

# “Living-with-dying”: the elderly’s language of terminal illness

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## Abstract

**Purpose** – This study aims to examine the way in which elderly people, men and women, with a terminal illness use language to construct a narrative about their “living-with-dying” experience.

**Design/methodology/approach** – This investigation is a secondary analysis based on a corpus of health and illness narratives collected by the Health Experiences Research Group at the University of Oxford and published by the DIPEX charity (available at: <http://healthtalk.org/home>).

**Findings** – This study shows that there are qualitative differences in the way in which not only elderly people but also men and women report their experience with terminal illness and their relation to death.

**Originality/value** – Understanding the different perspectives from which elderly people narrate their experiences of how they live while dying from terminal illness can help health professionals to develop more effective all-inclusive health policies and practices in end-of-life care.

**Keywords** Discourse analysis, Empathy, Corpus linguistics, Health narrative, Support group communication, Terminal illness narrative

**Paper type** Research paper

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## 1. Introduction and purpose

The purpose of this study is to examine the ways in which elderly people with terminal illness use language to construct a narrative about their “living-with-dying” experience. A terminal illness is a chronic disease or condition of which a patient cannot be cured; such a condition is likely to lead to someone’s death. Chronic illness may have an impact on the individual’s sense of identity (Williams, 1984). In particular, the notion of the self and one’s identity are constructed within one’s history and if one has or “owns” a disease, that person’s identity can coincide with the illness itself (Karnilowicz, 2011). While an illness is a “disruption” of life, chronic illness makes us reconsider life, realigning and interpreting it with society. Indeed, the limitations imposed by a chronic disease are not simply physical: they are primarily social; living a life of non-health, patients must resolve the demands of bodily existence and social life (Radley, 1989, p. 232).

Narrating illness is a way of providing a meaningful context to chronic disease; narratives, however, are not necessarily *about* illness: in most cases, illness is reported as a personal experience narrative (Hydén, 1997). The type of narrative under consideration in this study entails illness *as* narratives generated by narratives *about* illness: we have patients’ narratives *about* illness and, at the same time, about their chronic illness *as* their personal experience [1]. This type of narrative includes forms of expressions describing pain. Pain, however, is a subjective, personal and private experience. For this reason, it is almost impossible to assess (Breivik *et al.*, 2008) and describe pain (Padfield and Zakrzewska, 2017).

The type of pain people have in a terminal illness may certainly be caused by the disease itself and be physical, or it can be caused by the cognitive, social, psychological and

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emotive conditions of the terminal disease. This requires “healthcare professionals to embrace the psychological effects of illness” (Karnilowicz, 2011, p. 280). The embedding of healing modalities would need a switch in the medical framework, requiring more attention being paid to patients’ voices and their narratives, as well as to the meaning patients assign to their context (Radley, 1989).

In a situation of total absence of any healing modality, patients turn to the Web in an attempt to seek health information and make sense of their condition. There is a correlation between chronic illness, retrieving health information from the Web and changing health behaviour (Ayers and Kronenfield, 2007).

The potential of digital technologies within health care (Marent *et al.*, 2018; Robinson *et al.*, 2014, 2016) has been highlighted by online health communities: it is there that most patients can share and check relevant information (Lamberg, 2003), besides the fact that such communities have always been seen as *loci* for receiving and expressing empathy (Rheingold, 1993). *Empathy* is a cognitive or an emotional state of mind through which someone’s condition or emotional state can be understood without making it one’s own (Hoffman, 1981; MacKay *et al.*, 1990).

One of the major deficits in the interaction between doctors and their patients lies in the fact that professionals concentrate on pathology and neglect expressions of empathy (Semino *et al.*, 2018). The realization of empathy from a health-care professional’s perspective can simply be achieved through a set of core empathy-seeking and empathy-giving acts which are verbally realized by the following:

- eliciting patients’ feelings and views; and
- acknowledging patients’ feeling(s) and views, and withholding judgement (Pounds, 2011; Pounds *et al.*, 2018).

