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Article Title: Chapter 3. Benchmarking the End of Life in Long-Term Care. By Jaber Gubrium.

Article Author: Jon Nussbaum, Howard Giles, and Amber K. Worthington
Oddly enough, the first sentence of Stephen King’s (1989) thriller The Dark Half is especially pertinent to the subject matter of this chapter. Not because the end of life is thrilling, but because what King says about life at the beginning of the book is to the point. Making a distinction, King writes: “People’s lives—their real lives, as opposed to their simple physical existences—begin at different times” (p. 3). If asked, King would probably agree that, likewise, the end of life concludes at different times. This would suggest that an individual can have many lives, each or all of which can begin and end at different times. This chapter addresses the communicative contours of the distinction in long-term care, part of a larger concern about the narrative organization of aging and dying (see Kenyon, Bohlmeijer, & Randall, 2011).

The distinction between life and living is commonplace in the corpus of empirical material drawn upon for this chapter. It was often mentioned, for example, in interviews with Helen, an 86-year-old nursing home resident who lamented, “I’ll go on living, but my life is over.” As Helen spoke about life, I came to know what many of us informally recognize, that the life is as experientially real—more real perhaps if we are to believe King—than concrete bearings, such as the bodies that undergird it. The life is not reducible to its materiality, even though it significantly relates to that. Nor is end-of-life communication limited to the later years, as some star athletes assert at the end of their careers. Here, I will focus on old age and suffering, especially as the end of life is constructed in nursing facilities.
Pseudonyms such as Helen's have been assigned to individuals and places throughout the chapter.

It has been said that end-of-life communication ultimately transpires in places such as nursing homes, hospitals, and hospices. Sheldon Tobin and Morton Lieberman (1976) observed decades ago that more and more the nursing facility is “the last home for the aged.” Since then, another venue has emerged for managing the end of life, one that was there all along but not recognized as a site of long-term care, and that is the family home. Previously taken to be the place one left at the end of life to play out what remained of living, the family home has become part of a long-term care system. It increasingly structures dying and death in institutional terms, because its moral sensibilities and technical resources borrow heavily from institutional practices (see Gubrium & Holstein, 1999). The lines of demarcation between Tobin and Lieberman’s last home for the aged and the family home left behind have been blurred if not eliminated. The key question is, How and with what communicative resources do those who are concerned construct the end of life in this landscape?

THE HOWS, WHATS, AND WHOS

The question has three parts, dealing, respectively, with the hows, the whats, and the whos of the matter. These direct us to the operating components of assertions such as “my life is over,” which work together to shape the meaning of the entity taken to be separate and distinct from living.

The How Component

The hows refer to the communicative mechanisms used to construct everyday understanding. For example, in a much referenced article titled “The Social Construction of Unreality: A Case Study of a Family’s Attribution of Competence to a Severely Retarded Child,” Melvin Polnner and Lynn McDonald-Wikler (1985) describe six mechanisms by which the five-and-a-half-year-old child’s family communicatively sustains the normality of their retarded child. One is the mechanism of “putting words in Mary’s [the child] mouth,” which might be likened to visible ventriloquizing. While Mary’s verbalization is limited to “gurgling,” when Mary does gurgle in interaction with family members, they methodically speak for her following each gurgled utterance, thus constructing her turn-by-turn as normal.

On one occasion, when Mary is wearing a newly purchased robe and is asked whether she wants to see herself in a mirror, the following exchange is reported to have taken place. The exchange is “excerpted from a tape [recording] Mary’s family made at home.”
We can quickly see that the meaning of the gurgle is not obvious in its own right, but is interactionally made meaningful, in this case in collaboration with the parents. Pollner and McDonald-Wikler (1985) note that the point is not whether Mary or the family is delusional, a question they set aside for the purpose of their study, but rather that Mary’s everyday competence requires communicative work. According to the authors, putting words into Mary’s mouth is an operating mechanism of that work.

