

Discussion of Risk in Palliative Care as Personal Experience in Two Countries

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Palliative Care is known to be good for patients, their families and their care takers [1] as stated in the Royal College of Nursing's framework for nurses working in specialist palliative care Competencies Project in 2002. There are risks to any type of medical care. The end of life care that palliation suits well has many issues that need to be addressed. The risks of premature or late withdrawal of life saving interventions are the least of the problems encountered. The curative care model that has been the expensive and more futile variety of end of life care is being superseded slowly by Dame Cicely Saunders and her colleagues simple mantra, that one should not die in pain and one should not die alone. Occasionally, the providers are suspected of hastening the death, by attending to deep anxiety and pain, and reducing the quantity of life, by giving medication that turns the patient inward and away from desire to eat, drink and communicate. The care for the patient requires the care and informing of the family. The St Christopher House has been a source of experience and knowledge for all disciplines of medicine [2]. Palliative Care has ancient roots, but the modern Hospice Movement in UK and USA is barely a hundred years old yet. Many people, with all their personal ideas, trained thoughts and skills and the financial incentives are brought together for the benefit of the patient. The Family sometimes seems to lag in importance in their relationship to the providers. Striking the balance of goodwill, skilled physical and mental care can lead to spiritual satisfaction for all members of the deceased and nearest loved ones.

I posit a risk issue with the practice of palliation as a discipline. I have experienced Palliative Care as a doctor, patient, family member and caretaker in two countries, UK and USA. The expression below is my own experience and analysis.

Palliative Care as a Specialty is triggered by a deterioration in a patient's health, to the point that if they have a Family, the Family needs help with decision-making and care of the patient [3,4]. The diagnosis and prognosis will be determined by the patient's physician. The patient and family will decide with the physician what course will be taken. This may be a difficult moment for both patient and family, and sets them up for disbelief, grief and various stages of acceptance [5]. The palliative part is to manage the symptoms and prolong the quality of life, not necessarily the quantity. The tools to achieve this are nursing personnel, therapists and personal caretakers/aides along with equipment for walking, washing and toileting. The site of care can be at home, in a nursing home, a hospice or a hospital. In UK, hospice houses are scattered amongst communities and are often run by charities [6]. In the US, hospice houses are for short term respite care [7] and are rare. All the hospice houses are non profit.

Care in the home is provided privately in both US and UK. In UK, care agencies will see a patient up to 4 times a day, provided there is someone to care for him/her between visits. Some palliative care is provided by the continuing health care (CHC) part of the NHS (National Health Service) [8], if the patient qualifies. There are rigorous criteria to pass, in order to qualify. Macmillan Nurses (Charitably supported Nurses, who go into the homes of those dying with cancer) [9] offer terminal care on a volunteer basis, but cannot be depended upon for a long-term solution. Caretakers are contracted by the NHS, unless the patient does not qualify, and the patient bears the cost up to a maximum of sixty-five thousand pounds, under a Social care NHS

contract to the public [10]. After a very long and convoluted review, the patient may qualify for some financial assistance. The care agency signs a contract with the patient and follows a care plan. This may include a live-in care taker for safety. The care plan is supervised by the doctor and district nurses. The patient's family can be excluded in the arrangements, since the patient and family may have a slightly different understanding of the responsibilities and confidentialities [5]. The caretaker and agency sign with the client, if the client is of sound mind. This crosses the cultures. It is a good physician who can get both the family and patient to agree to basics. The district nurses in UK and Home Health Agency nurses in the USA will monitor the care provided and allowed. The basic ethic of home care at the end of life has much in common across the US and UK cultures. The details are different, possibly due to the type of funding and what is expected from each culture.

When Patients start looking as if they will not recover, basic decisions are reached by the patient, family and providers to prolong therapy or to only treat symptoms and to place the patient, where that care will take place. Debates erupt within families, between providers and patients and their loved ones as to the best path. Getting everyone around the proverbial table to have these discussions seems to have fallen to the old fashioned family doctor or to a team of people specialized to accommodate dying wishes [4]. The functionality of the family will pose challenges to the providers of medical and personal care.

