

AGED PERSONS: *their right to respect and choice when accessing health services*

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Introduction

A recent experience of watching an elderly family member die from dehydration and malnutrition because he was assumed by health professionals to be in his last stage of dying has left the grieving family asking lots of questions about ethical practice in the hospital and aged care sector. Further, preliminary research indicates that this experience is by no means an isolated case. There are multiple recent reports from both government and non-government bodies that aim to address the tension between patient-focused care and restricted resources to meet elderly and dying patients' needs.

Scope and Purpose

This paper is a reflective response to a personal experience of watching my father dehydrate and starve to death over a period of fourteen days without neither timely nor appropriate assessment for alternative options to meeting the basic needs of being fed and hydrated in the home setting.

This paper is also a response to the many narratives/accounts/anecdotes from others – including health care professionals who have had similar experiences with their elderly parents accessing health services and who were also denied the dignity of proper medical assessments and the opportunity to make informed choices about their health care plans.

Written from a human rights perspective the paper promotes ‘*people-centred decision-making*’, ‘*respect for the inherent dignity of older people*’, and the ‘*availability, accessibility, acceptability and quality*’ of resources and services to all people (Australian Human Rights Commission, 2012). Consequently this paper focuses on the right of elderly patients to their self-determination - to be treated as individuals with unique physical and mental capacities despite their same diagnosed illness; to be offered the same resources and quality of services as younger patients; and to have their choices respected.

The author acknowledges the international and national legal and policy frameworks for aged care, specifically highlighting *The Age Discrimination Act 2004* which prohibits *age discrimination in many areas of public life including the provision of goods, services and facilities*, and emphasises ‘*that people of all ages have the same fundamental rights to equality before the law regardless of age*’ (Australian Human Rights Commission 2012, pp.6-7).

Whilst acknowledging that morphine is indeed a blessing for patients who are genuinely in pain, this paper is highly critical of medical practices whereby patients are assumed to be in pain and are consequently fast tracked to their deaths without the patient’s knowledge or consent under the guise of ‘comfort’. This perspective is consistent with Palliative Care Australia’s: *Standards for Providing Quality Palliative Care for all Australians* (2005, p.10).

At the same time, this paper acknowledges with gratitude that there are genuine ethical medical and allied health care professionals who do prioritise the self-determination of their patients irrespective of their age, offering them timely options, and medical examinations to assist them and their families to make the most informed choices in both their recovery and dying processes.

Specific names of hospitals, doctors, nurses, or health care agencies have been deliberately omitted from this paper to avoid the self-preserving reaction of focusing on damage control instead of examining medical practices according to ethical standards that empowers humanity in its evolution as a whole.

Personal Experience

My father, aged 86 years when he died earlier this year, was diagnosed in 2005 with Lewy Body Dementia. In 2007 he was admitted to hospital to be treated for a urinary tract infection and a mild stroke. Whilst in hospital it was discovered that his mobility had deteriorated. Arrangements were made for the Extended Aged Care at Home (EACH) Package care assistance program to be provided for my father to enable the family to care for him at home.

In 2008 and 2009, my father was hospitalised for aspiration pneumonia. Four days after his admission to hospital in 2009, he contracted *Enterococcus Faecalis*. The attending doctor asked the family about what should happen if my father's condition was to deteriorate as there was 'skeletal' medical staff rostered over weekends. As this was perceived to be a life-threatening situation, the family firmly stated that we wanted to respect his wishes to die at home. The attending doctor then recommended that we take him home with an oral antibiotic and the support of palliative care.

However whilst still at hospital, when my father's geriatric specialist visited him later that day, he called me, my sister and the attending medical team aside and informed us that the antibiotics were not working and that there was nothing that could be done. He instructed my sister and me to take our father home and to give him whatever he requested to eat and drink.

When my sister asked about the oral antibiotics that were to be given to my father at home as recommended by the attending doctor, he reprimanded the attending doctor in front of us for making the recommendation. I asked the geriatric specialist how long he thought my father would have left to live. He replied that "probably by the weekend at max [sic] a week". We were shocked by his statement since our father did not appear to be dying – he had just eaten, drunk and had joked with us.

Confused, but trusting the geriatric specialist's knowledge, my sister and my mother went home to make preparations for my father's homecoming. I waited at the hospital with my father to accompany him home with the ambulance. I watched a nurse administer to him one dose of morphine. The nurse said it was to help him to be comfortable. I felt confused, as my

father had not been in pain. Another nurse then taught me how to draw and inject morphine into a subterranean butterfly cut. Still confused, the nurses assured me it was to help my father be comfortable. When the ambulance arrived later that afternoon a nurse injected my father with a second dose of morphine. My father had been peacefully asleep to this point when suddenly with the second shot of morphine he started to groan and moan. I couldn't understand why he was groaning. I asked the nurses why my father needed a second shot of morphine and they said it was in case he became uncomfortable in the ambulance.

