

Chapter 2

Time as a Concept in Caregiving

Abstract We have expectations about time and our health. People who have encountered and taken advantage of “the goodness of time” also seem to find peace and comfort in their dying. Seemingly they have few regrets and feel that they have lived successful lives. They used time to benefit themselves and others and have no reason to be regretful or angry about its finality. Examples are offered of how some people “fit living into dying,” while others resent the intrusion of dying in their lives. Perceptions of time change when we become ill and are dying.

Keywords Culture and dying • Expectations about time and our health • Perceptions of time • Social support systems

Life is about experiences and relationships. It is what happens when we connect with other people. It is the accumulation of these connections that we call a lifetime in Western cultures. We experience life events and relationships embedded in time. However, not all cultures live with time as we do. Often, when we are immersed in our own culture, it is difficult to understand how people from other cultures perceive our culture, customs, and way of life. In addition, some aspects of our culture are so engrained in our minds and so commonplace to us that we begin to feel that they are universally accepted. One of these cultural variables is how we perceive time. Time has a big effect on interpersonal relationships in a society. In the U.S. for example, life events are embedded in time while the people of Piraha, Brazil, living in the Amazon have no concept of time beyond the present so the concept of future for them doesn't exist. There is no past tense in their language, because everything exists for them in the present. The Piraha's view is in sharp contrast to Americans who often talk of not having enough time and, indeed, may have lingering regrets about not having spent quality time with their families in the past. The Piraha's have no regrets. The core of their culture is simple: “Live here and now.” All experience is anchored in the present. Whatever isn't important in the present is quickly forgotten (Levine 1997).

Another South American Amazon people, the Aymara, have had little exposure to outside forces that conflict with their traditional view of time. Aymara culture and

language emphasize the eyewitness point of view, which is literal and straightforward. It's based on the fact that you know where you have been, but you can't know where you are going. So they imagine the past is in front of them where they can see it and the future, which they haven't seen, is behind them.

There are other cultures that can be referred to as "people who live outside of time." The Amondawa tribe, also living in Brazil, does not have a concept of time that can be measured, counted, or talked about in the abstract. Rather they live in a world of serial events, rather than seeing events as being embedded in time. Researchers also found that no one had an age. Instead, they change their names to reflect their stage of life and position within their society, so a little child will give up their name to a newborn sibling and take on a new one. In the U.S. we have so many metaphors for time and its passing that we think of time as "a thing," i.e. "the weekend is almost gone," or "I haven't got the time." We think such statements are objective, but they aren't. We create these metaphors, but the Amondawa don't talk or think in metaphors for time. For the Amondawa they are not time bound or pressured by time. They don't have words or numbers to convey time as an abstract, measurable thing. Time has more to do with experience; and they enjoy freedom from the social expectations that certain life events should occur at certain times or life stages, like the age to marry or begin a family (Palmer 2011).

At the other extreme, the U.S. and many of its Western friends have cultures that are run by time and not surprisingly have the fastest pace. Most people in the U.S. would probably say that they feel rushed. It may be that the ideals and future hopes of American society drive people to be constantly hurried, to reach certain goals by specific times. The epitome of success, luxury, and happiness, often regarded as an illusion, but is a fact, pressured U.S. citizens to constantly do more, earn more, consume more, in order to achieve more. Therefore, for many Americans, free time is less available and, when it is, we often engage in structured competitive activities such as sports, racing etc. Indeed, in the U.S. people are publicly acknowledged and rewarded for being effective managers of time and exceeding expected productivity goals within certain time constraints. As the saying goes, "time is money!" As such, in the U.S., relative chronological boundaries are assigned to life stages or phases, which signal societal expectations regarding marriage, first job, children, stable career and earnings, and retirement. These boundaries, however, can be amended by unexpected forces which delay or permanently change personal and family career goals. Nonetheless, societal expectations regarding time progression along the life-cycle is a force to be acknowledged in a time-driven culture. For example, illness or an accident can delay marriage or having a family and disrupt the "normal" lifecycle progression expected in our society.

In the U.S. and similar time-driven Western cultures the "end of life review" of accomplishments, satisfactions, connections, and wishes often occurs when a person receives a terminal diagnosis. A life review, often used by hospice professionals, can occur spontaneously or it can be structured, it can be painful, but therapeutic, and can culminate in serenity and acceptance of the life one has lived (Jenko et al. 2010).

In Western cultures life reviews are often focused around an individual, but it can take many forms from sharing family histories to healing family conflicts (Remen

1996). Of particular importance is the opportunity to recognize with personal gratitude those persons who have made great contributions to one's life. Time is no longer a constraint to forgiveness and quality time. It is "free" time to examine and appreciate our connections. This freedom is often best experienced in the safe and supportive environment of a self-help group.

