Article

Beyond Last Words: Patterns of Linguistic and Interactional Behavior in a Historical Sample of Dying Hospital Patients

Michael Erard[1] ⊙

Abstract
Patterns of linguistic and interactional behavior by people at the very end of their lives are not well described, partly because data is difficult to obtain. This paper analyzes descriptions of 486 deaths gathered from 1900 to 1904 in the first-ever clinical study of dying by noted Canadian physician, Sir William Osler. Only 16 patients were noted speaking, and only four canonical last words were reported. The most frequent observation by medical staff was that the deaths were quiet ($n = 30$), though range of other behaviors were noted (e.g., moaning, delirium, seeming intention to speak). Osler's problematic study left behind data whose analysis is a small step toward empirically characterizing the linguistic and interactional details of a previously under-described phenomena as well as the importance of the social context in which they occur.

[1]Institute of Data Science, Maastricht University, Maastricht, the Netherlands

Corresponding Author:
Michael Erard, Institute of Data Science, Maastricht University, Paul Henri Spaklaan 1, 6229 GT Maastricht, the Netherlands.
Email: m.erard@maastrichtuniversity.nl

Introduction

One persistent challenge to studying language behavior at the very end of life has been obtaining reliable data. Descriptions in the medical literature do not provide specifics about linguistic phenomena, while opportunistic corpora, such as collections of 'famous' last words from deathbed scenes, are inconsistent and biased. However, a remarkable (if imperfect) resource exists in the first clinical study of dying, conducted 120 years ago. This study, known as 'A Study of the Act of Dying,' took place between 1900 and 1904 at Johns Hopkins Hospital in Baltimore, Maryland, at the behest of physician William Osler (1849–1919) (Osler, 1904). Four hundred eighty-six deaths were observed, and that observational data was recorded on cards that are now held at the Osler Library of the History of Medicine at McGill University. Despite the study's age and methodological shortcomings, the original data suggests a story about a range of language, interaction, and communication behaviors by dying patients. In this paper, I examine Osler's data as the first step into an unexplored linguistic and cognitive terrain.

Background

The Study of the Act of Dying

William Osler, a highly-respected, Canadian-born physician and medical educator, believed that the dying process was not filled with pain and anguish, but that most people died calmly and at peace. He set out to test this belief by studying the actual dying process of patients at Johns Hopkins Hospital, where he had helped found a medical training program. He called this project the 'Study of the Act of Dying.' For the study, cards were printed up for hospital staff, including nurses, physicians, and medical students, who were asked to record their observations of dying patients within 24 hours of the death. Spaces were provided for writing a patient's name, their number assigned by the hospital, and the date. Observers were asked to record a patient's age, nationality, religion, and length of illness. Originally no information about diagnosis or cause of death was requested. They were also prompted to record aspects of the 'act of dying': 'if sudden,' 'did respiration stop before pulse—how long,' 'coma or unconsciousness before death—how long,' 'if any fear or apprehension, of what nature. Bodily, ie., pain. Mental. Spiritual-remorse, etc.' At the bottom of the card, Osler included the study's rationale: 'The object of this investigation is to ascertain the relative proportion of cases in which (1) the death is sudden; (2) accompanied by a coma or unconsciousness; (3) by pain, dread, or apprehension'.' Then he requested that observers 'please note fully any other special circumstances connected with the act of dying.'

Over the four years, data on 486 deaths were collected, but the results were never formally published, though Osler himself made substantial contributions

to the medical literature, publishing over 1500 articles (Bryan, 1996). On May 18, 1904, he delivered a lecture, 'Science and Immortality,' at Harvard University, where he briefly mentioned tabulated results from his study. He reported that only 104 of the patients (21%) experienced physical, mental, and spiritual discomfort. 'The great majority gave no signs one way or the other; like their birth, their death was a sleep and a forgetting' (Osler, 1906, p. 37). The published version of this lecture contains the only mention of the study by Osler himself. Even in a 1911 letter to *The Spectator* (by then Osler was Regius Professor of Medicine at Oxford University), in which he disputed a claim about death by German writer Maurice Maeterlinck, he did not mention this study, asserting only that 'the truth is, an immense majority of all die as they were born—oblivious. A few, very few, suffer severely in the body. Fewer still in the mind' (Osler, 1911). Though he seemingly abandoned the study, biographies and scholarly work on Osler often mention it, as do histories of dying (Abel, 2013). It was most recently the subject of a critical re-appraisal (Mueller, 2007).

Language and Interaction at the End of Life

Though linguists have turned a linguistic lens to a range of peripheral linguistic phenomena, such as glossolalia (Samarin, 1973), drunken speech (Hollien et al., 2001), and remembered past lives (Thomason, 1984), they have not considered last words, final utterances, and deathbed language or interaction behaviors from a linguistic point of view. This is surprising, since the dying process, which is central to the human experience, involves linguistic phenomena. If linguists have written down what dying friends or family members have said, they have kept these notes private.

Some linguistic and communicative behaviors among specific patient populations have been described in the speech-language pathology, nursing, gerontology, health communications, and palliative care literatures. There, language phenomena are usually described in this literature in general terms (e.g., 'language disturbance,' 'verbal fluency'). As a result, it is difficult to provide any baseline of what 'normal' linguistic, interactive, and communicative behaviors would be like for a person dying of acute causes or chronic illness at any age.

