Anticipatory Dying: Reflections Upon End of Life Experiences in a Thai Buddhist Hospice

Abstract

Death and dying offer an important paradox for investigation. Both are feared and to be avoided but also generate considerable reverence, curiosity and mystery. The latter is investigated through thick ethnographic data collected in a Thai Buddhist hospice and the following pages provide some description of an alternative cultural-spiritual framing of anticipating death. The former part of this paradox is explored using detailed autoethnographic-autobiographical data arising from the cognitive-emotional conflict between the researcher’s cultural schemata and the phenomena in which the research process is embedded. Sociological speculations are offered as to the value and insights of this methodological approach and to anticipating dying as an important phenomenon for further inquiry into everyday social life.

Keywords

Autoethnography; autobiography; palliative care; cognitive sociology; death and dying

Introduction and research rationale

Death remains a powerful mystery; one that we usually prefer to keep far from our everyday preoccupations. So I was surprised a few years ago when by chance I came across a short documentary about Thai school children visiting a Buddhist hospice in northern Thailand. I was struck with the sparse conditions of the hospice and apparent calm of the emaciated people as they anticipated their soon to arrive death. As I watched the film I soon realized that these children were visiting the hospice as a school field trip to learn about Buddhist views of the impermanence and value of life. They, without any apparent awkwardness, talked with the dying about their lives and how they are experiencing the end of life. I was drawn to how bizarre this activity is within our cultural framing of dying, especially with the exposure of presumably innocent children to perhaps the most fearful of life experiences. Rather than being avoided, mortality and the associated suffering, was being embraced as...
an important lesson for engaging life. Are these lessons also accessible to us and if so what insights can they bring?

From our cultural vantage point, some have questioned whether we are the only species to know our biological death, there appears to be little debate that we are alone in having a clear awareness of death as an individual and universal phenomenon. Understandably then, questions about our mortality and its mysteries are therefore ubiquitous. Typically, dying and death are to be feared, resisted, managed, and of course avoided. Modern western hospice and palliative care innovations have been natural companions to developments in medical sciences, integrated professionalism, and a wide variety of concerns about dying. This article draws from selected ethnographic data collected as part of a three-month investigation of end of life experiences of the elderly at a Buddhist hospice in Thailand. However, the following discussion includes selective attention to three interdependent themes. First, a description of a Thai palliative care facility is offered to add to our growing cross-cultural understanding of end of life. While some may view these data as unconventional in length, I ask for patience. My intention is to offer a “thick” description so as to invite the reader into the experiences described and therefore a more “authentic understanding” (Denzin, 1989a). Second, I attempt to document some of the methodological shifts and personal experiences of the researcher during data collection of anticipatory dying in a disparate structural and cultural context. Here the lengthy introspective ethnography is used as a vehicle to facilitate Verstehen moments between the reader and the research process, as a way to invite the reader into the ecological milieu of the data so as to access the flavor of the interactional dynamics between self, cognition, and culture (Lyons, 1986). Third, I speculate upon some of the cognitive-emotional culturally embedded insights into social life offered through this type of sociological inquiry.

Substantial research has been undertaken in the past four decades with the purpose of establishing patterns from which to classify dying processes. Kubler-Ross (1969) and Buckman (1993) illustrate the developmental approach to dying. Glaser and Strauss (1968) contribute with more focus placed upon the context and implications of awareness of these processes of dying. Corr (1992) continues the emphasis upon the psychosocial context of the experiences of dying as they affect the person dying, their families, and medical staff with Sudnow (1967) offering an ethnography of the social organization of “passing on”. Notwithstanding the contributions of these undertakings, it is the dying persons who are in the most instructive position to provide insights into structured patterns of dying as well as its various forms of heterogeneity that underlie the human experience of end of life. These insights may well serve platforms from which hospice and palliative care arise. And, toward this end I focus my discussion upon cultural and spiritual intersections of end of life experiences. Cultural contexts have a significant impact on cognition, belief systems, and therefore the construction of meaning. Institutional and individual aspects of culture provide schematic structures that organize the information that constitutes our everyday lives (DiMaggio, 1997; Greenfield, 2000; Kitayama et al, 2004). As Pagli and Ambrovitch (1984) outline, the import of cultural contexts for thinking about the significance of death and dying is well established, originating with earlier research on dying such as can be found in the works by Glaser and Strauss. But for the purposes of this discussion, it is spirituality, which serves as the nexus around which cultural belief systems are structured. Albinsson and Strang (2002) note that the Latin origins of the word religion is religio, which translates as “to tie together” and they therefore argue that spirituality/religion occupies a core existential dimension around which meaning and meaninglessness revolve in palliative care
philosophy. The following discussion undertakes to offer a glimpse of end of life spiritual belief systems as they unfold in everyday occurrences within a Thai Buddhist hospice and an introduction to some the instructions this phenomenon may offer researchers and readers from disparate cultures where death and dying is so differently framed.

Methodology

This project was initially conceived as a means to learn of end of life experiences from persons who appeared to approach mortality differently than we do in our culture. My first approach was ethnographic interviewing. In order to limit contamination from the presence of myself, as a foreigner, and Jai dii as the interviewer and translator, my interview strategy was guided by existential-phenomenological parameters (Brockman, 1980; Albinson and Strang, 2002). Our interviews borrowed from phenomenology in that they attempted to describe and explore present internal states as they “appear.” And the interview process also included an existential mode so as to remain vigilant to the lack of reason, presence of spiritual reflection, emotion, and the non-linear aspects of the struggle for meaning as the participants faced the void of non-being. So, similar to Werth and Bleven’s study (2002), each of the thirty interviews began with only one general question: “When you think about your own dying and death, what comes to mind?” This one question was intended to open a channel to some of the complexities that make up the phenomenon of anticipatory dying. Selecting an interviewer was therefore done with considerable care, caution, and some good luck. I interviewed four persons who replied to my calls for someone who had some university education and was fluent in Lanna (the local dialect), Thai, and English. Unfortunately none of these applicants seemed suitable but during the interview process I was introduced to Jai dii who had not initially expressed an interest in this position. Jai dii had all of the qualifications I had hoped to find, plus he had been a monk so was therefore familiar with many cultural issues of which I was unaware, was already familiar with the elderly in this hospice, and had a very patient and compassionate manner. Jai dii quickly proved to be an astute and sensitive interviewer using only appropriate subtle probing questions to explore some issues in more depth while leaving the direction and content as open ended as possible. Once the interviews had started the participants became quite focused on their interaction with Jai dii and I seemed to fade into the background. My role during the interviews therefore tended to be more of an observer rather than participant’s role because of my restrictions to the English language. As the reflexive nature of my role became more apparent, it became clear that the interview discussion flowed best with no overt participation from me.

