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## Narrative medicine: A comparison of terminal cancer patients' stories from a Dutch hospice with those of Anatole Broyard and Christopher Hitchens

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### ABSTRACT



Not all physicians readily discuss death with their terminal patients. To explore whether physicians discuss dying with their terminal patients and to pursue an in-depth understanding of patients' perceptions of death, we interviewed terminal cancer patients in a Dutch hospice and compared their stories to quotes from two autobiographies on dying from cancer, Christopher Hitchens' *Mortality* and Anatole Broyard's *Intoxicated by my illness*. This narrative medicine study could potentially teach physicians they should discuss impending death to prevent the use of an invasive medical treatment that typically extends the quantity, but not the quality, of life.

### Introduction

Terminal patients with a variety of advanced chronic illnesses (i.e., acquired immunodeficiency syndrome (AIDS), metastatic cancer, end-stage renal disease, oxygen-dependent chronic obstructive pulmonary disease (COPD), and heart failure) have shown to prefer honest and straightforward physicians who are willing to talk about end-of-life issues unambiguously during the transition from curative to palliative care (Steinhauser et al., 2000). However, in the majority of cases in a study with 115 terminally ill COPD patients, physicians did not discuss patients' impending death (Curtis, Engelberg, Nielsen, Au, & Patrick, 2004) and this finding was confirmed in another study with COPD patients (Reinke et al., 2011). For patients, physicians' neglect to initiate a conversation on approaching death might hamper a proper transition from curative to palliative care (Huskamp et al., 2009). For physicians, their neglect to initiate such a conversation has shown to reduce their satisfaction about end-of-life care and results in less connection with dying patients (Sullivan et al., 2007). However, physicians' awareness of patients' impending death and willingness to discuss it humanizes medical care

and improves decision making (Houttekier, Witkamp, van Zuylen, van der Rijt, & van der Heide, 2014) concerning the trade-off in the quality of life for therapies that may extend life (Gawande, 2016). Nonetheless, for some physicians, discussing impending death is still a distressing subject of clinical care (Studer, Danuser, & Gomez, 2017).

Creative arts and the humanities have been increasingly implemented within medical education programs labeled medical humanities (MH) which is an interdisciplinary field aiming at the application of humanities (literature, philosophy, ethics) and the arts (literature, theater, film) to healthcare education and practice (Brody, 2011; "The literature, arts and medicine database," 2016). One approach of using the medical humanities within the medical curriculum is via narrative medicine education which aims to teach both medical students and physicians to practice medicine with the competencies to recognize and be moved by the stories of illness (Charon, 2006). This narrative competence consists of three skills: attention, representation, and affiliation. Attention is the physicians' ability to enter imaginatively in another person's narrative world. Representation is the expression

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of the story of a patient through written, spoken, performed, or visual art, while affiliation is the resultant bond between listener and teller, clinician, and patient (Charon, 2006).

Two methods of teaching narrative competence to medical students and physicians are the close reading of illness narratives in novels and medical autobiographies, and creative writing sessions to reflect upon the clinical experience. According to Charon (2006), these teaching methods “may strengthen those cognitive and imaginative abilities that are required for one person to take in and appreciate the representation—and therefore the reality—of another” (p. 113). As such, close reading of illness novels provides a valuable perspective on the medical curriculum (Florijn & Kaptein, 2013) because doing so develops attention, representation, and affiliation (Charon, Hermann, & Devlin, 2016), increases medical students self-reported levels of empathy and satisfaction with the clinical encounter (Kaptein, Hughes, Murray, & Smyth, 2018), and facilitates complex issues such as breaking bad news with patients (Skye, Wagenschutz, Steiger, & Kumagai, 2014). Therefore, exploring illness representations in narratives through close reading may enable medical students, future doctors, and physicians to recognize this same language when it appears in clinical practice interaction. This recognition is established when clinicians, just like readers, start “thinking with stories” (Frank, 2013, pp. 23–24) in clinical care. Thinking *with* stories instead of *about* stories means allowing the narrative to work on us instead of conceiving narratives as an object. Through thinking with stories, medical students and physicians acquire the narrative competence (Arntfield, Slesar, Dickson, & Charon, 2013) that recognizes patients in the context of their lives and encourages them to initiate a discussion on impending death with patients (Stanley & Hurst, 2011).