From a linguistics perspective, focusing on empathy means understanding how this condition is communicated and to what extent this state moulds online interactions about health issues, which, to the best of our knowledge, has seldom been investigated (Jaworska, 2018). Therefore, the research questions at the basis of our investigation are as follows:

*RQ1.* How do people communicate their terminal illness to others on the Web?

*RQ2.* Is there any difference in the way in which such communication is carried out between senior and relatively less senior people, and men and women with chronic illness?

More specifically, drawing on discourse analysis (Jones *et al.*, 2015; Gee, 2017), and based on Jaworska and Ryan (2018), we carried out an investigation of the narratives of all available terminal conditions in elderly people, their terminal illnesses and their narratives, as found on healthtalk.org, which were examined in a corpus-based approach (McEnery and Hardie, 2012). These were compared with all terminal conditions in less elderly people with the aim of detecting how information, knowledge (and empathy) are deployed in patients’ narratives in an attempt to help people to fill a cognitive and emotive gap. To this end, a qualitative analysis of the discursive patterns of the narratives found has been conducted, along with a keyword analysis of the corpora thus collected.

Healthtalk.org is a UK website managed by the Oxford-based charity DIPEx, which offers free, reliable information about health issues by sharing people’s real-life experiences with the aim of helping people who are facing a similar situation and assisting them in making decisions about health and treatment; supporting patients and their families in the decisions they have to take; helping health-care professionals provide care to patients and facilitating patient–doctor communication.

To achieve such a goal, this paper will proceed as follows. Section 2 describes the data, methodology and ethics applied to carry out the analysis of the findings explained in Section 3, in which data interpretation is also discussed. A conclusion is offered in Section 4.

With this paper we hope that an understanding of the various views in which the different groups within (the elderly narrate their experiences of how they live while dying from a terminal illness can help health professionals to effectively develop more all-inclusive health policies and practices in end-of-life care.

## 2. Corpus collection, methodological approach and ethical approval

To carry out the investigation at the basis of this study, we collected a corpus selected from a larger corpus of health and illness narratives collected by the Health Experiences Research Group at the University of Oxford and published by the DIPEX charity (available at: <http://healthtalk.org/home>). We were able to download all available terminal conditions (nine) in elderly people aged 71–90 (five men and four women) and their narratives about their terminal illnesses.

These were compared with other terminal conditions present in the website (ten), in less elderly people aged 50–60 (five men, five women). We thus collected a small corpus of 26,659 running words, in turn divided into four subcorpora as indicated in [Table 1](#) below.

All downloaded narratives are indicated with the abbreviation M for *Male narrative* or F for *Female narrative*, followed by a number corresponding to the number of the text found on healthtalk.org. They were also labelled as “S” – senior – or “Y” – young – according to the patient’s age, as found on <http://healthtalk.org>. Thus we have, for example, M16\_S, F08\_Y, etc., which correspond to narratives about male narrative no. 6, senior; female narrative no. 8, young, etc.

As all content published on <http://healthtalk.org> site is the sole property of DIPEX, consent to use the data for the purposes of this research was sought from DIPEX, which was granted. Permission to download, use and archive the collected texts from healthtalk.org to carry out the present research was granted by the Health Experiences Research Group and by the DIPEX charity that runs the website.

To carry out discourse analysis and corpus linguistics investigations, all texts were read to allow a better contextualization of the content and, if the video was available, this was watched.

All texts were examined by using discourse analysis ([Gee, 2017](#)) with a corpus-based approach ([Bondi and Scott, 2010](#); [McEnery and Hardie, 2012](#); [Baker and McEnery, 2015](#)). Drawing on linguistic research on online health communication ([Jones, 2010](#); [Koteyko and Hunt, 2016](#)), and on digital storytelling ([Page, 2012](#)), narratives were examined contrastively according to the subcorpora *seniors* vs *young* and then *men* vs *women* to detect in what ways, if any, discursive patterns of terminal disease discourse may change according to age and gender and then scrutinized in more depth in relation to keyness. The corpus thus collected was uploaded to Wordsmith Tool 7 ([Scott, 2016](#)) to analyse keywords, also in relation to concordance lines, to understand their different contexts.