Family and patient may start by being ambivalent about strangers in the home. They are often worried about criticisms to their domestic arrangements and décor, resources etc.

Basic agreements at the end of life will firstly be the "do not resuscitate" order, signed by the competent patient, or patient's guardian, with the doctor, for all to see. Secondly, the determination of what is treatable, like pain, neuropathy, a cough, urine infection, stuffy nose, fever, weakness, bleeding, wound, etc. and what is not treatable, like cancer, heart valve disorder, heart attack, blood clots, and thirdly what may make one change one's mind about going to hospital: broken bone, deep cut, twisted bowels, or pain that needs a surgical intervention must all be openly discussed to reduce conflict between family and caretakers, when the symptoms change. The caretaker may feel insecure and summon the paramedics, who will transport the patient to hospital, even if there is a "do not resuscitate" order (DNR). The fourth absolute knows who is caring for what and when,

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and having a fresh supply of non-fatigued, able bodied personnel to do the various jobs. Doctors will visit once or twice a month, nurses at least once a week, and caretakers, who live with patient and family, will require respite for two hours a day, and relief for all night. Daily respite is covered by arrangement with family, friend or volunteer. In UK some agencies rotate caretakers every two weeks, while others make separate arrangements with each caretaker. The latter sets the caretaker up for ennui and burn out. In the USA, Hospice Care paid for by Medicare will have non-residential carers providing light housekeeping, shopping and personal care. The family is responsible for meals and live-in safety care [11].

Having a family member live in the home with the patient, who is declining, means there is more than one vulnerable set of feelings. The relationship between the patient and the family member has to be assessed by the doctor, district nurses, agency and caretaker. The wishes of the patient must be seen to prevail, however weak the patient and however forceful the family member [5,8]. In the right circumstances, all will be aligned. The District Nurses in UK must monitor nutrition, elimination, clinical signs and symptoms at their regular visits to the patient. All is documented in the patient's record and is available for other nurses and the doctors to read. Home Health Nurses in the USA have similar practice. Nurses do not step out of their scope of practice, for fear of reprimand. This can make common sense issues complicated. Most nurses, who do work in the community, are very experienced and are able to address health issues squarely. The patients are grateful for the role of the nurses, and the relationship does not have major vulnerabilities.

The role of visiting caretaker and the role of live-in caretaker do come down to compatibility with patient and family, trust and scope of practice. The caretakers have to accommodate not only the quirks of their patient, but also must deliberate whether to include or exclude those of the immediate family, as well. In some circumstances, the family members are taught moving and handling responsibilities and are able to physically assist in the care of the patient. In others, family members are reluctant to participate in such care, while still others embrace the opportunity. The vulnerability arrives when the family member is not as capable as the caretaker/ agency would want, and excludes the family member from such participation, without being able to talk about the issue.

Such actions limit the care given the patient. If the caretaker is unavailable, for personal reasons (in the toilet) or is cooking for the patient, for example, and the patient may need to be toileted via a hoist, an alternate caretaker is needed. This could be the included family member. If the family member has been excluded it adds to all stress. The obverse may occur, where the caretaker criticized the family member, for not attending to a toileting crisis, when the family member had conflicting issues (midnight power outage precluded a complete wash, when the patient was soiled) and suggested additional care was needed, when it was not normally necessary. Both these illustrations are drawn from personal experience.

I have four examples of Palliative Care at different stages of my own journey. The first through my profession as a surgeon; second, as a patient with a near fatal illness; third, as a caretaker and relative for my parents and fourth, as a supporter for my husband in his role as caretaker and son of his mother.