In this study, our aims were threefold. First, we investigate whether impending death is discussed within the patient-physician relationship during the transition from curative to palliative care. Second, because this is a narrative medicine study which aims to explore the representation of patients’ perceptions of dying, we analyze the metaphors and diction of language which the interviewed patients use. Moreover, we explore how illness narratives can be used as a source of comparison with how hospice patients see their end-of-life experiences to teach medical students and physicians’ attention, representation, and affiliation. Therefore the patients’ stories are compared to a review of the literature on patients’

perceptions of dying in a hospice and two literary autobiographies on dying from cancer written by Anatole Broyard (1992) and Christopher Hitchens (2012). Broyard was an American writer, diagnosed with prostate cancer, who wrote a series of essays entitled *Intoxicated by my illness*. Herein Broyard described that upon illness, the patient should “start treating his illness not as a disaster, an occasion for depression or panic, but as a narrative, a story, which is an antibody against illness and pain” (Broyard, 1992, p. 20). Frank clarifies this statement as follows: “Broyard incites the recognition that his ill body *is* a story, and he wants it to be a good one” (Frank, 2013, p. 50). In Frank’s view, “Broyard talks about the ill person’s need to personify his illness and to “own” it, rather than allow it to be the anonymous disease that medicine depicts” (Frank, 2013, p. 50). We analyzed *Intoxicated by my illness* as a source of comparison with the patient stories to explore and illustrate Broyard’s representation of the patient-physician relationship. Furthermore, we selected Hitchens’ *Mortality* as a source of comparison with the patients’ stories to explore the words, metaphors, and diction of language that can be used in representing the experience of terminal cancer and impending death. Hitchens was a British writer diagnosed with esophageal cancer, after which he wrote *Mortality*, in which he described his terminal illness as “the banality of cancer, an entire pest-house of side-effects” (Hitchens, 2012, p. 92). Because both authors were dying from a malignant type of cancer, their literary accounts may provide the appropriate framework for a comparison with the perceptions of dying from the interviewed patients.

## Methods

### Patient selection

Twelve participants (Table 1) from the admitted patients at hospice Issoria, situated in Leiden, The Netherlands, were selected by the hospice staff (HVDG). Hospice Issoria was founded in 2003 and provides palliative support to 45–60 terminal patients on a yearly basis. All 12 patients had been diagnosed with malignant cancer with metastases that had made curative treatment ineffective. The patients were selected shortly after their admittance in the hospice setting, provided they were in a stable condition (i.e., without unbearable suffering or palliative support). If patients agreed to participate in an interview session and gave informed consent to both HVDG and BWF, the interview sessions were conducted in the patient’s

**Table 1.** Demographics of interviewed patients at the hospice setting.

Sex	Age	Marital status	Diagnosis	Year of diagnosis
Male	71	Widower, living alone	Prostate cancer	2010
Female	88	Widow, living alone	Breast cancer	2014
Male	84	Widower, living alone	Acute leukemia	2014
Female	90	Single, living alone	Breast cancer	2014
Female	86	Widow, living alone	Breast cancer	2013
Male	75	Divorced, living alone	Gastric cancer	2013
Female	73	Widow, living alone	Breast cancer	2014
Female	83	Widow, living alone	Chronic lymphocytic leukemia	2014
Male	67	Single, living alone	Esophageal cancer	2014
Female	81	Widow, living alone	Ovarian cancer	2014
Female	81	Widow, living alone	Colorectal cancer	2014
Male	55	Single, living alone	Glioblastoma multiforme	2014

room. Interviews were carried out by BWF and recorded on audiotape.

### Ethical considerations

The Medical Research Involving Human Subjects Act (WMO) in The Netherlands is applicable when persons in scientific research are subjected to treatment or are required to behave in a particular way. If a study falls under the scope of the WMO because these requirements are applicable, it must undergo a review by an accredited Medical Review Ethics Committee (MREC). However, the interviewed patients were mentally competent citizens who were neither subjected to treatment or an intervention nor were they asked to follow a behavioral strategy as referred to in the WMO. Therefore, the Dutch law (WMO) regulating medical research in humans stipulates that this study is exempt from any requirement regarding approval by regulating bodies. All participants gave informed consent to participate in the interview sessions and to use their statements in research or publications.

### Data collection

Data were collected through in-depth interviews in 2016 in Dutch. The interviews lasted for approximately 45 minutes and were conducted and recorded on audiotape in the rooms in which the patients stayed during their admittance at the hospice. The initial questions aimed at gaining insight into the patients' background. During this initial part of the interview, patients were asked the following questions: Can you tell us the history of your disease? How did you experience your treating physician? Did you have a good relationship with your treating physician over the course of your disease? Subsequently, patients were asked to answer the following questions: How did your physician communicate the transition from curative to palliative care? Did your physician discuss

death in order to prevent the use of invasive medical treatment? How do you define a good death? The recorded interviews were transcribed verbatim.