The most frequent general description comes mainly from cancer patients, even though globally more people die of cardiovascular disease in all age groups than from cancer (https://ourworldindata.org/causes-of-death). In 2016 in the US, the leading cause of death for people ages 45-62 was cancer, though for those 65 and older heart disease, diabetes, kidney disease, and chronic lower respiratory diseases were more frequent than cancer (Heron, 2018). One reason for the disparate knowledge about cancer patients is because in the United States, cancer receives research funding disproportionate to its disease burden (Moses et al., 2015).

Some of this research is relevant for building a language profile of the dying. For example, Morita et al. (2003) studied intellectual activity among advanced cancer patients and found that the percentages of patients who could achieve 'complex communication' were 43%, 28% and 13% at 5 days, 3 days, and 1 day, respectively. This was based on a 5-item measure of communication capacity that ranged from 'clear and complex communication to 'obvious incoherent.' (Morita et al., 2003, p. 829). However, this study did not delve into the particulars of this capacity or detail how communication was achieved (i.e., verbally, non-verbally, vocally but non-linguistically, etc.). In another study, 'decreased response to verbal stimuli' and 'grunting of vocal cords' were two of eight physical signs associated with death within 3 days in cancer patients (Hui et al., 2015). From a linguistic perspective, it would be useful to know what sort of stimuli engendered what sort of responses. In another study, 88% of advanced cancer patients at a Canadian hospital were diagnosed with terminal delirium, which means they satisfied the DSM-IV criteria for delirium at least 6 hours before death. These criteria include 'language disturbance' as one of three changes in cognition, along with 'memory deficit' and 'disorientation' (Moses et al., 2015). These language disturbances include dysgraphia, dysnomia, paraphasia, reduced comprehension, impaired verbal fluency, and impairment of reading (MacLeod & Whitehead, 1997). Also labeled 'acute confusional state,' delirium is also frequent among post-operative elderly patients, among whom language and communication impairments have been studied. One group of researchers described language during delirium like this:

> The verbal activity consisted of more or less incoherent speech, speaking continuously and without addressing anyone nearby, and changing rapidly from one subject to another. The patients returned in their speech to the same subject several times. These areas were seemingly associated with what was happening around them or to other things, unknown to the observer. They spoke about various events, experiences, places and people. The patients hovered between 'now' and 'then' and between 'here' and 'there'. The tone of their speech was somewhat speeded-up and the voice was normal at the beginning but the intonation became sharper and louder or mumbling. Some patients cried, shouted, wailed and groaned, called for a person, whistled or laughed. They asked questions without waiting for responses. The subjects were reflections on the current situation and/or reflections on events of a seemingly historic nature. These reflections were about the confusion, expressions of needs and discomfort, searching for help from others, expressing the need to be alone, not to be disturbed, talking about the injury and/or surgery. In addition they misinterpreted people, objects or events, misplaced themselves in the situation, tried to regain orientation, and commented on what happened around them (Andersson et al., 2002, p. 307).

Though these were neither cancer patients nor terminal, the description gives a sense of the language of delirium. Presumably some of the language of the dying

person that is taken to be mysterious and profound should more accurately be labeled delirious, but it is not known how much.

More broadly, rapid declines in both language production and processing appear to indicate hastening of death. Social withdrawal is another hallmark of impending death (Kennedy et al., 2004). Communication impairment has been identified in over a quarter of hospice patients (Jackson et al., 1996). Twelve hospice patients aged 49 to 87 were assessed by speech pathologists (Salt & Robertson, 1998) with tests of memory, verbal fluency, motor control, and sentence comprehension, and 11 of the 12 experienced problems in one or more of those areas. The most serious deficits were in sentence comprehension, where only two of the 11 patients scored within one standard deviation of the mean.

Also relevant here is the research on language and aging in neurologically healthy and diseased populations (Burke & Shafto, 2004; Engelman, 2010; Kemper et al., 2001, 2011; Riley, 2005) though even ambitious longitudinal studies, as by Kemper (2011) do not follow participants to the end of their lives. These studies note slowed speech rates, higher frequency of disfluencies, reduced grammatical complexity, decreased lexical complexity, and other traits as people age normally. Despite these changes, which are presumed to compound with advanced age, elderly people's conversational abilities (in terms of turn-taking, etc.) remain (Shadden, 1997). Patients with dementia and Alzheimer's disease, whose language has been well-studied, show deficits in nonliteral language comprehension and impairments in word recognition (Cuetos et al., 2017; Rapp & Wild, 2011). Alzheimers' patients have also been observed to retain the ability to produce formulaic language ('comprised of conversational speech formulas, idioms, pause-fillers, and other fixed expressions known to the native speaker'; Bridges & Van Lancker Sidtis, 2003, p. 2), even after flexible language use and cognitive abilities have eroded. The forms and types of formulaic language available to individuals have a sociolinguistic dimension, in the sense that individuals preserve language which they used in normal performances of gender, class, culture, and other dimensions of identity during their lifetimes. It is not known how much language at the end of life consists of formulaic productions.