As a physician, I have been in the honored situation of being invited into a family to help arrange for terminal care. The patient asked me to help her end her life, which made me burst into tears, since I did know her outside of my practice. I told her I would not end her life, but

would help her through her own death. I did not expect it to occur so precipitously. I spoke with her primary care physician and he promised to stand by, should I feel the need for his consultation. The patient was an elderly matriarch, with many children; some lived on the West Coast of the USA. We were in New England. Home Health and the family were organized and I was asked to accommodate her wish to die at Thanksgiving. She was on steroids for metastatic breast cancer and chronic obstructive lung disease. She no longer wanted to treat her bronchitis with antibiotics, which made her nauseous. She was in pain from her bony metastases and she was developing headaches. We started some injectable morphine and placed a foley catheter, so she did not have to get out of bed to void. She was joyful in stopping eating. She drank what she wanted. A week before her family arrived, she stopped her pills herself. She required oxygen, which she removed about two hours before she finally died on the evening of Thanksgiving. The entire family stayed in the room with her. She asked her grandchildren and friends to look up words in the dictionary. There was much laughter and crying. A video camera recorded it all. At her chosen moment, I was called and she removed the oxygen. I arrived as she was pulling it firmly from her face. At each moment, we asked her if she wanted to continue to remove treatments. She assented. None assisted her with decisions nor actions. Her daughter sat beside her as she rasped to her that she was now bequeathing the role of *Yaya*, (the Greek word for matriarch) to her. Though she struggled to breathe, the patient resisted the oxygen being replaced. We all knew our place. She died with her Family Practitioner, her entire family and I present. It was a privilege I cannot forget.

As a patient, I called on my palliative care colleague to assist in the help of my own family when I had Acute Myeloid Leukaemia and three transplants. This took 2 years of my time. I used the Healing Arts Program to its optimum. I have written of this in a previous article [12].

After I was recovering from the last transplant, my own parents failed acutely and I went from the USA to UK for an extended period. My sister and I had to arrange care for our bed-ridden mother, on three liters of oxygen a minute. She had taken all our father's final energy. He developed a myeloid dysplasia and that resulted in a myeloid sarcoma wound of the leg that required hospital care for sepsis. He had multiple issues unaddressed in the hospital, including a wound he incurred in the ward, with massive blood loss, due to an unattended fall. With full participation of his doctor, he was brought home and we arranged for a full time live-in care taker. She had my father at her heels all day. He was scoliotic from an old injury, intermittently ill, but not wishing to relinquish his role as *pater familias*. He had a long standing intermittent volvulus of the sigmoid colon that obstructed painfully from time to time. We had apprised his surgeon that we may need an emergency colonoscopy for pain control at some point. I took the advice of a friend who was a visceral physiotherapist and learned to position him in an upside down, on his left side stance, using the mechanical hospital bed to accomplish this. He needed my input and abdominal massage to reduce the colon and then the pain, without resorting to surgery. I had asked to teach his caretakers this manoeuvre, but they were reluctant to take my orders. My mother was anxious and isolated and called for help all day. She had memory loss, which appeared to be related to chronic oxygen deprivation and an overriding sleepiness due to CO₂ retention when she was oxygenated. She was insomniac and wore everyone down.

We then changed the caretakers and paid for a private contractor, suggested by another agency, who subcontracted self-employed caretakers to do the home and personal care. My sister was very busy with her obligations, yet offered every assistance she could. Due to

my relative freedom from a schedule and needing to still recover my strength, I stayed and took physical care of my father, cooked and shopped, and had the live-in caretaker look after my mother, who took more time and could not recall if she had told everyone how awful she felt. I slept near my mother, upstairs. My mother called many times and needed a visit to reassure her, throughout the night. The caretaker slept in the guest room. My father, downstairs, was less demanding and could void alone at night. I was available to him too, via a baby monitor. One night I took a tumble down the stairs and shocked everyone, that the care was so dependent on able bodies. My father became weaker and we stopped his hospital visits, caring for him on the ground floor, in a hospital bed. It took a long time for him to agree to the “do not resuscitate”(DNR) order. The deciding moment, between the physician, my father and me over signing the DNR form, was him asking me whether he would be *resuscitabile* and would not “being resuscitated is painful”? Our joint answer was that resuscitation would have limited success and he would probably have broken ribs and a tube in his throat for breathing. He signed with a grimace. We decided to treat his fevers, urine infections, fungal overgrowths, stuffy nose, congestive heart failure, prostate hypertrophy, and his pain and ulcer, which required daily nurse visits. I interacted comfortably with the physician and he visited less and less often, as I seemed to anticipate the situation fairly well. Our communication was unflustered and supportive either way. The medical chart was initially handled by me, until I got shingles and had to hand over all my physical care, plus the cooking to the care takers. I shopped on-line for the delivery of medicines, groceries and milk.