It was in a self-help group following her father's death that Betty confessed that she felt so alone although she had lots of relatives. "I feel so disconnected," she said. "Although I come from a big family it was my father who kept us together. He never forgot anyone's birthday; he would pick up the phone to congratulate someone on an accomplishment or write a note to tell someone to have a good day. He was outgoing, always optimistic, happy with a warm smile and a great heart. I didn't do those things. I was quiet and reserved and spent my time developing my career. Now I feel like an orphan. At this stage of my life I don't know how to connect with my own family!"

The group replied, "Connections require commitment. It takes time to connect—you have to decide that it's important and spend time connecting. To enjoy the benefits of connections you have to initiate connections. In order to be loved you have to show love. Too often we realize this too late in life, but there is never a lost moment to connect with others. It is the process of connecting that is important. The benefits will flow from your efforts. Every second of life counts—it is too late to wait until your dying seconds to live your life."

Our perceptions of time change when we become ill and are dying (Neuhaus 2002). We can become disconnected from our environment including family and friends when we no longer have the energy and commitment to maintain our connections and may slip into periods of withdrawal and depression (Cacioppo and Patrick 2008). We need to rely on caregivers who become gatekeepers for deciding with whom we spend our remaining time.

Nearly everyone who is involved in the care of an aging family member experiences grief, although they may not be aware of it. Grieving a loss before it occurs is called "early or anticipatory grief" (Allen 2012). This is a normal process of trying to prepare oneself for the death of a loved one. Anticipatory grief doesn't usually take the place of full-blown grief when the loss occurs. When patients have illnesses over a period of years the outward expression of caregiver grief may appear to be minimal to outsiders, while the survivors' covert reactions to the loss are deeply internalized (Cacioppo and Patrick 2008).

The Limits of Time

Time is paradoxical. Henry Austin Dobson, in 1887, expressed it, "Time goes, you say? Ah no! Alas, time stays, *we* go." For most of us time is viewed as a commodity. We try to organize it, manage it, save it, and remember it. Time is elusive. We seem to either have too much or too little of it, and it moves with speeds that leave us unhappy about both its deficiencies and its excesses. Time seems oblivious to our

wants and needs. Time goes on and persists unscathed from our human efforts to control its quantity and quality.

Our personal experience with time also influences our feelings about it. Time is fickle. Sometimes it is our friend, at other times it is our enemy. How we use time influences the outcome of our life experiences, both our accomplishments and our failures. How we evaluate time is closely tied to its meaning in our culture and varies with age, education, gender, and socioeconomic status, and the attitudes of our family, friends, peers and coworkers. How we view time and use it changes as we live our lives. A major lesson we learn about time is that it is a process; it stays and we go! There are multiple dimensions of time, for example there is eternity or time-less time. But our personal time has limits. One of the indicators about the possible quantity and quality of our remaining time is our health. How we use the time and cope with stress, our environment and unplanned events determines the quality and quantity of our lives (Sobel 2004).

Health is a barometer of time. Our health makes us look and feel younger or older than we really are. Older people feel, on average, about 13 years younger than they really are according to a six year study of aging among people between 70 and 104 conducted by the University of Michigan and the Max Planck Institute for Human Development in Berlin (Baltes and Mayer 1990; Baltes and Mayer 2001; Baltes et al. 1993). The aim of the study was to gauge whether the aches and pains of getting older force us to face reality, causing our subjective age to finally catch up with our chronological age. The study found that the very old feel younger than they really are, especially those individuals who were particularly healthy and active. How we feel about age is important because it defines how we act and is associated with our attitudes of hope and well-being (Hirst 2005).

Although we typically think of ourselves as younger than we really are, the study found that most people are not in denial about the aging process. During the course of the six year study, people were asked about their perceptions of age three times. The subjective age wasn't frozen in time, and instead aged with the years. Although the gap typically remained the same, the difference between chronological age and perceived age did begin to narrow as people became less healthy and drew closer to death.

We have expectations about time and our health. Our personalities reflect how we think and feel about our age and health. The effects of aging are both internal and external, nonetheless we pay more attention to the changes we can see. Yet, we have a sixth sense about how time has affected our minds and bodies. We seem "to know" when something is not right with our health. Maybe it's the sudden onset of symptoms, or a comment from a family member or friend about a change in our color, appetite, or energy level that makes us aware of the effects of time on our bodies. While some of us are inclined to deny or dismiss the effects of aging, and delay seeking a medical opinion, others immediately go for an exam. Doctors, after all, intervene to lessen the negative effects of time. They remind us of our accountability for the long-term care of our bodies, minds, and spirits. Not everyone has been a good steward in caring for their health and well-being, therefore, the doctor is not a favorite person on our list of persons to visit.

