

Loving to death

Sickness in the twilight years and end-of-life care

Deanna J. Trakas

The care of a society's elder members, as with the care of its youngest members, brings into focus all that is held sacred in a culture's ideology, contextualized in ideals of moral duty, self-sacrifice and love. These cultural idioms, visible in the context of the everyday life of family members and lay persons caring for their elderly, are also evident in professional care models. This paper presents a love story between an elderly couple and their caregivers in vignettes, which illustrate facets of harit s (haris), philia, erotas and agapi. It contrasts two diatheses of love 'holding on' and 'letting go' as manifested in mainstream medical nursing care and hospice care; the former influenced by the biomedical goal of the 'preservation of life' and viability, the latter (hospice care) committed to enabling a dignified release.

[love, end-of-life care, hospice, ethnography of dying, caregivers]

*Every strong emotion whose inner momentum hurls it toward
the unthinkable trembles with the anguish that anticipates death. ...
Once we feel the strength that turns anguish into joy in dying,
we are delivered over to all the joys that come in laughter
rolling over our defeats and mortifications,
in the blessing that greets everyone with passionate
kisses of parting, in every love risked.
(Lingis 2000: 162).*

For the inexperienced novice, the care of elders often seems like trying to knit a sweater while a naughty cat pounces on the ball, tugs on the yarn and, while the household sleeps, pulls out the loops. In the morning the snarl of yarn must be disentangled and the project begun again; however, homes with elders in them never quite sleep – day and night become one, barely distinguished by the darkness beyond the windows. In-home caregivers or 'health care aides', as they often refer to themselves, assist in bringing order and serenity to the situation. In-home end-of-life care is specifically

directed toward the comfort needs of the individual as death approaches. It is often caught between the dilemma of hanging on or letting go, as is love, a quandary, which is reflected in the philosophies of mainstream medical nursing and hospice care. In the spring of 2007 I had the privilege of being part of the care of an elderly couple living in a mid-western USA university town. I collected a tangled series of observations, which I re-knit, into a narrative of how they became the focus of love from their caregivers.

Nearly everything about the small urban centre is 'mid' – middle class, middling WASP, average Americana – and the care of the elderly is rarely handled in the home solely by family members. Those who have not migrated to Florida or Arizona opt for aging 'gracefully' in retirement and assisted-living communities which resemble the suburban condominium estates which they left behind in their seventies. For those who manage to 'hang onto' living in their own homes into their eighties and nineties, a number of in-home care options are available ... for a price. Most of these elderly in this scenario are ineligible for state subsidized care and most standard health insurance plans do not cover these costs; hence, payment is out-of-pocket, at least until private funds are totally depleted (and subsidies can be applied for). Practical and registered nurses (RNs) can be individually contracted or their services assigned through an in-home care agency, with hourly fees beginning at \$20 per hour for home health aides and perhaps double for specialized care of an RN. In the rapidly expanding market of in-home assisted care for the elderly, care assignment agencies competitively create their particular package of services. Local television advertisements show images of tailored-to-need care and names of agencies are selected to reflect the uniqueness of services through a 'comprehensive' (RN-supervised) or 'homey' (non-medicalized) care package.

In-home, end-of-life care is also provided by hospice programmes where the elderly can receive care in their own home without necessarily being transferred to a 'hospice house' centre where 'comfort' care is provided on a 24-hour basis. A staff of RNs, physicians, social workers, clergy, physical therapists, personal hygiene aides and vehicle drivers coordinate an in-home programme to fit the physical, emotional and spiritual needs of the 'terminally ill' and other family members. The diagnosis of 'terminal', in effect the prognosis of expected death within six months, is necessary for admittance to hospice programmes, which in turn allows for costs to be defrayed by private health insurance plans. In-home hospice assistance is available 24-hours a day; however, continual bedside care is usually not part of the programme and must be arranged from other sources such as family members and care assignment agencies. It is in this area where conflicts between the commitment to love (through) to death and the temptation to love (back) to life occur; the dilemma of love, to let go or hold on (even against all odds) is brought clearly into focus during a crisis. Family members and mainstream medical nursing caregivers may find it emotionally or professional difficult to defer to hospice policy which restricts heroic 'life saving' interventions such as intubation, resuscitation, artificial nourishment and hydration techniques.

Within the above context I would like to position the actors, allow them to move through their actions and speak their lines without the intrusion of too many external theoretical and methodological props. The journey through a terrain either quite

strange or all too familiar to the reader (in which case she or he is blessed) is organized through four 'types' of love: *haritos* (grace or charity), *philia* (friendship), *erotas* (romantic love), *agapi* ('unconditional' love). As an exploratory work, the analytical commentary is intended to introduce potentials for future investigation: parallels between heroic medicine and legendary love, cultural scripts of suffering and pathways to death, and mythologizing through love stories and illness narratives.

A lovers' meeting

By the Ides of March 2007, John and Virginia had been married for 64 years and nine months. Virginia was in the hospital where she was experiencing a week of paranoia and gathering data to support the scenario that her home was going to be taken from her and that I was part of the plot: "You look like my daughter, and that is her jacket and you're wearing her earrings – but *They* took them from the real Deanna and gave them to you." Turning to the nurse, she added, "When my daughter tells people to jump, they jump! She would never leave me here like this." Referring to one of the aides, "This young lady has been so nice to me and she's got such a lovely smile. What a pity. She's with *Them*." According to medical personnel, Virginia's behaviour was caused by the imbalance in her electrolytes due to infection. An innocent bystander might have also added her daily cocktail of anti-anxiety and 'other' calming chemicals, aggravated senile dementia, and being uprooted from her home – the centre of her life, along with John, her husband.