One care taker who came from Africa was quite shocked at the work she had to do, when I was ill, and became very rude to us all. My father was threatened by a comment she made, when she fell and twisted her ankle, and told him she would sue him for her damages. The contractor had to add another shift to allay the impending burnout. Multiple changes ensued, and I was told the situation would be easier when I no longer lived in the house. After a stressful Christmas, I left a day and a night care taker in charge, but was called back within three weeks; my father was dying and wanted me there. My son wanted to say goodbye to his grandfather and came with me. We returned to UK from USA.

On my return, I asked the District Nurses during the dressing change, if they minded if I removed the necrotic eschar 15 × 9 × 2 cms from his leg, which were seeping foul fluids. I was a surgeon in the USA, albeit, not working in the interim. I also held a current British Licence to practice medicine, having trained in Britain, before emigrating to the USA. In view of his impending demise and the increased care the messy wound entailed, it seemed a sensible move. The District Nurses were very careful to include me in the care of my Father. They comprehended my training, my status at work and the place in the family, as endorsed in their presence by my Father. We were prepared for hemorrhage. It did not occur. The antibiotics kicked in and the wound shrank to 7 cms × 4 cms, without any depth to it, over the next five months. His need for dressing changes dwindled. Though he no longer got up, he was hoisted to a chair most days. My surgical palliation had worked. However, I was excluded from his care, due to the contractor telling me “you are not one of my team and I will not be responsible for your father when you touch him”. The deep sadness this brought to all of us was not mitigated by my father, who said that although I was his daughter, I may not be there when he needed someone, and he preferred I step back and allow the contractor to care for him and my mother. I continued doing his business arrangements and passed the administrative chores on to a friend and trustworthy neighbor, when I returned to USA for a

rest. Within three weeks of my leaving the UK, my father died suddenly of pneumonia. I was told at the last minute and was unable to return to see him. I did not have concerns about the abrupt end to his life, which was preferable to his ongoing disability and dwindling ability to concentrate, but I was distraught that I was excluded from the front-line relationship, that being a doctor daughter had allowed me.

With my mother, I knew the ground rules. My father had left my mother provided for with money for at least a year of care. She had 24-hour care, and we moved her, where she had privately funded palliative care in a private home with a new doctor and new district nurses but the care takers she knew. Her house sold and five months later she died, attended, but lonely and sad; with me present for all, but the last few hours. Her care was very complicated. It was made difficult by her strength of character and the very poor health she had acquired from smoking. Her desire to appear normal and expectation of normality in response pitted less clever people against each other. Where familial relationships still motored along old roads, the honest response of the caretakers to her behavior was tantamount to disrespect. When my father died she grieved in her own negative way and community members were called in to reassure her. She was grateful when my sister and I were there, but she was divisive, which made for some tempestuous moments between caretakers and family and her and me. She died well loved by one caretaker (also from Africa) and well looked after by the others (English and African). The doctor she had in the final few weeks was inclusive to both her caretakers and me. She wrote me a letter a few days after the death, saying that I had anticipated her death well. The District nurses and the community specialists seemed to disappear. She was given antibiotics and anti-anxiety drugs prior to her death by the “out of hours” duty doctor, who never consulted me. She was very weak and died.