I will make a similar point for end-of-life communication, which is that the end of life is not self-evident, but rather is communicatively constructed through a mechanism I have called “benchmarking” (Gubrium, Rittman, Williams, Young, & Boylstein, 2003). Benchmarking is the ordinary process of applying a useful standard, or benchmark, for designating and communicating where one is in life, such as explaining that compared with such-and-such (the benchmark), one’s life is over or not over, as the case might be. Julius Roth (1963) coined the term. He discovered that he was using a version of the mechanism to construct the progress he was making in recovering from tuberculosis in a “TB” sanatorium. While he and other patients had access to medical reckonings of recovery, both patients and professional practitioners also used various patients’ progress in treatment to benchmark their own or their patients’ recovery. We can imagine that Roth—like 86-year-old Helen—upon seeing the rapid recovery of another patient similar to himself in the light of his own lack of progress, might have concluded, “I’ll live for a while longer maybe, but my life is over.”

This is something we do all the time in assessing ourselves and it is, indeed, quite ordinary in that regard. But understood as a distinct communicative mechanism among other possible everyday mechanisms of meaning-making, benchmarking becomes a useful analytic tool for discerning the variety of ways those in dire circumstances construct the end(s) of life. Kathy Charmaz’s (1991) book Good Days, Bad Days, for instance, provides an intriguing view of how those with chronic illnesses use their ailments’ daily vicissitudes as benchmarks for the shape and borders of their lives as a whole. On good days, life seems to be endless; on bad days, the end is near—along with their respective moral horizons such as one’s sentiments about life, the resulting choices, and related courses of action.
The *What* Component

If benchmarking (the verb) is an important mechanism by which the end of life is constructed, the benchmarks (the noun) used are the *whats* of the matter. This turns us from process to substance. In this regard, we can ask, What communicative resources do those concerned apply to benchmark the end of life? This will take us to the specific empirical material I have collected in studying how benchmarking constructs the end of life in long-term care. But before turning to that, let us consider the general issue concerning where answers to questions about the end of life are derived. Where, in other words, do those concerned obtain the benchmarks they use to construct the end of life?

One source of benchmarks is personal life history. We might figure that from time immemorial, the end of life has been constructed, in part, based on how one views other parts of the life. As I will illustrate later in long-term care, it was not uncommon in a study of recovery benchmarking among stroke survivors to assess their current level of functioning in terms of their views of previous levels of functioning (Gubrium et al., 2003). For example, when asked about the quality of his life now, a survivor who described his past as very active and who now felt himself inactive was likely to make the same distinction that 86-year-old Helen did, such as saying that he will go on living, but that the life he once knew is over.

A second source of benchmarks is others' experience. Others are the communicative resource Roth (1963) used to evaluate his own progress in recovery from tuberculosis. This, too, we might figure has been a source of benchmarks for the end of life since time immemorial. For example, when the question of why she felt the way she did about life came up in interviews with Helen, she would sometimes explain that “going on living” was not the same as “having a life.” As if to instruct me in the matter, she would sometimes add, “Just look around you, Jay,” directing my attention to other residents to make her point. I should note that Helen was not just mincing words, but was literally designating the basis of a distinction. Occasionally, she would extend her personal assessment to nursing homes in general, whose residents' lives by the fact of being residents were over (see Gubrium & Holstein, 1999, for a discussion of the nursing home as a discursive anchor).

A third source of benchmarks has not always been available and makes the end of life today different in this regard from what it was in the past. I am referring to today's booming cultural rationalization of suffering and dying (Gubrium & Holstein, 2000). What I mean by rationalization is that designated terms of reference, categories, formal accounts, and related systems of meaning are now widely available for discerning the end of life, if not the end of living. One no longer need look to his or her past or to others for benchmarks. Brochures, books, and videos are an ever-present part of the public information side of the death and dying industry, distributed by nursing homes, hospices, funeral homes, and
grief counselors. Virtually every bookstore and supermarket checkout point has a plethora of such resources readily available to customers.

Perhaps the most familiar and most widely used resource is the five-stage model of dying presented by Elisabeth Kübler-Ross (1969) in her book *On Death and Dying*. The model depicts the experiential course of the dying person’s view of life. Since the 1960s, the model has been applied to all manner of end-of-life experiences, from those of dying persons themselves to those who are witness to a death or who care for the dying, the latter of whom may be regarded as the so-called second victims of the end of life. The home caregivers of long-standing disease sufferers are depicted as experiencing the end of lives parallel to that of sufferers cared for, with an equivalent five stages of adjustment in their case to the dying and death of their loved ones. In the long-term home care of Alzheimer’s disease sufferers, the progressive dementia of those cared for presents caregivers with incremental benchmarks for their own adjustment to the “brain failure” of care receivers. An equally popular resource is the signs-and-symptoms model found both in medically oriented popular texts and in scientific literature. This model combines personal and medical categories for designating the end of life as well as the end of living. I will return to both later in illustrating communicative usage in institutional context.