Since I had presumed that I would be more active in the planned interview process, my new role of research outsider (once again a stranger) left me somewhat uncomfortable, as it appeared that I had lost control of the interview process. After wondering what to do as I sat passively for hours, I realized that this was not an impotent role, but instead presented important albeit unforeseen learning opportunities related to my questions about end-of-life experiences. First, I was able to have the luxury of the time to make field notes of everyday life in the hospice, a wide range of the elderly, staff, and volunteers. Second, as workers and the elderly became familiar with my presence I was able to sit with many of them not involved in the interviews. I became known as “Dr. Boot” (Bruce is a more difficult Anglo-Saxon name to pronounce in Thai) and treated with warmth. Throughout the hospice and other parts of the institution it became know that Dr. Boot was interested in learning
of end-of-life experiences. So staff would often inform me of when they thought someone not in our interview sample would soon die and invite me to visit these people as they expired. Third, as these events presented themselves I found that more and more of my attention was drawn to my own attempts to make sense of all that was unfolding in front of me. Here the research took a serendipitous shift related to what Wiley refers to as the “shock of recognition” (Wiley, 1987). My methodology came to include autoethnographic field notes so as to record and reflect upon some of my own cognitive, psychological, and emotional experiences as they necessarily unfolded in and as part of the research process (Frank, 2002; Hunt 1989; Denzin, 1989b; Kleinman and Copp, 1993; Ellis, 2004.). It is from these ethnographic and autoethnographic field notes that I draw from, while respecting their limitations (Freeman, 2003), throughout the following discussion regarding selected dynamics of the confrontation of the alleged dualism between the observable world of dying and anticipation of death with the internal experiential world of the researcher. And while these data are limited to but one hospice of its kind, they may serve as a platform for further similar and comparative investigations for extending our understandings to more generalizable claims regarding death and dying in disparate spiritual and cultural contexts.

Sampling

Before I could begin, one of our first pragmatic tasks was to identify persons for the project. Given my end of life research interests, we needed to locate persons who had been identified by visiting physicians and the regular staff as most likely having approximately one month of life left. These people also had to be of relatively sound mind and having the strength and willingness to participate in our project. From the thirty-three elderly, Jai dii was able to identify six people who were appropriate for our interests. He approached each of these people and explained that there was a foreign professor from Canada visiting and that he was interested in end of life experiences. From Buddhist ontology, I was asking to learn about impermanence (anicca) and suffering (dukkha) from their day-to-day experiences. Jai dii explained that I was hoping they would act as my teacher so I might learn of this part of Buddhism and Thai culture so I could pass on these lessons to others in Canada. Fortunately, each and every one of the elderly whose health permitted their participation eagerly agreed to the project and its ethical considerations.

At the beginning of each visit I would meet with Jai dii and ask his advice regarding the state of the elderly. Their availability varied considerably. At times all of the project participants would be weak, in pain, or having other health difficulties so they would be unable to talk with us. On some days only a few would be in such a state so we would talk with those who were willing and able. Other times their health and comfort would suddenly deteriorate and we would terminate the interview. When the elderly were unable to participate in an interview, with their consent we would usually just to sit in silence with them often resting our hands with theirs. Due to these considerations it took three months to collect thirty interviews. Numerous people died during my visits, but for unknown reasons all of my participants remained alive during my three months of visiting, although I have been informed they have all died since my last visit.

The ethnographic setting
The facility used for this project attends to the elderly of northern Thailand whose families are unable to care for them at the end of their lives. It is funded and administered by a government agency and a non-profit organization and hosts about three hundred people in various stages of later life. Those who are able care for themselves reside in two single room buildings, one for the men and another for the women. Their basic meals and medical care are provided for and some recreational activities are offered. Although I was a stranger and the target for considerable curiosity, staff and residents always warmly greeted me in Thai, and with the traditional wai (hands clasped together with palms open and touching) and smiles, as I walked through the home’s walkways on my way to the administration building to meet my translator and interpreter. My interpreter and translator Jai dii (not his real name) was a kind man who used to be a monk, spoke Lanna (traditional Thai dialect of the northern Thais), Thai, and English fluently, was university educated, and was well respected and liked by all persons at the home. He was also my cultural guide, became my friend, and was my trusted research associate.

