Submission to the Productivity Commission Inquiry into Caring for Older Australians July, 2010

Dr Maree Bernoth
PhD MEd(Adult Ed & Training Hons.Class1) BHlthSc(Nursing) RN
Lecturer
School of Nursing, Midwifery and Indigenous Health
Charles Sturt University

Contents

Submission to the Productivity Commission
Caring for Older Australians
July, 2010

Introduction

The contents of this submission are the outcomes of past research and emerging data from current research that I have conducted and continue to conduct in relation to the conditions of residential aged care. My engagement with residential aged care began in 1984 as a nursing student studying in the Postgraduate Gerontic Nursing Course. From there, I have held diverse roles including Registered Nurse, Manager, Education co-ordinator and researcher. My Masters and PhD research were conducted while I worked in residential aged care which enabled me to be totally immersed in the environment and culture of residential aged care.

The PhD research focused on what it means to be safe in residential aged care and was completed in 2009. Currently, I am involved in gathering data, through in-depth interviews, of the experiences of relatives and friends of residents in aged care facilities. Data included in this submission is derived from both of these research projects.

Issues to be addressed in this submission

This submission relates to the following sections of the Issues Paper released by the Productivity Commission:

- Section 3: Objectives of the aged care system

The data in this submission will show that an acceptable level of care, although guaranteed under the Aged Care Act 1997, is not always a reality and that high quality aged care is not afforded in all instances.

- Section 5: What role for regulation

Although the residential aged care industry may appear to be highly regulated, the issues are in the way the regulatory compliance is undertaken. The Accreditation and Standards Monitoring Scheme gives the general public the false sense of security that standards of care delivery are monitored but the way this monitoring is conducted ensures that auditors do not see the actual care that is given.

- Section 7: A workforce to care for the elderly

The nationally accredited aged care qualifications introduced in the mid 1990s provided opportunities to meet the needs of an ageing population and also provided employment opportunities for many. However, over the time since their introduction, these education programs have been denigrated through concepts such as flexible

learning. Often, there is minimal or no clinical experience and minimal formal learning in these courses. Practices include giving candidates books to complete rather than formal learning experiences and assessing competence does not always follow the guidelines in the Certificate IV Trainer and Assessor (TAA). The outcome is an environment where care is dictated by the most effective bully on that shift, rather than on the care needs of the resident.

The family of one resident told me:
And although we had a number of fantastic people working there, with a real spirit of care, there were also people in there who had English as a second language; they had trouble communicating effectively with the people. We had people [carers] *who were completely unskilled trying to look after … not knowing how to lift them* [the residents] *and people were being hurt. People who were nil by mouth, an ex-digger, was fed by someone! Even with a sign there: Nil by Mouth. What the hell!* (2010)

Type of data to be provided

The information to be included in this submission includes:

- My own observations and experiences as an educator and researcher in residential aged care

- In-depth interviews with aged care workers which are a part of my PhD thesis (2003–2008)

- In-depth interviews from relatives of residents who have been or are currently in aged care facilities (2010 and ongoing).

These incidents were related to me by families participating in my current research project and I have their permission to share their stories. The motivation for these families is to improve aged care so that other families are spared the trauma that they have suffered. For some of them, the death of a relative is not a relief for them because they are left with the residual trauma of the memories of what their loved one experienced in their last months of life. Some of these families have been traumatised to the extent that the family is shattered and splintered, no longer united but in conflict about what should or should not have been done to help their relative who was in the aged care facility.

I am aware that quality care is delivered in some residential aged care facilities. I have witnessed it and have taught aged care workers and Registered Nurses (RNs) working in this industry to provide quality care. There are venues and conferences where industry articulates their successes and espouses the innovative care they say they provide.

However, this submission gives a voice to people who struggle to be heard, that is, those who see another perspective of aged care. It is the aspect of aged care that the regulatory bodies, by the nature of their auditing processes, do not detect.

Acceptable standards and quality care

This section of the submission covers data collected, related to clinical care issues and the standard at which clinical care is provided.

Pain

Pain is a constant issue that arises from interviews with relatives and staff. A lack of awareness of pain and lack of assessment and treatment of pain is something that I witnessed frequently. It is terrifying for the residents and the relatives and friends of residents because they are helpless to do anything about it.

However, one man was so concerned for his Mother's comfort that he went to extreme lengths to ensure she was afforded comfort in her last days. Telling me about this situation was very distressing for him and we had to take several breaks because of the emotional nature of the conversation.

Probably in the last five years, I've been taking Mum to her GP on a regular once a month basis. When I took over the enduring power of attorney, her doctor and I were on very good talking terms. Her doctor … it just happened to be bloody Christmas, and she went away for the holidays and we had had her on some panadeine forte for some pain and she seemed to be going OK and then her GP went away.

We had a discussion, which included Mum. We were at a stage where we agreed to take Mum off most medications. She was diabetic and had emphysema and [was] *on oxygen 100% of the time. So her GP went away. We had her on morphine for a chronic urinary tract infection pain that she couldn't get rid of.*

Then I came in and she was in pain again and I said "Look, can you get her Mum's doctor in please". She was evidently in pain and the doctor came (not her usual GP), he looked at the notes and she had just been taken off morphine by her GP. "I won't be putting her on morphine for pain because she has just been taken off by her GP." What they are worried about is going against what the GP does and so they are: "no, don't do it, don't do it!" He said try panadeine forte. Mum was non-responsive to this in any way. She deteriorated greatly and then a day later I came in and said "Get the doctor again, please. If you don't get another doctor, I will get an ambulance and send her to hospital".

They got another doctor and he said "I'm not putting her on the morphine, just monitor". And I said "But she's in pain!" But they wouldn't do anything about it!