### Data analysis

The patients' answers to the aforementioned questions were analyzed using an existential-phenomenological method to examine the human experience in concrete situations with a focus on how a phenomenon is lived and experienced (Ashworth, 2003). A thematic analysis of this human experience uses eight different life-world dimensions (i.e., self, discourse (or narrative), spatiality, project, temporality, sociality, embodiment and, mood-as-atmosphere) to emphasize and describe the different aspects of the lived experience (van Wijngaarden, Leget, & Goossensen, 2016).

Analysis of the patient interviews was performed with a focus on the lifeworld dimensions "sociality" and "narrative". "Sociality" refers to the way terminal patients with cancer experience their relationship with others or the surrounding social world. Therefore in this study, we analyzed patients' answers to the first three questions with a focus on how patients evaluate the patient-physician relationship during the transition from curative to palliative care. An analysis of the "narrative" in lifeworld research aims to clarify the words, metaphors, and diction of language that patients use to describe their situation (van Wijngaarden et al., 2016). Patients' answers to all questions were analyzed with a particular emphasis on the words patients employ to describe their experience of terminal cancer and dying.

In their attempt to represent their perceptions of terminal illness and dying in their stories, patients are "declaring themselves witness to this experience" (Frank, 2013, p. 62). Physicians, in turn, have "to take the complementary responsibility for receiving this story" (Frank, 2013, p. 62). Therefore, in an attempt to further investigate and deepen these patient experiences, we selected quotes from *Intoxicated by my*

illness (Broyard, 1992) which were related to the patient-physician relationship and from *Mortality* (Hitchens, 2012) which were related to the terminal situation of cancer patients. We compared those to excerpts from the patients' stories that were similarly related to the patient-physician relationship or patients' particular experience of terminal cancer.

### Review of the literature

To complement the representations of patients' perceptions of dying within hospice settings, we also conducted a review of the literature by searching MEDLINE, EMBASE, and PubMed using "patient perceptions/experiences", "hospice", "qualitative research" and, "attitude to death" as search terms (literature search details can be obtained from the authors). Relevant articles (Table 2) were selected out of 573 hits and their references were searched for additional relevant articles. The patients' perceptions obtained from these articles were analyzed with a focus on the lifeworld dimension "narrative" to investigate the words and metaphors patients employ to describe their perceptions of dying.

## Results

### Broyard's representation of a patient-physician relationship

Broyard prefers an honest physician who gives the patient an appropriate amount of recognition and attention:

To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life. (...) I see no reason or need for my doctor to love me—nor would I expect him to suffer with me. I just wish that he would brood on my situation for perhaps five minutes, that he would give me his whole mind just once, be bonded with me for a brief space. (...) Just as he orders blood tests and bone scans of my body, I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness. (Broyard, 1992, p. 43–45)

By giving "his whole mind just once" (Broyard, 1992, p. 43–45), a physician, according to Broyard, can grope for the patients' spirit. Interestingly, this way of paying attention to the patient is preferred by cancer patients in general, who have similarly shown to value such recognition and also prefer that it is part of their whole clinical encounter with oncologists (Back et al., 2011).

During palliative care, Broyard prefers a physician who pays close attention to the patient and who

provides honest disclosures of prognosis. This becomes clear when Broyard describes his request for a personal prognosis from his physician on his condition:

The catheter hurt, and the diagnosis of my case ambiguous. When I asked the oncologist the usual question—How much time have I got?—he hesitated before answering. "I would say," he said, "that you have in the neighborhood of years". (Broyard, 1992, p. 11–12).

Because *Intoxicated by my illness* was written during the last 14 months of Broyard's life, Broyard did not have a good prognosis. However, still he hears his physician saying optimistically that he has a life prognosis of living "in the neighborhood of years."

What Broyard wants as an alternative for groundless optimism and more medical treatment, which extends quantity rather than quality of life, is shown when he writes about how way doctors should communicate with a dying patient:

Of course a physician may reasonably ask: "But what am I supposed to say? All I can tell the patient is the facts, if there are any facts." But this is not quite true. The doctor's answer to his patient is yet to be born. It will come naturally, or at first unnaturally, from the intersecting of the patient's needs with the doctor's experience and his as-yet-untried imagination. He doesn't have to lie to the sick man or give him false assurances: He himself, his presence, and his will to reach the patient are the assurance the sick man needs. Just as a mother ushers her child into the world, so the doctor must usher the patient out of the world of the healthy and into whatever physical and mental purgatory awaits him. The doctor is the patient's only familiar in a foreign country. (Broyard, 1992, p. 54–55)

It could be argued that Broyard advocates for less interventions for terminal cancer patients when he describes the hope that after the transition from curative to palliative care due to malignant cancer, his physician allows him a peaceful exit from illness and life:

