives risks losing the radical epideictic force of Saunders' anecdotes and shorter fragments which advocate for better care for dying patients by confronting practitioners with a complex emotional moment that risks Wasson's 'thwarted connection' and whose significance does not necessarily stem from being part of a wider narrative. Good end-of-life care, which is so much about the whole person whose life-story is coming to an end, might therefore be based as much on the emotive force of a single utterance or image that reduces an individual's experience to a few anonymous words but, in leaving the rest silent, allows the inaccessible emotional complexity of that experience to be communicated more universally.

I suggest Saunders' legacy offers a prominent example of how narrative interpretations that do not question how patients or practitioners might be performing or constructing their experience as narrative can preclude other less culturally validated forms of emotional engagement. While short forms are prominent in the hidden oral curriculum of clinical education, perhaps space should be made alongside case narratives for representing in publication patient experiences that cannot be expressed so fully. While projects like Wasson's ongoing *Translating Chronic Pain* network aim to provide a public forum for this, valuing brief articulations of experience as evidence in the medical literature – outside the mediation of qualitative research and with an acceptance of their evocative emotional content – is surely worth exploring.

Patient and Public Involvement Statement Patients or the public WERE NOT involved in the design, or conduct, or reporting, or dissemination plans of our research

Notes

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