**Table 1** Corpus and subcorpora breakdown

	<i>Seniors (a. 71–90)*</i>	<i>Subcorpora Young (a. 50–60)*</i>	<i>Men**</i>	<i>Women**</i>	<i>Corpus Total</i>
Tokens	7,868	18,791	12,343	14,316	26,659
Types	1,297	2,179	1,796	1,780	3,575

Notes: \*No sex distinction. \*\* No age distinction

### 3. Results and interpretation

The manual analysis of four subcorpora revealed differences in the ways in which terminal illness is perceived as a personal experience by patients and as such reported by them. Not only do young and senior people react differently at the news of their cancer but also men and women have different attitudes towards their terminal disease, as described in the following sections, where the main recursive narrative patterns and the most relevant examples related to them are shown.

#### 3.1 Senior vs young people subcorpora

From the manual examination of all texts, the most evident difference between the two subcorpora is the fact that the *young* people face a terminal disease with “shock,” whereas the *senior* patients show more “acceptance” towards the disease (our emphasis here and there), implicitly confirmed by the keywords analysis as follows:

- So it was all found, so it was a big *shock*, going in that Tuesday evening as it was, and being kept in (F08\_Y).
- [...] the biggest *shock* [...] [was] when we spoke to the surgeon and he said that he'd [...] what he was going to do for the operation, removing the lung and obviously the tumour. And we talked to him, about, you know, the cure and he said, 'Oh, it's not a cure.' And that was a big *shock* to us, knowing that I was going to have this radical surgery but still not be cured (M19\_Y).
- One can be afraid of a painful death or sorry for people you leave behind [...] but various arrangements can be made [...] and I think the thing is just to *accept* that that's what happens (M38\_S).
- It's said that there are five stages. One, that you disbelieve it, that you can't, that isn't, [...] Then you become angry [...] And then another one I think is that you grieve, not for yourself but for other people [...] And then there's an *acceptance* which is I think probably where I've got to at the moment. [...] It could be a terminal illness but *at my age it isn't going to be long anyway*, probably. It's a question of coming to terms with reality really (M16\_S).

Excerpts 1 and 2 clearly reveal the shock the *young* patients feel at the revelation of the type of disease they have. The shock is not so much about having a tumour, but rather about not having a cure, as Extract 2 indicates (“that was a big shock to us, knowing that I was going to have this radical surgery but still not be cured”). Example 3 is more sober in its description of what is going on in a cancer patient's mind (“one can be afraid of a painful death or sorry for people you leave behind”), but the very fact that everything is under control, that is, physical pain, arrangements with relatives, etc., helps him to better accept his condition. In Example 4, however, all these phases are more emotionally depicted in stages (“there are five stages”) of disbelief, anger, grief up to the acceptance stage, which is the one he has arrived at, as “it's a question of coming to terms with reality.” What is hinted at in Extract 3, that is the fact that people can be organized, is found in all the illness narratives of the *young* group, as we can see in Examples 5–7 below:

- The other thing is I want to find out *what to do with my body* because I wanted to leave it. [...] but I've got to ask my kids what they feel like first, I mean they've got to live with it haven't they[...] *It's got to be easy for them* [...] I shall go into this during my next chemo, when I've got time, and see if I can come up with something. If not, it's where my kids want to bury me and whether it's helpful or whether it's cremated (F41\_Y).
- *I've made a will* and I've made like *a living will* so that, hopefully, that helps the doctors make the decision whether to turn off the machines [...] I had the will before and *I've put everything in order* (M06\_Y).

- Oh well, *obviously making the Will*. Making sure that there is tax efficient provision for my wife and for my children [...] It's just going to be very simple, straightforward and no arguments and this is what it will be (M14\_Y).

What is always present in the *young* narratives, but is, on the contrary missing in most *senior* ones, is the acknowledgment that everything must be organized and put in order before their death. This helps them to cope with the idea of passing away, as if this can make death more bearable.