There comes a point where it's pretty obvious that a patient is going to die, and I think to eke out a few more days by mechanical means is a mistake, and I think that the patient should be allowed to glide or skate or dance into death in the way that he chooses rather than be ministered to until the last minute, which I think is obscene. You know when a patient is moribund, and then you leave him alone. You let him die in his own way, and you let him make his final arrangements unimpeded by technology. (Broyard, 1992, p. 64)

Broyard advocates for a physician who is willing to allow the terminal patient a peaceful exit. Ideally, in



**Table 2.** Previous studies on the narrative that constitutes terminal cancer patients' perceptions of dying.

Reference	Purpose	Study type	Sample size	Representation of terminal cancer and dying
Noh (2014)	Explore values important to older African-American hospice patients when receiving hospice care.	Face-to-face interviews with open-ended questions.	n = 28 African-American hospice patients	<p>Respondents have a preference for:</p> <ul style="list-style-type: none"> <li>dying at home</li> <li>independent decision-making</li> <li>autonomy in daily life</li> <li>unwillingness to be a burden</li> <li>open communication and supportive caring</li> <li>dependable relationships</li> </ul> <p>Respondents have a stronger wish to hasten death when they:</p> <ul style="list-style-type: none"> <li>experience physical symptoms and psychological suffering</li> <li>have the perception of being a burden to others</li> <li>experience fewer social support</li> <li>experience less satisfaction with life experiences</li> <li>have less religious belief</li> </ul> <p>Respondents prefer dying with:</p> <ul style="list-style-type: none"> <li>no experience of symptom distress</li> <li>negative correlation between pain level and QOL</li> <li>no correlation between closeness to death and QOL</li> </ul> <p>Respondents liked to exercise more control</p> <ul style="list-style-type: none"> <li>over their ability to be independent</li> <li>over incontinence, sexual performance, muscle and leg movement, appetite, physical strength and memory, physical function</li> <li>after their death on behalf of the next generation</li> </ul>
Kelly et al. (2002)	Investigate determinants of wish to hasten death	Semi-structured interviews	n = 72 hospice and home palliative patients	
Steele, Mills, Hardin, and Hussey (2005)	Describe QOL of terminally ill patients in a hospice program	Descriptive study.	n = 129 terminally ill patients	
Schroepfer, Noh, and Kavanaugh (2009)	Investigate the aspects of dying over which study participants seek to exercise control, the strategies used, and whether they desire to exercise more control.	In-depth face-to-face interviews	n = 84 terminally ill elders receiving hospice care of whom 43 experienced lack of control	
Volker and Wu (2011)	Explore the meaning of control and control preferences in a group of persons with advanced cancer diagnosis	Interviews using a hermeneutic, phenomenological approach	n = 20 patients with advanced cancer	<p>Respondents like to have more:</p> <ul style="list-style-type: none"> <li>control over treatment decisions/family issues/final days of life/arrangement after death</li> <li>awareness that cancer and death are controlled by a higher power</li> </ul> <p>Respondents experience dying in a hospice setting with:</p> <ul style="list-style-type: none"> <li>loss of self and identity nostalgia</li> <li>surprising positivity, but also frustration</li> <li>a wish for control</li> </ul>
Broom and Cavenagh (2011)	Explore the experience of living and dying in a hospice	In depth interviews	n = 20 patients receiving hospice care	<p>Respondents lived experience of dying in hospice setting is characterized by:</p> <ul style="list-style-type: none"> <li>"drifting" (loss of sense of being home)</li> <li>"sheltering" (center of meaning helping to reorient with chaotic space of illness)</li> <li>"venturing" (care is experienced as opportunity to reengage with life in a more meaningful and positive way)</li> </ul>
Moore, Carter, Hunt, and Sheikh (2013)	To explore the experience of the hospice as a place and how this changes over time	Photo-elicitation interviews	n = 11 day care patients attending a specialist hospice setting	<p>Respondents have existential concerns about:</p> <ul style="list-style-type: none"> <li>death which is always present at the hospice</li> <li>grief over what participants left when they were gone</li> <li>the wish not to think or talk about their imminent death.</li> <li>afterlife: most imagined something transcendent/something good.</li> <li>positive aspects of daily life like being together with family</li> </ul>
Moestrup and Hansen (2015)	To illuminate dying patients' existential concerns about impending death	Semi-structured interviews	n = 17 hospice patients	

QOL: quality of life; HADS: hospital anxiety and depression scale.

palliative care, a physician should let the patient leave life “in his own way” (Broyard, 1992, p. 64), without redundant invasive medical treatment that extends the quantity but not the quality of life.

