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Creating Discursive Order at the End of Life: The Role of Genres in Palliative Care Settings

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Abstract

This article investigates an emerging practice in palliative care: dignity therapy. Dignity therapy is a psychotherapeutic intervention that its proponents assert has clinically significant positive impacts on dying patients. Dignity therapy consists of a physician asking a patient a set of questions about his or her life and returning to the patient with a transcript of the interview. After describing the origins of dignity therapy, the authors use a rhetorical genre studies framework to explore what the dignity interview is doing, how it shapes patients' responses, and how patients improvise within the dignity interview's genre ecology. Based on a discourse analysis of the interview protocol and 12 dignity interview transcripts (legacy documents) gathered in two palliative care settings in Canadian hospitals, the findings suggest that these patients appear to be using the material and genre resources (especially eulogistic strategies) associated with dignity therapy to create discursive order out of

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their life events. This process of genre negotiation may help to explain the positive psychotherapeutic results of dignity therapy.

Keywords

dignity, death and dying, genre, eulogy, palliative care

> [My family is going to] miss me and I know they will. I know my children and [my husband], particularly but life goes on. . . . You have the funeral; it's all cleaned up; people walk away and life goes on. That's how I see it. They have to go home. They have to deal with things. . . . Get on with life and just embrace whatever I've left in memory. (P2)

This poignant observation comes from a legacy document produced by a dying patient as a result of a therapeutic intervention called *dignity therapy*. Dignity therapy, an intervention developed by Chochinov and colleagues (2005), consists of a physician using an established protocol (see appendix) to ask a dying patient about events in his or her life and their meaning. The physician transcribes and edits the interview and returns to read the interview back to the patient. Any changes or deletions that the patient wishes are included in the final document. The final version, or legacy document, is provided to patients. Our research team was provided with a rare and privileged opportunity to investigate a set of these documents, an investigation that we hope provides insights into the role of writing and genres as related to terminal patients.

Advocates of palliative care, Chochinov and his group (Chochinov, 2002; Chochinov et al., 2002; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002) developed their dignity interview protocol from a series of quantitative and qualitative studies investigating the experiences of dying patients and their sense of dignity. Three categories of patient concerns emerged: illness-related concerns involving level of independence and symptom distress; dignity-related concerns involving continuity, legacy, and pride; and social concerns involving privacy, burden to others, and aftermath issues. Chochinov et al. (2005) used emergent themes from these studies to inform their psychotherapeutic interview protocol. They then tested their protocol and reported that after dignity therapy, 76% of patients reported a heightened sense of dignity, 68% reported increased purpose, and 47% reported an increased will to live. Postintervention measures of suffering showed significant improvement and reduced depressive symptoms. These impacts assisted in preserving a patient's sense of dignity and led to better opportunities for a "good death" (Chochinov, 2006). Quoting Weisman (1972), Chochinov (2006) suggests that the following characterizes an appropriate or good death:

> Internal conflicts, such as fears about loss of control, should be reduced as much as possible; the individual's personal sense of identity should be sustained; critical relationships should be enhanced or at least maintained . . . ; and the person should be encouraged to set and attempt to reach meaningful albeit limited goals such as attending a graduation . . . as a way to provide a sense of continuity into the future. (p. 85)

Our interdisciplinary research group (consisting of two rhetoricians, a linguist, and a psychiatrist specializing in palliative care) accepted that the communication intervention of the dignity interview is having a positive effect on dying patients. But we asked, how and why does the dignity interview achieve this impact? To date, most of the research has been on the clinical impacts of the dignity interview and not on how or why they could be affecting patients. In a previous study (Tait, Schryer, McDougall, Lingard, 2011), we identified some of the narrative strategies that seemed to be assisting patients. In this article, we build from that study and focus on the genre of the interview protocol itself and how it could be functioning within the palliative care context.

We first provide an overview of the place of dignity therapy in the wider social context of research in palliative care. From this perspective, dignity therapy occupies and important position with respect to the larger social issues around the actual meaning of dignity. The dignity interview is, in fact, a response to these larger social issues involving strongly held beliefs about euthanasia. Using concepts from rhetorical genre studies (RGS) and from linguistics, we then investigate the strategies associated with the interview protocol as a genre and the role that it plays in generating another genre: the patient's legacy document. In our view, the immediate context of the dignity interview protocol and the nature of its questions could be assisting dying patients in constructing discursive order out of the events of their lives.

The Larger Social Context of "Dignity" and Palliative Care

As Fairclough (1992) suggests, a "social-theoretical" account should provide explorations of the "social practice" dimension or the larger social issues which help shape the expression of more local institutional issues

(p. 4). The term *dignity* is currently widely debated and discussed in areas, such as human rights legislation (Gerwith, 1992), law (Hogg, 1997), social justice (Meeks, 1984), and more recently, bioethics (Beyleveld & Brownsword, 2001). According to Jacobson (2007), the 1948 United Nations Universal Declaration of Human Rights garnered attention to the concept of dignity and that its inclusion as a foundational concept was an "explicit response to the atrocities committed by the Nazi state" (p. 295). The declaration aligns dignity and human rights and suggests that dignity is an essential human attribute.

Jacobson (2007) points out that the concept of dignity has in fact enjoyed a long history of debate in Western thought with two distinct meanings functioning as the fulcrum of the discussion: dignity as an inherently human characteristic and dignity as a social construct. Early Christian theologians believed, for instance, that all human beings, because they are made in the image of God, have dignity as an inherent ontological characteristic. Later Renaissance thinkers such as Pico della Miraandola still viewed dignity as the distinguishing feature of humanity but located it in the ability of human beings "to exercise will and choice" (p. 293). Immanuel Kant, too, viewed dignity as a quality belonging to all sentient human beings because of "their capacity for rationality and moral freedom" (p. 293). From this perspective then, human beings have the right to be treated with respect simply because they are human. Western thought, however, has also viewed dignity as a social construct. In the classical period, for instance, the term *dignitas* referred to an individual's status and was a measure of a person's (always a man's) reputation. As Lebech (2004) notes, for classical writers such as Cicero, dignity was "what merits respect" (p. 60) as a result usually of virtue and attainting public recognition through a political position. In other words, *dignity* was a contextual and relevant term bestowed upon a person, a form of social recognition.