The beginning of my visit is marked by the transition of walking down a narrow path lined with tropical foliage in the heat of the direct sun. I enter into the low one room green wooden building where those deemed to have only a short time to live have been moved from the two other residential buildings. This building is not referred to with any special name during my visit but it is what we commonly call a hospice for palliative care. The heat, humidity, and urine-cleaning produced odor that sharply draws the attention of my senses as I step through the double doors. The building consists of a few toilets and showers opposite the entrance at the far end of the approximately 30-meter building. The flies seem to be constant visitors and a regular activity involves keeping them at bay, usually with a hand fan (Buddhist precepts do not allow killing). There are four rows totaling thirty-three narrow old grey cots. All cots are visible from any location inside the building. The row on the far left is separated from the others by a low wall where those who are thought to die very soon are often placed. The row on the far right is where most of the men have their cots as most of the elderly are women and therefore occupy two rows of cots. The elderly sit or lie on their cots surrounded by their few personal belongings that share the small space offered by the mattress. Some cots have a bottom sheet but those who are incontinent have only the bare grey plastic mattress. Small images of the Buddha are placed irregularly on the wall above the cots. I am told that some of the men were monks in their youth. The elderly seem to prefer to sit or lie in silence and interaction between them appears uncommon. Small rotating fans mounted on the walls and support beams near the ceiling are always on but seem to have little effect, and the flies remain constant companions. As I enter the building there is an old large TV next to one bed where the staff and volunteer sit as they take time to rest. Donated items, including many packages of adult diapers, are stacked up against the wall closest to the TV. Usually the TV has Thai soap operas playing with various degrees of volume. However, most of the residents seem to pay little attention to the TV. I notice that the TV sound irritates me. I don’t see visitors and I’m told that visits from friends or family are very rare. I only witness one visitor who was the sister of one of the elderly. It is difficult not to think this a depressing, lonely, and even frightening environment during first contact. Time seemed to slow to a crawl inside this place and the elderly appear to be just waiting patiently in silent anticipation. I notice that I find myself also waiting for something but I’m not sure what this might be or involve. Being from a temperate climate I find the heat and humidity exhausting.

Most of my time in the hospice is filled with “waiting”, ironically much like the elderly who appear to be waiting for death. Since I cannot actively participate in the
interviews, I can observe the hospice environment and occasionally move to different locations to look at items and activities. I notice that two of the women appear to be blind. Like most of the residents, they appear frail with only skin covering their bones. One tiny lady next to the hospice entrance systematically feels her way around her bed as if trying to locate some object. She finds her pillow and spends some time positioning it and shifting her body as if trying to be comfortable. Once in position she reaches into a plastic container on her bed and begins to eat small balls of rice. Later she spends time brushing her bed with her hand to seemingly remove any dirt or food from her cot. When she finishes this task she feels under the bed with her hands looking for something. She finds her bedpan and slowly lowers herself on to it. After finishing she pulls herself upon onto the cot and reaches down to slid the bedpan under the bed. She appears exhausted after this activity and lies on her back with her chest rising and falling quickly as if out of breath. Later Jai dii informs me she is also deaf.

Another blind woman occupies a cot near the far end of the room near the toilets and showers. By thinking about previous visits, I notice that she is almost always crying softly and rocking back and forth as she sits holding her knees to her chest at the end of her cot. She regularly tries to adjust the blanket she keeps around her shoulders even though others lie almost naked in this heat and humidity. Every once in awhile her neighbor will become angry at her crying and shout at her to be quiet. She appears not to notice anything or anyone but continues her swaying back and forth and gentle crying. Her crying makes me react with considerable sympathy and I assist her with positioning the blanket around her shoulders. She doesn’t appear to be aware of my presence and continues with her rocking and weeping.

During today’s visit a new woman, now in Mr. A’s old cot, is attracting considerable attention. Her appearance is distinct, with long wild red dyed hair that is unkempt and an angry look on her face. She stares silently at her feet and then suddenly begins shouting loudly and pointing at others in the room, including myself. I ask Jai dii what she is saying and he informs me that she is seeing the ghosts of those who died here and is putting various curses on us. I can’t tell if she is angry or afraid. Jai dii later tells me she is both afraid and angry. Her neighbors try to calm her with soft words from a distance but have no success. She continues shouting and waving her one arm in the air. Her left arm seems not to move but hang limp at her side. She remains agitated during our time here today.

Today the “wild lady” seems quieter with only the occasional outburst. She looks at me for long periods, often tilting her head and muttering something. I decide to go over and sit on the edge of her cot as she begins shouting. She stops shouting and stares angrily at me. As the moments came and went I wondered what she might do. Her stare seems to soften so I gently put my hand on hers. She seems to relax and proceeds to enter into a pantomime conversation with me, something about her life before coming to the hospice, how she had suffered a stroke that caused her to lose the use of her left arm, and the demons she saw in the hospice. I look at her and nod as she held my hand so tightly it hurt. She uses her right hand to lift her left hand and then let it drop, using gestures to let me know she had recently lost the use of her arm and it is frustrating. It dawns on me that one of the odd gestures she has been doing toward me is an attempt at a one handed wai. She stops shouting and remains calm, talking about something in a quiet voice. I motion good-bye to her for the day. After we leave the hospice and ask I Jai dii about her. He tells me that at first she thought I was a dangerous ghost and was afraid but now thinks I am some sort of god who will look out for her, and protect her from the evil ghosts, so she isn’t afraid anymore. It seems that ghosts are taken very seriously here.
I notice today that each time I visit there is a woman who always drags and swings herself along the floor with her hands as if she has no use of her legs. She is always smiling and laughing as she moves among the cots to see if anyone wants to visit. There are few takers, as most people like to sit quietly. No attention seems to be paid to her exposed genitalia and trails of fecal matter that occasionally follow her as she moves about the hospice. I am becoming a bit more comfortable with what I had initially considered odd or even bizarre behavior. I hardly notice this elderly woman’s exposed genitalia as she moves about the floor. Because of their loose clothing, many of the female elderly have their genitalia exposed with no apparent concern or awareness of their body. Others pay no attention to this regardless of the strong adherent so to modesty in Thai society. I feel a warm affection for this woman who drags herself around. She always greets me warmly when I come through the door, always smiling. She seems to like sitting by the front door, apparently for cooler air, where she warmly greets us with a wai and an almost toothless smile. Using Jai dii to translate, I joked that she is the “security” for the hospice. This causes her to erupt in laughter. From this time forward, she always added a short salute to her smile and laugh as I entered the hospice. It was our private joke.