The Who Component

In today’s world, we all are exposed to models of life experience. Benchmarking the course of life seems to be everyone’s business. We not only benchmark stages of experience for ourselves, but others do it for us, both professionals and laypersons. It is everyone’s language game, so to speak. Personal experience is constructed through time by way of the actions and sentiments of friends, significant others, and family members, from the liked to the disliked, from the intimate to the estranged. All of them, in turn, respond to messages and images from networks of others with institutional bearings.

Consider Helen again in this regard. I once asked her to talk about her future. “You mean the future me?” Helen asked. Following a moment of thought, in a small way she brought a form of benchmarking-by-others with institutional bearings into the picture. A simple statement about “what to think about...life after cancer” derived meaning from constructions of others both close to her and far removed from living in her nursing home.

You know, Jay, I’ve just been thinking that maybe in the future it’ll [her cancer] disappear, just like Harriet said it did for her and I can have a life again. [Harriet is Helen’s sister-in-law, who, according to Helen, is now in remission from her own cancer and frequently recounts her remission as a possible model for Helen’s cancer.] Wouldn’t that be wonderful? To have a life
again? Like Harriet said she learned about in those [support] groups she goes to. Wouldn't it, Jay? I'm so glad about that—that Harriet told me what to think about that, you know, life after cancer.

Not only the *whats* but many of the *whos* in today's world are institutionally informed. It appears that no one any longer is on his or her proverbial own in communicating matters of experience (see Gubrium & Holstein, 2000). Endless others, in and about countless going concerns such as Harriet's support groups and their institutional sponsors, make it their business (some literally) to benchmark the end of life. The line of demarcation between self and others, while hardly ever clearly drawn, is now more difficult to discern than ever. As Helen and Harriet's exchanges over the matter indicate, benchmarking the end of life is a *collaborative* accomplishment mediated by countless models of experience, with influences extending well beyond the immediate environments of those whose living and end of life are in question.

## THE INSTITUTIONAL CONTEXT OF BENCHMARKING

Let us consider the way institutions shape the *whats* and *whos* of benchmarking for the end of life. What anthropologists call "apt illustration" is a well-established way of describing the lived detail of general mechanisms of action. The importance of exploring benchmarking's institutional bearings in situ stems from the overwhelming influence of institutions on the construction of experience, in our case for constructing the end of life. As I will show, traced ethnographically, the three sources of benchmarks discussed in the previous section—life history, social comparisons, and familiar models of experience—have remarkably complex institutional bearings, especially when the varied *whats* and *whos* of the matter are taken into account. The complexity stems from the broad communicative contingencies of ostensibly personal experience.

**Life History in Institutional Context**

To illustrate the use of personal life history to benchmark the end of life, I draw on narrative material dealing with constructions of the quality of life gathered in a series of interviews with nursing home residents. Some of the material was published in the book *Speaking of Life: Horizons of Meaning for Nursing Home Residents* (Gubrium, 1993), but the overall corpus is much larger. The corpus includes not only interview transcripts, but also field notes consisting of paraphrased ethnographic interviews, accounts of emotional expression, and observational records of real-time events, such as family visits and patient-care staffings. Evident in the
subtitle of the book, the focus of the study was on how the residents themselves spoke of, and in particular how they assessed, the quality of life now that they resided in a nursing home. The study was not so much concerned with residents’ evaluations of the quality of the nursing home or its care as it was with the quality of lives as figured in their present circumstances. In the following illustration, note how life history benchmarks the end of life in relation to the in situ perspectives of contrasting who/whos in the matter.

Alec Ranelli was an 84-year-old man who had been in skilled care at Holly Plaza for three years when I met him. He suffered from severe diabetes and the continuing pain of a double leg amputation. Alec, who had been a heavy smoker, now also suffered from chronic obstructive pulmonary disease and, according to the staff, exhibited early signs of dementia. As with other residents in this study, he was interviewed several times over the course of a year, and was interacted with casually at various locations on the premises, including convivial chats with him and others in and out of their rooms. I came to know Alec and family members well, especially his 82-year-old wife, Sara, and his adult, middle-aged children, Mark, Nina, and Kitty, who were regular visitors.