The debate surrounding the term *dignity* particularly resonates in areas of biomedical ethics and especially in palliative care literatures. Advocates for legalized assisted suicide, for example, have adopted the term *death with dignity* as signaled by the Oregon Death With Dignity Act, which was passed by ballot measure in 1994 and enacted in 1997 (Ganzini et al., 2001). Indeed, the term *death with dignity* has proved a rallying cry for advocates of euthanasia and assisted suicide and for those opposed to such practices. In the United States, advocates for both sides have invoked arguments related to dignity in cases involving patients in permanently unconscious conditions. The Terri Schiavo case in particular demonstrates directly polarized definitions. In 1990, Terri suffered a devastating brain injury that left her in persistent vegetative state. For the next several years, various rehabilitation efforts were pursued but to no avail. In 1998, Michael Schiavo requested that her feeding tubes be removed and that she be allowed to die. Her parents, however, disagreed and fought this decision at every level of the legal system until 2005, when she was allowed to die. Right-to-life supporters who rallied to her parents' side used arguments such as the following from an earlier legal decision (*Brophy v. New England Sinai Hospital*, 1987) involving an unconscious patient:

> By its very nature, every human life, without reference to its condition, has a value that no one rightfully can deny or measure. Recognition of that truth is the cornerstone on which American law is built. . . . [Any] declaration that not every human life has sufficient value to be worthy of the State's protection denies the dignity of all human life and undermines the very principle on which American law is constructed. (quoted in Cantor, 2005, p. 3)

This position is very much in accordance with the early Christian conception of dignity as an inherently human characteristic. Those supporting Michael's decision also used the concept of dignity to argue that Terri's existence was undignified because she lacked any quality of life. They argued that if she were conscious, she would choose to stop receiving treatment, the right of most dying patients in the United States. In fact, much research (Sehgal et al., 1992; Singer et al., 1995; Tomlinison, Howe, Notman, & Rossmiller, 1990) indicates that people care deeply about issues related to helplessness and dependency in the dying process. Cantor (1995) observes that "people care mightily about the memories and image to be left behind with their loved ones" (p. 13). For these advocates, diminished dignity and quality of life in a previously competent person ought to be the basis for intervention in the dying process.

These same arguments reverberate in other jurisdictions. For instance, Pullman (1996) reports on the Canadian Supreme Court case of Sue Rodriguez, a patient in the advanced stages of amyotrophic lateral sclerosis, who was requesting the right to assisted suicide. In denying her appeal, Canadian Supreme Court Justice Sopinka used dignity as the basis of his argument when he asked rhetorically,

> As members of a society based upon respect for the intrinsic value of human life and on the inherent dignity of every human being, can we incorporate within the Constitution which embodies our most fundamental values a right to terminate one's own life in any circumstances? (p. 197)

At the same time, another judge, Madame Justice McLachlin, presented a dissenting opinion that also used dignity as the basis of her argument:

> Security of the person has an element of personal autonomy, protecting the dignity and privacy of individuals with respect to decisions concerning their own body. It is part of the persona and dignity of the human being that he or she have the autonomy to decide what is best for his or her body. (p. 197)

Indeed, the terms of the debate have reverberated in jurisdictions across Europe and North America (Jacobson, 2007). One response has been to note the "culture-bound" (Billings, 2008, p. 138) limitations of the term. Another response has been to deny the concept any validity at all. Thus, in her editorial in the *British Medical Journal*, Macklin (2003) calls dignity a "useless concept" because it is either vague or being used as a "useless slogan" (p. 1419).

This larger social context provides the background for Chochinov's research and helps to explain his position regarding the concept of dignity. Like other participants in the palliative care movement, Chochinov insists on a multifaceted, holistic approach to the dying person. This approach wishes to account for not only the physical but the emotional and even spiritual aspects of dying. At the same time, Chochinov and many other palliative care providers resist the practices associated with euthanasia and assisted suicide. For Chochinov et al. (2004) and others, a "loss of dignity" and the resulting depression is one of the main reasons that patients request assistance in dying (p. 134). For this reason, he initiated his research program into investigating what dignity actually meant for dying patients. The model that emerged from his studies emphasized themes such as "continuity of self, maintaining pride and hope, role preservation, burden to others, and aftermath concerns" (p. 140). His group used these themes as the basis of their "dignity conserving" (p. 138) approach of which the dignity protocol is an important practice. As Chochinov et al. make clear, the dignity interview reflects other psychotherapeutic therapeutic traditions, such as logotherapy and life narratives, with their emphasis on meaning. However, the dignity interview is distinct in that it is designed to be a brief intervention—and thus more suitable for dying patients—and is based on patient insights. Its focus is to provide patients with an opportunity to review their lives, reflect on what matters most, and articulate how they want to be remembered.

Rhetorical Genre Studies

Research from a rhetorical perspective provides a general background into the meaning of "dignity" and into discourse practices around death and dying. Hyde (2001) examines the rhetorical function of dignity definitions among bioethicists. He points out that differing concepts of dignity occupy the center of euthanasia debates. Those opposing legalized assisted suicides, such as the bioethicist Leon Kass, see dignity as the human capacity to face death heroically. Hyde suggests that this definition "lacks a narrative structure" and that "a person's life from beginning to the middle to the end, is a story in the making" (p. 75). From this perspective, those supporting euthanasia define dignity as the ability to control the final act of one's life. Segal (2000) notes that there is currently "a disjunction between a growing *public discourse* of death as human experience and a *biomedical discourse* of death as medical failure" (p. 29). Segal argues that we need ways to speak about dying that are not so constrained by medical values. She reflects Mishler's (1984) insight that incompatible perspectives—the voice of biomedicine and the voice of the lifeworld—often characterize physician-patient conversations. As Hunter (1991) notes, narrative constitutes much of the knowledge making within medicine. Segal adds to this insight with her observation that biomedical accounts of dying are distinguished by warlike narratives wherein medical practitioners battle disease on behalf of patients, whereas patient accounts more often reflect concerns with acceptance and personal coherence.