Caregivers

Two middle-aged women are in charge of the administration of care for the hospice. They too always warmly welcome us at the beginning of each visit but do not involve themselves in our data gathering, as they are constantly busy with various duties. The bed next to the TV near the hospice entrance seems to be the spatial centre of their work. There is one elderly lady at the bed next to the TV who appears very ill and requires ongoing attention to feed and clean her, and to move and massage her limbs. I like the way they touch her so much and how gentle they are in putting various feeding objects in her mouth or through an IV. These supervisors usually have about three assistants who respond to any and all calls for attention, usually by a quick one-word shout or a gesture from one of the elderly patients. They always responded quickly and seemed to treat the hospice residents with kindness, patience, and respect. The hospice is also used as a teaching facility (although I do not see any medical staff as I have been asked to visit when they are not busy with their duties). I regularly ask Jai dii about the people, always women, who are visiting at the hospice that I didn’t recognize. Some are social work students doing their practicum but who did not spend much time at the hospice as most of their studies revolved around the non-palliative residents in the other two residences. Some are nursing students doing their practicum. Most new faces belong to young female volunteers visiting when they had a break from high school classes. About half a dozen of them would come for a few hours to assist the elderly. Most of their activities seem to revolve around the personal grooming of the elderly who are generally unable to take care of these needs. The patient and caring pedicures and manicures for the elderly are particularly noticeable. I ask Jai dii about the volunteers and am informed that they have no training but come to help because of the value placed upon the elderly in the community and the Buddhist notion of merit. When they have free time, they gather around the TV to watch Thai soap operas, often laughing, and leaning against each other apparently thoroughly enjoying themselves. I notice that this sometimes annoys me as the noise interferes with recording the interviews. Sometimes I gesture for them to turn the TV sound down or lower their voices and they seem willing to accommodate my requests.
Anticipating death: one case example

My first interview meeting today is with a slightly built frail man (Mr. A). He is surprisingly friendly; warmly greeting me with the traditional wai and without discomfort begins to address the interview question, in Lanna, put to him by Jai dii. We test the microphone and tape recorder and begin. His voice is very soft and calm and he smiles often and chuckles a few times. I am struck by how happy he appears to be given what awaits him in the near future. His few belongings are neatly stacked at the upper left corner of his cot. His arms support many stick like tattoos, which I learn later are symbols used to ward of evil spirits and cobras when he used to work in the rice fields. He claims that they indeed produced their desired effect, as he was never bitten or came to any harm while working in the fields when he was younger. Suddenly, Mr. A becomes quiet. Jai dii said Mr. A has grown very tired because of talking and we should move on for today. Mr. A smiles weakly, looks directly at me giving me a wai and closes his eyes to rest. I compare my rate of breath with his and his appears very shallow. The sudden shift in his energy level catches me off guard and I am left with considerable worry about his health.

This is the second time I am visiting Mr. A. However, when I arrive there is a new person in his cot. I anxiously inquire about his whereabouts and his health. I am told there is a temporary urgent need for a cot for a new person and that Mr. A has been moved to the long-term care men’s building for a couple of days because of the shortage of beds. I ask for directions and find him sitting quietly on his new bed, looking quite sad and staring at his feet, and occasionally rubbing his legs around his knees. His face brightens with a smile and he puts his hands together for a wai as Jai dii and I approach. He seems very eager to talk and quickly engages Jai dii in conversation. As usual I sit at the end of the bed and observe their interaction and this building, which is unfamiliar to me. This is the first time I have been in the men’s residence, which consists of one open room with about forty small beds in dormitory style rows. This room is brighter, with more personal belongings and colored décor, than the hospice. I don’t notice any flies. Each bed has a small locked storage cabinet with large open screened windows, the air is fresh, and I can see an old Buddhist wat (Buddhist temple) a few hundred meters across a green field. The interview with Mr. A almost immediately draws the attention of the other elderly male residents. Three of them slowly come over and stand around us, watching and listening. After only about one minute one of them begins to join in a conversation with Mr. A. Another man soon joins in and they seem to take over the conversation. Their excitement soon leads to a very loud and animated conversation as they share health related stories (as Jai dii informs me). Mr. A is quiet and nods occasionally in response to their comments. I’m not sure what to do as the interview with Mr. A as it has been interrupted. I notice that I am at first annoyed that our interview has been interfered with. So we wait and listen for about fifteen minutes, watching the men chat. Then I turn off the tape recorder and have Jai dii tell Mr. A that we hope to see him again soon. He smiles, makes a wai, and we walk out of the building. Just as we reach the door I turn back to look at him, and he is again sitting in silence moving his gaze from the men as they continue their animated conversation to his bed and then back again. His smile is gone as he is massaging his legs.

My encounter today with Mr. A is unexpected. I notice that he is standing alone with an old walker (mobile walking aid) underneath a small two bench gazebo-like covering on my way to the hospice building. I sense something is wrong with him today by the way he is standing so I bypass Mr. A before he notices me and I go to fetch Jai dii. We immediately return to his location where he is now sitting on one of
the slightly curved cement benches. He offers us a small-subdued \emph{wai} greeting. He appears to be quite agitated. We ask if he would like to be left alone but he insisted that we stay. He begins talking with Jai dii and looks more frequently than usual at me. Unlike his usual calm manner of speaking, his comments came in rapid jerky rhythms. His mouth is shaking and he spasmodically clenches his fists. He is in pain. Tears begin to roll down his cheeks. We again ask if we should leave and come later and if we could assist him back to his bed. He refuses, saying he wants to talk with Jai dii. Mr. A informs us he had been moved back to the hospice but had managed to come outside for air. He constantly rubs his legs; especially his left knee that he said is full of pain today. I notice lines of small black ants, marching over his legs and one arm as he talks, but he appears to be unaware of their presence. In a short time, about fifteen minutes, he is no longer able to talk and we help him back to his hospice bed to wait until the physician can come to the hospice and attend to him. I experienced strong waves of helplessness and other less definable emotions today.

Today we found Mr. A on his new cot in the hospice. After his usual warm greeting, his eyes fill with tears as he talks with Jai dii. His mouth becomes clenched and his voice is harsh. He appears to be quite angry today. After about fifteen minutes his body and voice soften and he returns to his usual smiles and chuckles. However, this too quickly passes and he again becomes angry. When asked if he is in pain today, he says no, the doctor has visited and given him some medicine. His eyes fill with tears again and Jia dii decides it is best to let him rest. We sit in silence with him for about twenty minutes, Jai dii on the cot next him holding his hand while I sit on an old white plastic garden chair next to his cot. His breathing seems more regular (I match it to mine as a gauge) and he appears to become calm so we say our good byes while he looks up at us silently. Today there is no energy for a \emph{wai} to end our meeting. Instead we touch his arm and leave his cot. As we interview the other participants today I look over at Mr. A and see that he is resting and calm. I notice I too am now calm.