In the meantime, John was at home, assisted by agency caregivers and his daughter, having his own rough time and not in much of a condition to make daily visits to Virginia. His strong legs no longer served him well, he was unsteady on his feet and subject to phases of forgetfulness which might be expected of a 93-year old man whose life focused on the care of his wife who had, four years previously, managed to survive the amputation of her leg. Early one morning, he shuffled into the kitchen and made himself an ice cream cone. Apparently deciding that he needed company to enjoy the treat, he then manoeuvred himself into his daughter's room to offer her a bite. It is unlikely that he purposely arranged to have a 'spell' at this time, a bad turn which left him breathless and unable to move, thereby securing his transportation in an ambulance to the emergency room of the same hospital where his beloved wife was four floors above.

John and Virginia met in the ER – when she was being released and he was being evaluated for possible admission. Her good senses seemed to be back in working order, until she learned that John would not be at home when she returned. "Ah-ha! I told you! They're still keeping my family away from me. I'm not even sure that I'm going home." Tamara, a health aide assigned by a care agency to transport Virginia home decided that the only way to quell her fears would be to take her to the ER to see John; a tricky proposition as seeing John quite totally incapacitated might add more fuel to her plot. The meeting went well; Virginia, in her hat and oversized sunglasses was wheeled to John's bedside:

Caregiver: John, yoo-hoo. Your wife is here to see you.

John [groggily]: O... o ... I love her.

Virginia: John ... Jun-oo. We've got ourselves into big trouble, honey. [She pushes the wheels to take her closer to the bed and kisses him on the forehead.]

A few hours after Virginia left, John was transferred to a double room upstairs where he spent a week under observation. Most of the time he talked about what a nice view he had from his room on the ship and the good food on the cruise, suggesting that the rest of the family should "think about all getting together and doing this every year". When he returned home, it was as if the ocean voyage never occurred. Upon his release a week later, 24-hour in-home care was arranged along with hospice services for both Virginia and John ... and they would become loved by strangers. But what is this thing called love? Or rather, how to make sense out of a series of observations which seem to reflect different types of affection, concern and intimacy?

In Anglophone treatises about love (both scientific and literary), terms to classify the colours in the spectrum of love usually end up as etic hybrids mixtures of words borrowed from other languages and, as Vandamme (2006) suggests, they tend to carry intrinsic moral connotations. Even so, I decided to organize my observations and thoughts using the Greek terms of *haritos* (or *haris*), *philia*, *erotas*, *agapi*. While discussion of these terms appears in various contexts, academic and popularized, my familiarity with them comes from everyday life in Greece, my adopted home where I have had the privilege of tackling the nuances of the language¹. I do not intend to build an evolutionary model where, for example, one manifestation of love is 'better', 'more mature' or 'more advanced' than the others – and consequently characteristic of a 'more evolved' approach to the care of the elderly.

Haritos

When John and Virginia were discharged from the hospital, it was only under the condition that 24-nursing services would be arranged for them in their home. During the first two weeks some 25 different health aides were paraded through their home; some for two-hour shifts, others for 12-hour night shifts. All but two were women; of the men, one was 18 (who "enjoyed entertaining the elderly") and the other was a retiree (who, during his years as a prison guard, had received an award as the "outstanding prison guard of the year"). Their stories revealed that they became involved in the occupation of giving by a number of routes; some by default which initially had little to do with charitable intent, others from a definite emotional or vocational calling to 'do good'.

Several pointed out that there were aspects of taking care of the elderly that made their job one which other people might avoid or could not 'stand' doing; for example, the 'bedpan brigade' in nursing homes. They did not express the idea that they were, by virtue of providing this kind of care, performing acts of pure charity, as a result of a 'state of grace' or *haritos*. Many had taken care of an elderly family member in the past, sometimes simultaneously raising three to four young children (at the age of

20, in one case), busy with organizing their life as single women, in the midst of an extended family with incredibly entangled commitments (but also support) or with acquired additions such as an alcoholic or incarcerated significant other. Thus, assisting with the bodily functions or mobility of others was part of everyday life; the one thing they felt they could do well enough to offer as a service for pay.

Charita, a large-set young woman with an engaging smile and a tattoo of her ex-boyfriend's name, explained:

I figured I was always takin' care of someone, anyway. So why not do it for money? And my momma, she took care of me when my boyfren drove me 'n his car through a store window, an' I'm gonna take care of her when she gets old.

It would be difficult to imagine Charita floating on the wings of gossamer charity; thus her comments below came as a surprise:

Have you ever been present when someone died?

Oh, yeh. Lots of times.

What happens? I mean ... ah, is it frightening?

Well, I did Miss Amanda right up to the end. She jist went. When all of her family was out of town at a wedding. They do that sometimes ya know; jist go when no one else is there. Ah-hum. Like they was jist waitin for the moment when no one is fussin over 'em. She jist went. I closed her eyes and kissed her on the forehead. Ah-hum. I always do that. Kiss 'em on the forehead.

In the midst of Charita's poignant commentary, the statement, "I did Miss Amanda ..." seems jolting and hardly charitable; a statement, which carries a sense of, task-oriented instrumentality rather than an image of care given from the heart. The repeated use of 'doin' (and its other conjugations of 'do' and 'did') in conversations between the caregivers during shift changes initially seemed to indicate a lack of care. However, the argot almost always included respectful and gentle terms of reference as well (emphasis added):

Sorry I'm late. I was up at the hospital doin a real sweet lady.

I got done early doin a gentleman at the county home so decided to come over here instead of driving home first.

What a morning! I did Miss Matty and thought I'd never get her done.

I'm not gonna do Mister John his shower today; I'm just gonna do him a little spiffy [a quick tidy-up].