More specific research from a rhetorical perspective has examined text types or genres associated with death and dying. Barton (2004) investigates the genre of prognosis and notes that medical practitioners can use this usually oral genre to, in fact, avoid providing difficult information, probably because a negative prognosis is not in accord with the biomedical narrative of successfully defeating disease. Barton (2007) observes as well that the "clinical and ethical standards of medicine which preserve the determination of medical futility" as the basis of professional judgment while limiting the scope of patient wishes remain the basis of end-of life discussions. Other researchers (Keränen, 2007; McDorman, 2005) have also observed that the biomedical model creates difficulties with regard to patient agency in end-of-life situations.

Reflecting our interest in what the dignity interview does through language, we position our work within a subset of rhetorical research, specifically RGS.

RGS research investigates reoccurring oral or written linguistic events in their social contexts, with special attention to the social action of these events—that is, how they enable and constrain the actions of participants. We use the RGS framework to refine our question about what the dignity interview is doing, how this practice is shaping the legacy documents that patients produce. Following a brief introduction to RGS, we focus on two concepts: genre ecology and negotiated agency.

RGS studies emerged in the early 1980s among rhetorical scholars such as Bitzer (1968), Campbell and Jamieson (1979), and, most notably, Miller (1984). These scholars rejected the notion of genre as referring to rigid systems of classifying texts, drawing attention instead to how text types enable and structure social actions and relations in particular contexts. As social actors recognize over time that sets of linguistic strategies (oral, written, visual, gestural) effectively respond to specific collective tasks, they tend to label these sets of strategies with terms such as *reports*, *eulogies*, *records*, *interviews*, and so on. These genres, because they encapsulate institutional, disciplinary, and community expectations, become forms of "social action" (Miller, p. 151). They are shaped by the needs of their communities, and they also shape the social actions of their users.

Research from a critical discourse perspective, notably that of Fairclough (2003), also supports this way of looking at specific text types as "relatively stable and durable ways of acting" (p. 28) in specific social contexts. He notes that some text types involve mediation or the "movement of meaning—from one social practice to another, from one event to another, from one text to another" (p. 30). For example, newspaper articles work this way in that their writing involves integrating a variety of sources from speeches to interviews. He observes that some mediation practices involve "networks of texts" (p. 30) or "genre chains" (p. 31). Genre chains are particularly significant, as they involve "different genres which are regularly linked together, involving systematic transformations from genre to genre." Such chains facilitate "the possibility of action which transcend differences in space and time, linking together social events in different social practices" and enable "action at a distance" (p. 31). The interview protocol that we investigate appears to be part of such a chain. The protocol itself is a result of research interviews and data analysis and produces another kind of genre—the legacy document.

In health care, RGS studies have investigated genres such as novice case presentations (Lingard, Garwood, Schryer, & Spafford, 2003; Schryer, Lingard, Spafford, & Garwood, 2003; Spafford, Schryer, Lingard, & Hrynchak, 2006), record-keeping practices (Berkenkotter, 2001; Schryer, 1993), referral letters (Schryer, Gladkova, Spafford, & Lingard, 2007; Spafford, Schryer, & Lingard, 2008), forensic reports (Schryer, Afros, Mian, Spafford, & Lingard, 2009), treatment forms (Popham, 2005), and medical consultations (Have, 1989).

Genre Ecology

As we have already noted, genres do not live in isolation. Some genres exist within chains that create the grounds for the production of other genres. Freedman (1994) suggests that the process of "uptake" (p. 62) explains how some genres, such as call for proposals, construct the expected response in actual proposals but also how agents strategize within those constraints. Spinuzzi and Zachry (2000) note that text types exist in interconnected systems, or "genre ecologies." Any individual genre develops connections with other genres so that the activities undertaken in that genre are mediated by an entire dynamic, shifting ecology of different genres (Spinuzzi, 2003). Because each genre has its own history, worldview, and ideology, we must consider what other genres the dignity interview is connected to and how these genres jointly mediate the social action related to the patient's legacy documents. Two genres seemed particularly salient for patients engaged in the dignity interview's genre ecology: the eulogy and the medical interview.

The Eulogy

Early in our analysis of the dignity interview protocol and the resulting legacy documents, we noted some underlying resemblances to a traditional popular culture genre: the eulogy. The eulogy has been recognized as a consolation speech associated with funerals since 500 BCE (Kent, 1991). According to Hewett, most modern eulogies work within the following four-part structure: a prooemium, or introduction that begins in the present and attests to the credibility of the speaker, his or her right to speak about the deceased; an epainos, or section wherein the speaker praises the deceased and recounts past vivid narratives about the loved one; a paramytthia, wherein the speaker expresses appreciation of the deceased's life and suggests future actions to help mourners deal with their emotions; and an epilogue, in which the speaker attests to the continuing bonds with the deceased (Hewitt, 2008). Kunkel and Dennis (2003) suggest that the eulogy continues as a powerful genre because it constructs "a coherent narrative from a chaotic and troubling event" and makes that event "more accessible, more understandable" (p. 5). This research indicates that several strategies characterize the eulogy—an appraisal of the deceased; a management of time that moves the listener from the present, through the past, to a future without the deceased; and, finally, an emphasis on constructing coherent narratives.

The Medical Interview

The medical interview is another genre that inhabits the dignity interview's genre ecology. As Lazare, Putnam, and Lipkin (1995) explain, the medical interview, reflecting its origins in biomedical discourse, has three main functions: first, determining and monitoring the nature of the patient's problem; second, developing, maintaining, and concluding the therapeutic relationship; and, third, patient education and implementation of treatment plans. Critiques of the traditional medical interview problematize its focus on the physician's goals, which can result in an objectification of the patient (Segal, 2005). This objectification also supports particular linguistic patterns, such as the tendency for physicians in general medical practice to repeatedly interrupt patients (Beckman & Frankel, 1984). As Stewart (2003) explained, the conventional medical model assumes that deviations from normal biological variables can account for disease, and it pays little attention to social, psychological, and behavioral dimensions. Over the past 20 years, there have been calls for reform of this method. New methods have emerged, such as the patient-centered clinical method, which has been championed as treating the whole person (Stewart, 2003). Notwithstanding this shift in the medical interview genre, it is likely that most patients with chronic and terminal disease have extensive experience with the conventional interview (Kassirer, Wong, & Kopelman, 2010) and its tendency to shift the patient from personhood to patienthood, from being a sick person to a puzzle for clinical reasoning to solve (Segal, 2005).