### Terminal cancer patients’ stories of their patient-physician relationship

Some patients we interviewed often do not experience a physician who, like Broyard has stated, is willing to “be bonded” with their patient during the transition from curative to palliative care. Therefore it could be argued that some physicians do not apply narrative competence skills towards their patients in such a way as to “become more attentive to patients, more attuned to patients’ experiences, more reflective in their own practice, and more accurate in interpreting the stories patients tell of illness (Charon, 2006, p. 107). This was particularly evident for one patient for whom another round of chemotherapy (initially meant to be curative) was terminated because the primary tumor had metastasized. This decision to quit chemotherapy because the patient could not be cured was communicated by the treating physician in a concise telephone conversation:

After I didn’t hear from him for weeks, my treating physician phoned me briefly and stated that the test results showed that metastases were pressing on vital brain areas making further treatment inappropriate. Medical care is like a chain which is only as strong as its weakest link. This doctor, in my opinion, was this weakest link because he seemed to avoid contact with me.

This shows that a discussion and diagnosis of impending death is often delayed. It could be argued that this is related to a culture that does not acknowledge death as a possible disease outcome until death is imminent (Reid et al., 2015). Moreover, when impending death is discussed in personal by the treating physician, the delivery style of physicians in communicating bad news is sometimes brief and with the use of medical jargon, as one patient said:

We talked about dying briefly during the final consult I had with my internist, who was very concise. But this conversation was mainly about how medication is able to sedate consciousness and how you slowly feel drowsy and relaxed by it.

For another patient, who had already been referred to a palliative care service, still a treating physician primarily persisted in treating the patient with curative intentions. This was experienced by the patient as follows: “After the disease metastasized, my physician

and I didn’t discuss my perspective of death at all. Instead, we only discussed how to further treat this disease.” This situation is what Broyard wants to avoid when he emphasizes that “to eke out a few more days by mechanical means is a mistake” (Broyard, 1992, p. 64). At the same time, it also shows the complexity of communicating palliative care for physicians, who as was shown in a recent study, sometimes use the term “palliative care” as a euphemism for death while death itself is expressed ambiguous or in technical terms (Collins, McLachlan, & Philip, 2018). Furthermore, patients’ emphasis on the duration of the conversation in which physicians deliver bad news is in accordance with a study in which it was demonstrated that terminal patients predominantly recall the pace and clarity with which bad news is conveyed (Hanratty et al., 2012).

When some physicians seem to overlook the possibility of a proper transition from curative to palliative care because of poor communication strategies, this proper transition can instead be asked for or initiated by the patients themselves through, for instance, the refusal of another round of chemotherapy. This is shown by several interviewed patients who decided on their own to give up an ineffective treatment. Interestingly, one patient described that treatment refusal was an independent decision without physician’s support at all:

“At the start of my treatment, my physician didn’t discuss the consequences of chemotherapy with me. But after my third chemotherapy, I felt so miserable that I realized that this chemotherapy wasn’t effective. Therefore, I quit on my own initiative.”

Sometimes, patients refuse chemotherapy because they are of advanced age:

I didn’t want treatment from the beginning. I am quite old and tired of being alone, which I am, since my husband died seven years ago. I accept death as inevitable and this I told my physician at that particular moment of my decision. We didn’t discuss dying at all.

Rejecting chemotherapy can also be decided because the patient feels that dying is inevitable due to poor prognosis:

I got radiation therapy to treat this oesophageal cancer. However, the cancer metastasized to my liver. I didn’t want to start the chemotherapy because feeling badly the remaining months of my life is not how I want to experience death.

Maintaining quality of life can also be a reason why patients refuse treatment at all:

After my diagnosis I was afraid of what chemotherapy might bring me. Generally, I am very steadfast against the self-evident way that medical doctors speak about chemotherapy. Therefore, I reluctantly decided that I didn't want to start chemotherapy because the cancer already spread to my bones.

This particular statement is in accordance with studies which have shown that the reasons for refusing chemotherapy in cancer care are often related to individual factors such as being of older age, prognosis, cancer stage or preexisting catastrophic illnesses (Liu et al., 2014; Suh et al., 2017).

### Comparison of Broyard's and terminal cancer patients' representations of the patient-physician relationship

Taken together, the aforementioned quotes of Broyard in *Intoxicated by my illness* illustrate his ideal physician who as the "patient's only familiar in a foreign country" (Broyard, 1992, p. 55) should be the patient's companion during palliative care. In their words and metaphors, the interviewed patients, however, have experienced physicians who are "self-evident about chemotherapy" or who communicate briefly and concise when discussing treatment options. Instead of being the "weakest link" because, according to one particular patient, a physician "seemed to avoid contact" physicians should, according to Broyard, give "his whole mind just once" (Broyard, 1992, p. 43–45) because the physician's presence and "his will to reach the patient is the assurance the sick man needs" (Broyard, 1992, p. 54–55).