Anyway, then I thought, what the hell am I going to do? I knew her GP's father and I had his phone number and I rang him and said "Mum is in great pain, can you get hold of your daughter". He said "I'll try". She rang me back and I told her what was happening and she just talked to the single RN that was on. Finally the GP talked to her [the RN] *and said "Get her on morphine straightaway". And we did. That relieved her and the GP got back two days' later and came and saw Mum.*

It took Mum five days to die. (2010)

Another instance was a daughter also distressed about her Mother's treatment. Her Mother had been managed at home by the local palliative care team. Her diagnosis was lung cancer. At home this woman had been kept comfortable with regular doses of morphine and break through doses when the pain became severe. She managed her own medications. When she was admitted to a nursing home, her pain control became problematic.

The daughter said:
I must admit, I didn't ask questions about Mum's drug regime when I went in to the nursing home. So she was getting morphine by mouth to control her pain at home because she had lung cancer and severe arthritis. But she was used to taking morphine by mouth as required. The palliative care nurses monitored it and when it was clear that her pain was worsening, they changed the dosage.

But when she got up to the aged care facility, from the very earliest times … because any drugs she took had to be administered by the RN and another RN had to sign off on it. This is a facility that had about 100 patients, maybe more and 2 RNs between it and so Mum rings the bell for pain [relief] *and sometimes it would be 20–30 minutes, an hour or more before she was even responded to by the nearest carer, let alone one that says "Look, she is in pain and wants another dose of her morphine".*

I was having a constant battle with the nurses in the early stages, and I remember one guy in particular, talking to them about how you are not supposed to let the pain get through; you manage it before it gets there and this is what we had been taught and Mum had been used to managing it and the palliative care nurses were closely monitoring it.

I said "Why aren't you giving her the drug when she needs it!?" And this guy (the RN) *fought me on it and I said "Look, if we have to get back to her doctor about this, we need you guys to know that when she needs this, she should get it".*

So the pain management from then on was disastrous. What they did, was give her more 'knock out drugs' that made her sleep more; spend more time in 'gaga' state.

The main thing was fighting with this guy, this nurse (RN) *about how she needs this pain relief and how it works and him saying to me "WelI, I'm a nurse" and me saying to him "Well, I don't understand how you don't understand that she is a palliative patient; she has been looked after by palliative care for this long and has had control, to a large extent for her own pain management".* (2010)

This lady died in pain. She also suffered severe coughing fits which lasted for long periods of time because effective palliative care was not available. The RNs not only did not listen to the family and their concerns, the staff actually fought against them.

A few weeks ago, an Assistant-in-Nursing (AIN) approached two residents and asked them about their pain. The AIN had been undertaking extra education about 'pain and the older person' and wanted to implement the strategies that she had been learning about. She asked what score they would give their pain if 10 was the worst pain and 0 was no pain. One gentleman stated that his pain was 7 because he had been sitting for some time and he had arthritis in his knees. The lady said her pain was 6 because she had not been moved and her bottom was sore. The AIN reported this to the Registered Nurse who told her abruptly that those two residents: *"Would have no idea what their pain was because they both had a diagnosis of dementia"*. When the AIN asked if there was anything that she could do to alleviate their pain she was very rudely dismissed.

The following is an incident I observed while gathering data for my PhD research. While walking through a residential aged care facility my attention was drawn to a woman sitting in a restraint chair at the end of the corridor with her arms outstretched to me. She was shouting out incoherently. As I got closer I could see the terror in her eyes; she reached for my hands and I held her, stroking her face and trying to re-assure her. She had my hands held so tightly, I couldn't have let go even if I wanted to. I looked around for assistance and at a table in an adjacent room was a group of five aged care workers writing their notes. They saw me with the lady, they heard me speaking to her, they heard her distressed cries and they continued to write their notes. After several minutes, one of the workers in the group approached me. I asked what was wrong, why was the lady so distressed and why had they ignored her? The aged care worker said *"She always does this, we just ignore her, if we give her any attention, she is worse"*. On assessment, it was found that the woman was in severe pain which was only relieved with opioid medication.

These incidents illustrate the attitudes of some aged care staff to pain and the ignorance of pain assessment, pain management and good palliative care strategies. They also demonstrate the outcomes when there is no partnership in care between the resident, their family and the staff. These issues are not being recognised by the accreditation teams because the facility can have systems in place to manage pain but these systems and strategies are not implemented if staff do not even recognise that

pain is an issue. It is then that systems and strategies are not implemented and the person remains in pain.

Oxygen therapy

The following case was related to me during my most recent fieldwork. It is an indication of how basic skills are not mastered by care staff or monitored by management. It is left to families to monitor standards of care in this instance.

So, Mum went from her unit into the nursing home [with oxygen] *at 3 litres per minute and we took her oxygen concentrator over and did it up for her. She would go and get her hair done and they would just take the oxygen off, leave it off. She would be up there for about two hours with no oxygen. I said "You can't do that with her. The oxygen sats are low, she is living on 80% oxygen, if you take it off she is on 70, you can't do that!" They'd turn the oxygen on but they didn't take the seal off. They'd put an oxygen regulator on the bottle to move her around but the seal was still on it! Jesus! Then I'd go "Oh my God!" Then I'd go up* [to management], *show them this is what's happened and they'd go: "Oh, we have got to get them trained". They said, "You could show the staff how to do it". I said, "I'd do that". And then they'd employ somebody new again … who is on, along comes the oxygen again, they'd put her on the oxygen but they don't turn it on. So she's up there with a nasal prong on, normally wearing a mask, by the way, and she is not getting oxygen. I'd come in and find her up there with the oxygen on her, waiting to have her hair done but it is not on. Then I'd come into her room when they brought her back from the hairdresser, on one occasion, and the bloody oxygen hadn't been turned off* [in her room while she was away]. *They had just let it pour, the whole cylinder into the room. Light a match: all over. The oxygen was just a nightmare and in the end I was changing the bottles and monitoring the oxygen for her and they were saying to me "When I took her out for a walk in the wheelchair, she'd be off the oxygen for awhile, costs us too much to have the oxygen, it's expensive". And I said "She has got to have the oxygen, it's crazy". So I'd take her for walks and I'd just go into their cupboard and get the oxygen bottles myself and set them up.* (2010)

Atypical presentation of pathology

The signs of serious illness in older people can be different to those of a younger adult. Confusion may indicate infection rather than an elevated temperature; the pain of a heart attack is not as intense in an older person but carers are not educated about the unusual or atypical presentation of illness in older people. Some do not recognise even very obvious signs of pathology, delaying access to acute care and thus putting residents at risk.