Meanwhile, the palliative care nurse rang home and spoke with my sister instructing her not to give my father any food or drink. My sister was confused by this direction as the geriatric specialist had specifically told us to give him whatever he wanted. The palliative care nurse insisted that my father was to be "nil by mouth" as he could choke. The conversation turned into an argument, wherein my sister was arguing about how my father was to survive without food or drink and the nurse was arguing that any food or drink would definitely choke him. The palliative care nurse eventually became frustrated and asked my sister what she had been doing at the hospital, to which she replied that she had fed him and had given him fluid. There was a moment of dead silence before the palliative care nurse quickly asked for my mobile number and said to my sister not to give my father anymore morphine.

The palliative care nurse called me on my mobile whilst I was in the ambulance on our way home and asked me to pass my telephone to the ambulance officer who then tested my father's response to light. Luckily he responded. The palliative care nurse then instructed me not to give my father any more morphine.

My father slept until about mid afternoon the following day, woke up and chatted normally to the family, but was breathing with a noticeable chesty cough (a symptom he did not have in hospital). A second palliative care nurse visited that same afternoon, and when we requested another medical opinion, she said that there was no point because she could hear the coughing. (She came to this conclusion from outside his room and without examining him). We were too scared to give him anything to eat or drink that weekend,

as we did not want to risk him choking. However by Sunday afternoon my father called the family together and asked us: “doesn’t anyone cook in this house anymore”, to which my mother replied: “Why? Are you hungry?.” He replied: “well of course I’m hungry, I haven’t eaten since Friday”. We fed my father that day without any problems. He was later examined by a respiratory specialist, who shook his head at reading the hospital discharge papers. My father resumed his normal living routine until January 2013.

At no time had the geriatric specialist informed my father nor his family about why he was administering and prescribing morphine to him (since my father was not at any stage in pain). Furthermore, neither my father nor his family were given evidence as to why the antibiotic was not working. After all, the attending doctor had told us that the antibiotic would take up to ten days to see if there was any progress, and my father had only been administered with the antibiotic for two days prior to discharge.

It should be noted that in the interim 2009 -2013 my father had not been hospitalised for aspiration pneumonia, as it was appropriately managed from home with an oral antibiotic. However, he was admitted into hospital in 2010 for a blood clot.

It should also be noted that the first palliative care nurse remarked that she was horrified as to what had happened and that in the future she would check the patients first, instead of assuming that they were in a coma. The family were later informed by the same palliative care nurse that the continual administration of morphine when there was no pain would have significantly deteriorated my father’s lungs, and that would have certainly curtailed his life much sooner.

As a result of this frightening experience with the geriatric specialist and hospital staff, my mother began associating hospitals with the ‘killing fields’ for the aged and was very reluctant and fearful of going to hospital for a heart condition when she really needed medical assistance.

Since December 2012 my father’s swallowing gradual deteriorated. On the 3rd of January 2013 he was having difficulty swallowing an oral antibiotic, although he had managed to eat large meals the day before. With a high temperature, and not having swallowed much fluid, the family General

Practitioner (GP) recommended that it was important to take my father to hospital. Reluctantly, we admitted my father to hospital because it was the only option for administering him intravenously with the antibiotic and fluids he needed. For four days my father was 'nil by mouth', and he desperately pleaded with the family for three things: water (the thickened fluid we normally had given him for the past six years); to have a shower; and to go home.

The constant mouth swabs the family were giving him were very ineffective to allay his feeling of thirst. On my father's first day in hospital a speech pathologist tested my father's capacity to swallow and thought it was not advisable to give him thickened fluids until further testing to reduce the risk of further aspiration. On the second and third day another speech pathologist came and without any examination said she would not advise testing my father's swallowing capacity because she could tell he could not swallow. She then turned to me with an angry tone and said: "Why do you want to prolong his suffering?" We had constantly asked my father if he was in pain and he assured us that he had no pain, only severe thirst.

On the evening of the day after hospital admission, I overheard a doctor discussing with a nurse about pain management and "keeping him comfortable". As I was now alert from my 2009 hospital experience with my father, I asked the doctor if this 'comfort plan' meant administering morphine and she replied "yes, but only in small doses". The family repeatedly and firmly informed this doctor and the following attending doctor on the same evening that at no stage was my father to be administered with morphine or any comatosing drugs without our consent. The family informed them that we would check with my father first if he were actually in pain, before consent would be given. The attending doctor appeared surprised and stated that it was written in my father's medical notes that a doctor had already discussed this 'comfort plan' with the family. Further alarmed, I informed the doctor that no one had discussed with either my father or the family about any such pain management / 'comfort plan'. This was a repeat scenario of 2009 that occurred in a different hospital.