### 3.2 Women vs men subcorpora

The manual analysis of two subcorpora revealed differences in the way in which terminal illness is perceived by men and by women. The main concern men have is that of getting organized to help their family, whereas for women it is how to tell their children about their condition:

- I can't really particularly remember what he said when he told me I had cancer but *I can remember thinking how can I tell the children* (F26\_S).
- The thing that concerned me the most was not so much that I was ill with an incurable cancer but *how on earth was I going to tell the children?* (F35\_Y).
- He [the solicitor] was wonderful. He understood my condition and the thing that he said to me which made me want to go ahead was, he said, "You have to decide whether you want to claim and *get the benefit of compensation* while you are alive or whether your widow claims when you are dead" (M19\_Y).
- I've no problems at all really. *Financially, I think for being in the state I'm in I think it's pretty generous* and I find it's we don't have problems at all like you know. No problems financially like you know (M30\_Y).

In Extracts 8 and 9, the two women are not so much worried about their incurable condition but about how to tell their children. In Examples 10 and 11, the two men are concerned about financial issues: in Extract 10, the man accepts the piece of advice given by his solicitor in relation to the type of benefit compensation his family can have while he is alive or the one his widow can claim after his death – which requires being organized and thinking about the aftermath; in Extract 11, the man has already decided about the compensation to be claimed when alive – which, again, means being organized and deciding what to do during the disease and after his death.

What both *men* and *women* subcorpora have in common is the idea of not being a burden on anybody:

- If I were to have a stroke or any sudden illness that impaired my ability to communicate [...] I've made it very clear to three separate people that I do not wish to be revived under any circumstances. *I don't want to be a burden* on other people (M09\_Y).
- I mean everybody says they *don't want to be, that dreadful burden*. I'm prepared [...] prefer to say goodbye in a much more loving, rational situation and when you've got more control over your bodily functions, or more or less your mind (F32\_Y).

Nobody wants to be a burden if they lose control of their body and/or mind. This, again, is another way of getting organized and putting everything in order. It is a way of having control over their own life, showing independence and strength over their disease – they are commander-in-chief of their own body and before the situation can worsen, they rule over themselves.

### 3.3 Keyness analysis

The analysis with Wordsmith Tools (Scott, 2016) allowed us to identify the keywords that are illustrated in Table 2 below. Keywords were generated by checking one subgroup against

**Table 2** Breakdown of keywords in the subcorpora

<i>Senior</i>	<i>Young</i>	<i>Keywords</i>		<i>Women</i>
		<i>Men</i>		
Yes (45 hits, keyness 24.75)	Things (123 hits, keyness 25.93)	No (60 hits, keyness 23.11)		Group (28 hits, keyness 27.68)
Death (15 hits, keyness 19.87)	Know (173 hits, keyness 21.67)	That (351 hits, keyness 22.16)		Breast (16 hits, keyness 19.9)
One (44 hits, keyness 16.24)	Group (28 hits, keyness 13.34)	is (165 hits, keyness 18.67)		Hospice (23 hits, keyness 14.63)
Accept (6 hits, keyness 14.65)	Want (74 hits, keyness 11.57)	Euthanasia (11 hits, keyness 16.95)		Remember (16 hits, keyness 13.84)
Belief (8 hits, keyness 13.95)	Actually (44 hits, keyness 10.70)	Death (17 hits, keyness 15.89):		Mum (11 hits, keyness 11.68)

the other (i.e. *seniors* against *young* and *men* against *women*), and vice versa, so that each subgroup could be used as a reference corpus for the other group (cf. Baker and McEney, 2015). Keyness is computed with the log likelihood statistical test set by default by Wordsmith Tools with  $p < 0.01$ . Only keywords with  $p \leq 0.01$  have been taken into consideration. Owing to lack of space, only the first five keywords in terms of keyness for each subgroup are analysed in this paper.

In the *senior* subcorpus, 44 keywords with  $p \leq 0.01$  were generated against the *young* subcorpus. The top five keywords are *yes*, *death*, *one*, *accept* and *belief*.