In this context, doin is a merely a functional term which, under its tough-sounding exterior, designates acts of caring and charitable love rather than care-less routine. Not all caregivers adopt the argot; for example, whenever Gloria heard care referred to as doin (or any other seasoned caregiver argot), she would assume an inscrutable expression and pat her high, heavily lacquered 'beehive' bouffant which she had styled for

“Sunday church goin”. While on duty she often read the Bible in her spare moments – which were frequent as she was hesitant to take on some of the heavier tasks which Charita seemed to take in stride. Margaret, after devoting herself to the home-schooling of her three children, was too new to her vocation of elderly care to have acquired the habit of referring to her care as *doin*. It was doubtful that she ever would, regardless of how long she managed to stay with the job which, for the first time, provided her with her own income – and which she considered as an act of pure charity in the celebration of goodness.

The idea of charity as part of a vocational calling is evident in the stories of many of the caregivers. Tamara characterized herself as someone who “just loves old people. I don’t know why – maybe it’s ‘cause I loved my granny so much and took care of her before she died”. Already fully employed as the recreational director at a major nursing home, she decided that she could also work a few extra hours a week through an in-home care assignment agency. Once she was assigned to John and Virginia’s home, her few hours became many, several of them as on a volunteer basis. Shannon, had worked as a hospice caregiver in another state and currently employed by the assignment agency as a ‘health aide’, described herself as

... someone who has been around the block more than once. I’ve taken care of the rich and the poor and I’ll tell you something. There’s no big difference when it comes to the end of life. But you know what? This is where I belong.

Her shifts were regularly from 11 at night to 7 in the morning; however, she frequently stayed longer in the morning to make sure that the next caregiver had arrived and was properly informed about the events of the night (which were often many).

Megan, a young blue-eyed blonde, used her \$8 per hour wages from the assignment agency to help pay for her nursing training at a local university. She was preparing to graduate as a registered nurse soon and, motivated by experiences with her aging grandmother, decided that her area of specialization would be geriatric nursing with her sights set on becoming a hospice RN. Her high aspirations did not interfere with (and probably enhanced) her charitable affection for the details of John and Virginia’s care during tumultuous mid-night shifts. During the day, Becky, the hospice RN made her rounds. Her youth (as blue-eyed and blonde as Megan) was belied by her quiet efficiency, which was interrupted only by her almost imperceptible expressions of deep compassion. Only once did she make a reference to her own life, and this was under my prodding when I suggested that she must have lived a particularly worry-free life to be able to give so much serenity to her patients. In her reply, she indicated quite to the contrary, limiting details to only a brief reference to her relationship with her father as a “little problematic”.

The compassionate, charitable persona of love is the one, which is promoted in the brochures and television advertisements of in-home assistance agencies. They ostensibly make an effort to ‘match’ their employees with their clients and discuss the importance of ‘bonding’ between their aides and the families they serve. At the same time, however, most agencies adopt a ‘no friendship’ policy which is obliquely

referred to in written contracts which warn the client to not make personal arrangements about time or transportation (for example) directly with the caregivers. The clauses are intended to prevent offers of independent payments to aides by clients and lead to the loss of the better aides to this type of an arrangement (where they would probably make considerably more than their minimal hourly-wage rate). Any hint that the 'match' and the 'bond' might become 'friendship' can result in potential slippage between care as per the agencies payroll and care given as charity, in this sense, free care. This can cause distress in the order of things for the agency coordinators; after all, they are running a business not a charity. Even under these conditions, many of the aides not only gave care above and beyond the limits set by their agency, but friendship emerged as well.

Philia

Friendship is ideally based on some notion of equality; here the power is in the hands of the caregiver – but there is also a recognition of 'another power' at work when death approaches, a feeling which seems to allow friendship to bloom in a situation of power relations which would act against it. Friendship is based on a sense of stability – of remaining true through time – upsets are smoothed over by a number of tactics including 'inside' jokes, sharing secrets and even gossip. Friendships are also jealously protected from those seen as outsiders – as persons who are unable to understand what comprises the source and content of the particular friendship bond. Thus, there is an element of competition in friendship, which can upset the already fragile matrix of interactions between caregivers (see McLean 2001).

The women caregivers were drawn into friendship interactions with John around the kitchen table where they pampered him with snacks, played cards, playfully argued about his requests for cognac and discussed their boyfriends, husbands and children with him. Those who perfunctorily played cards with him were taken off guard (and sometimes frustrated) when he suddenly introduced a new rule. Tamara, Shannon and Megan would use card-playing as a chance to evaluate his capacities on any given day; e.g., "He's really sharp today", "He's not having a good day". However, some (all non-hospice) would become critical of his trying to play the wrong card; Tamara, in spite of the magnitude of her tender loving care, repeatedly scolded him: "No not that card. Put it back in your hand."

It was nearly impossible for John to begin eating before he had offered portions of his meal to anyone in the vicinity of the kitchen table, a rule of etiquette, which he attributed to his Greek upbringing. Offering another person a bite of food from his fork was an act of friendship; declining to take a sip of cognac out of his glass meant "you don't want to share my secrets". Caregivers joked, "Of course now you're going to want to taste food off my plate, aren't you?", and most of them found it difficult to deny him. Only a few were unable to adapt to John's idea of friendly commensality through sharing of food and drink – consistently the same caregivers who avoided playing cards with him and rebuked his enquiries about their "love life and wild men" (his words) with a scowl.