It did not take much prompting in interviews for Alec to speak about his life, both before and after becoming a Plaza resident. He was naturally chatty, as several of the other residents were, not hesitating to reminisce at length about what they referred to as “the old days,” more recent times, and their present and future lives in the facility. Said by the staff to be enduringly “active and busy,” Alec was a big man and reported to have lived with adventure in his veins. One of the daughters described him as the Ernest Hemingway of the family. As a younger man, Alec had been a lumberjack and later continued to work in other capacities in the lumber industry.

The following is an interview extract, one of many similar exchanges that illustrate the use of life history to benchmark what Alec’s life once was compared with what it is now living at the Plaza. The bold contrast of then-and-now not only designated a life ending, but also was emotionally palpable.

Alec: You know how it is when you’re that age [his 20s], you’re as active as all get-out. Look at me now; you wouldn’t know it, would ya, Jay? I’m a big guy. Shit, buddy, I was a really a big lunk then; I got around like none of the other guys [at work]. What a life! I was looked up to, too. No messin’ around with Alec. No sir! [He elaborates, detailing his life at the time, pausing here and there, marveling and then sighing, as if to convey what he once was in relation to what he’d become.] Hey, what a difference, huh? I’ll bet you can’t believe it, can you, Jay? [Pause] Can you believe that this ole dying body once upon a time coulda had a life? Can ya, buddy?
Jay: That's amazing, Alec. Tell me about it.
Alec: Aw, come on. What's to tell? You heard me a hundred times by now. [Laughs] I'm like a broken record, right buddy? Well, hells' bells, they take good care of you here; don't ya know. But this ain't no life. I'm dead meat, man. I sit here [laughing] and I shit here. Right here, right? [Points to his bottom and we both laugh] Sit and shit. You wouldn't find me doin' that before I got here. Don't get me wrong, the gals [nursing aides] are really good...they better be or else! Big talk, huh? Can't wipe my own ass. [Sighs]

Jay: Well, life...

But this was not the whole story when others' benchmarking was taken into account. What interviews with Alec told could contrast mightily with what interviews or passing chats with others such as family or staff members suggested. Stories and life histories have multiple versions. What Alec benchmarked in this account was benchmarked differently by family members, for example. Set side by side with other constructions, both past and present, the end of Alec's life becomes communicatively complex, beset by the perspectival contingencies of the construction process.

As I had become what Alec's wife and three adult children called a “trusted friend,” they often took me into their confidence in private chats that often started with the question “How's Alec doing, Jay?” In these chats, what Alec clearly and sometimes emotionally demarcated in interviews could be a source of considerable contrast. Put simply, the what of benchmarking could run up against who of validation. If Alec emphatically and consistently communicated in interviews with me that his life was over, interactions with family members often challenged what was otherwise forcefully designated.

For example, in the Plaza's lobby one evening, far from Alec's room, something I had said about Alec's feelings about life prompted Sara and the children to set me straight, so to speak, before I saw them off. As the following reconstruction from field notes indicates, family members used aspects of the same life history I had heard Alec recount recounted in an equally emphatic, but distinctly different, way. Dismissing Alec's insistence that his life was over, they used life history to benchmark life continuity. Virtually teaching me the social psychology of benchmarking to start, Alec's wife Sara described the perspectival side of a personal construction, suggesting that usage is linked with one's circumstances.

Sara: [Facing me] I'd take some of what he [Alec] says with a grain of salt. You know what he's like, Jay. [Explains] At the same time, I know you know what it's like for him. Like it would be for you, too, right? [Whimpering
as she elaborates] Living in a place like this does that to you. I could cry when he tells me like that, that his life is over...So many of them here are just, I hate to say it, just vegetables, but not my Alec. No way, José.

Mark: Come on, Ma, don't get yourself all riled up. He's [Alec] being dramatic. You know Pa. Always puttin' on a show. [Sarcastically] His life is over, my foot! Give him a drink and you'll see whose life is over. Good thing he can't drink anymore. That's why his life is over.

Sara: [Annoyed] That's not true and you know it! Don't talk about your father like that. I know exactly what he means and he's right, goddamn it!

Kitty: You guys, geez. Stop beating yourself up, Ma. Now you're going to make me cry.