*Yes* (45 hits, keyness 24.75) is mainly used by *senior* men (interestingly, *no* is used by men in general) and is found to be an affirmative answer to the question of whether religion influences the way in which they see and cope with their terminal cancer, especially in relation to euthanasia, as confirmed by the concordance lines; in other words, they think it is unfair or even immoral to ask to die to escape from cancer precisely because they believe in some form of religion:

- That just seems immoral to me. That's giving another person not only the power to do it but also the power of life and death and that doesn't belong to anybody. No.

And you say that because of your religious faith? Is that right?

In a way, *yes* it is (M16\_S).

The notion of *death* (15 hits, keyness 19.87) seems to be linked with the idea of an afterlife (in Excerpt 15) and a fear of dying (Excerpt 16). These two aspects are connected with the perceptions patients have about the way they have lived their own life. In the example below, however, there is a sense of acceptance in describing how they are approaching their own death:

- A lot of people are convinced there is life after *death* [...] That is not one of my philosophies. My belief in life after *death* is that the way you live your life influences other people (M31\_S).

While *one* (44 hits, keyness 16.24) is simply an impersonal pronoun, *accept* (6 hits, keyness 14.65) is used to indicate acceptance of terminal illness and the fact that death is near:

- 16. now I aim just to *accept* what comes (F07\_S).

The discourse about the immorality of seeking death to escape cancer death, of making sense of one's death and finding comfort in religion thanks to which one can find acceptance, is linked to senior people's *belief* (8 hits, keyness 13.95). This is mainly the *belief* they have in God and the relief they can have in prayers:

- But I pray for the trust and *belief* that this life is a prelude to the afterlife and that the afterlife is what counts (M18\_S).

In the *young* subcorpus, the number of keywords with  $p \leq 0.01$  is 32. The top five keywords in terms of keyness are *things*, *know*, *group*, *want* and *actually*. Given that in oral speech *actually* (44 hits, keyness 10.70) is used as a filler or as an emphaser (Quirk *et al.*, 1985, p. 583), only the first four keywords are analysed.

The item *things* (123 hits, keyness 25.93) is found to be used with the following collocates: *life is a lot of things*; *you can do a lot of things*; *thinking positive things*; *you are dealing with worse/better things*. The keyword *things* is therefore related to aspects of life while living with or against cancer, as Example 18 below indicates:

- And so we started to do a lot of our own research and found out, yes there were other options, there were other *things* we could do (F32\_Y).

The verb *know* (173 hits, keyness 21.67) is a keyword that collocates with the negative auxiliary *don't* in the expression *I don't know* and makes the whole narrative more informal or colloquial – it is mainly used as an interjection, rather than expressing uncertainty, as in 19:

- Well there might be a time when I would like her to pray with me, I *don't know* (F17\_Y).

Interestingly, the keyword *group* (28 hits, keyness 13.34) collocates with *support group*; *healing group*; *telephone group*; *writing group*. The keyword, therefore, seems to make reference to support groups people can belong to in order to share their experiences and have support.

The verb *want* (74 hits, keyness 11.57) as a keyword is found in the following expressions: *I don't want to be a burden*; *I don't want they think of me dying*; *I don't want to rage*; *I don't want to be resuscitated*; *I want it to be natural*; *I want to be buried*. The verb *want* is, thus, connected to the idea of getting prepared for death in the best possible ways (examples of which can be seen in Extracts 12 and 13 above).

The *men* subcorpus has 48 keywords with  $p \leq 0.01$ ; the top five keywords are *no*, *that*, *is*, *euthanasia* and *death*.

As seen above, while the *senior* subcorpus has *yes* as the top keyword, the top keyword in the *men* subcorpus is *no* (60 hits, keyness 23.11). Here, the negative adverb is used in such expressions as *there is no reason to believe [I have cancer]*; *there are no problems [financially]*; *there are no regrets*. The term is therefore linked to a discourse of shock, of getting things in order and accepting the idea of death.