To summarize: a linguistic profile of the dying would aggregate these and other linguistic profiles of patient sub-populations, to the degree that researchers have described them at all. Given this segmentation, as well as the funding priorities and other factors that influence attention paid to any group, the resulting profile would likely be a highly discontinuous mosaic omitting potentially salient phenomena. An observation in one institution during one period of time that is agnostic to disease type or cause of death potentially offers a more continuous assessment of relevant phenomena. Until research in contemporary settings becomes feasible, we turn to some interesting historical data.

The Sample in Osler's Study

This description of Osler's original patient sample is drawn from Mueller (2007), who examined the data cards for his re-analysis of Osler's findings.

Sex. Sex was not explicitly marked on the cards but can be inferred from pronouns and names. Mueller determined the gender of 477 patients, 65% of whom were male.

Age. Mueller calculated that the median age at death was 39 years, ranging from 9 months to 83 years old. The median age at death was similar for both males and females. They appear to be dying young by contemporary standards, but average life expectancy in the US in 1900 was only 47.8 years for males and 50.7 years for females (National Center for Health Statistics, 1999).

Cause of death and disease. As Osler did not design his study to link death and dying to causes of death, the data cards did not provide space for observers to describe diagnoses or illnesses at the outset of the study. Later, for an unknown reason, once 288 deaths had been observed, the data cards were modified and a blank space to note the 'nature of illness' was added. For his re-analysis, Mueller determined a diagnosis or cause of death for 188 patients, most of which were acute in nature. Of these, 60 died of infectious disease, 33 of cardiovascular disease, 21 of cancer, 16 of renal failure, and 31 of postoperative complications, which was the most common cause of death for women. Twenty-seven died of trauma, burns, and miscellaneous causes. There is no information provided on the cards about treatments or types of sedatives and analgesics that might have alleviated pain and altered consciousness.

Consciousness before death. As Mueller (2007) notes, the data cards for 458 patients (94%) noted the presence or absence of coma before death. Observers noted coma in 311 (68%) patients. Of these, length of coma was observed for 296 patients (65%), and the median length of coma was 3 hours. In Osler's (1892) textbook, *The Principles and Practice of Medicine*, he attributes many causes to coma, which he describes as a profound unconsciousness, though not in particular detail. His contemporary, neurologist William Gowers, wrote that 'Complete loss of consciousness, from which a patient cannot be roused, is calle 'coma' if prolonged' (Gowers, 1888, p. 99). Inferring from the absence of mention of coma, Mueller calculates that 147 patients (32%) were 'alert at the time of death.'

Discomfort. For his study, Osler sought to determine whether or not individuals experienced physical, mental, or spiritual discomfort during their death. In his textbook he does not define 'discomfort' directly but his comments throughout suggest that it encompasses a lack of ease as well as 'actual distress and pain'

(Osler, 1892, p. 323). In the 'Study of the Act of Dying' itself, reported patient discomforts included pain, dyspnea, convulsions, weakness, fever, fear, anxiety, irrationality, mental distress, and depression (Mueller, 2007, p. 59). In his 1904 Harvard speech, Osler reported that only 104 patients (21%) experienced one of these discomforts. Mueller (2007) compared the original data cards to Osler's tabulations in a spreadsheet and determined that many more patients experienced discomforts than Osler had reported, calculating that 186 patients (38%) experienced discomfort. Most of this discomfort came from physical pain. (Only one patient was reported to show spiritual discomfort.) 'Rather than supporting a conclusion that dying patients rarely suffer during the dying process, the data instead support the conclusion that a substantial number of patients experienced discomforts' (Mueller, 2007, p. 60). For this study, however, I was interested in a feature of the data cards which Mueller did not note: whether or not patients were observed speaking, vocalizing, interacting, communicating, or were silent.

Osler's Study's Methods

Understanding the methodology of this study puts its results into perspective. According to Mueller (2007), the bulk of the observations were made by nurses. Of a total of 411 cards signed by an individual, 258 (63%) were signed by nurses, and 137 (33%) by physicians. This suggests that patients' deaths were observed by people who worked with them directly. However, as Mueller also notes, after the first year of the study, the number of deaths included in the study dropped precipitously. In all of 1903, only 2 deaths were observed and in 1904 only 23. At the bottom of each card, after the rationale for the study is given, is a plea: 'Prof. Osler requests the intelligent co-operation of the members of the medical and nursing staff.' Osler signed none of the data cards himself. This 'suggests that, after instructing the nursing and resident physician staff to complete the cards, he did not sufficiently encourage them to continue the study (e.g., feedback, interim data summaries)' (Mueller, 2007, p. 60). Over the years, the study seems to have fallen by the institutional wayside.

Methods of the Current Study

Permission was granted to view the data cards at the Osler Library of Medical History, as neither the cards nor their contents are digitally available. Since the patients' identities are still protected according to Maryland law, their names were not copied down, though patient numbers were. Every card was examined for content related to language, vocalization, non-verbals, gesture, and interaction, and any instance was copied into a spreadsheet. They were then grouped into non-overlapping categories to completion. Only two descriptions were double-coded. No cards were excluded because of any patient attributes.