Caregivers who were determined to keep John on a healthy diet tended to view others who generously gave him cookies and ice cream as more concerned about his friendship than ruining his appetite. Learning that he had been allowed a little extra cognac (or even any at all), as evidenced by the amount still in the bottle, served as an opportunity for criticism. However, for most, axioms of 'proper' nursing care, limited to 'healthy standards' became comfortably intertwined with the desire to see John happy and contented. Indeed, the indulgent caregivers seemed to be in competition with each other over who could be the better card player or the more entertaining when it was captivating when talking about their personal life. They also elicited comments from John which affirmed their being 'best at' various personal care moments; e.g., combing his hair, trimming his mustache, scratching his back.

The primacy of proper care ('versus' friendship) was most evident in the controversies which developed about John's choking episodes which became increasingly frequent. Learning that he had suffered a choking episode during someone else's shift became a source of friction between caregivers; arriving in the midst of an episode caused a face-to-face confrontation. Retrospectively reported episodes were fastidiously reviewed by the in-coming caregiver in an attempt to locate blame; e.g., the food was not mixed with enough liquid, it was not mashed enough (had lumps in it). In short, someone had not been careful; someone was either too lenient with John, or they were too eager to please him by participating in his generous sense of commensality and, as a result, not been vigilant; putting his sharing rituals over his safety.

Virginia's care was centered on her bedroom, where hospice had arranged for her to have an adjustable bed and other accoutrements to facilitate her mobility and ease her pain. Caregivers were usually so involved in continually attending to her physical needs (acts of pure charity) that little time was left for developing friendship interactions. Tamara made special efforts to place their relationship beyond the boundaries of physical care, into the realm of entertainment and spiritual sharing. She spent time on 'girly' activities – transforming the cloud of suffering in the bedroom into the aura of a teenager's slumber party. She massaged hand cream on Virginia's hands and arms, combed and even trimmed her hair (as Virginia was always looking for those few hairs that did not 'blend in' with the rest), laid out 'pretty nighties' for Virginia to choose from. She arranged Virginia's collection of toy animals and read to her from a humorous book for women about their relationship with God. In return, Virginia told her about the boys of her youth and gave her advice about her up-and-coming wedding. Although some 50 years younger than Virginia, she located a 'sing-along' collection of songs popular in the early to mid-1900s and the three of us 'rehearsed our act' – which Virginia claimed "we three girls should definitely take this show on the road".

Meanwhile, Virginia began to make plans for taking her own show on the road. Some mornings she would awake and ask, "Am I still here? I really can't figure that one out." Indeed, the night caregivers were also amazed that she had made it through yet another night, passing on this information to the morning caregiver as they changed shifts. I broached the subject of what 'kinds of plans' she might have in mind:

Plans? What plans??

[Silence]

Ah-h-h! *Those* Plans [raising her eyebrow and opening her eyes wide]. I just want everyone to have a great big paaar-ty. With lots of music and dancing. I'll be there, too. Won't I? Or ... well, not exactly there either. Right? But I'll be there. Yes, I'll be there ... sort of. What do you want to do about ... about people 'seeing' you?

Well, they'll see me because I'll be there. Ah-h-h. I know what you're talking about now. Yeh, they can see me. But you have to make sure my hair is OK. I want you to check that out. If my hair doesn't look OK ... If I don't look good ... just shut the door on me. [Gesturing with her hands to emphasize 'shutting'.]

Following this chat, she was awake for three nights planning her party; making a verbal list of food to serve, asking if there would be enough chairs and parking spaces, suggesting that a buffet would be better than a sit down dinner. "They can come and have just a little taste of everything. We don't need to set all the plates and glasses around. They can just take what looks good." She shared these plans with the night caregivers, calling them into the room with a strong voice to ask questions about her plans. Sometimes she alarmed them with a sudden shout, rousing herself out of a dream-state; "Ou-ou!!! I just dropped the entire plate of peanuts on the floor" and "Oh-Noo-o!! Don't walk on the floor in your bare feet. It's full of glass from the champagne goblets that slid off the tray!"

Erotas

Intimating that love as *erotas* might be even remotely involved in care of the elderly may seem almost heretical according to the codes of nursing and hospice. My interpretation of my observations would suggest otherwise – at least according to what I would characterize as manifestations of romantic love. Flirtation, allusions to intimacy, veiled familiarity, even jealousy were all visible. After all, the more imminent death seems, the more life struggles to continue – and *erotas* must certainly be considered as the life force par excellence. Perhaps the overwhelming [permeating] feeling of 'love is in the air' which I experienced while observing and participating in the care of John and Virginia was a product of both of them reaching out for that life force of exhilaration associated with romance, legendary love and *erotas*.

Virginia passed those weeks as a coquette – with a sparks of girlishness even when she was experiencing considerable pain. Her capacity to smile through the pain may have been "only the morphine speaking"; that is, partially due to the effects of the morphine which she was given, although the doses were, according to the caregivers, at the minimum range. It may have had more to do with the kind of care she was being given which allowed her to rekindle her feelings as a young woman; now in the company of other young women with whom she could reminisce about her of her girlhood circle of friends. She attempted to imitate the arm movements of football cheerleaders, adding at the end of her performance a seductive 'come-hither' gesture with her index finger, explaining, "You know what that's for. It's for the boys!" She

participated in Tamara's song fests – and was heard humming to herself long into the early hours of the morning (without any particular assistance from morphine). She decided that it would be OK if John “crawled in with” her (joined her in bed), if she had “music, lots of candles and a brilliant drink”.

Meanwhile, John was concentrating on developing the habit of asking the caregivers (including the men), “Is anyone going to crawl in with me?” – meaning, join him in bed, clearly hoping for the warmth of others. This prompted Virginia to scold, “What is this ‘crawl in with me’ that you keep talking about, John?! If you don't stop bothering those girls, I'm going to get right out of this bed and slap you!” Virginia had never used, as far as I know, such a direct approach in managing John's “appreciation of the women” as she called it – adding, “But, you know, he's always a perfect gentleman” (and he was). The story circulated among virtually all the caregivers who responded with comments such as “That's our gal – keeping up with our John” and “Oh that John – I just love him to death”.