Before breakfast one morning, an elderly resident of a nursing home complained of feeling weak. The carers noticed that she was perspiring and seemed a bit confused so they put her back to bed and put a fan on her to cool her. This all seems very appropriate however, the carers did not appreciate that the woman's blood sugar

levels were dropping and she was going into a coma. She would have died if her Pastor had not called to see her. He knew of her diabetes and insisted she be given food.

In one rural aged care facility (in 2008), I was instructed not to use Multistiks (test strips that indicate if there is a urinary tract infection) to test the resident's urine because they were too expensive. Instead, if I suspected someone had a urinary tract infection, I was to encourage them to drink more. The same instructions were given with taking temperatures. I was not to take temperatures because the covers on the tympanic thermometers (the ones that go in the ear) were too expensive.

In June, 2010 in a large aged care facility, carers noticed that a patient diagnosed with alcohol-related dementia had suddenly developed Bell's palsy and had trouble moving his left leg and arm. This was reported to the RN who informed the carers that it was just a part of his dementia and they should not be concerned. In the same facility an elderly lady sustained head trauma. The carers wanted to perform neurological observations but were told not to bother. A few days later, the carers convinced senior staff that there was a soft area on her head where she had sustained the trauma. She was taken to hospital and a fractured skull was diagnosed.

Responding to calls for assistance

Because of the lack of staff in aged care facilities, the ability to respond to call bells or buzzers is problematic. Visitors can hear bells ringing and call systems being activated and continuing for long periods of time, without response. What has become common practice is for the aged care workers to remove the buzzer or bell so that it appears that everyone is comfortable.

This is done by placing the mechanism in a position so that it cannot be reached. Another practice is removing the mechanism from the wall or removing batteries so the resident actually pushes the button but there is no call registered and visitors do not hear the incessant ringing.

I had to call the staff up because Mum had been sitting on the loo waiting for them for at least 20 minutes, beyond the time she had finished being put on the loo. She said I had rung the bell 20 minutes ago for them to come and get me and so I arrived that afternoon and I was ringing the bell and this nurse came along and she was moving Mum from the bathroom to the bed. I complained then that there weren't two people looking after her.

Then the nurse dropped her. Mum had bruising. I know she was injured because it was one woman lifting her when it was supposed to be two. The instructions from day one on Mum's chart were: 'two people to lift all the time'. I was actually sitting there watching this woman with Mum and watched her drop her and then have to lean

down and Mum got pushed against the bed and I ran over and helped and immediately said "Aren't there supposed to be two of you doing this?" (2010)

Another family told me:
The only frigging time they would come when a button was pressed was … they have two buttons: one that the resident presses and one that a nurse presses if a nurse needs assistance. You press that one [the nurse assist] *and they are there, can't get there any other time! Jesus that annoyed me! That was terrible, terrible. Some of them leave the buzzer so that they can't reach them. We got a chain for Mum to help lift herself up and we tied the buzzer to that and for people that were inexperienced or just too busy or didn't remember, I had to write a note saying "Please remember to put the chain and the buzzer down for Mum, please" and I put it at the door as they came in and tied to the chain, a big A4 sheet because they wouldn't do it. And I'd come in, I left in the morning to go to work and get back there at 3.30–4 o'clock and Mum hasn't had a drink because she couldn't reach it and she couldn't reach the buzzer to tell anybody.* (2010)

Yet another incident:
Part of my frustration was people got to the point, the workers, were refusing to do the work that wasn't their job. There were people who were ENs or carers on some shifts, and on other shifts they were allocated as Activity Officers (AO). So they'd be out there with people doing an activity and there'd be people [who had] *fallen over in bedrooms who had been calling out for help and I've gone in and said "Do you need a hand?" and they'd say "Yes, I've fallen over". Then I'd go out and say to the AO, "There's a person who's fallen over in their room, can you go and help?" They would say to me "I am the AO today. I can't do that!".*

How ridiculous is that!! And I'd say "Just go and do it, please. I think the bingo can wait". A person is hurt on the floor. She was furious with me. Red, flushed, threw down the bingo calling numbers and stormed off to look after the lady who was on the floor. It was disgusting! (2010)

And another:
On weekends you could shoot a gun down these long halls. There was one RN for four areas, although they say we put staff on in the high demand times, in the morning when you're getting people up, showering them and dressing them and the evenings, when you're feeding them. But in the middle of the day anything could be happening and there would be nobody there. And you'd press a button and ask somebody to come and help and the button would be beeping, and you know that it's been activated and then after awhile, you'd wander down trying to find somebody and then you'd see somebody, one of the carers on their mobile phone, outside on the landing talking and having a cigarette. People could be dying, people could have fallen over, press their buttons for assistance and they're having a smoke. It just didn't work. Then when they only had a few staff on, in the end, I got so angry one day because they have their

break together. They'd have two carers for each wing and they'd decide to have their break together, to go off to the kitchen: ***there was nobody on at all!*** *What a joke.*

One day when I found Mum trying to get out of bed and she had pressed the button [nobody there], *I just went off and went down and found them. I said "How dare you do that, why are you doing this?" They were having their break. They said "We are having our break". I said "Why are you having it together? There are people who need help". They are not treating them as humans, they are objects that they are being paid to look after and it's a bit of a pain.* (2010)

And another incident:
Mum's not a person who draws attention to herself: "Don't want to make trouble" she'll say. So she'll sit there until someone comes to her.