Negotiated Agency

Recent research in RGS has attended to issues of agency—that is, the ability of the speaker or writer to act. The concept of negotiated agency recognizes that while genres constrain their users' actions, they provide resources that enable actions. Similar to Atkinson (1997), Schryer et al. (2003) have observed that the notion of a totally free agent is a mythic construct. But the notion that social structures completely control human activity is also reductive and does not reflect the social fact that change occurs. Rather, researchers such as Winsor (2006) have explored agency as an articulation of material-semiotic forces. As she noted, "people achieve status as agents by enlisting other forces into their own program of action" (p. 419). Herndl and Licona (2007) agreed when they argued that "a speaker's authority is a social identity that . . . emerges from a set of social practices" (p. 143). Patients in end-of-life care situations often experience a loss of ability to control their social and physical worlds. The social practices in the dignity interview involve the health care provider offering the patient the semiotic (generic) resources of the protocol and the material resources of recording, transcribing, and reading.

Bakhtin (1986) noted that genres have particular orientations to space and time that create more or fewer opportunities for human agency. Researchers have used this time-space orientation to investigate agency in occupational therapy interactions (Detweiler & Peyton, 1999), nurse practitioner interactions (Dunmire, 2000), insurance writing (Schryer, 2000), medical record keeping (Schryer, 1993), experimental research reports (Schryer, 1994), and cover letters (Crossley, 2007). Certainly, a unique orientation to time is present in the dignity interview protocol. In effect, the protocol could be assisting patients to construct discursive order out of the events of their lives, akin to the discursive order characteristic of the eulogy.

Method

The study occurred in palliative care settings in two academic hospitals that were associated with one medical teaching institute. The interviewers were psychiatry and family medicine residents completing a rotation on the palliative care service as part of their first-year residency. We secured ethics clearance for all aspects of this study.

The study sample consisted of 12 legacy documents that were the result of dignity interviews conducted by 12 first-year resident physicians. This was a convenience sample in that patients and residents were volunteers. One invited patient declined; four residents consented but could not accommodate interview schedules.

Patients were identified as potential participants by the palliative care physician caring for them. Participants had been diagnosed by their physicians as having fewer than 6 months to live. We did not include patients if they were experiencing cognitive impairment or were too ill to participate. Interested patients were provided information, and one of the investigators secured their informed consent. Resident physicians were provided with a guide that outlined the nature of the intervention. All dignity interviews were coadministered by our psychiatric collaborator to ensure that the interview approximated as closely as possible Chochinov et al.'s protocol (2005).

While the interviewers followed the interview guide, they tailored follow-up questions to the patient in an attempt to clarify and facilitate memories. The recorded interview was then transcribed verbatim, resulting in transcripts from 8 to 17 pages in length. After transcription, the resident physician edited the transcript. Unrelated parts of transcript were eliminated (e.g., a clinical conversation with a nurse that entered the room). Residents were asked not to "correct" specifics, such as grammar, as such corrections would not preserve the person's natural tone.

Within 1 week of the original interview, the resident physician and principal investigator returned to read the document to the patients. Patients heard their stories read back to them and were offered the opportunity to ask for changes. Such requests were rare and for the most part involved wanting a paragraph deleted or a sentence or family member's name added. The resident physicians made these changes and returned the final document to patients.

Four researchers participated in the data analysis: two experts in discourse analysis, a communications researcher, and a psychiatrist. Our early analytical process involved individual reading of transcripts and group discussion of emergent patterns. Preliminary analysis suggested the importance of a timeline in the legacy documents, which we explored in more depth through a discourse analysis of two linguistic cues: verb tense and pronouns.

Thematic and linguistic analysis proceeded simultaneously, allowing us to describe an overall narrative pattern of thematic elements marked by linguistic cues. One researcher (A.M.) conducted the analyses, coding grammatical and thematic features from the corpus of dignity interview transcripts. The group held regular meetings to review emerging patterns, to attend to discrepancies, and to refine its thematic categories (Corbin & Strauss, 2008).

Linguistic Analysis of Time

Early in our deliberations, we noted that eulogistic strategies seemed to be present in the interview protocol. As Hewett (2008) notes, eulogies move listeners from the past, through the present, to a future without the deceased. Characteristic of eulogies is the impetus to provide narratives that reflect summative moments of a person's life. To locate the temporal orientations of the dignity interview and its related narratives, we used features of tense and aspect to conduct a discourse analysis that identified features associated with the discursive ordering of time. At the same time, we examined carefully the narratives that were associated with these temporal orientations.

Scholarship on syntax (Binnick, 1991; Reichenbach, 1947) posits two often interrelated verb formations for indicating temporality: First, tense situates events in the past, present, or future; second, aspect situates a sequence of events and their relation to a reference point. Reichenbach (1947) argued that verbs and auxiliary verbs orient utterances along three points of time: speech time, the time that a statement is spoken or written (actual present time of the dignity interview); reference time, the segment of time on which the statement focuses (the narrative construction of time); and event time, the time at which the event took place (actual past time). Adding the auxiliary verb *have* (also called the perfective *have*) to the main verb of a sentence often signals this subtle manipulation of time. For example, with reference to vacationing, one patient stated that she and her husband "had planned to have many, many more trips" (P6) before she became sick. The patient stated that travel plans were made, the event time. But the use of the perfect aspect ("had planned") indicates that those plans were interrupted. This point of interruption is the reference time. Use of the perfect aspect focuses attention not on an event time but on how events from a reference time relate to speech time. In this instance, the perfect aspect becomes more than just a verb form that creates a causal link between past events and the present; the perfect aspect gains meaning by being understood as the main verb form that patients use to discuss their changing health conditions.