His appreciation of the female form (a life-long hobby) was almost palpable as he openly admired the faces and bodies of his young women caregivers. His daring in asking the young ladies to sit on his lap (when they would approach to push his wheelchair) or join him in the shower, was balanced by gentlemanly notations when a caregiver arrived with a new haircut or different dress. Occasionally he would hesitantly reach out to stroke the shapely arm of Becky, the hospice RN who was young enough to be his grand daughter, who also possessed the professional capacity to look beyond the medical case to the human. Her small glance in his direction apparently convinced him to stop his hand in mid-air, but adding, “You have the nicest arms – just ... so nice.” Becky replied, fluttering her long eyelashes and giving him a wide blue-eyed look, “Why John! I do think you're flirting with me.”

Hospice-trained caregivers seemed more likely to reciprocate John's flirtations than the women following more standard nursing protocols. The latter met his continual invitations to sit on his lap by trying to divert attention; even Tamara, otherwise always dignified in her care behaviours, tended to ignore (or not encourage) these types of comments. Sometimes there were punitive overtones (and mainstream nursing is particularly unwittingly vulnerable to this); e.g., “Now John. I'm going to have to leave if you keep talking like that”; or “You already said that to me today; once is enough”. Scripture-reading Grace, not trained in hospice care, but evidently following a vocational calling, was probably the least receptive to any of John's flirtatious chatter. In contrast, hospice-trained Shannon responded to lap invitations by saying, “Well, I just think I might do that sometime”, which was followed by John's sudden silence to which she comment, “Oh you're just all talk and no action.” Megan, with her sights set on becoming a hospice RN, developed a different approach. Whenever (which was often) John told her “You have the most beautiful lips. So nice and red and soft”, she simply giggled a lot.

Caregivers (independent of hospice or mainstream nursing training) openly admitted that they felt possessive about the elderly under their care; however, their comments were usually focused on decisions about care rather than ‘feelings’. Nevertheless, some decisions seemed to be based on simply wanting to share special time with John

or Virginia, rather than what might have been in the ‘patient’s best interest’ according to protocol. For example, early one morning I found Shannon playing cards with John at the kitchen table; he was eating ice cream and having a little cognac as well. Trying to decide whether to intrude, I asked with hesitation:

Do you realize it’s five o’clock in the morning?
Hum-hum, yes.
Aren’t you a little tired?
No – well maybe just a little.
So why are you playing cards and letting him have cognac?
Look – time is not a problem. I can sleep tomorrow. And it’s not as if John has to get up early and go to work.
But, you know tomorrow John has an appointment with the doctor?
OK, OK. [Patting him on the hand.] Come on John. Let’s get you to bed.

In days to come, Shannon would jokingly refer me to the incident as “that time you were pissed off at me”.

All but a few of the women caregivers commented on John’s still-handsome features and seemed to feel committed to ‘keeping him up’ (combing his hair, trimming his moustache, picking out a “really nice” shirt). Tamara put her own sunglasses on John when she took him outdoors in the sun, commenting, “Now he looks just like the ‘godfather’ – straight out of the movies.” (When I returned the glasses to her after his death, she burst into tears.) It was Shannon who had the most provocative in her comments about her intimate care of John; “He has the cutest ass. I should know ...”, adding a wink which indicated that not only was he in capable and caring hands, but appreciative ones as well.

Agapi

Indeed, Shannon was not hesitant to declare “I just love that man. He reminds me so, so much of my father. Such a gentleman. So handsome.” It was not unusual to find her watching television, sitting next to him on the sofa with her arm around his shoulder or holding his hand.” Tamara, too, would stay on after her shift had ended simply to watch the end of a movie with John – as well as finish reading the end of a story to Virginia, sing an extra round of songs with her, change her clothing when it became suddenly uncomfortable, add one little extra touch to her personal grooming. Margaret would sit by Virginia’s bedside, even when she was asleep, quietly weeping because she could hardly bear witness to her suffering, saying “I feel so helpless”. Megan would jump up from the dining room table and nearly fly to Virginia’s room at the slightest noise, wondering if maybe just a little morphine would help when moving her into a (hopefully) more comfortable position. These women, although not biological kin, formed a collective halo of family affection and provided a sense of security.

Bath times, meal times (such as they were) became scenes of parental love – the kind of love which claims to have no strings attached, but which often is besieged by

frustrating contradictions. Perceiving the elderly as 'child-like' evokes intentions of nurturing and protection, but it also allows caregivers to rationalize discipline as part of their duties. In all of the best intentions, they attempt to (re)socialize their 'children' into proper hygienic and self-care behaviours. At the same time, however, manuals about senile dementia stress that difficulties in the processing of new information is one of its consequences. When enticements for daily showers fail and a battle of wills follows, caregivers may resort to what McLean (2001) calls "punitive nursing with the infantilized elder".

I was fortunate not to have witnessed any examples of punitive nursing used to get John into the shower, although I could understand how bath time might have been managed in other settings. His bath times were a continual battle; he alternated between resistance and flirtation; between practiced pouts and invitations to join him in the shower. In response to the former, caregivers used all the coaxing strategies in their arsenal; however, some were at loss as to what to do in the latter, particularly the 'new girls' with little experience. The hospice agency provided a crew of 'bath aides' (or 'shower girls') who rarely failed in their mission, although some emerged from the bathroom with wet uniforms.