Nina: [Gathering the family] See ya later, Jay. Thanks for looking out for him.

The competing truths of the preceding accounts are not uncommon in the empirical material, which differential positions in institutional life can pattern in vivid contrasts. While I will not exemplify it here, staff members' own varied positions in nursing facilities add to the complexity in distinctive ways. Their varied professional training and job descriptions mediate the construction of residents' life endings in their own right. Professional staffings are especially eye opening in this regard, where models of experience are brought forth and applied in complex ways to the construction of residents' past, present, and future experience, in particular constructions of the end of life (see Gubrium, 1997/1975, for illustrations of the influence of different institutional “worlds” on the construction of individuals and events).

Life history is also used in distinctive ways by residents with contrasting pre-institutional backgrounds. If the preceding extract from one of Alec's interviews reflected a popular construction of life in nursing homes, it was not the only way the personal past was used to figure life in the circumstances. Equally compelling usages could be presented by residents to benchmark new lives as well as life continuity in the nursing home. Extracts from interviews with two other nursing home residents serve to make the point.

The first extracts are from interviews with Martha Gilbert, a 76-year-old widow suffering from congestive heart failure and emphysema. She had lived at Oakmont Nursing Home for five years when first interviewed. Lifelong illness, hard work, and poverty were the continuing themes of her recollections. She emphasized that hers was a difficult and unhappy life from the start, far worse than her life at Oakmont. She pointed out that she had been “on my own practically since I've been eleven years old.” Dividing her responses into thens and nows, she repeatedly marked the distinction between her older life and her life now. Her two sons' reluctance to maintain contact with her had been especially distressing. She wanted them to be part of her life. But, as she explained, when she began to construct a new life without them, it became easier. They are not a part of her life
at Oakmont, which is another life—a different life—one yet to end that she had reluctantly grown to like.

It's [Oakmont] part of my life now. It's home. I know I can't depend on my sons. I haven't seen my son from South Carolina in ten years. Not much of a son, huh? He's not one to visit. And Jimmy, my youngest one, he drives those big convoys and he's on the road [much of the time].

They [her sons], neither one, was ever too homey anyway, I guess. So here I am. It's hard, but after you accept the things you know you can't have, things begin to run a little bit smoother.

But when you look back, I've never had a family life. I always had to work. It was bad, real bad.

Well, after the rough life that I've lived all my life and then you come along and live in here and you don't have your problems, I mean that's easy. If I didn't have such a hard time breathing sometimes, I think I'd be on Easy Street.

The second extracts are from interviews with Peter Rinehart, a 77-year-old widower, paralyzed from the waist down, the result of a roof fall. He had spent much of his life on the road selling Oster products, taking his wife along with him, a house trailer hitched to the back of their van. Theirs was a life together on the road, as he put it, living here and there along the way. He now suffers from severe chronic back pain, cannot sit upright, and is completely incontinent. As far as living is concerned, he figures he is in good health. If talk about his life is sprinkled with references to time before and time after the fall, this is not used to benchmark a new life, but rather a change only in venue and lifestyle. In his view, life has continued into the three-and-a-half years he has resided at the Bayside Nursing Home and will move along there into the foreseeable future.

In what follows, at first Peter compares himself with others, one of the what's more directly illustrated in the next section. He moves on to describe a life that hasn't ended, but rather that has had distinct “points” along a continuum, such as the point at which he was no longer able to sit upright.

I see people that are worse off than I am. I feel sorry for them, but I'm not looking back with remorse. It's something I can't help. It happened [his fall] and I have to live with it. Life's been happy and pretty good to me otherwise. I made a good living. You take the good with the bad.

[Asked whether he feels living at Bayside is “part of your life or separate from it”] I think it's part of my life. I've seen people that weren't as well off as I am and some of them were very far from where I am. They're very despondent. Can't face it. Well I don't have that feeling. I can adjust very easily. I think part of that is the fact that we traveled so much.
Yeah, it's part of my life all right. What would I do if this place weren't here? I'd be in another place like it, probably not as good as this place. I've adapted myself for quite a while here. I did adapt all right.

So that's life for me. Easy come, easy go. Barring a change, Jay, I'll be just like I am. Hopefully, I'll get to the point where I can sit up.