Results

In the Osler data are a range of behaviors whose occurrence and frequency have never been described nor compared in the published literature. These behaviors, summarized in Table 1, are arranged from quoted speech to silence.

Utterances. Patient's verbal communication appears in four forms in the data cards:

1. When an observer has recorded that a patient was experiencing some discomfort or other symptom, which they may or may not have relayed verbally.
2. Directly quoted words, which come closest to 'last words' in the canonical sense of a directly quoted utterance that is a 'final, self-validating articulation of consciousness in extremis' (Guthke, 1992, p. 4).
3. Utterances paraphrased by the observer.
4. Descriptions of verbal communication that do not specify a content ('she talked').

Here I focus on 2), 3) and 4).

2) Quoted words. Contrary to popular conceptions of 'famous last words,' a final utterance in the canonical sense actually encompasses a variety of speech acts. It could be a) a person's literal last utterance, b) someone's last comprehensible utterance, c) the last utterance that observers recall because it was significant emotionally, biographically, or symbolically, or d) some combination of a, b, and c. Additionally, sometimes these utterances are observed directly; sometimes they are second-hand. What becomes known as someone's last word can also refer to fabrications of what someone said or might have said.

In the data cards from the Osler study, four directly quoted utterances appear:

1. A 38-year-old male with an undiagnosed illness was conscious to the moment of death. 'He's got me now—took advantage while I was asleep,' the patient

Table 1. Types and Frequency of Language, Communication, and Interactional Behaviors.

Type of language, communication, or interactive behavior	Number of patients
Quoted last words	4
Paraphrased last words	12
Intention to speak, but unintelligible	2
Comprehending	2
Rousable	5
Vocalization	4
Nonverbal expressions (of pain)	2
Delirium	26
Silence	30
	Total: 87

said an hour before his death. The record also states evidence of his mental discomfort, noting the patient's 'fear of having been caught.'

2. A 24-year-old postpartum woman is quoted as asking, 'Am I dying?' No other utterance was quoted.

3. A 45-year-old woman with unknown diagnosis said she was 'afraid to die' 24 hours before her death. The phrase 'afraid to die' was put in quotation marks on the data card.

4. A 63-year-old patient, gender unknown and diagnosis unknown but postoperative, had a 'mind clear' until 15 minutes before death. Written on the data card under 'spiritual discomfort' was 'last words were of a new world and of feeling better.'

Of these four, two patients were reported to be conscious until death; one was unconscious for 18 hours prior to death, and another 15 minutes.

3) Utterances noted but paraphrased. In 12 instances, an observer either made reference to a patient's words or utterances but paraphrased their content or noted some verbal communication. This indicates that these patients, in addition to the four whose utterances were quoted, were still communicative.

5. A 56-year-old female with unknown diagnosis 'called out 10-15 minutes before death that she was dying.'

6. A 49 year old, with neither sex or diagnosis marked, 'called out loudly to be taken home — about 3/4 hour before death.'

7. A 23-year-old male with no diagnosis marked 'realized at least one hour before that he was going.'

8. A 42-year-old male with no diagnosis marked 'expressed fear' about six hours before death 'that he would not live.'

9. A 40-year-old male with no diagnosis marked 'complained of pain in heart.'

10. A 24-year-old male said he was going to die 30 minutes before a cardiac arrest and 'asked orderly to stand beside him and hold his hand.'

11. A 57-year-old male diagnosed with myocarditis and nephritis 'cried out that he was dying—seemed to feel that he was suffocating.'

12. A 35-year-old patient with unrecorded sex and diagnosis 'complained of fear before unconsciousness and groaned on being [illegible] until 2 or 3 hours of death.'

13. A 24-year-old patient with unrecorded sex and diagnosis 'begged for another chance to be allowed to get well' and did not want to die.

14. A 38-year-old patient with unrecorded sex and diagnosis who was 'talking few 32 [sic] minutes before.'

15. A 32-year-old with unrecorded sex and diagnosis was delirious but 'kept saying she was not ready to die.' (This patient was also grouped in 'delirium' below.)

16. A 46-year-old male diagnosed with 'double pylo-nephritis and double-dilated ureters' was unconscious for four days after death. But he 'could be partially

aroused by frequent shaking and responded fairly intelligently to questions.' (This patient was also grouped in 'rousable' below.

Of these 12 patients, four experienced no coma before death; others were unconscious for periods ranging from 5 minutes to 2 hours.

Intention to speak, but unintelligible

In two instances, patients were observed making nonverbal gestures that indicated a possible intention to communicate that was cut short.

1. A 61-year-old male diagnosed with chronic myocarditis was reported to 'just at death — stretched out rt [right] arm and uttered an inarticulate exclamation or two.' (This patient was also included in 'vocalization' below.)
2. A 69-year-old male who died of pneumonia, right before he stopped breathing, his 'eyes opened widely and pt. turned toward daughter with apparent look of intelligence but made no sound nor did his lips move.'

The first patient was in a coma two hours before death; the second patient six days.

Comprehending

In two instances, patients were noted as understanding what is said to them but not observed to be attempting to communicate verbally or non-verbally.

1. A 24-year-old female with no recorded diagnosis was noted as having no discomfort or apprehension, 'but great pain drew her attention from her surroundings. Up to the moment of her death she understood when addressed.'
2. A 31-year-old male, dying of typhoid, 'looked at the [illegible] as tho' he understood questions.'