"Does she get herself to the toilet?" I asked.

No, no she wears continence pads and I think some of it is her own level of awareness and some of it is "I don't want to make trouble". She'll just sit and wait and yes, she can be a mess at times. There have been times when I've tried to get staff to deal with her. She smelt because she was wet or whatever and you could tell it didn't fit into their routine. They didn't want to know … "Oh well, I just changed her an hour ago". "Yes, well she needs it again now"… Oh but … "No, she needs it again, now!" It would be quite a struggle. "I've got to go and do something else". "Well, I expect you to come back" and if they didn't come back, you go and chase them. So it is an issue to get staff to help you so I think individually they would like to but the thing is they are just asked to do too much. There's not enough of them. (2010)

If our aim is quality care, then we are far from that goal. There are not enough carers and there is not enough staff with clinical expertise to support the care staff in prioritising their work and ensuring that care is appropriate to the needs of the residents and provided in a timely way.

Infantalisation
Infantalisation is endemic in residential aged care. When there is pressure of time and staff with no or little skills, in their frustration, those staff will relate to the residents as if the residents are children. Treating them like children means ignoring all of the residents' rights, especially to self-determination. The staff member knows what is best and will chastise the resident if they transgress what the staff member deems to be the right thing to do. The staff member knows best!

There is an elderly gentleman living in an aged care facility in a large regional town in NSW. A group of his friends visited the facility and noticed he was withdrawn and lonely so they invited him on one of their social outings. Even though he needed assistance with various tasks, the group felt that they could manage to assist him. He

was delighted to be invited and had a wonderful evening out with the group. They returned him to the nursing home about 10pm. One of the carers came to the door to let him in. The group heard the carer admonish him saying *"What do you think you are doing staying out this late! If you can stay out this late, you can get yourself to bed!"* That night he slept in his clothes. The gentleman rang the group the next day to say that he could no longer go out with them because he was fearful of the treatment he would receive when he returned to the facility.

Another incident was at change-over between the morning and afternoon staff. The staff was gathered around the nurses' station, ready for report. A male resident, who was in a wheelchair, approached one of the nurses. He was trying to apologise to her for something that had happened the previous day; it was difficult to understand what it was he was apologising for but he seemed genuine. The female nurse turned and leant over his wheelchair; she yelled obscenities at him and told him loudly what a dirty old man he was and she would have nothing more to do with him. Everyone in the area heard this: other residents, other staff and visitors. No one reacted; it was as if this was common practice for staff to yell at residents and the general consensus seemed to be that he deserved what he got. The man in the wheelchair turned around and wheeled himself back to his room. These were his carers, those he depended on for assistance with living or rather, existing.

A female resident of a rural aged care facility was lethargic and withdrawn. She did not want to leave her room and her appetite was poor. The RN decided that this behaviour was going to stop. After handover between night staff and day staff, the RN told an AIN to accompany her to the resident's room. The two staff members proceeded to drag the woman out of her bed, forcibly dressed her and dragged her to the lounge area. "That's how it is done!" the RN stated.

I accompanied two of the aged care workers while they were getting a resident, Betty out of bed. Betty is a thin, frail woman who was curled up in a foetal position facing the wall. The two aged care workers approached the woman, grabbed her knees and rolled her onto her back. One removed her wet incontinence pad and then left the room to get another pad. They swung her around, took off her night dress, put on her top and bent down to put on her pants. They had not spoken a word to the woman or to each other. At this stage, Betty woke up and started to kick her feet. When I contained my anger at the treatment of this woman, I suggested to the aged care workers that if they spoke to her and gained her co-operation, she would not kick them. They ignored me and continued to put on her footwear. It was as if they had gone into some sort of routine, performed each day, unable to be varied even when I was there with them. A walker was produced and Betty was stood up into it. They moved a wheelchair in behind her and sat her on it. Then they started to push her out of the bedroom door. I asked if they were going to wash her. With this, they pushed her over to the basin where the staff wash their hands and they wet some paper towel with water that was cold. The coarse paper towel was then roughly rubbed over

Betty's hair and then her face. She was then pushed into the lounge area where a tray was attached to the chair and a drink placed on the tray. Betty picked up the liquid and threw it at the aged care workers. The aged care workers then made some comment about her being '*A cantankerous old bitch'*.

Freire (2002: 44) observed that " … sooner or later being less than human leads the oppressed to struggle against those who made them so". Even Betty in her frail, debilitated state was struggling against her oppressors. " … dehumanization … is *not* a given destiny but the result of an unjust order that engenders violence in the oppressors, which in turn dehumanizes the oppressed" (Freire, 2002: 44). Further, Freire (2002: 56) recognises that in dehumanising others, the oppressor also becomes dehumanised. Even though Freire made these observations when working with and writing about oppressed communities in South America in the early part of last century, they are relevant to the residential aged care industry in Australia today.

Food

I was working with a group of carers and we went into a room of four very emaciated older women to feed them their lunch. These women were very slow chewing and swallowing their food. On the tray there was a main meal and dessert as well a drink. We had just started to feed them when my mobile telephone rang so I left the room to answer it. I was away for only a few minutes but when I returned to the room, all of the dishes had been cleared away and the carers told me they had finished feeding the women. It was impossible that those women had eaten two courses and a drink in the time that I was away. How often did that happen?

A family member told me:

Everybody's so busy, they didn't even feed her. Near the end when she couldn't feed herself anymore, she couldn't see. She was being handed these tubs of fruit, you have got to peel off the top, piece of plastic. She couldn't see it, and she didn't have the dexterity with her fingers. She should have been fed probably for a long time before we said: can we, and we used to feed her ourselves when we were there.