Similar conflicts developed over food and liquids. With John, it centred on keeping "too many" sweets, ice cream and cognac out of his, again in a parental mode. Food was used as a reward when, for example, he cooperated with the 'shower girls' or used his walker which he otherwise ignored (until he became increasingly immobile and was introduced to the wheel chair – which he took to without complaint as it gave him a chance to invite one of the caregivers to sit on his lap). He also needed to have his liquids 'thickened' with a powder for people with difficulties in swallowing. Among the caregivers, their ability to thicken his liquids to exactly the right consistency was under continual scrutiny – the source of several quarrels. The issue of whether his cognac should also be thickened or even allowed was also brought into these battles.

In contrast, Virginia wanted only small amounts of food and liquids, causing a great deal of concern for the mainstream nursing caregivers. Tamara wondered, "If she doesn't eat, how is she gonna get her strength back?"; Margaret asked, "Maybe she isn't eating because she's depressed." Hospice policy defuses the issue of food and liquid-refusal by allowing the elderly to decide what they can and cannot eat or drink – which, at the end of life, is very little. This is difficult for caregivers trained in mainstream nursing (as well as family members) to accept; food is love. Tamara was forced to abandon her project of "putting five more pounds on her". When she was told by Becky, the hospice RN, "From now on, please don't force her to eat", her reply was, "What am I supposed to do? Just let her starve? When Virginia's liquid intake radically decreased, Tamara repeatedly complained, "If this happened in the nursing home, we'd have her on an IV drip". She was torn between wanting to take Virginia to the hospital, but knowing that if she did so, hospice would discontinue care.

Shannon took a frustrated Tamara aside and explained the 'mechanics' of the body when it is 'shutting down', explaining that if a drip would result in flooding the body with more fluid than it could handle. Her insistence that forcing Virginia to eat would

result in only bad consequences was demonstrated (unfortunately) when a new caregiver enthusiastically and proudly reported that during her shift, Virginia had eaten half a sandwich. The results painfully (for everyone) demonstrated Shannon's point; Virginia's body was no longer able to process food as witnessed by several hours of severe, 'unproductive' retching. Nevertheless, Tamara held strongly negative attitudes about hospice:

I can't help it. I don't like the morphine part. It doesn't always work the way it does with Virginia. Sometimes people get real wild and hysterical on it. I know that what hospice does in the home is good. And we even work with hospice people at the nursing home and we do mostly the same things anyway. But every time one of our people goes to a hospice house, they're dead in a few days. I'm not sayin' that somebody gives them too much morphine on purpose ... but ... ah, I don't know ...

It was Tamara who was present the afternoon that Virginia "passed" (as she called it). She took John in the wheel chair into Virginia's bedroom, stood at his side as he tried to find a pulse and then sank backwards, saying, "Look at her. She's a doll. She was always a doll. God bless her. God bless us all." Tamara added the "amen". Four weeks later she was joined in her regular shift by Shannon, who "came running as soon as I heard" to be with John in what looked would be his last hours. Together, "John's two girls" (which they proudly insisted to label themselves as) pampered him, ministered to him, and eased his way (which he had decided was going to be travelled in the nude). They told him, "Don't worry John. Your girls are here" as they sponged him off (and tried to coax him into putting on a pyjama top to keep warm), each on one side of his bed, encircling him with something that was not quite visible to the eye. When he ceased to breathe, they formed a triangle – each taking one of his cooling hands and reciting the 'Lord's Prayer' for his ears, which they believed, could still hear.

A gift is truly a gift only to the extent that, however, modest, there is an element of impetuosity, recklessness in it. Giving is a passionate act. Giving, by abnegating ownership of resources, puts the giver at risk. Every act of giving already reduces the passion to give one's life (Lingis 2000: 174). The giver must withdraw her name from the gift – to the point that the recipient does not know or no longer remembers who gave him this. Nietzsche wrote that whenever you do a good deed, you should take a stick and thrash any bystander, to muddle his memory. Then you should take that stick and thrash your own head, to muddle your own memory ... (Lingis 2000: 179).

These two ladies can never become anonymous ... their names will always be on their gifts; hence I must take issue with the final lines. The objectification of giving, making it 'purposeful', is central to nursing care as an extension of pragmatic biomedical protocols. Engagement with suffering blurs the lines of giving and receiving, and care is motivated not only by pragmatics but emotion. The following sections offer some perspectives from the anthropological literature in an effort to create further lines of inquiry in the future.

Heroic medicine and legendary love

The traditional task of medicine – to allow a person to die in peace and with dignity – has been “usurped by medical technology’s mandate to keep the patient alive at any cost” (Kleinman 1988: 153). “In ‘western’ cultures, death has become an almost unattainable goal as people are barred from it by technology, judiciary and religious groups” (van der Geest 2002: 25). Care of the elderly as their life draws to a close has become imbedded in expectations of heroic medicine. When old people finally die, it is likely to occur in the company of more machinery than people. Even so, medical interventions reign supreme; they are “not only part of the story of death, they constitute the ‘hinges’ of the narrative” (van der Geest 2004: 902). The insistence of preserving life at any cost is not only compatible with the goals of modern medicine (and transferred into mainstream nursing); it is the very embodiment of legendary love. Epic literature is replete with tenacious love, which holds on to the beloved against all odds – even self- and metaphoric cosmic destruction.

The visible fading away of the elderly challenges the quest of legendary love, which single-handedly attempts to breathe life into the shadow of the beloved. Contrasting images from the anthropological literature about aging and death in non-western cultures, where the patriarch is surrounded by children and grandchildren and decisions are left in the hands of the kin. Kleinman (1988: 152-155) recounts his last visit with a Chinese colleague who was in close to death. He had placed medical matters in the hands of his brothers and, even though he was aware that he was dying, seemed to be embarrassed by questions regarding treatment prospects and illness trajectory. Kleinman concludes that his colleague “... is part of an immortal vehicle – the Chinese sensibility about the family – which existed before he arrived on the scene, in which he occupies a temporary place, and which after he departs continues on with his descendants and ancestors” (1988: 155).