**Death moments**

Today as we enter the hospice Jai dii tells me that I may want to go and sit with the woman on the last cot in the partitioned section of the building. I ask why, since we haven’t included her as a project participant. He tells me she will die soon, perhaps in an hour and that I might want to sit with her. After a few apprehensive moments, I sit on the side of her cot. Her breath is shallow and since she is alone I remain sitting occasionally resting my hand on her arm. She appears unresponsive. After about fifteen minutes I return to Jai dii to see how the interview with one of our participants is progressing. One of the staff comes to us and asks Jai dii if Dr. Boot could return to the corner cot as the woman has just died. I notice that a couple of the other hospice residents have now come to her cot and are saying some prayers so I join them. They then leave to return to their cots and I remain behind, standing at the end of her cot. It’s like nothing out of the ordinary has happened, and hospice activities continue. This woman is not covered but is left as she was with the exception of the head nurse closing her eyelids. The man on the next cot sits looking at her in silence and then turns on his side away from her and rests. About half an hour later two men come to her cot and lift her into the rough wooden coffin they have brought with them. They try to gently lift her into the coffin but experience some difficulty doing so, almost dropping her. Jai dii tells me she will be taken to the \emph{wat} (Buddhist temple) next-door and cremated tomorrow. I look around the hospice again and observe no change related to this death event, as if this is a routine event that
warrants no special ritual. The normalcy of this event leaves me disoriented and numb for a while.

Today I meet Jai dìi in his office prior to our interviews. He suggests I visit one of the elderly in the women’s residence. I had not visited this building before so I ask him why we would go there before the hospice. He informs me that there is a woman who will not live out the day and I might want to sit with her. When we arrive three women are by her bed talking amongst themselves and with her. The woman I am to visit seems quite agitated and Jai dìi tells me she is in pain. She appears to be uncomfortably hot and is removing her clothes to cool herself as she gasps for air. I sit with her but unlike others I have sat with she does not like to be touched, perhaps because of the extra heat generated from contact. Or maybe she just doesn’t want me there. She continues to struggle to get cool and comfortable but seems to become only more agitated, twisting and turning, and attempting to fan herself. Jai dìi suggests I leave her after a few minutes. I welcome his suggestion as I am feeling very awkward and out of place with her.

I am feeling more comfortable during my visits now after visiting for what seems like so many times. What was so strange and caused me such emotional discomfort is now more of my taken-for-granted view of things. During my visit today Jai dìi takes me to a woman two cots down from the person who was to be our first interview participant for today. He tells me this woman will probably die soon and that I might want to sit with her during my visit while he does his interviewing. This woman seemed to be quite popular and has about a dozen of the elderly women standing around her cot. I watch them from a distance, sitting in my plastic lawn chair at the end of the cot where Jai dìi is doing his interviews with one of our female participants.

About an hour later the popular woman dies and like others before her, is left uncovered. However, something different unfolds here. The women who have been standing around her cot collectively remove her clothing and gently wiped her body with wet cloths. They place a clean diaper on her, dress her in clean clothes, and carefully comb her hair. They say a prayer and leave her uncovered on her cot. Many of the women stay for about five minutes talking amongst themselves adding more silent prayers. Jai dìi later informs me she has a son who will come for her tomorrow and take her back to their village for cremation. Again, as in all the previous deaths, the hospice quickly slips back to its daily routines as if nothing special or out of the ordinary has just occurred.

Discussion and reflections

My research was guided by interests in end of life experiences in a collectivist and Buddhist cultural context. The main thrust of the project was to use the dying as teachers in order to witness some of the content and range of the elderly’s experiences. And, I intended to take advantage of my observer role in this process, while Jai dìi did the interviews, by undertaking some ethnographic observations. Some of these observational data have been presented in this paper to offer some empirical glimpses into the physical and socio-cultural environment in which this research was embedded. Some of the physical environmental conditions differ considerably from our knowledge of palliative care and or hospice facilities. This Thai hospice provides nominal levels of everyday infrastructure comfort through no fault of the facility administration. This impression is reinforced with the open space concept of the building with the resulting lack of private space and personal amenities. And the tendency for the elderly to sit silently on their cots, as if waiting, again added to
the potency of the impact of this apparently inauspicious place. However, as the worn cliché informs us, “things are not as they seem.” In contrast to the western tendency toward an increasingly bureaucratized and professional palliative care (Aranda, 1999) conditions in the Thai hospice reflect a more informal use of resources. For example, while attitudinal differences and resulting tensions between medical staff and volunteers have been reported elsewhere (Payne, 2002; Addington-Hall and Karlsen, 2005) this does not appear to be reflected in this setting. Public school students commonly volunteer to assist with hygienic and other duties during their holidays without formal training. They appear to respond without complaint, in a compassionate and deferential manner to requests for assistance from the elderly or the staff. During my time at the hospice I did not witness any staff-volunteer interactions that might indicate conflict or tension. The staff also replied to requests for assistance from the elderly in a calm and respectful manner, even when demands for their attention were made from physical or emotional duress. Perhaps even more notable, the elderly also reflect this same demeanor towards the staff and volunteers. For instance, the elderly appear to occupy most of their time sitting quietly on their cots even when their discomfort is obvious. When demands are made upon the staff and volunteers they are predominately done so, with the possible exceptions of emergencies, in a polite and patient manner. To this observer, claims of the impersonal flavor of institutional roles and bureaucratization at the expense of personalized care often found in western hospices do not seem to predominate here.