Another thing is that the food was shit, shit. One night a week they used to get two little half sausage rolls and a little container of tomato sauce and maybe a container of orange juice or something like that that you had to pull the lid off and that was dinner. I can't believe that was dinner for anyone – possibly a snack on a special day or something maybe, but not dinner and it was like, the most horrible quality. The soups, like, when Mum was here I used to cook Indian, but she loved food. It was her only joy left in life, the taste of food. She was still tasting food but at the nursing home, she tried to eat something but there was never, never, anything. She didn't complain. (2010)

Another food issue:
And then I noticed that the plates were dirty, always dirty. The tea cups had stains in them that were obviously there for a long time. And I watched them put out the dinners; the dinners were being put out on plates that were dirty with dried food from soup that they had. Sometimes they used the cups for soup and then sometimes they'd be cups of tea. They had a trolley coming around mornings and evenings with soup, dried soup on the cups. (2010)

This was an incident between a family member and care staff in another facility:
… one afternoon, we were having trouble. One of the kitchen staff came around with afternoon tea and I forget why I looked at the cups … um I picked it up and said "You can't use this, you can't use this" and started taking all the cups off the tray because they were foul. And, shoot the messenger, she turned on me and sort of said what was I doing. I said "Would you drink out of this?" She said "No". "But you expect these people to?" She said "But I haven't got time to ...". And I said "Well, I want you to check them. It is fair enough that someone else has loaded them on your tray but you have got to check them before you put tea in them". [She said] *"I haven't got time!" I very nearly picked up the cups and smashed them, but I didn't, I restrained myself. But I could not believe the response: "I haven't got time". When coupled with "No, I would not drink out of this cup" it was just totally incomprehensible! So I went and I found clean cups and I put them on her tray.* (2010)

One family member was concerned about the lack of fluids:
Because the workload was increasing, the workers decided, without telling anyone, to stop having the tea cart come around in the mornings and afternoons. So people were not getting hydrated. They had their cup of tea at breakfast and nothing 'til lunch and then nothing 'til dinner, which is disgusting (2010).

This family member went on to say that the residents were given a bottle of water which was placed beside their beds. However, some of the residents could not open the bottle and others could not reach it so, even though the bottle was there, it was of no use to the majority of residents. So this family member took it on themselves to go around the residents' rooms to open the bottles and give them some fluids.

One resident's daughter told me:
Quality of food … that's revolting but as for what is being presented, often it looks alright but I think a lot of it is inappropriate for the age of the people we're dealing with. But things have improved because one of the other resident's wives is there all the time and she has got them so that they are allowed to have sandwiches. She buys bread and jam.

I needed to have this clarified so I asked, "She brings it in from home, bread and jam?"

Yes, yes … But she does it. As far as I am aware, she'll get a loaf of bread every now and then and a jar of strawberry jam or something, and she goes around at most meals and offers them bread and jam and they all love it! (2010)

With staffing levels inadequate, it is going to be the most dependent residents who are neglected, especially with nutrition and hydration. They can take a long time to feed and to get them to drink so the carers choose who will be fed and who will be inadequately fed or even not fed at all. Carers make decisions about the amount of food a resident will receive so that, even though the diet has been determined by a dietitician, the nutritional requirements of the residents are at the mercy of unskilled carers or the beneficence of other resident's relatives.

Personal hygiene

In relation to personal hygiene, one family reported that:

So poor Mum, who's no dummy - and she was no dummy at the end either - she knew exactly what was going on. I think it was disgusting, I think it was disgusting that someone who was an old, high quality, qualified RN who had even worked in nursing homes, had to put up with that stuff.

I came there one day and I realised that they weren't doing her teeth and I thought "I wonder what else they are not cleaning?". So I look at her fingernails and I found that there was dried faeces under her nails. I got my daughter to clean them. She came in and she cleaned under her nails and from then on, what did I do? I checked her fingernails.

It was just terrible. I did things like: I thought "Are they cleaning her up with face washers that I would then use later to clean her face after she has eaten?" So I would strategically take face washers from the store and I had a stack of them in there so I was actually getting my own face washer every time. (2010)

The man telling the story above went on to tell me how he cleaned his Mother and changed the incontinence pads that she wore. He would go in to the facility at 6.30am to wash her and get her ready for the day and feed her breakfast. He became distressed telling me about how he had to wash around his Mother's bottom to prevent the scalding that occurred because the carers did not do this. Both he and his Mother felt ashamed because he was forced to do such a personal thing with his Mother but if he did not do it, the carers did not. At 8am he would leave and go to work and then return at 4pm after work. Sometimes nothing had changed since he left. His Mother's water bottle was still full with the cap securely in place indicating that she had nothing to drink all day. As his Mother became more frail, he would also go to the nursing home in his lunch break to ensure that her incontinence pad was changed (he frequently found her saturated in urine and faeces) and that her position was changed and that she had something to eat.

And another:
Mum's toenails: I checked. One of her toenails was growing over and in, she brought it to my attention. I went "shit" and she hadn't been there that long and the woman in charge said we have a new system to do with hairdressing and toenail checks and "it obviously hasn't happened this time and we'll have to check and make sure it is introduced properly". (2010)

And another:
I would put her toothbrush down and I would come in next day and it would be in the same spot I had left it. So I would come in and wipe her down, clean her up, do her teeth. I started doing her teeth every day, twice a day. Then I started doing more of the cleaning up. I was finding her in bed, covered in faeces. (2010)

The absence of skilled mentors, the lack of staff and the level of education all directly impact on the quality of care given. Carers are responsible for making decisions about care for very frail, older people with multiple complex conditions. They are caring for people who, in some cases require palliative care but there is no one working with them to guide them, advise them and assist with prioritising the care they need to give.