Critical linguists Kress and Hodge's work (1979) on the perfect aspect and modality in syntax provides a theoretical backdrop for how verb forms can influence social action. Hodge and Kress argue that a language's syntactic and semantic systems affect "the flux of experience of physical and social reality" (p. 63); that is, a language systematizes what speakers can and cannot mean and how speakers can and cannot think. In a manner similar to RGS, with its focus on identifying the generic resources and constraints through which humans negotiate communication, the task of critical linguistics is to understand the resources and constraints of syntactic and semantic systems. By necessity, discourse involves the exchange of information, which can in many cases be "a commodity" in the economy of social power (Kress & Hodge, 1979, p. 99). If information is considered a possession, then the use of the perfective *have* takes on an important valence. A traditional syntactic approach considers the verb *to have* as indicating possession and the perfective *have* as a grammatical marker. Yet the perfect aspect is also a way that speakers turn completed events into fixed states. The perfect aspect allows for events to take on the form of a commodity that is spatialized, possessed, and exchanged in discourse. For example, half of the patients in our study use the perfect aspect to express that they “have lived a good life” (P2, P3, P4, P6, P7, and P10). For individuals at the end of life and perhaps feeling dispossessed, the perfect aspect may encode a subtle linguistic strategy for repossessing past events to be used as commodities of social power at the speaking moment. In effect, the use of the perfect *have* may offer dignity interview subjects rhetorical agency.

Results

The Dignity Interview Protocol

The interview protocol creates the temporal ground against which the legacy document unfolds. That is, the linguistic tense of the questions encourages patients to temporalize their responses in the past, the present, or the future. The following list (see also appendix) outlines how each protocol question falls into one of four temporal types:

Past: Questions 1 and 2 situate a question just in the past. While Question 5 is also a past-tense question, it picks up on Question 4, which is in the perfect aspect.

Present: Questions 1, 6, 8, and 12 ask patients to discuss their feelings or opinions about current or past events in relation to the present moment.

Perfect: Questions 4 and 9 ask patients to connect past events to their present self-characterization via the perfect aspect.

Modal future: Questions 3, 7, 10, and 11 ask patients to envision the future after they have died. Importantly, each question uses the modal auxiliary *would* to allow more flexibility in the question’s reference time than the present tense *will*.

In essence, similar to the classical eulogy, the interview protocol invites patients to recall stories that create an overall trajectory that reflects the Western belief in coherent personal narratives.

Analyses of the 12 legacy documents revealed that these patients responded to the interview protocol by producing narratives and observations that echoed the management of time in the protocol. Three dominant discursive moves occurred: evaluations of the past, transitions to the present, and legacy observations related to the future. Overall, the legacy documents worked within a timeline: Patients shared details about their upbringing, career, and family lives; their changing health condition and its implications; and, ultimately, their legacies.

The protocol seemed to provide a time-oriented template that assisted patients in generating this trajectory: Questions relating to a patient's life history often generated evaluation narratives, while questions relating to the patient's legacy generated legacy perspectives. However, while the dignity interview protocol questions fell into four temporally marked categories, patient responses did not necessarily fall within the temporal framework created by the protocol. In other words, although patients used the temporal strategies present across the interview protocol, they did not always align their responses to the time frames suggested by specific questions. We now describe the thematic patterns in these three narrative types and outline how linguistic structures signal and support specific themes, indicative of patient negotiations.

Evaluation

Told primarily in the past tense, evaluation instances described patients' lives before terminal diagnosis. Evaluation narratives related past events and followed them with statements that briefly expressed patients' feelings about those events. In this way, past-tense assessments are a strategy of rhetorical agency, allowing patients to add personal opinions or moral judgments—like the moral at the end of a fable.

Throughout the evaluation instances, one overarching theme frequently reoccurred: overcoming adversity. Evaluation narratives frequently related patients' experiences of illness, poverty, or persecution and described how these obstacles were overcome, as the following example illustrates:

> We wore hand-me-downs, but so did everybody. You never thought twice about that. We've been talking lately about the package of Muffets Cereal in those days. There were three round Muffets in a box and then there would be a cardboard thing in between and then there would be three more and a cardboard. And by golly, we took that cardboard out and we put it in the kitchen drawer, and when your shoes started to get holes in the bottom of them you'd grab about three of those cardboard papers, cut them to fit, and that was how you soled your shoes. Like, who had a nickel to go the shoemaker? . . . And you knew that every other kid on the block was doing the same thing, so who cared? (P3)

Evaluation examples contain three prevalent subthemes. First, patients recounted narratives, as illustrated below, about their heritage, including the social, cultural, or political contexts of their birth, their parents' careers or personalities, and, similarly, their upbringings:

> I was born in 1945, the eleventh of October, so it was just after the war when things in London were quite scarce. My mother, my father and I (I'm an only child) used to go away a lot of weekends which was not possible for many people. We had a car, so we used to go to the seaside or go away for weekends. (P6)

Second, patients discussed maturation, including marriage, raising children, spouses, and careers:

> It was very bad times because it was a war and a new country. It wasn't easy . . . my husband's family was living—he was from Russian Ukraine. He wasn't in the camp; he was in the army. So, after the war it was very bad for [his family], so we used to send them parcels. . . . We brought the brothers here, we helped them with everything. . . . We shared whatever we had. (P7)

Third, patients spoke of their social lives or their travels:

> [Our cottage] was more like a shack. . . . The roof leaked. There was no electricity, it was strictly propane. There was no running water. There was a pail-a-day toilet. It was the basics, but, boy, we loved it. It was a sandy beach and it was a lake. You know the Muskoka lakes, they're mostly all rock and once in a while, because of the current or whatever, you might get a sandy beach. Well, that's what we had. It was beautiful. (P3)

Although only the first question of the dignity interview overtly asks patients about their past experiences, on numerous occasions patients drew on evaluation strategies to answer questions seeking to temporalize narratives into the present or future. For example, one question asks, "Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?" This question seeks to temporalize a patient's response into the future so that he or she will leave a message for loved ones. Yet several patients' responses were grounded in the past:

> He's always been [there] for me. Everything, . . . was always for me and he was very successful with his banking considering our education level he ended up as a corporate manager at the Bank of Commerce, whatever. . . . [He] was so supportive; he was always for me. He was so, he'd sacrifice for me any enjoyment but we also did everything together. We golfed together; we played bridge together; we did the entertaining together, all that stuff so it was very much a team. That's how I feel we were, a team. (P2)

Patients used evaluation as a resource for discussing their personal histories and leaving a message behind for loved ones. Evaluation strategies were a resource for patients to discuss how they remembered their lives and how they wished to be remembered.