On the third day in hospital, a doctor from the aged care unit examined my father and said that the antibiotic was working and that his chest infection was clearing. Pleased with this progress report, the family were

waiting to see a speech pathologist on the following day to undertake a proper examination of my fathers' swallowing capacity. However, no speech pathologist attended. Instead, the hospital registrar arrived and at the end of the bed without giving my father any examination, concluded that the antibiotic was not working and that it was to be ceased immediately. She said that from then on we were to give my father "comfort food", "only when he asked for it ", and that "nothing else can be done" since he was in the "dying process". We assumed this meant that we would feed and hydrate my father as undertaken prior to hospital admission, and that my father's "dying process" was similar to the 2009 experience. At this stage we had no idea about the extent of my father's swallowing capacity.

The family then requested that since there was to be no further administration of antibiotics there was no reason for my father to remain in hospital, and that we would thus grant him his wish to go home. The hospital registrar then stated that my father could not leave the hospital for two days because of "paperwork". In her next breath, she requested for the family to sign a medication consent form. When I asked if morphine was on the list, she said yes and continued to reassure us that it was "just in case he becomes uncomfortable". We refused to sign this form as we believed they would administer him with the drugs whether he was in pain or not. "In that case", the registrar replied, "he can go home this afternoon". Suddenly the "paperwork" could be completed within a couple of hours!

Upon discharge, my father was not offered alternative means for hydration and nutrition. Tests were not undertaken to see if a feeding tube could have been inserted to keep him hydrated and fed. It was assumed by all, including palliative care nurses, that my father's internal organs were "shutting down", and that he was in his last stage of dying.

Arriving home, it was priceless to see the smile on my father's face at recognising he was home at last. We were glad we were able to give my father one wish. By now the continual vigilance at the hospital had exhausted the family. However, there were further struggles to fight for my father's rights.

We discovered that since palliative care had become involved, the EACH Package protocol forbid carers from using lifters and other transferring equipment. It was a constant battle between these two agencies to set up an efficient service. As my father had been clamouring for a shower (which he was not able to have for the four previous days in hospital), and the fact that he hated being in bed during the day, this was an immediate problem. It meant that he was being stripped of the few quality of life pleasures that he had left. We insisted that other than my father's swallowing muscles, his physical capacities were in no way different than before admittance to hospital. A palliative care nurse did not visit until the third day after my father's discharge from hospital. By the time palliative care were able to arrange for their staff to give my father a shower it eight days had elapsed during which time he had no food and five days without water. At this stage it was too uncomfortable for my father to enjoy a shower and we had to give it a miss.

The day after my father arrived home from hospital it was his birthday. We attempted to feed him his favourite food (figs). We watched him try so hard to chew, and we will never forget the look of desperation on his face when he realised he could not swallow and nor could we feed him any other way. As an attempt to lift my father's spirits I said: "Happy Birthday dad" to which his reply was a direct look at me in the eye and a shake of his head to indicate 'no' it was not a happy birthday.

As my father regularly had blood tests each fortnight for his INR levels, the family GP suggested my father have a blood test to check the functionality of his organs. The GP rang the family on the evening of the same day reporting his surprise upon finding that my father's kidneys were "better than they had ever been". We felt confused as this did not sound like my father was in his last stages of dying.

We asked the palliative care nurse about how else we could hydrate and feed my father. She assumed that my father was in his last dying stage and said that he could choke because his stomach muscles would have deteriorated and that his organs were beginning to shut down. However, no tests were undertaken to confirm this conclusion. It was simply assumed that a person's body of my father's age with his condition would be shutting down. A person's body of any age that was not hydrated and fed over many days would naturally shut down and die.

In any case, on the eighth day of 'nil by mouth', due to our persistent requests to hydrating options, the palliative care nurse suggested she could arrange for a doctor to see if it were possible to hydrate my father through a sub-terrain cut. However, it could not be arranged for a doctor to attend before the following Monday. By then, it would have been eleven days of 'nil by mouth', and the medical assessment that "the water would pool in an area of the body because the organs were no longer able to function properly" may well have been correct.

At every turn, at the family's constant frustration of questioning and insistence for hydration and nutrition, options were suggested at later stages when they would not have been effective. Palliative Care and the EACH Package agency spent a lot of time clarifying their respective roles; consequently their services during this time were unhelpful, untimely, and ineffective.

It took my father 14 days of 'nil by mouth' before he died, and we seriously question in a first world country like Australia, whether there were more humane options in the dying process other than starving and dehydrating a person to death. We were told that a dying person does not want food or water. In the early days after returning from hospital, my father did not refuse food or water. It was assumed by hospital and palliative care staff that no other option would work, and that my father was actually in the final stages of dying. Had my father been in a coma, these assumptions would have passed unquestioned. At least we have the consolation that we were able to give my father the dignity to die consciously without pain, in the comfort of his own home.