If these people were in the community, they would have access to a range of specialised nursing services – continence assessment, wound care, women's health and palliative care to name some. However, because they are in an aged care facility, they are not afforded this level of service and care. Why the disparity?

It is deemed that the care is given under the direction of a Registered Nurse but the RN is not available. They are responsible for a large number of residents and are not physically available to the carer or the resident. Also, the RN may not have the specialised skills and knowledge that are required in all circumstances.

Aged care is a specialty, it requires RNs with particular skills just as Midwifery requires nurses with specialised skills yet, this is not acknowledged in many ways; one of these is in the rate of pay for RNs in aged care.

Both the RN and the carers need to be able to access specialised services to assist in complex situations, especially palliative care and continence assessment and management commensurate with a nurse working in acute care or community care.

What role for regulation?

The inadequacy of the Accreditation and Standards Monitoring which is currently in place in aged care is illustrated by the following incidents reported to me by a carer.

The carer said that she was delighted when management purchased a beautiful dip-sided bed that could be electronically lowered to the floor. They used it for a resident with Huntington's disease so that she could easily get into the bed and safely get out when she wanted to, rather than relying on staff. However, after the facility successfully passed an accreditation visit, the bed was returned to the manufacturer.

The unit had received non-compliance on the previous accreditation visit so Management was eager to do whatever it took to pass the follow-up visit. There had been much activity with maintenance of the unit prior to the second accreditation, including repainting the canary yellow walls to a softer hue. The staff were excited and relieved that at last something positive was happening for them and the residents; that their many requests to management about the poor standard of maintenance and lack of maintenance were being acknowledged and acted upon.

Maintenance stopped the day of accreditation. As soon as the accreditors had walked through the building and inspected the work being done, it all stopped. It just stopped. The half painted walls, the unfinished door frames, it literally just stopped. The accreditors walked back to the 'big house' [main building] *and the workmen walked out the back door. So much for listening to us and being concerned about us! It was all just a show to pass accreditation.*

In 2004, a large aged care facility was given accreditation for four years. Four months later, after public complaints about the full accreditation, the Agency went back to the facility. They were at the door, unannounced at 6am, they worked with the staff and it was found that the facility was in breach of 25 of the 44 standards. How can that happen in a matter of months? The difference was not in the care delivered in that period of time but rather in the way the monitoring of standards occurred.

It was hoped that this means of monitoring clinical care would continue but that was not to be.

Unannounced visits were instigated but these have become as ineffective as the regular accreditation. Managers have folders and strategies ready to cover contingencies for any type of visit.

The monitoring process must involve team members actually going into the clinical areas and observing or working with the carers, assessing levels of care while observing it take place. The agency team must include one RN with particular skills in aged care nursing who can identify appropriate care strategies actually being implemented and/or making recommendations in relation to care. Monitoring standards is not just about having systems in place; it is about delivering care to frail, vulnerable people with complex care needs and observing this happening.

When the outcomes of my PhD research were forwarded to the Minister for Ageing, her response, through the Chief Nurse of the department, was questions around the relevant facilities. The point is that these incidents could occur in any facility. The monitoring process was established to ensure quality care but it does not do this and standards monitoring should not be left to individuals. Individual reporting does not underpin quality aged care and even with whistleblower protection, individuals pay a price for speaking out. That price can be too high for some. They recognise that they cannot make a difference and they leave.

The following illustrates how aged care is losing the people we need to stay. A student doing her Certificate III Aged Care Work wrote this during her course:

A Reflective Journey

> *I had so much to learn so I brought along eagerness, willingness and commitment. I applied it to everything I learned. When I felt overwhelmed I applied commitment. When I was confronted with something new and different I applied eagerness. And when I felt unsure I found my willingness to explore new ideas, feel the responsibility and grow. My journey has been eventful, a blessing, thought provoking and one that will continue as it opens up new pathways. I have been blessed with the humour of the job. Do not leave the shower nozzle in the hands of those who will point it in your direction while being encouraged to wash. I have seen the tears of sadness while reminiscing stories of independence lost. I have witnessed wisdom in dementia, words of insight when you least expect it.*
>
> *I have sat quietly and listened to anger blurted out in my direction but all the time knowing it was not a personal attack. Just a way for someone to say 'I am hurting!' I have held a spoon to a mouth willing to eat only to watch a difficult swallow. I have whispered words of encouragement with a small smile. I have watched aching joints try to stand, to walk, to sit, knowing it is the best their body can do and I smile and say, 'it's OK, take your time, we have all day' knowing I have ten more people to see. I have gently wiped a brow and held a hand as they slowly but surely slip little by little from this life and said a small prayer. I have seen death and said goodbye knowing I have supported, encouraged and cared to the best of my ability. By giving I truly have received. I learned new lessons with each new experience; each time I allowed myself to overcome my fears and stretch myself a little further has been another step towards my authentic self.*
>
> *The people I am privileged to care for have had life experiences so vast, some born before the inventions of the motor car, refrigerators, television, and the microwave. They have witnessed world wars, man on the moon and genetic cloning. They have loved and been loved, they have grown from children, ruled their world and now they are on another journey and nothing they have*

> *thus far achieved can prepare them for it. And I have been given the chance to be part of this with them. I can make a difference … because I dared to reach out for knowledge and put it into practice. I care and I will be there, because this is just the beginning …*

Just over 12 months after completing her course, this wonderful, sensitive carer who wants to be there for the residents, was distressed and disillusioned. She has left aged care because of the stress she was working under and her ability to make a difference was stymied. The pressure of work was such that she cannot engage with the people she wanted to care for. Being overwhelmed was happening too frequently and she was finding that there was no respite. Even though she wanted to spend time with the residents, the workload did not allow it.

> *What we were taught was the right way. I know it was the right way to care because the residents responded with gratitude. It was satisfying. I could acknowledge their personhood. I thought the pressure of time was because I was new and still learning but it doesn't get any better. If I can do tasks more quickly, they will give me more to do 'Ignorance is bliss' perhaps.*

She has resigned and is now employed in another industry and is lost to aged care.