Transition

Transition instances straddle the terminal diagnosis boundary, transitioning between a life lived and the present context of dying. These examples contain clusters of the perfect aspect where the perfective *have* precedes the past-tense form of a verb. Patient 11 used the perfect aspect when she said, "I have had people come in when I have looked terrible and say, 'You look great.'" In this sense, transition narratives were a strategy for patients to add relevant present value to narratives situated in the past or to use events from the past to add relevance to the present situation.

Transition instances use the perfect aspect to discuss the impact of past events on the context of dying, as in the following instance:

> My life's been quite happy, no very happy really. I've been very lucky apart from this, this is a bit of a stinker and that's mild. (P6)

Throughout all transition examples, the overarching theme is a changing health condition.

Naturally, the major topics addressed during transition narratives involved patients' illness-related concerns. For example, some patients discussed how they have experienced societal conceptions of illness since their diagnoses. Yet patients more often related how their terminal diagnosis had changed their lives and the lives of their loved ones:

> My mother lived until she was 92; had smoked for like 55 of those years and never had a sickness in her life. Because I was her stature and whatnot,

> I just figured I was going to live until I was 92 as well. So it's been a bit of a shock. I feel cheated out of 20 years because I've always led a very healthy life. I've never smoked, never been a drinker so to speak; am a golfer, curler and all those kind of Canadian things. (P2)

Aside from illness-related concerns, transition examples recounted how patients' past experiences had influenced their current worldviews. Subthemes within patients' transition comments spoke of personal growth, changing character, and a sense of altruism—karma, the golden rule, and forgiveness—themes not mentioned in evaluation narratives:

> I've really softened; I feel I've softened and been more understanding; just more understanding where maybe I wasn't before. . . . It's been really a gift to have this part of my life because I swear having this kind of life ending experience is a good thing. (P2)

Along with discussing new insights as a coping mechanism for loved ones, several patients' transition comments described writing autobiographical narratives in the form of letters for their loved ones—another way that past events have an effect on the present context:

> I spent hours sitting at the computer sobbing and writing the letters and I think what I've written is sufficient. It was written with a clear mind. If I'd have left it even until now I think I wouldn't have been able to write as clearly as I did and offer them as much comfort as I think there would be in the letters. (P6)

Although only two dignity interview questions (Questions 4 and 9) temporalize patient responses through the perfect aspect, patients used the perfect aspect as a response to most interview questions. When asked about her life history (a question prompting an evaluative response), Patient 3 began her legacy document with a transition observation:

> I think I've lived a really full life. I've had a lot of, probably difficult experiences, in that I was a caregiver at a very early age to a sick mother. . . . I've done a pretty good job. I've got three great kids and they're just so supportive in this. They're knocking themselves out to be here for me. (P3)

While the dignity interview protocol often temporalizes patient responses into discussions of the past, present, or future, patient "uptake" of this time frame was not rigid but used the constraints of the protocol to express their stories and observations in their own ways.

Legacy

Legacy instances are explicit discussions about the future. In this palliative care context, legacy comments and stories consisted of discussions of the future without the patient. In English, speakers use a variety of modal strategies to express the future. The future is typically created with two verb forms: (a) the modals *will* or *would* + a verb or (b) the verb *be* + *going to* + a verb (or "gonna"). The distinction between the two forms is illustrated in the following two statements: "I would hope that [my son] can find love" (P12) and "I'm going to be here for a while, so don't count me out" (P7).

Legacy narratives and observations were also marked by high concentrations of generic second-person pronouns—the singular second-person pronoun *you* or the plural first-person pronoun *we*. In legacy instances, statements containing high concentrations of generic pronouns (in bold) often made existential statements about life, such as "**your** perspective changes when **you're** facing death" (8) or "**we** all need love, **we** need affirmation" (P3). Although generic pronouns occasionally occurred in transition and evaluation instances, when combined with the simple future tense, they were indicative of legacy narratives.

Patients also appeared inclined to use a variety of strategies for discussing their legacies—specifically, speaking about the future, expressing general truths about the human experience, and using verbs of cognition, emotion, and attitude that semantically implied the future, such as *want*, *hope*, *pray*, and *worry*.

The overarching theme of these instances was legacy—the parables and messages that patients wished to leave for their loved ones:

> I really hope my legacy will embrace them and influence them to living, not necessarily my life but just to live a good life, a charitable life, that kind of thing. That would be my wish because charitable means a lot of things. I would mean just be gracious, open and just generous in that way, not necessarily with money but generous with her spirit and stuff. (P2)

Patients' discussions of legacy involved three primary subthemes. The first situated the patient's newfound perspective when facing death. Patients remarked that facing death has left them with few regrets, often feeling "more alive" than ever before:

> I actually feel pretty alive now, ironically, but I think that's just wisdom. . . . Your perspective changes when you're facing death, so I think you do see things differently and time is of essence and you appreciate things more. I always did because I always knew that time was always of essence for me because I was always sick, but this is different. . . . It's almost like you step outside of the group and you look into the group and a lot of the little chatter goes away. In my head I find I can find more peace in my thinking. Things aren't important that used to be important. (P8)

The second subtheme involved how patients believed that their loved ones should conceive of time. These instances espoused a "seize the day" message for loved ones and endorsed appreciating life before it's too late.

> The body disintegrates, so you shouldn't spend too much effort on that part of it. The fact is that everyone will go through it at some point. I think that's what we all have in common. So, don't get caught up in things that are not important. Stay focused on what's important. (P8)

Last, legacy comments involved the subtheme of condolence in the form of advice on how loved ones should move on with their lives. These instances discussed forgiveness and faith as paths to general truths or better living; patients encouraged loved ones to remember the "good times" and to go on and lead "good lives."