To this day palliative care have not visited or contacted the family since my father's death other than sending a brochure on grief counselling.

Experiences Disclosed From Others

In speaking about the above experience with others the response has fallen into two camps: those who claimed their loved ones had been given health care choices; and those (including health care professionals) with stories similar to our own where their loves ones were not given adequate choices.

One woman reported watching her mother-in-law shaking her head with a look of terror on her face refusing the morphine she was been administered, and then dying shortly thereafter. A carer working in a nursing home reported having seen a client jovially eating, drinking and conversing fully conscious one day and within less than twenty-four hours of his next visit seeing the same patient totally comatose. One allied medical health practitioner reported both his elderly parents were given the wrong medication, which consequently shortened their life; another allied health practitioner reported her elderly parent was misdiagnosed; and a doctor had to have recourse to medical legal services to ensure his elderly parent received CPR and appropriate treatment for healing in the case of an emergency whilst in hospital.

What was most alarming in most accounts was the overall resignation to the generally perceived status quo: “we know hospital staff fasten the dying process of elderly people in hospitals and nursing homes - they do it all the time”; “we all know it happens”; “doctors in hospitals have an unofficial licence to kill – there is nothing you can do about it”, “they do that alright, the nurse did it to my mother in-law...she gave her one shot and that was it... she died shortly after that...it’s one thing if people are in pain but they give it to elderly people who are not in pain too.”; “they do it because of hospital funding cuts”; “you better not challenge the health system otherwise other family members may suffer consequences because you are in their data base” (2 people).

Despite the anecdotal nature of these responses, it does however show a trend in dehumanising attitudes and practices towards elderly patients.

A quick perusal of similar experiences and reports on the internet indicates that the culture of disrespect towards elderly people in health services is pervasive not only in Australia but also globally. These reports include:

- Hunter 2012, “Neglect and Abuse in Aged Care”
- Raghavan 2012, “Ageist’ doctors negligent of elderly?”
- The New American 2013, “British Hospital Patients Dying in Drones From Lack of Care”
- CMF 2012, “Is the NHS really killing 130,000 patients a year with the Liverpool Care Pathway?”

- Allan 2013, “Elderly patients are being ‘deprived of food and drink so they die quicker and free up bed space’, claim doctors”
- Australian Publishing Resource Service 2010, “Hospital elderly: malnourished and underfed”
- Raschella 2012, “Hospital probes claims elderly woman neglected”
- Courier.com.au 2012, “Hunger and thirst blamed for 2000 patient deaths in Queensland public hospitals in 2011-12”
- Helpguide.org 2013, “Health care fraud and abuse”
- Mackay 2013, “Without Due Care: An Australian Hospital Tragedy”
- ABC LATELINE 2012, “Public hospitals in Crisis”

Websites such as: Older People Speak Out (2013) and Agedcarecrisis.com: where little voices can be heard (2013) are specific advocacy responses to the discriminatory trend towards older citizens in Australia.

According to a media release by Palliative Care Australia (2010) poor quality care towards the elderly and the dying is acknowledged: *We know that in Australia there is great inconsistency in care provided to people at the end of life. Some people receive the care they need, many do not. Some experience excellent care in hospitals, hospices and at home, many do not.*

The Productivity Commission (2011, p.186) supports this finding:

the community is often concerned when they read and see media reports about poor quality care being provided to older Australians, it seems that everyone has a personal story and experience. Some participants to this inquiry were clearly satisfied with the quality of care provided, while for others the quality of care fell far short of their expectations.

In terms of older people denied choices in their health care plans, due to being assumed incompetent, the Productivity Commission (2012) reflected this practice in their statement: *‘Older Australians and their carers expressed strong views that they should have a greater say in their care’* (Commonwealth of Australia 2012, p.41). The Australian Human Rights Commission (2012, section.3.3, p.16) also refers to this practice, attributing the assumption that older people are unable to make their own decisions, to *‘age-stereo-typing’*.

Discussion

Our human dignity depends on our courage to expose dehumanising behaviours and promote respect and justice for all people, especially the vulnerable. My father's experience in the aged care system has highlighted discrepancies between ethical professional standards and health care practices.

Tension

We do not have to accept the cultural belief that the elderly have a 'use-by date'. Nor do we have to be 'sheep easily led to the slaughter' by services that tend to prioritise 'cost effectiveness' over 'high quality' in their service delivery, despite the lip service to quality care (NSW Government Health 2013; Catholic Health Australia 2012, p.12; Bigelsen 2011).