Social Comparison in Institutional Context

Countless social comparisons can serve as benchmarks for where one is in life in residential care, especially for whether a life has ended. This is particularly glaring in an institutional context, as there are so many sources of comparison immediately available for benchmarking. I often heard such comparisons in fieldwork conducted in the early 1980s in support groups for the home caregivers of Alzheimer’s disease sufferers. The institutional bearings of the Alzheimer’s disease movement were looming in importance at the time (see Gubrium, 1986a). The movement’s aim, in part, was to construct the failing mind in old age as a disease, rather than just a normal part of aging. As a disease, it justified professional intervention and institutional management, not just continued family living.

Part of that study dealt with how family members benchmarked the difference between normal forgetfulness in loved ones cared for at home, otherwise called “benign senescent forgetfulness” or BSF, on the one hand, and Alzheimer's disease (AD) or senile dementia, on the other. The difference centered on whether those affected continued with lives only compromised by BSF or were now the “empty shells” of what they once were and whose lives had ended for all practical purposes. It was a significant divide to cross and could be heartbreaking, because the new understanding framed the experience in question as leading to the end of life, if not living. To figure that someone loved and intimately cared for had become “the mere shell of a former self,” was to conclude that that person’s life was over, the moral consequences of which were deep and often frightening.

According to a growing number of caregiver guidebooks, widely available informational brochures, and the seemingly endless messages communicated and caregiver newsletters distributed in local chapters of the Alzheimer’s Association, being an empty shell was no life at all for either the AD sufferer or the caregiver. The received wisdom was that, in time, nursing home placement was the only reasonable course of action for an empty shell. It would not only “realistically” recognize the end of life for the disease sufferer who was “no longer there” and required institutional management, but also did not cause the caregiver to be the disease’s second victim. For family caregivers, recognizing that “it’s time” (for nursing home placement) avoided the risk of their own lives ending.
End-of-life communication in the support groups for family caregivers interlarded the family home and institutional placement. Participants not only were ensconced in home care but also had varied degrees of knowledge about AD and spoke poignantly about what it would mean for themselves (respite) and their loved ones (life as empty shells) to live in a nursing home. As will be evident in the following illustration reconstructed from field notes of the proceedings of one of the support groups studied, discerning the end of life was anything but straightforward. Comparisons of home care experiences could be as contentious and emotional as they were earlier in Alec’s interview and during his family’s departure one evening following a nursing home visit. Benchmarking navigated its way between what participants had learned about AD from professionals, were persuaded to think, or had read on their own, on the one hand, and what they believed they knew and deeply felt from the personal experience of caring for a loved one at home, on the other. In such circumstances, the end of life not only was benchmarked comparatively but also was dyadic. The moral contours of one life ending (the AD sufferer’s life) were profoundly linked with the moral contours of another life ending (the home caregiver’s life).

Participants in the illustration are the caregiving spouses of AD sufferers. They are well acquainted with each other, are generally friendly and supportive, and speak openly about their circumstances and the decisions they either have made or are being confronted with concerning continued home care. Here again, the benchmarking presented is not just a set of anecdotal details, but a lived microcosm of the institutional complexity of social comparison. At one point in the proceedings, as participants compare each other’s home care experience, attention turns to the mental status of caregiver Rita’s husband, George. One of the other participants asks Rita how she feels about George’s “very demented” behavior of late. Earlier in the meeting, Rita had described her husband’s increasingly troublesome “wandering,” his growing incontinence, and his inability to communicate properly, which had generated lengthy discussion. The following extract begins as the conversation returns to George’s home care. Rita is admittedly puzzled and states,

I just don’t know what to think or feel. It’s like he’s not even there anymore, and it distresses me something awful. He doesn’t know me. He thinks I’m a strange woman in the house. He shouts and tries to slap me away from him. It’s not like him at all. Most of the time he makes sounds but they sound more like an animal than a person. Do you think he has a mind left? I just wish I could get in there into his head and see what’s going on. Sometimes I get so upset that I just pound on him and yell at him to come out to me. Am I being stupid? I feel that if I don’t do something quick to get at him he’ll be taken from me altogether.

Another participant, Cora, responds immediately. As if to say that the continuation of life and not just living depends on maintaining the semblance of a life in
your “heart of hearts,” Cora explains that the end of life is as much others' moral obligation as it is an individual decision.