Because these patterns of interaction are so common they likely suggest the presence of a more collective phenomenon important to our understanding of palliative care in Thailand: culture. While space does not allow a thorough review of the relevant literature here, it is nonetheless important to note that there is significant research investigating the more individualistic versus collectivistic attributes of Western and Eastern cultures. At this point in time we believe Asian societies to be more generally collectivistic and Western societies more individualistic, although there are variations with some specific situations (Takano and Osaka, 1999; Parkes, Schneider and Bochner, 1999). These claims offer some insight into the nature of the interactions between volunteers, staff, and the elderly. First, these societal contexts also impact upon the formation of cooperative and conflict structures with the former being associated with Asian cultures (Parks and Vu, 1994). Second, at the individual level of analysis these societal structures appear to be significantly associated with specific cooperative forms of cognitive, emotional, and police structures (Markus and Kitayama, 1991; Kitayama et al., 2003). These claims appear to fit with my hospice observations thereby offering some explanation of the apparent passive yet personal behavior between all parties in the hospice. These behaviors can therefore be seen as an extension of the cultural emphasis upon interdependence, which is usually an inevitable and salient circumstance at the end of life, as opposed to the tensions and distressed among the elderly in western societies who struggle from positions of independence to ones of dependence during the latter stages of their lives (Aleman, 2001; Hines, Babrow, Badzek and Moss, 2001).

This paper began with questions about our fears of end-of-life in western cultures. However, my observations suggest the Thai elderly in the hospice I visited bring a different perspective to their anticipation of death. To explore this phenomenon more closely we must shift our attention so as spirituality is included in our usage of the concept of culture. Spiritual care in western palliative care settings is seen as being of paramount concern in offering an holistic approach to anticipatory dying yet it too remains fraught with problems associated with bureaucratization and allocation of often sparse resources (Wright, 2002). In contrast, the Thai hospice is
deeply embedded in Buddhist ontological traditions that appear to permeate most of the activities and persons involved in the anticipatory processes of death. To some extent this may be a result of Buddhism being more of a philosophy of life and death rather than a religion in the Western sense of the concept. As my ethnographic notes indicate, the elderly appear to be only “waiting”, and did not demonstrate many noticeable instances of fear or anxiety, for their soon to arrive death. While the complexities of Buddhist non-dualistic approaches to life and death are well beyond the scope of this discussion it is nonetheless important to note a few key principles relevant to our task at hand. For Buddhists, our Western presupposition of the dualism between life and death is not embraced. Instead of fearing the unknown transition from our ego-centered view of self to that of not existing, Buddhists see death as an integral part of life itself. Our concept of ego is replaced with that of “no-self” or annica which posits the self as something temporary and in a constant state of flux and therefore in a continual state of becoming and passing. For Buddhists, death therefore manifests the impermanence of life around which the meaning of our existence is continually constructed and death is an ongoing part of life (Bond, 1980). Time is a cultural construct around which life-moments, which consist of all of who we are, are organize and from which anticipation of the future has therefore no place. From this perspective it would appear the calm, “waiting” stance exhibited by the elderly is a product of their Buddhist spiritual ontology. One might then infer the elimination or at least a reduction of some of the existential issues of dread associated with death in western cultures (Albinsson and Strang, 2002). Perhaps the most gripping illustration of the differences between Buddhist non-dualistic ontology of life and death versus the more Western views of death comes from the almost casual, accepting, and compassionate response to those who have just died in the hospice. The apparent symmetry between the moments of life and death in the hospice provide provocative preliminary insight into our Western cultural cognitive parameters of self and death. Perhaps these moments were most acute in this observer’s recognition that cognitive and emotional expectations were incongruent with cultural rituals of death in this hospice. And as a result, something in this researcher’s ontology began to shift; perhaps what Miller refers to as initial stages of “quantum change” (Miller, 2004) that can occur in and partially because of various ecologies.

The embedded researcher and research experiences

The reader will recall that this discussion has two interrelated components. The first was to offer some ethnographic description of palliative care in a Thai hospice from which to provide some preliminary inferences of sociological meaning. This discussion is found above and I now turn my attention to the second task; that of investigating questions regarding the researcher as embedded in the research process. The thrust here is not to place yet another worn challenge to science and objectivity. Instead I draw from traditional science, such as physics, which also have an appreciation (e.g. the Copenhagen interpretation) for interactive dynamics between the often-blurry boundaries between observer and subject matter (Walker, 2000). My intent is to revisit and add some clarity to selected researchers’ experiential process that tacitly influences the direction and development of data gathering and interpretation. The following discussion, while avoiding the thorny conceptual issues of what constitutes experience, offers an ethnographic introspection of some bodily, cognitive, emotional, and cultural milieu into which the
researcher and research are woven in such a fashion so as their shadow appears religious or cult-like in form and meaning (Durkheim, 2001).

Alfred Schuetz (1944: 503) informed us that when thrust into unfamiliar environments an existential moment can emerge when there is, “The discovery that things in his new surroundings look quite different from what he expected them to be at home is the first shock to the stranger’s confidence in the validity of his habitual ‘thinking as usual’.” Previous cross-cultural and research experiences did not offer the cognitive buffer I had expected from which to balance my stranger role with research so as to facilitate data collection. For example, as I sat near the end of Mr. A’s bed observing his conversation with Jai dii during my first visit, I became somewhat anxious and claustrophobic. My senses appeared to be under assault. The humid heat heavily pressed itself against me and my body reacted with considerable perspiration. The sound of the small fans, the flies, the gentle crying at the end of the room, and pounding of heart seemed so incredibly loud. Between breaths seemed to take such a long time, and the pause at the exhalation was disturbingly long. With each inhale came the strong odor of urine, mustiness, a cleaning product, and mixtures of unknown scents. My vision moved ever so slowly, perhaps because my head seemed to have considerably increased in weight. Points of contact between my body and the floor, chair, my hands on my thighs, seemed heavy, almost unmovable. I appeared to be captured by sensory confusion, agitation, discomfort and I wanted to leave this place. Things were not as they are expected to appear and as a result did not “fit” with my cognitive schemas. Moreover, my physiological, cognitive, and emotional reaction indicate a distinct resistance to the anomaly of sense datum and ontological parameters. Cazeaux (2002) notes that the validity of our world and our place in it may well be but a child of our history of classification and, in particular, the classification of the senses. Given the intensity of the environmental challenges to my senses in the hospice, compared to the two more familiar ones noted here, my taken-for-granted classification schemas became suspect and vulnerable to moments of existential chaos. This is reminiscent of the existentialists’ message that the role of stranger necessarily is accompanied with estrangement from self and an otherwise latent or repressed phenomenon that advances into the foreground in death and dying research (Palgi and Ambramovitch, 1984).