Response to complaints in residential aged care

All of the families had tried to complain about their situation; none received any satisfaction. One family attended a resident's meeting to raise their concerns about the filthy state of the crockery and cutlery.

The family stated they said to management:
I want to bring up something of great concern to all the people here and I walked up and said have a look at these please and they went, "Oh". I said this is just not good enough, there is something wrong, this is unhygienic. People are being asked to eat and drink off filthy plates.

"Oh yes, we'll do something about it, this is terrible, this is terrible". So they got someone in to look at the new, brand new dishwashing machine saying it was that.

Nothing happened, so we raised it again two weeks later.

One family was concerned about the level of staffing when residents were moved from a smaller area to a larger, newly built facility:
They were talking about it anyway, that they had to have a certain number of staff for the people. I could not get through to them, they did not want to see, if you had 3 people for 20 people in the smaller area, it was a different level of staffing from 3 people for 20 people spread over 4 communities instead of the 2 communities. Just

would not see that, did not want to know; [they said they] *tried to have the right number of people on shift, or their roster was full and again, I knew from what staff had said to me, that if they require say 12 staff, they have 12 staff but to run the roster, you need 15-18 staff so people can have time off, be sick. They don't get replaced. They are regularly 2-3 down.*

The daughter of one resident tried to communicate with management by email which was ignored:
I sent it as a pdf on my computer and I sent a letter as well to the woman who is in charge of the nursing home. I didn't think to say please acknowledge receipt of this. About 2 weeks later I hadn't received anything so I sent it again and said, please respond if you receive this. No, still got nothing. So then I sent one off to S and when she got it she said that was the first she had known of that so I pointed out to her that was of significant concern to me because it indicated a tremendous breakdown in communication and she tried to justify for this other woman, she is away alot and I said, I don't care! Someone had to have responsibility for looking at that email and responding to it when I sent it through. When I was making that complaint she read it because I set it for a read response to come through and she read it about three days later but there was no acknowledgement … no response to the email, nothing has come from her at all and she is the local manager and I find that totally unacceptable that someone at that level can completely ignore my email.

And another family's interaction with management:
I also met with her [the manager] *personally, and my main complaint was "there's not enough staff here to do the job properly" and she admitted that, I said to her "I know, I talk to people in aged care and in nursing all the time and we know that aged care nurses are not only underpaid but there just aren't enough of them. Well nothing changed as far as her treatment went. They made reassuring noises. There was one letter that my brother wrote and she responded to, the manager, but …*

A trainee carer in an aged care facility contacted me recently; she was distraught because of what she had witnessed that day at work. She observed another staff member attending to a resident. The resident was handled roughly; he was forced out of bed and abused for being slow. The commode was forcefully pushed against the back of his legs causing bruising. The trainee ran from the room in tears. She went to the other staff and told them what had happened. They just smiled at her and stated that *"She is always like that, don't worry about it"*.

The trainee was too frightened to report this incident to the Complaints Investigation Scheme because of the repercussions for her. She felt that Management would know where the complaint originated from and that her working life would be untenable and she wanted to complete her traineeship.

If abuse is not recognised as such, it will not be reported. If aged care staff take a dismissive attitude to complaints, from whatever source, the chance for improvement is lost and residents remain vulnerable.

I started to speak about the conditions of aged care when the data from my PhD research started to emerge in 2004. What I was seeing and being told about was reported to managers with one manager accusing me of lying and another threatening physical violence. Two of the most senior managers attributed the poor clinical care, bullying and abuse to my skills as an educator; that is, I was to blame because I had not taught the staff effectively. I resigned which is what they wanted me to do; the usual outcome for those who speak out.

My findings were reported in the local newspaper but that prompted a public rebuff from four CEOs of aged care organisations.

The ignorance and carelessness of what I had seen and been told about and the public humiliation caused my husband and I to sell our property and move away, leaving extended family.

The outcomes of my research were forwarded to the Minister for Ageing in 2009 but, when the response came in June 2010, she referred me to the Accreditation and Standards Monitoring Agency that had proven to be ineffective in detecting the poor quality care, the bullying and abuse that had been exposed through my research.

The only way to have the voices of the residents and their families heard is to continue to research, giving them a forum in which to speak.

What families say needs to change in residential aged care

I asked the families of residents in aged care facilities what they would like to see changed to improve residential aged care. The following are their responses:
It's probably to do with respect for the people who work in it. To give respect but it is a societal change; it is not just the Minister. But if it came from the top so that it is … so society accepts that these people are doing an important job and one that society can't do without, which would be flowing on to paying them a reasonable living wage, forget good high money but a living wage. An RN that I was talking to has two jobs in the aged care sector. He sometimes goes from his day job to his night job or vice versa but he works in two nursing homes and I made some comment one day and he said "Well, I have got to live some how!" But to me, with respect, if I respect the job that you are doing, I am willing to pay you for it. Um … somehow to change society's views so that people are doing a really valuable job, they are doing a job that most of the rest of us couldn't do. No matter how much money I was paid, I couldn't work there. I don't have what it takes to work in the aged care sector, to be a nurse at all but to work in the aged care sector. I can't look after my Mother. To do so

… she needs care 24 hours a day. To do so I would have to give up my job … because I think what aged care is, the people who work there, the majority of them, it is because the money is so poor, those who work there are committed. To give them support, to put more numbers in so they can actually look after the people who are there because individually, my contact with them … they really care about the individual residents. But it is what's required of them that means that they just don't have time to care. But how … but if I was the Minister, yeah … it is more money into the sector basically but where that comes from I don't know.

To me it all comes back down to respect. Acknowledging the job that is done in that sector and giving respect to the residents because I think that it is a very soul destroying place to live.