Using data from another part of the world, Ghana, van der Geest (2002) shows how elders often want to be left to ‘go’. Dialogues from his field notes demonstrate that people ‘long’ for death, do be free of their pain and also the pain they feel they are causing others (ibid: 10). Part of their preparation for release, for a ‘good death’ is in making the necessary arrangements for after their passing (ibid: 11). Here we can be reminded of Virginia’s plans for her ‘paaar-ty’; a bitter-sweet scenario to listen to as it developed – a celebration which Virginia believed she could see clearly in her mind as real but which the ‘survivors’ could not see or imagine. In contrast to legendary love which is on a quest to conquer and hold onto true love, hospice philosophy teaches that love can and should let go. The message needs to be sent from the ‘survivors’, the ones to give permission for departure and taking one’s place in the ‘immortal vehicle’.

The ‘good death’ – release from pain, completion of tasks, settlement of debts, preparation for departure, permission to ‘go’ – seems to be a ‘universal’ desire, which is reached through culturally meaningful acts and symbols. The figure of the good physician can be easily reinserted back into the essential ingredients of the good death. In philosophizing with his physician about dying of metastasized cancer, a 33 year-old man thanks his doctor for the time he spent, the things he did: “I know I couldn’t

be here without you. I couldn't take dying in a hospital. It goes against the grain of everything I value: nature, home, life, that which is human and tender" (Kleinman 1988: 148). In Kleinman's commentary on the young man's case, he points out that the physician played a double tableaux, switching his objective from curing to managing the course of suffering, thus he was able to assist his patient to die the good death with dignity in the intimacy of his own home. (ibid: 153). This was possible because the physician empathetically listened to the patient: "Empathetic witnessing is a moral act, not a technical procedure" (ibid: 154).

Cultural scripts for suffering

It is never certain exactly how the prognosis of impending death is actually lived and played out, "no single, timeless pathway toward death that is most serviceable for the dying person" (Kleinman 1988: 154). Even though Kleinman points out that the practitioner has no way of knowing where an individual is headed on the pathway, it is something to be determined in the doctor-patient relationship. This arrangement sounds egalitarian enough, however it does seem to place the physician in the role of prime-mover in the pathway; other persons and forces are apparently of lesser impact (see Scheper-Hughes 1990 for critique on Kleinman's reliance on the doctor-patient relationship). "The practitioner does not (cannot) bring a teleology (a doctrine of final causes and ultimate meaning) from medicine. If such a teleology comes from the physician, it is from a religious or cultural background, not medicine" (ibid). It stands to reason that when the physician intends to alleviate the patient's spiritual suffering – such as the agony of the soul – the tools are not going to be found in medicine. Aside from biological (e.g. physical resistance to the ravages of the disease entity) and medical interventions, there is an implicit agreement that the pathway is also shaped by socio-cultural and emotional factors – habits, support system, ways of loving, beliefs, emotionally charged meanings. This is what has been called the "cultural script for dying" (see van der Geest 2004: 884 for original references and expansion of this concept).

Hospice has a different cultural script for dying from that of mainstream nursing and biomedicine. It has created a protocol – a roadmap that addresses the desire of people to have a 'good death', a concept which cross-cultural research on death and dying indicates seems to carry the same weight and include the same definitive components independent of social context. While specific rituals, rites, practices, taboos, preferred observances and so on hold different content (according to sociocultural context), the desired endpoints are essentially the same: a sense of peace, emancipation, reconciliation, completion, preparation for afterlife (meeting one's maker in all its varied manifestations), settlement of debts, a clean slate, making amends for wrong doings – all elements in the configuration of the 'right time'. Or stated differently, the goal of 'the right time' and all it encompasses, is mediated by culturally shaped symbols and meanings, which are produced and re-affirmed through ritual.

The cleverness of hospice is precisely in its de-medicalization of care. Love, ethics, morality are disassociated (in terms of meaning and legitimacy) from the routine

care protocol (e.g., life-saving, heroic interventions) in deference to a 'let nature take its course' praxis. However, in light of recent anthropological re-theorizing about a number of old guard dichotomies such as nature-culture, the problem is in the definition of what is 'natural'. In hospice a 'natural death' is synonymous with 'letting nature take its course' – which is tautological, unless I have misunderstood the meaning of the statement I repeatedly heard in a variety of contexts. If death takes place in a specific cultural context – complete with the culturally relevant script – can death ever be natural? Hospice has a script; biomedicine can challenge its own script – one that might write that pain is a natural part of death; hence casual use of morphine is not natural, not 'right'. It was perhaps to this issue that Tamara's gut-level feeling that morphine use is somehow intrinsically wrong; further, it reduces the weight of mainstream nursing and its practitioners who have received a spiritual vocational calling to their profession. The cultural script is, perhaps, given too much weight in a journey which is usually not repeated and from which ethnographic data are scarce.

Does the reassurance that a loved will be saved from a painless death serve as a balm on the suffering of those remaining? (a point which is raised by others, commented on in van der Geest 2004). Rather than be led astray by a philosophical debate about whether death should or should not be painful – if the 'natural' pain of death has some redemptive value. The point is that in contemporary pain-free mentalities and existentialisms, pain has lost its value. Since pain relief chemicals are available, the slogan is 'use them'. Perhaps a reference here to birth is stretching the point but, the potential for pain-free birth is in the grasp of obstetrics in spite of the indignation from advocates that birth is natural and must not be medicalized (and in spite of a long-standing religious basis for keeping it full of pain and sorrow). If death should be pain-free for all (including the 'survivors'), then the 'natural' outcome is to allow those who remain to blur their pain with chemicals or dip into the morphine drops.