The first patient was conscious until the moment of death, while the second patient was unconscious for four days.

Rousable

Several patients were described as unconscious but either rousable or unrousable.

1. A 65-year-old male with no recorded diagnosis 'seemed to be dazed and would not answer questions.'
2. A 38-year-old with unrecorded sex and diagnosis was absolutely comatose for 2–3 hours before death and had been comatose 'yet able to be roused' for the previous 24.

3. A 46-year-old male, grouped in the 'utterances noted but paraphrased' above.
4. A 66-year-old man with no recorded diagnosis was unconscious for 2 to 3 days before dying and had 'an occasional lucid interval.'
5. A 56-year-old patient, with unrecorded sex and diagnosis of gout and urae-mia, was in a coma for 24 hours before death but 'would still rouse to name.'

Vocalization

The data cards recorded five instances of vocalizations without apparent linguistic content. Only one was assumed to be an expression of pain.

1. A 35-year-old patient with unrecorded sex with amoebic dysentery 'groaned often.'
2. A 51-year-old patient with unrecorded sex and diagnosis 'groaned constantly for 24 hours.'
3. A 10-year-old with unrecorded sex and diagnosis 'moaned as if in pain.'
4. A 35-year-old with unrecorded sex and diagnosis 'groaned on being moved until 2 or 3 hours of death.'
5. A 61-year-old male diagnosed with chronic myocarditis 'uttered an inarticulate exclamation or two' at the moment of death.

Nonverbal expressions of pain

In two instances, observers remarked that patients were in physical pain from an expression on their faces.

1) About a 49 year old, with unrecorded sex and diagnosis, the observer noted that their 'facial expressions denoted pain.'

2) About a 72 year old, with no recorded sex and a diagnosis of pneumonia, the observer remarked that 'in a conscious person the facial expression during the last few convulsive gasps would indicate pain.'

Both were unconscious for 3 hours before dying.

Delirium

Sixteen records referred to 'delirium' or 'delirious,' stretching from a period of days to 1 hour, and an additional nine records refer to patients as 'irrational.' One calls a patient 'demented' and another 'mind wandering.' As noted above, delirium is a complex, sometimes reversible condition noted by restlessness, confusion, and language disturbances, which manifests in multiple ways. These 26 patients may or may not have presented with language disturbances in their deliriums.

Silence

Thirty of the 486 data cards contained the words 'quiet' or 'quietly.' No coma was reported for 12 of these; the other patients were in comas from 5 minutes to 7 days, with a median coma length of 4.5 hours. Noting the absence of speech or any vocalization, rather than its presence, is therefore the most frequent language and communication-related observation in the data set, as well as its most ambiguous.

Distribution in the study timeline

The study card number (1 to 486) showed roughly when the observed death took place over the course of the four-year study. Of the observed behaviors, only delirium and silence were observed consistently throughout the four years, while the quoted and paraphased speaking was mostly consistent except for a gap beween patients 200 and 300. The instances of an intention to speak, comprehension, and rousability were observed relatively late in the study, while the instances of vocalization and expressions of pain were observed in the middle.

Discussion

Summary

Very few patients in Osler's sample vocalized on their deathbeds, just 36 out of 486: the 4 'last words,' the 12 paraphrased utterances and observed verbal behavior, the 18 delirious, and 5 moaning and groaning. (Two patients were double-coded, so these do not sum to 36.) Only 16 of these patients produced utterances, according to the observers, that made sense or did not merit a blanket term referring to delirium.

One might think that these 16 patients were the only ones with a desire and ability to communicate and interact. They had meanings to express and retained the linguistic and cognitive capacity to say them. However, they amount to only 3% of the entire sample, even though 32% were conscious until the moment of death (Mueller, 2007). At the very least it suggests that the last words of the dying have been noted less because they are necessarily profound but because they are exceedingly rare.

At the other end of the spectrum, a slightly larger group, 6% of the whole ($n = 30$), were labeled 'quiet.' Assuming that this refers to an absence of vocalization, this is the most frequent language and communication-related observation in the data. It is also the most ambiguous. Apart from the issue of whether or not silence is intentionally deployed by patients or an epiphenomenon of social withdrawal or unconsciousness, the exact nature of the label 'quiet' is difficult to determine. It might refer to the absence of patient vocalizing or to some aspect of the dying process, e.g., the patient had no dyspnea, there were no

distraught visitors or observers, there were no attempted interventions by medical staff, and so forth. We also do not know whether or not vocalizations happened and were unheard or opportunities or interaction not pursued, in cases where a patient was too young, did not speak English, or had been unconscious for a long time. It is also not clear to what degree the quietness was due to sedation of the patients. The number of patients experiencing physical pain suggests that under-sedation may have been more the norm.

Besides the patients who were quiet and talking were 9 (1.8%) who evidently had some preserved interactional abilities. In two instances, patients seemed to demonstrate a desire to interact via inarticulate vocalizations and eye gaze, and in seven instances patients could take on some interactional burden only sporadically or after being urged to do so. The observations about this group show that medical staff did attempt to rouse them.