### Hitchens' representation of terminal cancer and impending death

Compared to Broyard, Hitchens does not want an obliging physician to be bonded with him for a brief space or be willing to brood on his situation. Instead of this relational type of ethic, which takes place in the reciprocal narrative engagement of the patient-physician relationship, Hitchens sees no other option than facing his terminal illness by himself because he knows that denying the situation means denying he is alive:

I have been "in denial" for some time, knowingly burning the candle at both ends and finding that it often gives a lovely light. But for precisely that reason, I can't see myself smiting my brow with shock or hear myself whining about how it's all so unfair: I have been taunting the Reaper into taking a free scythe in my direction and have now succumbed

to something so predictable and banal that it bores even me. Rage would be beside the point for the same reason. Instead, I am badly oppressed by a gnawing sense of waste. (Hitchens, 2012, p. 5)

Although cancer patients who display a certain level of denial experience positive effects on social and emotional outcomes (Vos, Putter, van Houwelingen, & de Haes, 2011), it could be argued that Hitchens above statement that he has "succumbed to something so predictable and banal that it bores" (Hitchens, 2012, p. 5) could lead to a patient who is willing to do anything to get cured. Frank calls this narrative that reflects "a natural desire to get well and stay well" (Frank, 2013, p. 78), the restitution narrative. Frank has argued that nowadays "medicine's hope of restitution crowds out any other stories" (Frank, 2013, p. 83) This is the "culturally preferred narrative" in which nothing is at stake but only the modernist project of "deconstructing mortality" (Frank, 2013, p. 83). To Frank mortality and its mystery have to be faced, which requires a "story outside the restitution narrative" (Frank, 2013, p. 83).

Eventually, however, it could be argued that Hitchens abandons the restitution narrative when he advocates that "battling" cancer illness as in fighting a war is a cliché that does not apply to himself:

Myself, I love the imagery of struggle. I sometimes wish I were suffering in a good cause, or risking my life for the good of others, instead of just being a gravely endangered patient. Allow me to inform you, though, that when you sit in a room with a set of other finalists, and kindly people bring a huge transparent bag of poison and plug it into your arm, and you either read or don't read a book while the venom sack gradually empties itself into your system, the image of the ardent soldier or revolutionary is the very last one that will occur to you. You feel swamped with passivity and impotence: dissolving in powerlessness like a sugar lump in water. (Hitchens, 2012, p. 7)

Nonetheless, Hitchens pointed out that even though a terminal illness may severely limit his physical condition, he wants to maintain a conscious mind when dying is near:

... when faced with extinction I want to be fully conscious and awake, in order to "do" death in the active and not the passive sense. And I do, still, try to nurture that little flame of curiosity and defiance: willing to play out the string to the end and wishing to be spared nothing that properly belongs to a lifespan. (Hitchens, 2012, p. 58)

Even though Hitchens wishes to be spared nothing that belongs to a lifespan, this does not make him long for immortality:



With infinite life comes an infinite list of relatives. Grandparents never die, nor do great-grandparents, great-aunts... and so on, back through the generations, all alive and offering advice. Sons never escape from the shadows of their fathers. Nor do daughters of their mothers. No one ever comes into his own... Such is the cost of immortality. No person is whole. No person is free. (Hitchens, 2012, p. 93)

### Terminal cancer patients' representation of impending death

The interviewed patients show a rather diverse landscape of words that constitute their perception of dying. One patient used previous experiences with dying loved ones and relatives to portray one's own death:

"I have experienced my father's and mother's death, who died from old age, so I think I know what dying is. However, I prefer the way my husband died, who died from a myocardial infarction. He went to bed at night and I found him dead the next morning."

When the way of dying of a deceased loved one has not been a positive experience, this can be reflected in the way patients prefer their own death:

My husband died seven years ago from cancer metastases. He suffered so much that in the end he kept calling for death and said: "dying does take a lot of time". I myself have no idea how long it will take. I don't fear dying but only if it's a slowly leaving into death.

Another patient used the experience of witnessing the death of her parents to envision her own death: "When my parents died, it was like they slowly fell asleep, which is exactly the way I'd like to die. But, currently I feel no pain, so I'm trying to push thoughts about dying as far away as possible." Interestingly, in representing one's own death by referring to past experiences of the death of others is common in palliative care, as was demonstrated by a recent study (Kastbom, Milberg, & Karlsson, 2017).