The Productivity Commission (2011, p.202) has recognised this tension: *Too much emphasis on process and documentation adds to costs, and can detract from care quality, without adequate benefits to the wellbeing of care recipients.*

At the same time the Australian Medical Association (2006) Code of Ethics section 1.1.23 unequivocally states: *place your professional duties and responsibilities to your patients above the commercial interests of the owners or others who work within these practices.*

Assumptions and Absence of Timely Medical Examinations

Whilst in hospital on both occasions (2009 and 2013) it was wrongly assumed that my father was in pain, and that he consequently needed morphine. At no time did hospital staff factually check this with my father nor with his family as to whether he was actually in pain. Furthermore, a blood test post exit from hospital in 2013 revealing my father's kidneys were in optimal condition left the family seriously questioning the other assumption by both the hospital and palliative care staff that my father was in his last stages of dying at that point in time.

Assuming people are in pain, and/or are in the dying process without carrying out a proper medical examination is clearly negligent practice. According to the Medico-Legal manual (Department of Health 2007, p.10) negligence or '*ways in which health care professionals have been found to breach their duty of care include: failing to treat (adequately or at all); failing to diagnose; and failing to attend or examine.*'

This practice of making assumptions and thus not conducting timely medical examinations is in contradiction to:

- The Medical Board of Australia (2009):
*Good medical practice is patient-centred. It involves doctors understanding that each patient is unique (1.4, p.1);
Treating each patient as an individual (3.2.2, p.5);
Ensuring that your personal views do not adversely affect the care of your patient. (2.2.12, p.3);
Your decisions about patients' access to medical care need to be free from bias and discrimination (2.4, p.3);
Refrain from denying treatment to your patient because of a judgement based on discrimination (AMA Code of Ethics 2006, 1.1.10);*
- Palliative Care Australia (2005, p.6) affirms that palliative care is about considering 'the *unique needs of dying patients*' and '*care, decision-making and care planning are each based on a respect for the uniqueness of the patient.*'
- The National Health and Medical Research Council (2011, p.10) highlights that this practice breaches the ethical concept of 'respect for people':
The key ethical issues in relation to respect for people in this last phase of their lives concern - Providing accurate and timely information about a person's advanced chronic or terminal condition and the available care options, with timely and transparent referrals to the most appropriate health care professionals.

Absence of Informed Consent

Prescribing patients with morphine without informing them or gaining their consent and when they are not in pain, knowing full well the deteriorating effects of this medication on the body's internal organs is a serious breach of human rights and the Australian Medical Association's Code of Ethics:

- *Respect your patient's right to choose accept or reject advice and to make their own decisions about treatment or procedures (Australian Medical Association 2006 revised, 1.1.11);*
- *1.4: Respect the patient's autonomy regarding the management of their medical condition (Australian Medical Association 2006 revised, 1.4);*

- *Obtaining informed consent or other valid authority before provide treatment* (Australian Medical Association 2006 revised, 3.5.2).

The National Health and Medical Research Council (2011) states:

- *Respect for persons requires that people's wishes be respected and that they be helped to participate in decisions about their treatment or care, to the extent that they are informed, willing and able* (p.6);
- *People's wishes about their care and options are sought and respected* (p.11);
- *Respect is the most fundamental value that should govern people's relationships with one another. In the context of advanced chronic and terminal conditions it requires that people's wishes be respected, and that they be helped to participate in decisions about their treatment or care, to the extent that they are informed, willing and able* (p.22).
- *Palliative Care for all Australians* (2005, pp. 6,16) also resonates the same principle about patient decision making held as '*a primary focus*': strategies '*are to be developed to address those needs in line with their wishes*'.

The Australian Human Rights Commission (2012, 2.6, p.13) is equally clear:

- *Active and informed participation of people and groups in health related decision-making is an essential component of a human rights approach to community and residential aged care.*

The Australian Human Rights Commission (2012, p.17) also refers to Article 12 of the Convention on the Rights of Persons with Disabilities, which states that '*a person's decision-making capacity may not be taken away simply by reason of their disability*'. Furthermore, the Australian Human Rights Commission (2012, p.17) quotes the Convention as critical of paternalistic practices where health care professionals make health care plans on behalf of patients. This is what happened to my father in 2009 and 2013.

Options For Hydration and Nutrition Not Offered

Withholding, or not offering hydration and nutrition to a patient without proper medical examination as to why this is done, and without the patients' consent, is also a serious breach of human rights – '*Availability extends to the underlying determinants of health such as .. adequate nutrition*' (Australian Human Rights Commission 2012, 2.3 p.10).