Finally, six patients were observed expressing that they felt pain — four patients were described as moaning and groaning, and in two other instances, an observer read a patient's facial expression and determined that the patient felt pain. Under the circumstances, it is reasonable to assume the vocalizations were expressions of physical pain, even though only one observation explicitly mentions it. It is also reasonable to think these vocalizations were written down because of the study goals, but it is not actually clear whether or not these vocalizations indicated an intention to communicate. It is also curious that there were so few vocalizations like these. As for facial expressions of pain, they have been studied in dementia patients, who are unable to verbally express pain and discomfort, though like moans and groans, the correct interpretation of those expressions is culturally shaped (Bouchard, 2014; Henry & Matthias, 2018).

Twenty-six patients (5% of the sample) were described as 'irrational,' 'demented,' mind wandering,' or having 'delirium.' Previous research has shown delirium's high prevalence among cancer patients at the end of their lives (Lawlor et al., 2000) and among post-operative elderly patients, but less is known about other patient populations.

No instances of 'terminal lucidity' were reported. This refers to the 'unexpected return of mental clarity and memory shortly before death' (Nahm & Grayson, 2009). Cases of terminal lucidity have long been reported (Nahm & Grayson, 2009) but reports on its prevalence are inconsistent. In a 2008 study (Brayne et al., 2008), seven nurses out of ten at a UK nursing home noted seeing patients who had been unconscious or confused 'unexpectedly became lucid enough just before they died to interact with relatives and carers' (198). Another study on the behavior of the dying (Witzer, 1975) with 110 patients noted that 'many patients exhibited a short increase of vitality, appreciated food again, and appeared to be generally improved' (82). However, a New Zealand hospice director reported attending 100 consecutive hospice deaths and witnessed only six cases of 'lightening up' in the last 48 hours of a person's life (MacLeod, 2009).

No other phenomena associated with 'near-death experiences' or 'end of life experiences' (such as hallucinations) were reported in the Osler data.

Limitations

These data cards provide a useful snapshot of death and dying in one institutional setting and at one point in time, and contain otherwise unavailable information about language behavior in dying patients. However, Osler's study was limited in numerous ways and lacked rigor in the most basic contemporary sense, and no study protocols or ancillary documentation exists to shed light on how people were trained or instructed to fill the cards or how consistently these instructions might have been followed over the four years of the study. Evidence suggests other factors, such as institutional support and staffing, played a role in results. For example, in one year of the study, only two deaths were recorded, and inconsistent patterns of some observed behaviors suggest variable commitment by data collectors.

Other aspects of the context that might help clarify the data are similarly lacking, such as how much time medical staff stayed by each patient, whether or not visitors were allowed and for how long, and even whether or not patients had individual rooms or were placed in larger wards. Consequently it is difficult to interpret some of the observations. Did 'quiet' mean that the patient was quiet or that the person filling out the card was not present to hear any vocalization? If a data card indicated that a patient experienced discomfort, was this verbally relayed by a patient, observed by hospital staff, or both?

Furthermore, the information about diagnoses and treatments that would have impacted language, communication, and consciousness is not consistently provided. Diagnosis and cause of death is available for only 188 of the 486 patients.

Conclusions

'The last words of dying persons are always interesting,' wrote Joseph Kaines in 1866 (Kaines, 1866, p. vii). However, data from Osler's study show that a variety of speech, language, and communication phenomena occur at the deathbed which may also be of interest. In Kaines' anthology of famous last words, *Last Words of Eminent Persons*, the dying process is mainly depicted as filled with clearly enunciated talking and attentive listening. In the Western tradition reflected in his collection, any 'final, self-validating articulation of consciousness in extremis' (Guthke, 1992, p. 4) ought to be an interpretable word. Yet this analysis of Osler's data locates several prevalent language ideologies in this tradition, among them the lexical fallacy, or the idea that a final communication must be a word.Another ideological elaboration is that a final communication, to matter, should also be spoken. To the contrary, the patients at Johns Hopkins Hospital display a range of non-interpretable, non-verbal, and non-word

behaviors that should also count as 'articulations of consciousness in extremis,' from moans to glances and outright silence. Because they are not lexical items, these utterances arguably may never circulate in the anecdotal economy of last words. Thus, not only does the folk linguistic category of the 'last word' not capture the full range of phenomena, but it erases the reality that the most common vocal behavior by the dying person seems to be not saying anything at all.

What Joseph Kaines's anthology (and others like it) provides are canonical last words that serve some social purpose, often abstracted from longer death-bed scenes, often taken from biographies of the person, notes by contemporaries, or memoirs of physicians. Part of literary and spiritual traditions, they reflect ideas about what a good or notable death entails. By contrast, what we have in the Osler study is suggestive of a very different linguistic reality for ordinary people.