A shared wish among the patients who we have interviewed is that they do agree with Broyard for a way of dying that is: "a glide, skate or dance into death" instead of "being ministered to until the last minute" (Broyard, 1992, p. 64). To enable this way of leaving, patients hope their dying is without too much pain. One described:

I know that I do need peace in order to experience a good death but a few nights ago, I experienced heavy breathing difficulties due to this fluid which was

trapped inside my lungs. This really scared me to death because all of a sudden it felt like I was drowning.

The absence of suffering is sometimes also seen as the preferred condition that has to be fulfilled to enable a peaceful way of dying: "I am not afraid of dying, but I do hope it's without too much pain because only then I can make peace with dying and with the fact that I won't be able to enjoy my retirement from work." Another patient said that if she would be suffering from an unbearable pain, she would prefer complete sedation of consciousness: "I prefer not to suffer from too much pain and have therefore asked if I will be allowed to have complete sedation making dying like falling asleep."

Even though approaching death can be experienced as an uncertain perspective, the fact that sufficient palliative care was affirmed for one patient set the mind at rest:

I have no certainties in life right now, but nobody has that. My GP doesn't want to perform euthanasia, and therefore they can only comfort me with palliative sedation in the end to relieve any form of distress. Still, I do hope and expect that this way of dying will be silent and without pain at all.

Being without pain becomes the pleasant and preferred way of leaving life, even though dying will always remain a first experience:

I have no idea what death is because it will be a first experience which is why I cannot have any expectations. However, when speculating about dying, I hope it will be without pain, and with a cumulative narrowing of consciousness until only nothingness is left.

### Comparison of Hitchens' and terminal cancer patients' representations of terminal cancer and dying

Compared to Hitchens who wants "to be fully conscious and awake, in order to "do" death in the active and not the passive sense" these patients prefer not to be conscious when they talk about dying from terminal cancer. For patients, dying should be like a "complete sedation making dying like falling asleep" or a "cumulative narrowing of consciousness until nothingness is left" while another patient advocate a death at night, like "the way my husband died, who died from a myocardial infarction." Moreover, while Hitchens prefers absolute patient autonomy in palliative care in order to "nurture that little flame of curiosity and defiance" these patients hope that a good

dead is “silent and without pain at all”, and that it can only be with comfort “with palliative sedation in the end to relieve any form of distress.”

Ideally, for cancer patients, a good death is made possible when palliative sedation is initiated before suffering becomes unbearable (Eun, Hong, Bruera, & Kang, 2017) because this could result in the loss of meaning, the loss of autonomy or the experience of being a burden (Ruijs, Kerkhof, van der Wal, & Onwuteaka-Philipsen, 2013). The interviewed patients in this study confirm that a good death is without such accompanying symptoms. In their view their palliative care should allow them such a good death which is without pain, with sedation and, without accompanying symptoms. This emphasizes the need for a good patient-physician relationship during palliative care because, according to Broyard (1992), “The doctor is the patient’s only familiar in a foreign country” (Broyard, 1992, p. 55). Because palliative care is “a foreign country” to patients, studies have shown that they prefer such a personal patient-physician relationship based on narrative competence in which the physician is speaking the patient’s language, displays honesty and, the ability to listen (Masel et al., 2016). Collectively, it could be argued that the interviewed patients predominantly use words which express their preference for a good death which is without accompanying symptoms such as unbearable pain and loss of autonomy.

## Discussion

The patients’ stories demonstrate that their transition from curative to palliative care is shaped by a brief conversation in which physicians inform the patient about the decision to restrain from additional, but ineffective, chemotherapy. Occasionally, it was the patient’s, and not physician’s, initiative to quit chemotherapy. On the whole, however, the patients tended to describe experiencing a detached physician who seemed to overlook the benefits of an in-depth way of communicating the possibilities of end-of-life care for patients during the transition from curative to palliative care.

To improve the experience of dying patients, making the transition from curative to palliative care, a recent systematic review showed that palliative care should be incorporated early in the disease trajectory by emphasizing palliative input and quality of life considerations, while also recognizing that treatment goals evolve (Gardiner, Ingleton, Gott, & Ryan, 2015). This type of care is in accordance with what Broyard

(1992) prefers from his physician, who “ushers the patient out of the world of the healthy into whatever physical and mental purgatory awaits him” (Broyard, 1992, p. 55). “Bonding and recognition”, may comfort a patient like Broyard, before the moment of “gliding into death” is forthcoming (Broyard, 1992, p. 44–45).