When my father realised that his swallowing muscles had deteriorated to the extent he could not swallow, he realised he had no other option than to die because timely alternatives for hydration and nutrition were not offered. This is contrary to acceptable medical practice:

Discussing with patients their condition and the available management options, including their potential benefit and harm (Medical Board of Australia 2009, 3.3.4, p.5); and Taking steps to manage a patient's symptoms and concerns in a manner consistent with their values and wishes. (Medical Board of Australia 2009, 3.12.1, p.7).

The National Health and Medical Research Council (2011) clearly states:

when it becomes clear that treatments for an advanced chronic or terminal condition are no longer effective and that life may be coming to an end (even though death is not yet imminent), then the introduction of a general palliative approach to care should occur in a way that does not exclude other care and treatments (p.7); and

clinical integrity in the context of advanced chronic or terminal conditions requires that: People are given the best available continuing and integrated treatment and care as their health care needs change due to advanced chronic or terminal conditions (p.8).

Confusion in Palliative Care Terminology

Since there was no factual diagnosis that my father was dying when he returned from hospital other than his swallowing muscles had significantly deteriorated, there was much confusion experienced by the family, not knowing at what stage my father was actually dying, and the role of palliative care. According to Catholic Health Australia (2012, pp.7, 11) end of life care, palliative care, specialist palliative care, and supportive care are all terms that are often used interchangeably with palliative care.

Pertinently, as in our case, *this confusion over terminology does not help the person who requires a service response for their care needs. Consistency in the use of terms is important in ensuring access to equitable, high quality, supportive palliative care (Catholic Health Australia 2012, p.7).*

Furthermore, Catholic Health Australia (2012, p.9) also recognises that this confusion is partly due to the fact that specialist palliative care mainly services cancer patients, and that '*the service structure for people with life limiting non malignant disease needs to be re-examined*'. Catholic Health Australia (2012, p.9) continues to accurately report that:

the model of supportive care in place with diseases other than cancer raises issues of access, equity and efficiency... Chronic obstructive pulmonary disease has high rates of morbidity, but often palliative care teams do not get involved in the care management of these patients. Anecdotally, these types of chronic patients consume large amounts of resource in health services. It can often be the experience for this type of patient that they become dis-empowered.

This is precisely the category of patient to which my father belonged, and the subsequent experience of inefficient care and support.

Recognising this service gap of faulty or inconsistent assessments, Catholic Health Australia (2012, pp. 8, 11, 16) urges for the inclusion of '*assessment and access to specialist palliative care, and compulsory data collections with clear definitions about types and levels of care*' in the development of a National Health Service framework.

The Use of 'Comfort' Terminology

Using emotive language (words such as 'comfort') to justify medical practices can sometimes confuse exhausted family members, however it does not conceal the fact that elderly patients are not given choices in their health plans. This point is particularly poignant where elderly patients are either no longer able to speak or make themselves clearly understood, or are in a comatose state. In such cases, elderly patients are particularly vulnerable and open to abuse as they are not able to contest treatment nor make their choices known, and hence malpractice justified as 'comfort' can proceed unquestioned.

Spiritual And Cultural Beliefs

Taking into consideration the spiritual and cultural beliefs of patients and their families is an important aspect of respect. The Medical Board of Australia (2009, 3.12.1, p.7) states:

'Taking steps to manage a patient's symptoms and concerns in a manner consistent with their values and wishes.'

This principle is corroborated by Catholic Health Australia (2012, p.13).

From the perspective that human beings are first spiritual entities in material bodies rather than primarily human bodies with spirits, (Kubler-Ross, pp.3, 26, 63) the right to die naturally in one's own time without external pressures to hasten the dying process is crucial for a dignified death. It allows the patient to have the time they need to prepare for the next stage of their journey beyond this world. This can be likened to the metaphor of the butterfly chrysalis – if it is opened before its time, its wings are not formed properly. Resonating with Kubler-Ross, humans in the dying process are in the transition stage similar to the chrysalis - they require their own natural time for preparing to return to the spirit world (Kubler-Ross pp.3, 4, 40, 48).

Hence, from this perspective, hastening a person's death without their consent diminishes a dying person's human dignity.

Ethical Procedure That Should Have Happened

The ethical approach in my father's case would have been a proper medical examination prior to his hospital discharge, which would have indicated the options available for his hydration and nutrition. This information should have been provided to my father who was fully conscious so that he and his family could make an informed decision about his health care plan. If a feeding tube was an option, then my father should have had the choice to either accept it or refuse it. This would have been consistent with the medical ethical standards of practice as indicated throughout this paper.