A daughter who was still grieving for her Mother and was devastated by the standard of palliative care that her Mother received in the aged care facility stated:
I have a friend who works in aged care in Canberra. I said to her, when she was boasting about her role in re-writing the Aged Care Act (because she is right up there at a high level) … I said "Well can you do something about a nurse to patient ratio in nursing homes and aged care facilities please because at the moment there isn't one". She pulled out the Act for me and she talked about stuff and I said "And can you find the bit about nurse to patient ratio?" and she found a bit that doesn't say anything about an actual number. I said "If you can't get that Act changed to deal with that … you can gloss over everything, if you are not going to deal with that fundamental human … it is a cost so you don't want to talk about it".

So we need more RNs in the facility or more nurses who are able to administer drugs. People who have been put in there on some regime of oral morphine, they shouldn't be taken off that. There should be some system of managing the drugs better. There is so much room in Mum's room but you had to go down this stupid little corridor and sign away on the drugs and two of them bring them back down and one signs off saying this is how it works. How time consuming is that! More holistic care, like when she was here [at home] *she had massage and it was a great relief and it's good for so many things. And acupuncture. Try other ways to relieve suffering.*

This man is left with devastating residual memories of his Mother's last days in residential aged care:
They are not treating them as humans, they are objects that they are being paid to look after and it's a bit of a pain sometimes: "Oh dear, that person needs another nappy change, it's not too wet, we'll leave it on her a bit longer". What happens next – scalding from urine. "Will we wait 'til they poo before we change it because it is a lot more effort?"

It is just not good enough!

Recommendations

1. Firstly, the whole community must recognise that aged care is everyone's responsibility not just those currently interfacing with the residential aged care industry. Aged care can be delivered in the community and this is the preferred setting. Older people remaining in their own communities will have better quality of life making residential aged care only one option in a suite of services rather than an eventuality for all older Australians. To this end, public education is needed in issues such as healthy ageing, caring skills and education about how the aged care system functions. Multiple forms of education need to be considered taking into account that many older people do not use the internet so web pages are not sufficient to meet the needs of this group.

2. The accreditation process must be changed. The accreditation team must include a Registered Nurse who is skilled and experienced in aged care. They would work with the staff to identify problems with clinical care, not just look at paperwork. The way the accreditation process works currently, the aged care facilities that are delivering high quality care are disadvantaged because the process does not recognise this just as it does not recognise when poor quality care is given. Most facilities pass accreditation because managers and staff know how to subvert the process. It is not about care given, it is about having systems in place and on paper. It is irrelevant whether or not those systems are functioning because the real, tangible outcomes are not looked at, that is, the actual care delivered (or not) in the bathrooms and the bedrooms.

3. In each aged care facility there must be a skilled and qualified clinical mentor who is an Endorsed Enrolled Nurse or Registered Nurse. They must be above the usual clinical numbers and be available to provide clinical support and advice to the carers about prioritising care and giving the most appropriate care to the residents. They would not be involved in paperwork or activities for accreditation but be solely focused on supporting the staff who are giving direct care.

4. Staff ratios must be fixed so that there are adequate RNs to assess care needs, monitor care and ensure that the most appropriate care is delivered to the residents in both high and low care facilities. Their role also must include that of education of staff, relatives and residents. Tertiary institutions need to provide postgraduate opportunities for these RNs with incentives of various types to encourage RNs working in aged care to take advantage of improving their knowledge and skills. Aged care must be made an attractive place to work not somewhere to go prior to retirement or because skills are problematic.

5. Palliative care and other specialised services must be available to all residents of aged care facilities. There needs to be formal agreements between aged care facilities and local palliative care teams to support, educate and monitor pain and symptoms of those residents in the last stages of life. Currently, this is impeded by the different funding sources for community health services and residential aged care. Different funding sources also impact on the ability of residential aged care facilities to access other specialised community services such as continence specialists, wound care specialists and women's health specialists.

6. A serious review of pay rates for carers and nurses in aged care is imperative. The discrepancies in rates of pay for nurses in the acute sector and aged care are an insult to the aged care nurses. They are of equal value and they need specialised skills just like those nurses in acute care.

7. The Complaints Investigation Scheme needs to be reviewed. Despite the number of complaints being received, little is changing. Again, this Scheme relies too heavily on paperwork and the word of managers rather than investigation of the actual situation, talking to residents, talking to families, talking to staff with confidentiality assured.

8. The situation of managers in aged care is problematic. Skill levels vary widely. Often they are sandwiched between CEOs and staff. They may hear the concerns of staff but are stymied by demands of senior managers who are driven to meet key performance indicators or achieve profits.

9. The issues around educating and licensing carers in aged care are a priority. Current modes of education are focused on getting staff to the workplace disregarding skill levels or mentoring. Carers can move freely from one facility to another without any history of skills or competence or suitability. Carers who are deemed to be a problem are encouraged to leave with the promise of a good reference so subsequent employers are ignorant of issues experienced at the previous facility.

Conclusion

Society, demonstrated through ageist attitudes and government policy, is uninterested in what is happening to the aged care workers and to the residents. This patriarchal and patronising environment, with inadequate rates of pay, inadequate levels of staffing, poor skill mix, and insufficient knowledge and experience, means that it is difficult to be aware of these circumstances and continue to work in aged care. My submission is in the hope that the review by the Productivity Commission will have positive outcomes for a stigmatised and ignored industry.

References

Bernoth, M. 2010. Stories of relatives and friends of residents in residential aged care. Current, on-going research.

Bernoth, M. 2009. "… and the word was made flesh" – the impact of discourses of embodiment in promoting safe manual handling practice in aged care. A thesis for the award of Doctor of Philosophy. Monash University. Churchill.

Freire, P. 2002. *The Pedagogy of the Oppressed*. (30th Anniversary ed). New York. Continuum.