It could be argued that in the aforementioned statements, Broyard refers to the goals of “narrative knowledge” (Charon, 2006, p. 9), particularly when he refers to “the intersecting of the patient’s need with the doctor’s experience and his as-yet-untried imagination” (Broyard, 1992, p. 54). Physicians could develop such knowledge through reading of or listening to patient narratives which are meant to “take in and appreciate the representation—and therefore the reality—of another” (Charon, 2006, p. 113). Regardless of “whether that representation is in visual art, a fictional text, or the spoken words of a patient in the office, the one who absorbs and confirms the representation must have the capacities to witness and give meaning to the situation as depicted” (Charon, 2006, p. 113). In this way, narrative knowledge “enables a person understand the plight of another by participating in his or her story with complex skills of imagination, interpretation, and recognition” (Charon, 2006, p. 9), which allows the physician to establish therapeutic alliances with patients and therefore more effective clinical care (Charon, 2001). This could potentially benefit physicians in clinical care because a recent study among 131 included hospitalized cancer patients has demonstrated that in the last 24 hr of life, 24% of the patients still receive diagnostic interventions, while the awareness of a patients’ impending death is significantly associated with a lower use of diagnostic interventions. (Geijteman et al., 2018) However, instead of interventions, Broyard prefers honesty in physicians’ disclosure of prognosis which is in accordance with a systematic review that showed that although patients have a bad prognosis, they prefer honesty from treating physicians and also a broad indication of their prognosis (Innes & Payne, 2009).

Narrative medicine seminars that teach medical students attention, representation, and affiliation have shown to increase students’ professional development (Miller, Balmer, Hermann, Graham, & Charon, 2014). Interestingly for physicians who receive such seminars, a recent study demonstrated that Word Cloud formation (which requires a list of words that captures the essence of each patient) as a narrative orientation to end of life care in an intensive care unit, could shift physicians’ perspective of care from detachment to engagement (Vanstone et al., 2016). This shows that

more attention, representation (i.e., the act of representing the lived experience of the patient), and affiliation to the patient encourages initiating conversations about illness and death (Charon, 2017). In this study, however, the interviewed patients have experienced physician's communication of the ending of an ineffective chemotherapy often in a medical way (i.e., because of a disease metastasis). Alternatively, there is no communicating of treatment ending at all. These particular experiences confirm previous data which have demonstrated that the transition of advanced cancer patients towards end of life in palliative care is a confusing time of mixed messages, poor communication and uncertainty (Larkin, Dierckx de Casterle, & Schotsmans, 2007). Although it could be argued that patients have a responsibility to participate in decision making during the transition from curative to palliative care (Tinetti & Basch, 2013), poor communication negatively affects the patient-physicians' relationship and disturbs the dying patients' ability to cope with impending death (Friedrichsen, Strang, & Carlsson, 2000).

The narrative that represents patients' coping strategy with death shows that interviewed patients use previous experiences with dying relatives and loved-ones to model their conception of death. Moreover, symptom control, being pain-free and, not being a burden to others are factors that are commonly wished for. This is confirmed in our review of the literature and other previous research that demonstrated that "the positivity" of the dying experience depends on pain and symptom management, family presence and good communication among the patient, family, and healthcare team (Granda-Cameron & Houldin, 2012).

This narrative medicine approach comparing patient stories with medical autobiographies has several limitations. Our patients differ in background and the way decisions are made over the course of their disease and their treatment history. Nonetheless, their stay within the hospice setting generates a commonly shared background within the palliative care of these patients. Furthermore, this study was conducted within the Netherlands in which legal guidelines allowed some interviewed patients a granted euthanasia request, which could have influenced their perception of dying from cancer. Despite these minor differences in palliative care preferences, patients' reflections on their physicians suggest that a narrative medicine study (with its emphasis on the dying experience in patient stories and medical autobiographies) might benefit physicians in palliative care.

Therefore, an implication of this study could be that through reading and absorbing these stories of terminal cancer and dying, future doctors and physicians involved in palliative care adopt more awareness of the importance of listening to the patient's story because it reflects how patients evaluate end-of-life treatment decisions in palliative care. As such, this study aims to stimulate enhanced communication and empathy skills when discussing death with terminal cancer patients. This narrative competence could benefit physicians because several studies have demonstrated that narrative medicine education has a positive impact on empathy and communication skills although it is worth noting that there is insufficient large-scale data to establish a higher clinical value (Barber & Moreno-Leguizamon, 2017). Therefore, future studies assessing the clinical contribution of this particular narrative medicine study for physicians should investigate whether this exercise improved physicians' awareness and communication skills to initiate a conversation on impending death and quality of life, as an alternative to treatment, with their terminal patients.

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