Recommendations

In the light of preceding discussion, the following recommendations require our serious consideration:

- It is an essential component of professional integrity for health care service professionals to regularly examine their practice in the context of their profession's code of ethical practice.
- It is important for elderly patients and their families to exercise their own power of discernment about medical and allied health care practitioners' assessments and health care plans, in order to maximise their capacity to have their human rights respected. Subsequently, elderly patients and their families are to be encouraged to seek second opinions from other health care professionals when unsatisfied with the quality of health care services.
- To ensure that mission statements and professional codes of practice are followed, health care professionals and organisations need to undergo a regular review and supervision by an external body with whom there is no conflict of interest.
- Health care professionals are to be held accountable for negligent practices.
- In the face of an undercurrent pervasive trend towards an economic rationalist view of diminished resources, it is important for health care professionals to consciously prioritise their elderly patients' right to make their own choices and decisions about their health care plans.
- In keeping with a dignified and respectful treatment of patients regardless of their age, it is essential for health care professionals to be cautious about making generalised assumptions in their health care assessments. At all times, individual patients require individual case assessments based on thorough examinations.
- To preserve the integrity of medical and health care services, medical and allied health care professionals need to be certain that when using terms and practices in the name of 'comfort' that they are used appropriately according to the wishes of patients.
- Practitioners need to be sure that they do not use 'comfort' terms and practices to cloak or justify agendas that are not patient consented and patient focused.

- Grief is difficult enough when losing a loved one, however it becomes complicated when a loved one dies without being given the dignity of choosing how, when and where to die. Hence it is important for family members of elderly loved ones in their terminal stages of life to be vigilant in ensuring that their loved ones are given choices in terms of medication and health care treatment plans.
- In the event that elderly people become unconscious in their illness, it may be expedient for them to write their health care plan choices prior to becoming unconscious and to secure this document with family/or chosen authority who can advocate for them at the appropriate time.
- Health care services that work together to assist patients are required to genuinely follow their mission statements that prioritise the efficient service of their patients above their time consuming concerns about funding boundaries.
- In order to strengthen a human rights approach to aged care, it is important for medical and allied health care professionals and aged care organisations to implement in their practice the recommendations as outlined in the following reports:
 - [Australian Human Rights Commission 2012](#),
A human rights approach for ageing and health – Respect and Choice: Home based and residential care for older people;
 - [Catholic Health Australia 2012](#),
Community Affairs Committee- Palliative Care in Australia Inquiry;
 - [The National Health and Medical Research Council 2011](#),
An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions;
 - [Palliative Care Australia’s 2005](#)
Standards for Providing Quality Palliative Care for all Australians;
 - [The Productivity Commission 2011](#),
Caring for Older Australians, Report No. 53;
 - [Commonwealth of Australia, Department of Health and Ageing 2012](#),
Living Longer. Living Better: Aged Care Reform Package.

Conclusion

Sadly, my father's experience in his last days with the aged care system is by no means unique. This paper has drawn heavily from a number of government and non-government funded reports that are a response to current gaps in the hospital, palliative care and aged care services. As such, this paper presents little that has not already been previously discussed in these reports. However, the function of this paper is to highlight the urgency and importance of implementing the recommendations of these reports and bridging the gap between politically correct ethical rhetoric and professional practice in aged care/health care services.

How we treat all individuals impacts on how we value ourselves as one humanity. To the extent that we treat all people with dignity (despite their age and socio-political, economic status) by respecting everyone's right to make choices about their own lives, we nurture the sovereignty of the whole of humanity, making it less vulnerable to the destructive forces existing in our cultural and socio-political systems.

It is within the context of this broader picture, that this paper makes a stand for the value of ethical practices in the health care sector, particularly addressing an underlying pervasive devaluing of our elderly citizens' human rights.

If this paper has stirred enough discussion to enable even one elderly person being given the dignity of making choices about their timely health care options, which otherwise would not have occurred, then this paper: has achieved its goal; my education has been used for the better service of humanity; and my father's death and that of others who were denied choices in their living and dying, have not been in vain.

REFERENCES

ABC Lateline (2012) Public hospitals in crisis [online], available: <http://www.abc.net.au/lateline/content/2012/s3602451.html> [accessed 26 February 2013].

Agedcarecrisis.com: where little voices can be heard (2013) Your Stories [online], available: <http://www.agedcarecrisis.com/your-articles> [accessed 17 May 2013].

Allan, E. (2013) Elderly patients are being 'deprived of food and drink so they die quicker and free up bed space', claim doctors [online], available: <http://www.dailymail.co.uk/news/article-2170792/Elderly-patients-deprived-food-drink-die-quicker-save-hospitals-money.html> [accessed 26 February 2013].

Australian Human Rights Commission (2012) *A human rights approach for ageing and health- Respects and Choice: Home based and residential care for older people* [online]. Sydney: AHRC, available: <http://humanrights.gov.au/age/ageing/index.html> [accessed 22 February 2013].

Australian Medical Association (2006) AMA Code of Ethics 2004. Editorially Revised 2006 [online], available: <https://ama.com.au/codeofethics> [accessed 22 February 2013].