Love stories and illness narratives

Love is intangible; we can discuss it only as a construct. As such, we cannot see it, only its effects – ripples on the pond, trees moving in a breeze. Love stories are like these ripples and trees, making the emotions tangible for others to see; stories of love triumphant, love lost but lessons learned, tumultuous love becoming serene, and so on. Illness narratives too, as many have observed, have their 'types'; for example, chaos, restitution and quest narratives (Frank 1995). As with love stories, illness narratives mythologize; when told in the first person, the afflicted person engages in a process of making mythical figures of self, family, caregivers – just as the person in love assigns superhuman attributes to the beloved or underworld traits to figures and forces which threaten the sacred space of love. When told by others, such as in the case of this particular article, the similar processes occur.

We tend to mythologize the people and phenomena we study. 'Closeness' prior to or developed during immersion fieldwork does not seem to be a factor. We engage in mythologizing independent of how long we have 'known' or been familiar with the

people or the situation – particularly when we delve into sensitive or forbidden areas; areas which may elicit a certain sensation of nostalgia and pain. Indeed, the Greek roots of nostalgia directly implicate pain whenever the past is contemplated: *nosotos*, the past; *algos*, pain. Love in its ‘true, unconditional’ variety is idealized as ‘all suffering’; nevertheless, love is not all about suffering; nor is sickness. In re-telling the stories about John and Virginia, the narratives are not all about *algos*. Even so, how much of the narrative is confession is unclear. Confession may be good for the soul, but perhaps not for ethnography; however, to paraphrase Geertz (if my memory still serves me), ten percent of ethnography is observation, the rest confession. This does little to settle the question of how much of staying with the ethnography is because it is a source of almost morbid fascination (what will or can happen next?), as were the long nights with John, Virginia and their caregivers.

Van der Geest (2007) points out the difference between participation as methodology and participation in everyday life. As a caregiver and an ‘interested third party’ – and nearly a patient as well – I was simply participating in everyday life. In comparison to other ethnographic experiences in, for example, clinics where participation was less continuous (or less ‘immersion’ ethnography), it seems to me that witnessing illness and suffering was somehow more even startling and disturbing. I cannot reconcile this contradiction; i.e., how it is that ‘totally living’ a 24-hour day situation, ‘observing’ death attempting to conquer two people I have loved for my entire life, feels less horrifying than ‘distanced’ research in clinics? Perhaps physical distance (e.g., daily forays into the field) acts to keep a certain ‘edge’ on observations and helps to crystallize moments of intersubjectivity. Distance may or may not make the heart grow fonder, but keeps the ethnographer on her toes. In contrast, total immersion fieldwork somehow acts to normalize illness and suffering – and allows us to see beyond the pain and dying process, to gain glimpses of joy, fascination and an elusive life force. In this sense, writing the stories which result is always an act of love and remembering ... as this has been.

Notes

Deanna J Trakas is an Associate Professor at the University of the Aegean (Greece), where she teaches a series of courses in medical anthropology. Her research experience includes the coordination of European Union funded concerted actions on children’s perceptions of medicine and illness, and participation in multidisciplinary studies on perinatal health. Address for information: Department of Social Anthropology & History, University of the Aegean, Lesvos, Greece 81100. E-mail: d.trakas@sa.aegean.gr

A draft of this article was presented at the ‘Sickness and Love’ Symposium held at that University of Amsterdam, December 2007. I would like to thank Catarina Frois for her commentary at the Symposium along with other participants who generously supported the directions and content of the paper.

- 1 The decision to use *haritos*, the possessive declension of *haris*, is an arbitrary one. *Haritos* is rarely heard in everyday, contemporary Greek conversation, except in the expression “*hari tou haritos*” – the gift of divine grace. *Hari* is regularly used to refer to an act performed as a ‘favour’, something which is ideally given without expectation of a return – usually not the reality in most social interactions. The term *harisma* (charisma) returns the concept of *hari* to its earlier meaning of ‘being gifted’ or even ‘touched by the divine’, meanings which are still very present in theological discourse about charitable giving and divinely inspired love. The visible analogue between *haritos* and charity also contributed to selecting its use (rather than *haris*) in this article.

References

- Frank, Arthur
1995 *The wounded story teller: Body, ethics and illness*. Chicago: University of Chicago Press.
- Kleinman, Arthur
1988 *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
- Leavitt, John
1996 Meaning and feeling in the anthropology of emotions. *American Ethnologist* 23 (3): 514-39.
- Lingis, Alphonso
2000 *Dangerous emotions*. Berkeley: University of California Press.
- McLean, Athena
2001 Power in the nursing home. *Medical Anthropology* 19: 223-57.
- Scheper-Hughes, Nancy
1990 Three propositions for a critically applied medical anthropology. *Social Science & Medicine* 30 (2): 189-97.
- Vandamme, Sofie
2007 Sickness and love: Une médecine dans le corps et cent sottises dans la tête. *Medische Antropologie* 19 (1): 163-75.
- Van der Geest, Sjaak
2002 ‘I want to go!’ How older people in Ghana look forward to death. *Ageing & Society* 22: 7-28.
2004 Dying peacefully: considering good death and bad death in Kwahu-Tafo, Ghana. *Social Science & Medicine* 58: 899-911.
2007 Is it possible to understand illness and suffering? *Medische Antropologie* 19 (1): 9-21.