> [My family is going to] miss me and I know they will. I know my children and [my husband], particularly but life goes on. . . . You have the funeral; it's all cleaned up; people walk away and life goes on. That's how I see it. They have to go home. They have to deal with things. . . . Get on with life and just embrace whatever I've left in memory. (P2)

While four of the dignity interview protocol questions temporalize patient responses to the future, again we found that patients constructed legacy instances as responses to questions located in the past or present. The best example of this type of negotiation involved responses to the question "When did you feel the most alive?" Four of the 12 patients stated that the experience of dying has made them feel more alive than ever before, with claims such as "I think I feel the most alive right now" (P3). This dignity interview protocol question is firmly fixed in the past tense, meaning to temporalize a patient narrative of pride in past experiences. Yet patients used this as a resource to invert the expected response, "ironically," and leave a message for loved ones about their dying experience. This is another example of patients not being constrained by the temporal structure of the interview questions but rather using that structure as a resource to express their perspectives.

Discrepant Cases

Among the patient legacy documents, three discrepant cases emerged. P1's interview was discrepant due to an apparent hearing impairment. P4's interview was discrepant in that it contained half the content of the average interview because this patient spoke slowly, quietly, and at times incoherently due to a weakening physical condition. P7's interview was discrepant in that this was the only one in the data set not to move through evaluation to transition to legacy moments.

Specifically, P7's interview did include evaluation and transition moves; however, it did not include any legacy instances. P7's spouse had died, leaving this patient to feel abandoned ("Most of the people that were very good friends before [my wife] died I haven't seen since"). When prompted to discuss hopes and dreams for his son, the response was somber:

> I just feel badly sometimes that everything falls on his shoulders. . . . Like, when my father died before my mother, at least when I did things for my mother my brother was also there to do things for my mother. But my son has to do it all himself. (P7)

With P7, the lack of legacy comments appears to be related to a weak sense of audience: The patient's wife has died; friends have dropped away; and his son is not discussed in terms of the hopes for a future "good life."

Discussion

Inherent within RGS is the concept of "exigency." The concept describes situations for which a social-cultural response is required and, over time, recognized ways of responding have evolved. Genres of apology exist—for instance, to repair the effects of inappropriate social behavior. In the context of our research, two interrelated sets of exigencies exist. The first is the wider social debate around the concept of dignity within palliative care. The appropriation of the term *dignity* by advocates of assisted suicide and euthanasia created perhaps the exigency to which palliative care practitioners, such as Chochinov, had to respond. The term clearly resonates across Western culture, even if its meaning is not clear. The practices related to the dignity interview and, particularly, the interview protocol reflect a response to this exigency. At the same time the more crucial exigency is death itself. Cultures around the world have to develop resources to deal with the profound disruption related to our mortality. In Western thought, one of the richest sources of coping with the death has been the eulogy. As Campbell and Jamieson (1979) note, the eulogy enacts a constellation of resources, such as the management time and narratives to assert that the deceased survives as a coherent narrative at least in memory and thus helps to heal the grieving community.

An analysis from the theoretical perspective of RGS suggests that the dignity interview may have an efficacious effect on patients by providing them with semiotic and material resources to create a sense of discursive order out of their life events. In effect, the dignity protocol provides patients with a form of rhetorical agency wherein they can shape the interpretation of their own memories. These interviews inhabit a genre ecology in which the social actions performed by the legacy documents are influenced by the eulogy and the medical interview. The effects of the traditional eulogy on the interview protocol and the subsequent legacy documents are fairly evident. Practitioners and patients are accessing the time management and coherence strategies that have evolved within the framework of the eulogy. Less evident is the effect of the medical interview. Medical interviews are always controlled by medical practitioners and typically reflect the voice of biomedicine, with its emphasis on combating disease. In contrast, the dignity interview was designed by Chochinov as a stark contrast to the interview. From the perspective of those opposed to euthanasia, the act of carefully listening to patients without interruption assists in conserving dignity and more reflects the lifeworld of patients. In other words, the dignity interview is also characterized by what it is not—a medical interview. Patients' experiences of these two genres could be shaping how they wield the resources of the dignity interview, and this may help to explain why the experience might act on them in positive ways, as Chochinov's (2002) results suggest.

However, the rhetorical agency that the legacy documents illustrate is a negotiated agency wherein we see patients both controlled by and in control of the semiotic resources associated with a genre. At the heart of each legacy document is the interview protocol, and certainly much of what happens in the interviews themselves is shaped by this central text. In particular, the protocol sets up a timeline that, similar to the eulogy, invites patients to shape their memories and observations into past, present, and future orientations. In this way, the protocol and the interview transcript or legacy document evince the bidirectional relationship that RGS characterizes as "uptake": A text (interview protocol) secures a class of uptakes (the transcripts), and these uptake texts confirm the protocol's generic status by conforming to its structure (Freedman, 1994).

The uptake texts reveal that the protocol presents interviewees with constraints and resources. While patients discuss their unique life experiences, the linguistic and thematic similarities across the transcripts express the ways that the resources and constraints of the protocol are taken up by each patient. For example, there is nothing in the protocol that suggests that patients outline narratives of overcoming adversity, and yet they take up the protocol and respond with evaluation narratives that highlight this theme. Similarly, nothing within the protocol directs patients to discuss how their worldviews have changed since facing death, yet patients repeatedly assert that they "have never felt more alive."

That patients' legacy documents follow strikingly similar thematic and linguistic patterns is not only a consequence of their response to the same central interview text. Patients' tendency to produce similar legacy documents is also a consequence of their drawing on popular culture knowledge of the eulogy. As a mourning community uses the eulogy to construct a coherent narrative from the chaotic and troubling event of death (Kunkel & Dennis, 2003), so too do patients use the dignity interview to construct coherent accounts from the chaotic and troubling experience of dying. These accounts are clearly reflective of the conventional structure of the modern eulogy. Evaluation narratives contain elements of the epainos, which praises the deceased and recounts vivid past narratives (such as overcoming adversity); transition moves resemble the paramytthia in expressing appreciation of the deceased's good life; and legacy moments share with the epilogue its testament to continuing bonds with the deceased. Remarkable in the completed legacy documents, however, is a radical change from the traditional locus of agency. In these legacy documents, patients are not only the subject of the eulogy but the agents of its creation as well. They self-eulogize or, more appropriately, work with a physician through the interview protocol to co-construct their eulogies. In fact, the daughter of P1 shared that her mother's legacy document was read by her rabbi as a eulogy at her mother's funeral.