Australian Publishing Resource Service (2010) Hospital elderly: malnourished and underfed [online], available: <http://www.aprs.com.au/australian-health-news/hospital-elderly-malnourished-and-underfed> [accessed 26 February 2013].

Bigelsen, H. (2011) *Doctors Are More Harmful Than Germs*, California: Atlantic Books.

Catholic Health Australia (2012) *Community Affairs Committee- Palliative Care in Australia Inquiry* [online]. Canberra: Catholic Health Australia, available: www.cha.org.au [accessed 24 February 2013].

CMF (2012) Is the NHS really killing 130,000 patients a year with the Liverpool Care Pathway? [online], available: <http://www.cmfblog.org.uk/2012/06/25/is-the-nhs-really-killing-130000-patients-a-year-with-the-liverpool-care-pathway/> [accessed 26 February 2013].

Commonwealth of Australia (2011) *Caring for Older Australians- Report No. 53* [online]. Canberra: Productivity Commission, available: <http://www.pc.gov.au/projects/inquiry/aged-care/report> [accessed 26 February 2013].

Commonwealth of Australia (2012) *Living Longer. Living Better: Aged Care Reform Package* [online]. Canberra: Department of Health and Ageing, available: <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> [accessed 26 February 2013].

Couriermail.com.au (2012) Hunger and thirst blamed for 2000 patient deaths in Queensland public hospitals in 2011-12 [online], available: <http://www.couriermail.com.au/news/queensland/hunger-and-thirst-either-wholly-or-partly-to-blame-for-2000-patient-deaths-in-queensland-public-hospitals-in-2011-12/story-e6freoof-1226473683833> [accessed 26 February 2013].

Department of Health (2007) *Medico-legal issues: Rural Collaborative Practice Project* [online]. Melbourne: DLA Phillips Fox, available: <http://health.vic.gov.au/ruralhealth/downloads/dla-phillips-fox.pdf> [accessed 24 February 2013].

Helpguide.org (2013) Elder Abuse and Neglect [online], available: http://www.helpguide.org/mental/elder_abuse_physical_emotional_sexual_neglect.html [accessed 26 February 2013].

Hunter, R. (2012) Neglect and abuse in aged care [online], available: <http://www.abc.net.au/unleashed/3808370.html> [accessed 26 February 2013].

Kubler-Ross, E. (1991) *On Life after Death*, Berkley Toronto: Celestial Arts.

Mackay, T. (2010) Without Due Care- An Australia Hospital Tragedy [online], available: <http://withoutducare.com.au/> [accessed 26 February 2013].

Medical Board of Australia (2009) *Good Medical Practice: A Code of Conduct for Doctors in Australia* [online]. Canberra: AHPRA, available: <http://www.medicalboard.gov.au/Codes-Guidelines-Policies.aspx> [accessed 22 February 2013].

National Health and Medical Research Council (2011) *An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions* [online]. Canberra: NHMRC, available: <http://www.nhmrc.gov.au/> [accessed 24 February 2013].

NSW Government Health South Eastern Sydney (2013) Local Health District [online], available: <http://www.seslhd.health.nsw.gov.au/SGH/default.asp> [accessed 24 February 2013].

Older People Speak Out (2013) Our Aim/Vision/Mission Neglect [online], available: <http://www.opso.com.au/about-us/our-aim-vision-mission/> [accessed 17 May 2013].

Palliative Care Australia (2005) *Standards for Providing Quality Palliative Care for all Australians Australia* [online]. Canberra: PCA, available: <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow090570.pdf> [accessed 24 February 2013].

Palliative Care Australia (2010) *The right to quality care for the dying*, media release [online], available: <http://www.palliativecare.org.au/Portals/46/media/PCA%20media%20release%20-%20The%20right%20to%20quality%20care%20for%20the%20dying%20-%2029-9-10.pdf> [accessed 26 February 2013].
Raghavan, B. (2012) 'Ageist' doctors negligent of elderly [online], available: <http://www.thehindubusinessline.com/opinion/columns/b-s-raghavan/article3642907.ece> [accessed 26 February 2013].

Raschella, A. (2012) Hospital probes claims elderly woman neglected [online], available: <http://www.abc.net.au/news/2012-10-03/st-vincent27s-investigating-claims-elderly-woman-was-neglected/4293784> [accessed 26 February 2013].

The New American (2013) British Hospital Patients Dying in Doves From Lack of Care [online], available: <http://www.thenewamerican.com/world-news/europe/item/14489-british-hospital-patients-dying-in-doves-from-lack-of-care> [accessed 26 February 2013].

**“Our lives begin to end
the day we become silent
about things that matter.”**

Martin Luther King