Yet given its limitations, why should its resulting data be of interest at all? Predominant is the fact that what circulates about language at the very end of life has been opportunistic and anecdotal, so any attempt to create an empirical footing should be seen as an advance. In this case, the data were not reported *post hoc*, so bias caused by high emotional salience is likely low. Even without reliable information about why these patients stopped talking specifically, the data cards provide an otherwise unattainable view of the dying process, though without a comparison sample, one must be wary of concluding that these data are in any way representative of language at the end of life. Data from contemporary medical settings, where the causes of death, settings, and treatments differ greatly from those 120 years ago, would be a challenge to gather in this way. Though the causes of death early in the 20th century differ, the one virtue of these data is that they come from a single institutional setting in a relatively conscribed period of time and over a wide range of patient demographics and disease types. As long as one understands the dangers of generalizing, they pull back the curtain of taboo from a universal yet empirically unexplored moment in human experience. No similar collection has ever been published or reported.

These data and their analysis can also set the stage for contemporary research by helping to make visible persistent cultural ideas about language and interaction behaviors of the dying, which need to be considered by researchers. Along with personal attachments, these ideas color second-hand reports, so immediate observation is preferred. These data suggest other methodologies for future research. The phenomena are multimodal, which points to data collection methods beyond audio recording. Not only would the entire communicative context would need to be described, but the events should be described from as many participants' point of view as possible.

Along with their inconsistencies and ambiguities, the language and interaction patterns noted in Osler's study serve as valuable evidence of operative cultural models about linguistic and communicative agency at the end of life

that existed for American medical professionals and others in the early twentieth century. Such cultural models exist for contemporary professionals as well. Without interlocutors willing to prompt the behaviors and observers present to record what happens, few 'last' linguistic behaviors would have been observed. In other words, dying people do not say intrinsically interesting things, but 'last words' and other behaviors are recorded to the degree that the dying are considered to have something meaningful to say. They are more likely to be recorded if these expressions involve words, are vocalizations, and are sensible.

Expectations about the communicative agency of the dying are additionally embedded in medical training and attitudes about the demographics of the dying. For instance, the professional training of doctors and nurses would have taught them to remain emotionally distant from patients. In such a setting, 'dying remained an extremely lonely and dehumanizing experience' (Abel, 2013, pp. 53–54), which may partly explain why 401 patients at Johns Hopkins Hospital, or 82% of the total group, were described neither as talking, vocalizing, or interacting nor as quiet. The sparse linguistic content in the cards may also reflect a lack of interest by medical professionals in the patients of the represented demographics, which led to under-reporting. We do know that the Johns Hopkins Hospital was designed for traditional charitable goals of providing care for 'the indigent sick of [Baltimore] and its environs, without regard to sex, age or color who may require surgical or medical treatment' (Hopkins, 1873, quoted in Risse, 1999). The types of care extended to those dying at home or in private hospitals differed from those available at Johns Hopkins, which may have influenced the study results as well. Observations of language and communication behaviors seem to rely heavily on histories of medical care in the US in the 19th and 20th centuries. Was anyone trying to rouse patients because they expected some interaction? What did the living expect the dying to do? The resulting variability of the data in Osler's study may be strongly shaped by conceptions of what dying people have to say and its importance. Here last words resemble first words, which occur in culturally-shaped interactional settings that make them more or less salient to remember, talk about, record, and analyze. Even Osler made this seemingly far-fetched analogy between birth and dying: 'The great majority of the dying gave no sign one way or the other,' he said in his Harvard lecture. 'Like their birth, their death was a sleep and a forgetting.'

Acknowledgements

Declaration of Conflicting Interests

Funding

ORCID iD

Michael Erard https://orcid.org/0000-0002-7721-781X

References

Abel, E. (2013). *The inevitable hour: A history of caring for dying patients in America.* Johns Hopkins University Press.

Andersson, E., Norberg, A., & Hallberg, I. (2002). Acute confusional episodes in elderly orthopaedic patients: The patients' actions and speech. *International Journal of Nursing Studies*, *39*, 303–317.

Bouchard, L. (2014). A linguistic approach for understanding pain in the medical encounter. In M. Incayawar ?0026; & T. Knox (Eds.), *Culture, brain, and analgesia: Understanding and managing pain in diverse populations* (pp. 9–19). Oxford University Press.

Brayne, S., Lovelace, H., & Fenwick, P. (2008). End-of-life experiences and the dying process in a Gloucestershire nursing home as reported by nurses and care assistants. *American Journal of Hospital Palliative Care*, *25*, 195–206.

Bridges, K. A., & Van Lancker Sidtis, D. (2013). Formulaic language in Alzheimer's disease. *Aphasiology*, *1*, 27.

Bryan, C. S. (1996). Fever, famine, and war: William Osler as an infectious diseases specialist. *Clinical Infectious Diseases*, *23*, 1139–1149.

Burke, D. M., & Shafto, M. A. (2004). Aging & language production. *Current Directions in Psychological Science*, *13*(1), 21–24.

Cuetos, F., Arce, N., Martinez, C., & Ellis, A. W. (2017). Word recognition in Alzheimer's disease: Effects of semantic degeneration. *Journal of Neuropsychology*, *11*(1), 26–39.

Engelman, M. (2010). Propositional density and cognitive function in later life. *Journal of Gerontology B*, *65*(6), 706–711.

Gowers, W. (1888). *A manual of diseases of the nervous system* (*Vol. II*). Churchill.

Guthke, K. (1992). *Last words*. Princeton University Press.