A few brief considerations of relevant cognitive implications may be useful here. Cognitive scientists, notwithstanding debates within this field of inquiry, inform us that we construct mental categories or “schemas” to attach meaning to our environments. This occurs through a variety of complex mechanism that facilitate information processing, building and testing knowledge structures, accessing memory, and which also lead to what we might refer to as our view of self and reality (Fiske and Taylor, 1984; Schneider 1991). Many, if not most, of these schemas operate automatically, spontaneously guiding our thoughts and activities, and regardless of their import we tend not to be conscious of their presence (think of the familiar experience of arriving at your destination by car only to become aware that you don’t recall much if anything of the journey itself). This phenomenon is what we might experience when we perceive of being in control, or things are unfolding as they are meant to be, and are therefore valid. However, these processes require both ongoing social and environmental reinforcement to maintain the transformation of subjective reality into objective reality and thereby avoiding or at least reducing ambiguities, uncertainties, and moments of mental chaos and anxiety (Schwarz, 1998). In my case, not only were my familiar personal and research schemas not “fitting” with my perceptions at the hospice, but since I was the only stranger there were no familiar resources to
draw upon for schematic validation adjustment and transition. Since, as noted above, my taken-for-granted schematic categories also provide socio-emotional glue for my sense of identity; my bodily discomforts were accompanied with uncomfortable and unfamiliar emotions.

Emotions are significant partners with cognition. Together they collaborate to negotiate a tenuous balance between and within the objective and subjective complexities of our interactions and therefore experiences of our world (Damasio, 1999; Jason, 2003; Mandel, 2003). And while there is considerable acknowledgement of respondent emotions, the emotions of the researcher are equally vital to the research process and data interpretation. This phenomenon is an extension of what Hochschild (1983) identifies as “emotional labor” which, while commonly underreported or absent in fieldwork records, can play a significant role throughout the research process (Blee, 1998; Hubbard, Backett-Milburn and Kemmer, 2001). And while the emotional appeal was a part of the research and its mystery that drew me to my topic I had not, partially as a result of my previous statistical and positivist research orientation, anticipated the demands involved. I expected more of an emotional distance from the milieu of anticipatory dying as a result what is typically a background phenomenon rushed to become a foreground presence. As the process of sorting all this out continues, I will only refer to a few selected instances for illustrative purposes.

My expectations, based on my research and cultural knowledge schemas, were that while at the hospice I would experience many negative emotions commonly associated with misery, pain, and fear at the end of life. From my first day at the hospice I was struck with the warmth, friendliness, and happiness of the staff and clients. Perhaps the most overwhelming emotion during the earlier visits was that of confusion as result of the mismatch of my cognitive schemas and my observations. For instance, regardless of his physical state, Mr. A generally appeared to exhibit indicators of happiness, or at least not fear nor dread, during all my visits. This too appeared to be the case when sitting with those who had only minutes to live. This does not mean to suggest that there were not moments of pain and fear but they seemed to pass rather quickly rather than being the norm. I noticed myself wondering if these people knew they were on the doorstep of death because surely it must be a fearful place. Often I caught myself lost in thought and not really focused on my observations. Instead, my mind would be full of unpleasant fantasies and feelings of anxiety that can accompany a stranger into this kind of dream-like emersion into a new cultural milieu (Hunt, 1989). Some of these instances appear in my experience of negative emotions; for instance, my impatience and annoyance with the volunteers watching television or some of the elderly not participating in the project interrupting us during interviewing. At other times I just felt out of control of the research and would feel anxious and guilty about being so project preoccupied and judgmental given the circumstance of the elderly around me. Following these episodes I would notice myself mentally scrambling to regain cognitive equilibrium and reduce the uncertainty. Perhaps the most intense moments that might illustrate these phenomena are those surrounding my witnessing the first few deaths of the elderly. During these moments the incongruence between my cultural emotional projections and the cultural milieu in which I was currently located become intensely present. Briefly put, nothing appeared to happen when someone died. As I stood or sat next to the dying person I expected something, something unique and powerful, to occur. The person stopped breathing; there was no explosion of emotion or drama of any kind from anyone. Instead, the person was left as they were, exposed, not covered or concealed, but left as they were moments earlier when they were alive. Sometimes a
few friends would come to give a blessing, or to rearrange some item of clothing, but the bodies were left open with no apparent ceremony. A staff member would arrive later to check if death had come, without using medical diagnostics, and then leave without comment. About an hour later some men would come with a rough wooden coffin and lift the body into it for cremation at the Wat the next day. And the day would go on as if nothing occurred. Death was a normal event; the anxiety and drama were my projections (Hunt, 1989; Rodriguez and Ryave, 2002). As I looked around after a death, the others would be doing what they were usually doing, and this was typically sitting or lying in silence on their cot, waiting in apparent calm. After awhile, I too somehow became a part of this and wondered how this had happened to me and what became of this image I had of myself as I arrived so full of negative and fearful images and expectations on that first day.