We all have gone through it. I know the feeling, like, you just know in your heart of hearts that he’s in there and that if you let go, that’s it. So you keep on trying and trying and trying. You’ve got to keep the faith, that’s it’s him and just work at him, ’cause if you don’t...well, I’m afraid we’ve lost them. That’s Alzheimer’s. It’s up to the ones who care because they [AD sufferers] can’t do it for themselves.

Other participants question the wisdom of “keeping the faith” that life has not ended for sufferers like George. While support group participants can be supportive, they also are not mere puppets of received wisdom, professional or otherwise. The received wisdom in question is the familiar refrain that once a sufferer has become the proverbial empty shell, it is reasonable to conclude that life is over for the sufferer and to seek institutional care. There was as much contested in the groups studied as there was agreement on this matter. If this institutional wisdom was a continual communicative resource, it also was continuously open to differential usage. One of the participants, Jack, whose wife, Louise, suffered from AD at home, soon asked Cora whether she would not feel foolish to realize that all her faith and effort were for naught because, as he claimed about Louise, “She’s like the living dead,” adding:

That’s why I’m looking for a nursing home for her. I loved her dearly but she’s just not Louise anymore. No matter how hard I try, I can’t get myself to believe that she’s there anymore. I know how that can keep you going, but there comes a point where all the evidence points the other way. Even at those times—which is not very often—when she’s momentarily lucid, I just know that’s not her speaking to me but some knee-jerk reaction. You just can’t let that sort of thing get your hopes up because then you won’t be able to make the kind of decision that’s best for everyone all around.

At this point, Cora interjects, challenging Jack by raising questions that could be metaphysical if they were not so ordinary. The whos and the whats of the matter rise in comparative tension and institutional bearings to become an existential dilemma.

Well, I know what you’ve gone through and I admire your courage, Jack. But you can’t be too sure. How do you really know that what Louise says at times is not one of those few times she’s been able to really reach out to you? You don’t really know for sure, do you? You don’t really know if those little plaques and tangles are in there, do you? I hate to make it hard on you, Jack, but I face the same thing day in and day out with Richard [her husband]. Can I ever finally close him out of my life and say, “Well, it’s done. It’s over. He’s gone.” How do I know that the poor man isn’t hidden somewhere, behind all that confusion, trying to reach out and say, “I love you, Cora”? [Weeps]
The Everyday Accountability of Institutional Models

If it was not explicit in the preceding extracts, support groups participants, including Rita, Cora, and Jack, knew of and referred to a popular five-stage model framing the end-of-life experience of AD caregivers. It was an adaption of the Kübler-Ross (1969) five-stage model of dying, with the last stage referring to the caregiver giving up on home care and seeking nursing home placement. Whereas there were different views of the model’s applicability, it was, nonetheless, a part of home care benchmarking culture. Participants in support groups were continuously accountable for why they did or did not follow the model in benchmarking the end of life for themselves. Being communicatively accountable meant that, regardless of personal preferences, when the issue of the model’s applicability in particular cases was raised, participants were expected to account for the reasons their own or the sufferers’ experience did or did not conform to the model’s designated benchmarks. In everyday accountability, the model presented itself to caregivers as a pathway to alternative futures—one foreclosing “any life I have left of my own” with continued home care, and one “returning to my life” following institutionalization.

Another popular model for benchmarking the end of life is a resource that cuts across the health care landscape in general. This is the typical signs-and-symptoms model present in what Lester King (1982) calls “medical thinking,” and adapted to the end of life. Signs refer to what professionals look for in arriving at diagnoses, while symptoms are what patients or sufferers report or complain of. The hospice movement especially has taken this approach in describing the stages of the end of life, providing widely available lists of the usual signs and symptoms of dying for both professional and lay consumption (see Szabo, 2010, chapters 18 and 25).