Hamilton, M., Matheson, D., Cairns-Smith, S., George, B., Palisch, C., & Dorsey, R. (2015). The anatomy of medical research: US and international comparisons. *Journal of the American Medical Association*, *313*(2), 174–189.

Henry, S., & Matthias, M. (2018). Patient-clinician communication about pain: A conceptual model and narrative review. *Pain Medicine*, *19*(11), 2154–2165.

Heron, M. (2018). Deaths: Leading causes for 2016. *National Vital Statistics Reports*; vol 67 no 6. Hyattsville, MD: National Center for Health Statistics.

Hollien, H., DeJong, G., Martin, C. A., Schwartz, R., & Liljegren, K. (2001). Effects of ethanol intoxication on speech. *Journal of the Acoustic Society of America*, *110*(6), 3198–3206.

Hopkins, J. (1873). *Letter of Johns Hopkins to the Trustees of "The Johns Hopkins Hospital."* Baltimore: Wm. K. Boyle & Son.

Hui, D., dos Santos, R., Chisholm, G., Bansal, S., Crovador, C., & Bruera, E. (2015). Bedside clinical signs associated with impending death in patients with advanced cancer: Preliminary findings of a prospective longitudinal cohort study. *Cancer*, *121*(6), 960–967.

Jackson, P., Robins, M., & Frankel, S. (1996). Communication impediments in a group of hospice patients. *Palliative Medicine*, *10*, 79–80.

Kaines, J. (1866). *Last words of eminent persons, comprising, in the majority of instances, a brief account of their last hours.* George Routledge.

Kemper, S., Marquis, J., & Thompson, M. (2001). Longitudinal change in language production: Effects of aging and dementia on grammatical complexity and propositional content. *Psychology of Aging*, *16*(4), 600–614.

Kemper, S., Schmalzried, R., Herman, R., & Mohankumar, D. (2011). The effects of varying task priorities on language production by young and older adults. *Experimental Aging Research*, *37*(2), 198–219.

Kennedy, C., Brooks-Young, P., Brunton Gray, C., Larkin, P., Connolly, M., Wilde-Larsson, B., Larsson M., Smith, T., & Chater S. (2004). Diagnosing dying: An integrative literature review. *BMJ Supportive & Palliative Care*, *4*(3), 263–270.

MacLeod, S. (2009). Lightening up before death. *Palliative and Supportive Care*, *7*, 513–516.

MacLeod, S., & Whitehead, L. (1997). Dysgraphia and terminal delirium. *Palliative Medicine*, *11*, 127–132.

Moses HM III, Matheson DHM, Cairns-Smith S, George BP, Palisch C, Dorsey ER. (2015). The Anatomy of Medical Research: US and International Comparisons. *Journal of the American Medical Association, 313*, 174–189. doi:10.1001/jama.2014.15939

Morita, T, Tei, Y., & Inoue, S. (2003). Impaired communication capacity and agitated delirium in the final week of terminally ill cancer patients: Prevalence and identification of research focus. *Journal of Pain and Symptom Management*, *26*(3), 827–834.

Mueller, P. (2007). William Osler's Study of the Act of Dying: An analysis of the original data. *Journal of Medical Biography*, *15*(Suppl. 1), 55–63.

Nahm, M., & Grayson, B. (2009). Terminal lucidity in patients with chronic schizophrenia and dementia. *Journal of Nervous and Mental Disease*, *197*, 942–944.

National Center for Health Statistics. (1999). *U.S. decennial life tables for 1989–91, vol 1, no. 3, some trends and comparisons of United States life table data: 1900 − 91.* Hyattsville, MD: National Center for Health Statistics.

Osler, W. (1892). *The principles and practice of medicine.* Appleton.

Osler, W. (1904). A study of the act of dying. Johns Hopkins Hospital. Osler Library of the History of Medicine, B.O. 7644.

Osler, W. (1906). *Science and immortality*. Houghton-Mifflin Company.

Osler, W. (1911). Maeterlinck on Death. *The Spectator*, November 4, 1911.

Rapp, A., & Wild, B. (2011). Nonliteral language in Alzheimer dementia: A review. *Journal of International Neuropsychological Sociology*, *17*(2), 207–218.

Riley, K. P., Snowdon, D. A., Desrosiers, M. F., & Markesbery, W. R. (2005). Early life linguistic ability, late life cognitive function, and neuropathology: Findings from the Nun Study. *Neurobiology of Aging*, *26*(3), 341–347.

Risse, G. (1999). *Mending bodies, saving souls: A history of hospitals*. Oxford University Press.

Salt, N., & Robertson, S. (1998). A hidden client group? Communication impairment in hospice patients. *International Journal of Language & Communication Disorders*, *33*(Suppl), 96–101.

Samarin, W. (1973). Glossolalia as regressive speech. *Language and Speech*, *16*(1), 77–89.

Shadden, B. (1997). Discourse behaviors in older adults. *Seminars in Speech and Language*, *18*(2), 143–157.

Thomason, S. (1984). Do you remember your previous life's language in your present incarnation? *American Speech*, *59*(4), 340–350.

Witzer, L. (1975). Behaviour of the dying patient. *British Medical Journal*, *2*, 81–82. https://ourworldindata.org/causes-of-death.

Author Biography

Michael Erard, PhD, is a linguist and author.