That was the case of Frank, who had not been to a doctor for several years. Frank had lived 69 years with only minor ailments and no major surgeries. He was overweight and didn't worry about his diet or exercise, but he did have one habit that was beginning to show some physical effects. Frank had inhaled a pack or more of cigarettes a day for the majority of his life, however he had stopped smoking when he retired at age 65. Getting away from the stress of work helped him quit, he said. He had always had what he called a "smoker's cough," experienced shortness of breath, especially with physical activity, a mild degree of wheezing when he breathed, and most recently, tightness in his chest. One Saturday it was the tightness in his chest that he thought was a heart attack that caused him to visit a hospital emergency room. Detailed examination and lung function tests found that Frank had minimized other symptoms such as increased swelling in his ankles, recent weight loss, and lower muscle endurance. He was admitted to the hospital. Frank was diagnosed with severe chronic obstructive pulmonary disease (COPD).

Frank's medical history stated that for many years his symptoms were mild; some he didn't notice or made adjustments in his lifestyle to accommodate them. For the most part Frank had attributed changes, for example, in his decreased mental alertness as signs of aging. Now his symptoms required treatment in a hospital. Frank and his family were told that there was no cure for COPD, that it was progressive and terminal, and would require changes in his lifestyle, such as the use of portable oxygen, not driving a vehicle, and the use of a walker to steady his gait. He would be able to be cared for at home by his family until the recommended treatment for symptoms, that were progressively getting worse, were no longer working. The prognosis of less than one year to live came as a shock to Frank and his family. They were expecting to hear something more hopeful. As they heard the news they knew that all of their lives would be changed. Their sadness and anger prevented them from asking questions. Could the doctor be wrong? Would a second opinion be more hopeful? Was there an experimental treatment that might work or an alternative healer who could talk of hope? How could the news that the person they loved had only a few months to live be real? After all, Frank looked healthy.

Frank and his family drove home in stunned silence. Frank had not felt right for the past year, but had kept his thoughts to himself. He was not prepared for such a short prognosis. He was a person who accepted the fact that, as a male, he might die before his wife, but he never took the time to discuss such an event with his wife. Therefore, Frank had no will, power of attorney, nor had he talked about his end of life wishes, or made any preparations. Now the doctor had explicitly told Frank and his wife to do so.

Frank lapsed into a depression soon after his hospital stay and lost enthusiasm and energy. With the encouragement of his wife they talked openly about what Frank would like to do with his time. He liked the computer, keeping in touch with family and working on the family genealogy. This sharing and networking activity raised his spirits especially as it opened up the opportunity for virtual and face-to-face visits from forgotten or newly-found relatives. Indeed, the entire family environment was transformed from one of gloom to one of optimism and enjoyment, which facilitated

the enjoyment of all in planning an end of life celebration for Frank that centered around his wishes.

In addition to facilitating greater family cohesion, Frank's illness also caused family members to become more aware of their diet, weight and daily health habits such as exercise, sleep and stress management. The entire family had become fully involved in Frank's caregiving. To prevent caregiver burnout Frank agreed to enroll in a local hospice that provided at-home care including a nurse who monitored vital signs, medications, and equipment needs, a nurse's aide who helped Frank in his activities of daily living, and a hospice volunteer who became a friend and provided weekly respite for Frank's caregivers. Indeed, hospice provided an additional layer of social and emotional support for the family. Time became less of a burden as the extended social network embraced Frank and helped maximize his quality of life. Frank died peacefully, as the family held his hands and the family dog lay at his feet, just as he had wished.

Time is a measure of the quality of our lives. Time shapes us from birth to death. There is some truth to "being in the right place at the right time." Opportunists and optimists are particularly skilled at sensing the "right" time to intervene to seize the particular benefits from situations and people. They seem to make time work for them in positive ways. Indeed, life's successes are often due to the degree of astuteness a person has in understanding that time never repeats itself in the same way. Success is the accumulation of select moments in time, which, in turn, create other select moments. Time is a process so we can't go back and relive it, or save it. Regrets are missed opportunities in reading time.

On the other hand, people who have encountered and taken advantage of "the goodness of time" also seem to find peace and comfort in their dying (Buchwald 2006). Seemingly they have few regrets and feel they have lived successful lives. They used time to benefit themselves and others and have no reason to be regretful or angry about its finality.