If this model also was not referenced in so many words in Rita, Cora, and Jack’s preceding exchange, everyday lay communication about the “signs” (medical thinking’s “symptoms”) of the end of life were legion in the AD support groups. Indeed, inasmuch as everyone is somewhat familiar with medical thinking, the model has a lurking presence in all groups. Time and again, for example, support groups’ participants both discussed and argued about whether the AD sufferers they cared for showed signs of the end of life, some comparing professional opinion with their own sensibilities. When Jack described Louise’s actions as “not her speaking to me,” he implicitly referenced an absence of signs of a former life in his still living wife. According to Jack, Louise was now completely incommunicative and just living. In contrast, what Cora sensed in her interactions with her husband, Richard, was a life that was no longer able to reach out to her and say, “I love you, Cora.” In their respective accounts, the same what were light-years away from each other in meaning.
Like other *whats* of benchmarking, if such models and lists are clear-cut combinations of physical and behavioral indicators, they are, nonetheless, continually subject to the practical vicissitudes of everyday reckoning. Lack of communicativeness, for example, appears to be one of the most frequently listed benchmarks of the end of life, ostensibly evident in observable conditions such as losing interest in others, focusing inward, and feeling less need to talk. Some lists are divided into conditions that sequentially benchmark the so-called pre-active and those that benchmark the later active phase of the end of life. But, if the signs-and-symptoms model and its lists are widely known, accepted, and applied, the general pattern is that they are working *whats*, variably accountable in practice.

**CONCLUSION**

Across the landscape of long-term care, there is empirical warrant for concluding that life can end at different times, with time itself losing its linear bearings. As the first sentence of King’s *The Dark Half* (1980) suggests, like the start of life, life’s conclusion has variable and variegated endings. The illustrations presented above are just the tip of the larger world of life endings. The end of life is as changeable as the communicated spaces that populate that world, from chance encounters and ordinary chitchat to the venues of going concerns such as support groups, nursing homes, and hospices. Both in time and in space, there are more life endings in practice than physical living and dying can possibly indicate.

What *The Dark Half* does not broach is that, in today’s world, the shape of life communicatively navigates discernible networks of concern. The start and the end of life are hardly a matter of individual reckoning. Inasmuch as we have always lived in relationships, it would be difficult to imagine that ever being truly the case. In a world of going concerns, it now is especially hard to imagine. Whether or not one is physically alive or dead, countless others, perspectives, models, and institutions refer to and serve to construct the shape of life. More and more, in discernible settings and at regularized intervals, those considering the end of life are encouraged to speak of, and reflect upon, their own dying and that of others. The end of life does not just happen. It is communicatively and institutionally assembled into being, locally contingent, and, as the case might be, similarly challenged and undone.

This provides two directions for future research. Centered on the *hows*, one direction is to explore other communicative mechanisms for constructing the end of life. In their work, Pollner and McDonald-Wikler (1985) identified six communicative mechanisms, one of which was described earlier. An additional mechanism, the one under consideration in this chapter in relation to the end of life, is benchmarking. It is entirely possible that each of the mechanisms identified
by Pollner and McDonald-Wikler for everyday communication with a severely retarded child would apply to the communicative construction of the end of life, extending the *hows* of end-of-life communication well beyond benchmarking.

A second direction for future research centers on the *whats* and *whos* of communication at the end of life when specific institutional contexts are taken into account. In a growing world of going concerns, resources such as personal history, others’ experience, and local cultures are likely to vary in pertinence from one institution to another. Comparing the institutional usage of particular resources should provide promising findings on the specific institutional *whats* and *whos* of communicative practice on this front. One hypothesis to consider, for example, is whether constructions of the end of life in home care differ significantly and, if so, in what ways from constructions in a hospice. While I suggested earlier that cultural resources for constructing the end of life resonate across the broad spectrum of long-term care, its specific patterning should be subjected to systematic comparative analysis.

**NOTES**

1. In an edited book dedicated to the exploration of a narrative gerontology (Kenyon et al., 2011), Mark Freeman (2011) refers to this as “narrative foreclosure,” noting that the phenomenon is not restricted to later life. Compare, for example, Cassandra Phoenix’s (2011) chapter in the same book, which addresses the phenomenon as it is expressed among athletes and bodybuilders. Also see Carol Rambo Ronai’s (1992) article on the aging table dancer.

2. This chapter includes the home as a venue of family care for increasingly frail elderly. It is in regard to the associated increasing burdens of home care for family members that Tobin and Lieberman (1976) argued that institutionalization and the nursing home were becoming the “last home for the aged.” The growing legion and professionalization of home health workers complicate this, especially as care takes place in the households of families who can afford this form of care, in which case the nursing home may not be a last home for the aged. See Eileen Boris and Jennifer Klein’s (2012) book *Caring for America* for a history of this long-hidden facet of long-term care.


4. See chapter 3 of Lester King’s (1982) book *Medical Thinking* for a presentation of this resource.

**REFERENCES**