Indeed, our case study illustrates how genres can actively mediate exigencies in sometimes unexpected ways. Genres such as the eulogy provided discourse resources, we claim, for both the interview protocol and the resulting legacy documents. Like a good piece of jazz or a well-remembered tune, these resources provide just enough structure so that social agents can improvise and construct, if they choose, their own unique version of the telling of their lives. No two legacy documents could ever be the same. In this situation, the fact that these familiar discourse resources reflect a deeply felt need within Western thought for personal narrative coherence and relevance only adds to their appeal.

Our results also point to one of the mechanisms for change or dynamism within a genre system or network. These legacy documents are part of a "genre chain"—a set of transformations that began with research on dying patients. Those patients' concerns were reflected in the interview protocol. It is also possible that many of these concerns are deeply embedded with the traditional eulogy. In a fascinating twist, however, the legacy documents now offer a new resource to traditional eulogies. Traditionally, someone speaks about (and often to) the diseased. As noted earlier, legacy documents preserve the voice of the dying patient and are sometimes used at funerals as part of the eulogy. This change of voice marks a fundamental shift of discourse resources for the eulogy.

At the same time, material resources are being expended on the dignity interview intervention, resources that are usually spent on clinical care. Indeed, for both patient and physician, the dignity interview provides a sharp contrast to the traditional medical interview in that the interviewer is not focused on gathering clinical information; rather, the expressed goal is to elicit the patient's life story, without interrupting. As Chochinov et al. (2004) make clear, the "empathic, nonjudgmental and respectful tone of the therapist . . . is intended to bolster the patient's sense of purpose, meaning and worth" (p. 140). The fact that the role of the health care provider is so distinctly different in the dignity interview as opposed to the medical interview could be encouraging patients to configure them as true audiences in Toolan's (1988) sense. The transformation of the health care provider from an interrogative gatherer of information to a "listener" may be mirrored by a similar transformation for the "patient" back to "person"; this could be one important reason for the efficacy of the dignity interview.

Another important feature might also be that the provider returns to the patient with a written transcript of the interview. In contrast to other medical interventions wherein patients do not see their medical reports, the dignity interview becomes their product. This transformation of oral language into written documentation could not only be encouraging patients to not only address audiences (their loved ones) outside the framework of the interview but invoking the kinds of discursive order characteristic of eulogies. It is noteworthy, for instance, that P7's transcript lacks the final move toward legacy. We speculate that due to the loss of his wife, P7 could not project a future audience and therefore could not complete the full trajectory of either the interview protocol or a eulogy.

The co-construction of legacy documents is another critical dimension of the social action of the interview protocol and likely relevant to their therapeutic power. In the dignity interview, patients experience an interview entirely different from the conventional medical interview, of which they will have undergone innumerable instances. Where the conventional interview is predicated on the physician's clinical reasoning activity (Kassirer et al., 2010; Stewart, 2003), the dignity interview is predicated on the patient's existential meaning making. Whereas the first function of the medical interview is to "determine the nature of the patient's presenting problem," the first function of the dignity interview is to provide patients with the opportunity to create a legacy document that captures their unique story.

This co-construction also reflects the wider social context of the discussions around the meaning of dignity in relation to palliative care. As Jacobson (2007) notes, dignity has two main meanings—human dignity and social dignity. During the dignity interview, patients seem to be asserting human dignity through negotiated forms of agency. They also, of course, choose to participate in the interview process, another form of agency. At the same time, through the attentive listening strategies and the time spent on the interview, health care providers are supporting patient dignity in very real-time and material ways; thus, patients could be experiencing the personal recognition associated with social dignity. It is impossible, of course, to state that the dignity interview assists patients to achieve a good death. But Chochinov et al.'s (2004) appropriation of the term *dignity* to support the development of practices that appear to support the dying patient is noteworthy.

In summary, in line with the interview protocol's discussion of the past, present, and future, the legacy document creates a historical persona and a life lived; within the document, transition instances explicate a health situation and its meaning; and legacy narratives and comments discuss a future without the patient. This negotiation between the rhetorical structure of the interview protocol and each patient's unique agency can explain the linguistic patterns of the dignity interview and the processes leading to its positive effects. The therapeutic impact of the dignity interview might be explained by the fact that the resulting legacy documents are a joint, improvisational accomplishment that uses the material resources of the dignity interviews and the conventional, generic resources of the eulogy, an ancient and socially available set of resources, to create discursive order at the end of life.

Appendix: Interview Protocol

Protocol Questions	Tense
1. Can you **tell** me a little about your life history, particularly those parts that you **remember** most or **think** are the most important?	Present
2. When **did** you feel most alive?	Past
3. Are there specific things that you **would want** your family to know about you, and are there particular things you **would want** them to remember?	Modal future
4. What are the most important roles (e.g., family, vocational, community service) that you **have played** in life?	Perfect aspect
5. Why **were** they so important to you, and what do you think you **accomplished** in those roles?	Past (perfect connotation)
6. What **are** your most important accomplishments, and what **do** you **feel** most proud of?	Present
7. Are there particular things that you feel still **need to be** said to your loved ones or things that you **would want** to take the time to say once again?	Modal future
8. What **are** your hopes and dreams for your loved ones?	Present
9. What **have you learned** about life that you would want to pass along to others?	Perfect aspect
10. What advice or words of guidance **would you wish** to pass along to your (son, daughter, husband, wife, parents, other[s])?	Modal future
11. Are there words or perhaps even instructions that you **would like to offer** your family in order **to provide** them with comfort or solace?	Modal future
12. In creating this permanent record, **are** there other things that you would like included?	Present

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