Fitting Living into Dying

Mary's motorized wheelchair conveyed her strong feelings about being independent and active. At age 97 she lived in her own apartment in an assisted living facility. Her weekly schedule of talking with family, visitors, bridge, entertainment events, and spiritual time, was a denial that congestive heart failure was applicable to her. She did acquiesce to the part-time assistance of a helper who prepared meals and arranged transportation to medical appointments, but insisted in being in charge of her life. After a recent hospitalization her family was unsuccessful in getting her to talk about her wishes for the end of her life. Whatever preparations she had made she kept to herself.

Her bed seemed insignificant in the room where she spent most of the day where a desk piled high with papers, correspondence, and pending fiscal matters was readily accessible to her. The bedroom walls were covered with pictures of

family members—her late husband, sons and their families, significant events of the grandchildren, including pets, all conveying loving memories, smiles of happiness, and gratitude for her support and contributions to their lives. In between the pictures were small plaques of religious quotes and sayings conveying hope and the importance of a positive attitude in life.

She looked forward to each new day. It was part of each day's routine that she get connected with her portable oxygen, put in her hearing aides, find her glasses, put on make-up and get settled in her wheelchair before she started a conversation—which was always a question about how the other person was doing. She didn't wear a watch and there were no clocks within sight to make time important. Her stamina determined the frequency and duration for visits. Pain, fatigue or her disease were never brought up as topics for conversation.

Mary fit living into her dying. The progressive effect of age, rather than illness, was a challenge to living a full life. She never talked about death, her fears (if any) or beliefs; she lived as if life was a seamless progression of events to be shared and remembered. So it was, she died alone during her sleep, in her bedroom, with her artifacts of a life fully lived.

The diagnosis of a chronic, progressive disease brings out the pessimism or optimism in people. Pessimists seem to give into their disease concluding that their future plans are limited and there is little hope since there is no cure for their disease. Optimists, on the other hand, conclude that there is always hope and each moment should be lived as if it were the last. Indeed, some believe that retaining a zest for life, and being grateful for their life so far, are strong enough to make plans; they may realize some of their dreams and goals. A progressive, chronic disease need not be a death sentence. Diseases, like the individuals who have them, have different attributes that make them unique in their effects and consequences. We have all seen the variability of the progression of chronic diseases; likewise we have all seen patients surrender to their disease, while others become motivated to fight even more.

Much of our attitude toward disease is influenced by our social support system. If we face our illness alone, we feel its effects more keenly—when there are not others who can provide encouragement and hope. If we have a strong support system, which includes visitors, cards, and family taking the patient out for a visit to a park, a ball game, or a restaurant, we feel more connected and hopeful. Hospice personnel, especially volunteers, can be a reliable source of friendship and support (Sheehy 2010).

Illness affects our perceptions of time and what to expect from it, yet we all have the same amount of it. The use of time is very personal, some people feel chronically robbed of time, while others have time on their hands. Our views about time and how we use it change as we age and our lives fill up with new responsibilities and demands. We still have the same amount, we merely value time differently and portion it out to meet new and changing priorities. Therefore, a terminal illness can change the length of a life, it need not change our attitudes towards life or how we live it. It is possible to fit living into dying.

And living, despite the limitations of his various illnesses, was what Bob was determined to do. He was not sure what being a newly admitted hospice patient was

all about; it was his new doctor and wife who convinced him that hospice would provide a wider range of services than where he had been enrolled and unhappy. He especially liked the option for a volunteer to provide respite for his wife and he could continue to live at home. Several falls precipitated a concern about Bob's safety; he needed a walker to support his slight frame and unsteady gait.

In his mid-seventies, Bob had a varied career as a business owner after his service in the Air Force. He enjoyed telling stories about WWII, especially the time he met and married his wife. His long oxygen line permitted him to retrieve several models of various airplanes which have a prominent place in his bedroom. He cups his right ear and leans forward to engage in a conversation while telling the listener he can't read due to macular degeneration. Bob is also a lung cancer survivor; he says he smoked as much as five packages of cigarettes a day for most of his life. He now has Chronic Obstructive Pulmonary Disease, but sneaks a cigarette on the patio when his wife is out running errands.

Bob's pleasures in life are travelling, gambling, and good restaurants. He and his wife have enjoyed many vacations to Europe. Visits to casinos are feasible for a few hours of blackjack a few times a month as long as his stamina holds out, which is determined by whether he is winning or not. And Bob and his wife also enjoy weekly visits to restaurants. The closeness of the family is evident in the numerous pictures of their children and grandchildren that are grouped along the walls of their living and family rooms.

Bob's dry sense of humor helps him keep his emotional balance. He humors his wife who he worries about because she is so protective and caring of him. Bob says his wife needs the respite and can get out of the house to be with her friends.

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