Concluding comments

In addition to the dialogue above, investigating the anticipation of death introduces many possibilities for insights into social life. And one only has to enter “death” into an Internet search engine to quickly discover not only a degree of fascination but also the wide range of academic disciplines laying claim to insight into the anticipation of and arrival of death. Without a doubt, death is essentially a slippery conceptual and empirical challenge. However, rather than being defined as a problem requiring a solution, it is this very uncertainty that can casts some light on this phenomenon. Here lies the potential to move away from dualisms that are typically found in western views of symbolic boundaries. As well, death, dying, and those who are near death, rather than being avoided or sanitized, offer precious lessons into life itself (Frankl, 1984: 151). Readers will recall that the Thai school children mentioned at the beginning of this paper appear not to recognize our distinct separation between death and life. In place of the taboo and anxiety that commonly fill our Western views of the gulf between death and life these schoolchildren, indeed all of the persons mentioned in my ethnographic data (with the exception of the “wild lady”), appeared to approach the anticipation of death with compassion and tolerance as opposed to an anxiety projected into an unknowable future event. As mentioned previously, this is to a great extent the result of Thai culture and spirituality arising from the everyday psychological metaphysical practices of Buddhism (McGrath, 1998). Within this paradigm (and ironically similar to Darwin’s theory of evolution) the emphasis is placed upon the processual role transformation of the past into the future through the intermediary all transitional forms that in themselves have no permanent substance. These forms include the objects of the ordinary world, including the physical self, so dying is an ongoing process rather than a unique time-specific event to be repressed from thought or experienced as a terrifying shift to non-existence. Indeed, even with to regards to our biology most of our cells survive for only a short duration to be replaced by others; death is therefore already within us but temporarily held in abeyance (Secomb, 2002). So, while the elderly appear to wait, they are likely to be participating in their moments as they have done so throughout their lives. Similarly, the calm and patient response by staff and volunteers to the elderly and those who have just died reflects the ongoing presence of dying throughout life (Barham, 2003; Dinh, Kemp and Rasbridge, 2000).

Ethnographic and autoethnographic descriptions and inferences drawn from this project may be of potential interest to a variety of readers. However, cross-cultural studies of dying, death, and the study of this phenomenon, also present us
with an important paradox. It is the very dynamic of cultural variances that produce both our interest in as well as resistance to foreign social practices. I now turn to this paradox and its ambiguities for two interconnected reasons: first, to comment on this researcher’s observations on methodological practices and processes that became salient during my fieldwork; and second, to make some inferences about the structural milieu in which research is embedded and reproduced. Willmott’s (2000) offers a useful platform from which to begin these two undertakings. He argues that the symbolism, or ontological boundaries, around which death is referenced is decidedly a social product. From a traditional Western vantage point death is therefore taboo, an event or experience associated with pain and fear, an urgent sense of uncertainty, and therefore to be avoided or ignored, and sanitized when inevitable. As a researcher embedded in this cultural point of view, I brought these cognitive and emotional presuppositions with me. I do not simply refer to the more manifest and familiar features of these structural presuppositions but include their informal and not always conscious schemas, emotions, and metaphors which also make up the mental aspects of human resources. These resources are often regarded as “transposable” (Giddens) or “generalizable” (Bourdieu) because they exert some degree of influence through individual agency allowing one to integrate past and current experiences into a matrix of perceptions, appreciations, and actions (Sewell, 1992). However, these resources become impotent when persons are challenged with significant degrees of sense datum incongruent to these mental structures. Routine, everyday cognition and emotion are dependent upon readily available culturally available object, events, interactions, and relationships and whose fragility becomes apparent in culturally diverse ecologies (DiMaggio, 1997). Introspective ethnographic research in dying and death are robust undertakings that can therefore potentially expose underlying structures of our otherwise mundane and taken-for-granted parameters for understanding, indeed experiencing, the relationship between and our lives and death (Frank, 2002; Mamo, 1999). As previously noted, this researcher experienced these types of events as cognitive confusion, emotional turmoil, and momentary loss of identity. These phenomena emerged from ambiguities arising from the collision between two different ontology regarding existence and non-existence and are therefore reminiscent of the Nietzschean view that incongruities can transform oversimplified classifications used in sociological and everyday life into creative even transformative acts and discoveries (Frank, 2004; Manning, 1991: 72).

This research indicates that autoethnographies, or time-framed autobiographies, hold promise for excavating some of the more paradoxical and subtle structural tapestries of social life. In particular, substantive inquiries into anticipatory dying and death can benefit from and contribute to current discussions of Durkheim’s views of social emergence (Sawyer, 2002) and symbolism (Janssen, 1997). The former, similar to recent work in social cognition (e.g. Varela, Thompson and Rosch, 1993); revisit the dialectical relationship between social structures and the emergence of individuals. The latter extends this notion of dialectic by situating it within the stable yet flexible boundaries of symbols. If we think of anticipating death in symbolic terms, as a metaphor, apparent divergent and paradoxical phenomena can be unified in an alternative schema. Social products as metaphors therefore present to us, “… fleeting resemblances between apparently disparate phenomena, the incite us to make a cognitive leap or connection that subsequently appears to be both inspired and self-evident (Manning, 1991: 71). So now death takes on a different form, a vehicle that invites consideration of interdependent time specific life trajectories, which include transitional events of origins, endings, and the
linear and non-linear unfolding of moments in between and the inevitability of our own temporal mortality (and therefore no recognizable form). Here Gell (2001) recommends us to G.H. Mead to remind us:

Reality exists in a present. The present implies a past and a future, and to both of these we deny existence. Time arises through the ordering of passage of unique events, ... The causal conditioning passage and the appearance of unique events ... gives rise to the past and future as they arise in the present. All of the past is in the present as the conditioning nature of passage, and all the future arises out the present as the unique events that transpire. The long and the short of it is that the present (the meaningful structure of the past) is as hypothetical as the future. (p. 155)

Throughout this paper I have placed emphasis upon the term anticipatory dying in order to illustrate that the convergence of structures is a dynamic process that necessarily includes and also produces ambiguities of which death and therefore non-existence surround all social activities and products. All dimensions of mental and embodied social structure die away, meaning drifts away beyond rational contemplation, and our sense of self becomes transparent, and like all other forms matter, temporal and in motion. Anticipatory dying research presents us with significant opportunities to extend our understandings of self and the structures within which we pass through and create our human social world.

References


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