The keyword *that* (351 hits, keyness 22.16) is found in *that*-clauses and is not relevant for the analysis of this paper, as the keyword *is* (165 hits, keyness 18.67) which is used as a copula or as an existential verb.

The discourse of *euthanasia* (11 hits, keyness 16.95) is about control. It is not a matter of deciding to end one's own life but rather of allowing others to end it. Nobody wants euthanasia, because accepting this means losing control of one's own life, as already indicated in Excerpts 12 and 13 above.

Once again, *death* (17 hits, keyness 15.89) is a keyword and, exactly as in the *senior* subcorpus, the item is embedded in a narrative about the notions of life and death, life after death and fear of death. As some of the people are religious, it is obvious that the sense of life and death and whether they think there is an afterlife depends on whether they believe in God or not. Apparently, this does not seem to determine any fear of dying (cf. Examples 14 and 15, above).

The *women* subcorpus comprises 43 keywords with  $p \leq 0.01$ . The top five keywords analysed here are *group*, *breast*, *hospice*, *remember* and *Mum*.

As in the *men* subcorpus, the keyword *group* (28 hits, keyness 27.68) appears in clusters as *support group*, *healing group*, *telephone group* and *writing group*, and therefore refers to groups where people can find support and share their experiences and feelings about their own terminal disease.

The keyword *breast* (16 hits, keyness 19.9) collocates with *cancer* and indicates *breast cancer*, which is particularly frequent in women.

Interestingly, even though everybody claims they do not want to be a burden to anybody, only women use the term *hospice* (23 hits, keyness 14.63) as the institution to go to in order not to be a burden on the family when they are no longer independent and autonomous.

The keyword *remember* (16 hits, keyness 13.84) is used by women when they report what they felt when they were told they had a terminal disease. The description of feelings is on a very personal level – which is missing in most men’s descriptions. In this remembrance, the figure of their mother is a constant element. *Mum* is indeed one of the keywords (11 hits, keyness 11.68). Most women explain that their mother had a similar health experience: precisely because they remember what they felt when they were young and what they went through with their mum, they do not want to repeat the same experience with their own children.

#### 4. Conclusions

Our investigation aimed to show how people communicate their terminal illnesses to others on the Web and in particular to detect communication differences between senior/less senior patients and men/women with chronic illness.

This study has shown that there are qualitative differences in the way in which these groups report their relation to death and how men and women narrate their experience with terminal illness, pointing to the existence of distinctive lexical repertoires of terminal illness talk. From a manual and digital analysis of four subcorpora, we can say that some common features emerge from illness narratives as follows:

- Shock at the news about the disease because the disease is incurable.
- No one wants to be a burden on their family.
- They all (particularly women) look for support groups to share their emotions and find psychological help – i.e. to receive and give empathy.

When comparing *seniors* with the *young*, the narratives of “living-with-dying” experiences are very different. Younger patients communicate their impotence *vis-à-vis* the situation, their inability to overcome the shock of the mental pain relating to their awareness of facing death. The elderly group, in contrast, are ready to face their destiny. When, on the other hand, we compare *men* vs *women*, the linguistic repertoires conform to some stereotypes surrounding masculinity and femininity in society. Men seem more detached when speaking about their terminal illness: their concern is about providing economic support for their family. Women, in general, refer more frequently to aspects showing the interaction between their illness, themselves and their role in the family or their position as expected in society.

Although there are limits to this investigation, owing to the small number of texts available, we hope it may contribute to a better understanding of the different gradations in which different groups within the elderly narrate their experiences of how they live while dying from a terminal illness, which in turn can help health professionals to develop more effective all-inclusive health policies and practices in end-of-life care.

## Note

1. A lot of studies have been carried out showing how people report their illness (Semino *et al.*, 2018; Demjén and Semino, 2017; Hunt and Carter, 2012; Sarangi, 2004). In these studies, language acquires a preeminent position because it is through language that health-care practice is carried out and illness is mediated (Semino *et al.*, 2018).

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### Further reading

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