After my mother died, I returned to my husband, whose mother had started to become demented and weak. We arranged for Home Health to assess her for personal and nursing care. The local Home Health and Hospice Agency was one I had hoped to join as the alternate Medical Officer, when my colleague, the physician was away. There were issues of my being employed there, so I dropped back, but knew it was a good agency. My personal criteria for a trustworthy agency included a Family oriented approach to the care of the patient. This I had seen as a member of a weekly committee, held to discuss the care of the Hospice Patients.

My mother-in-law was evaluated, seen to have acutely deteriorated by the doctor, and was admitted to Hospice. We had suggested she stop her diabetic pills, which she did. Her medicines and personal care was done daily by a visiting aide. My husband developed great pleasure in feeding her a healthy diet. Physical Therapy and Occupational Therapy sorted out some of her needs. My husband put up 17 handholds around her small apartment. We were given a baby monitor and special bed rails, which reduced her likelihood of falling and improved communication, respectively. She has since been able to manage her own toileting, to a point. When she cannot clean herself, it is managed by the next day's aide visit. My husband will visit her many times a day and at night if he hears anything. Her care is well received by her, although she took a few weeks to adjust to the invasion of her privacy. Her memory is poor, but she seems happy most of the time. On occasion she was very suspicious of the aides and my husband has reassured her that they were there to help her. We, the family, are still supported, despite the possibility of problems with my relationship to the doctor and the agency. Confidentiality works efficiently amongst the caretakers and providers, knowledge to care for her passes freely between family and providers.

On looking at the risks associated with palliative care, communication and intent are very important. Moral compassion is encouraged in those that can be compassionate naturally. Taught compassion has an edge to it, that any child or demented patient understands in a visceral fashion. The risk of everyone being taught emotional behavior means that those who are not “street smart” have to navigate by rules. The rules are inflexible in their hands. These people are difficult to encounter in a patient’s home [5]. Everyone has a different level of knowledge and comfort with hard and fast rules. The higher up the hierarchy, the more relaxed the relationship is with the patient and family. The closer to the physical care of the patient the provider is, the less knowledge is possible and the more the reliance on “the rules”. The flexibility of the relationships to each other and to the patient depends on the rapport engendered between the patient and each member.

In the first example, as a physician, I was in the thrall of a competent, well organized family with the intention of seeing out their matriarch together. Their cultural background was Greek American. Fortunately, it all went smoothly. I was a naïve doctor, but intentions were for the best. The first example “Yaya” (matriarch) dying in the bosom of her family was outstanding. The family and community were supportive. In the second example, as a patient, I felt the palliative care team in a major US Hospital, where the Arts helped me recover, was very helpful and the experience has propelled me into a successful survivorship [12]. In the third example as a family member, I was thwarted in one of the truly important relationships and times of my life. I was not supported by the UK care takers and their contractor. In fact I was excluded and my father was made to feel vulnerable. The general practitioner and the district nurses were very helpful, kind and treated me as well as my father. Managing that relationship prepared me to care better for my mother. In the fourth example, my husband’s care of his mother is being supported by a Vermont (USA) Home Health and Hospice Agency. The custom of the agency is inclusive and helpful. The weakest part of these experiences was a technically capable caretaker for my parents, who did not have an intuitive streak of compassion. This was a sad time for me.

The difference is a matter of training and philosophy in including the family as part of the patient’s needs. In “Palliative Care Ethics” [5], the patient is considered the centre of the care model, and the ethics

of how to include or exclude the family is discussed. This was written for physicians and nurses in 1996 in UK and has a much more top down attitude to my view. That way was observed in the caretakers in UK. Their training is simplified and competences are technical, not intuitive. My own opinion is that the family members are part of the patient’s frame of reference and the negotiations should always include the supporter of the patient, whether family, partner or closest friend. I see every relationship between all the participants in a palliative care situation as having its singular vulnerabilities. The closer to the patient, the less educated and intuitive the caretaker is, the situation is less flexible as well. The relationships emanating from the patient determine how functional all the others are. The lead providers must take an inclusive role. This analysis touches the surface, and should be studied at length and depth, if we are to handle dying people more commonly at home and pay attention to the mental, physical and spiritual needs of the people in the home [1].

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