The power of collective action

Practice change programs are often seen as the way for care organisations to achieve person-centred care. **Sarah Cope** questions this approach and says instead, residents should be given more opportunities to support one another

In Australia it is well understood that people living with dementia in residential aged care facilities (RACFs) live within organisations that spend large amounts of money on practice change programs. The goal of achieving a person-centred culture for many RACFs is often elusive. All too often programs can become diluted by day-to-day care, leaving the rollout of person-focused practice approaches to revert back to time-focused routines. Therefore care then becomes once again dictated by the structure of the organisation rather than by the consumer.

This article highlights ideas for practice change in achieving a more collective person-centred approach from observations of interactions from a facility in the Pacific.

Confronting conditions

In 2017 I joined 12 undergraduate nursing students as an academic facilitator on a clinical placement to an island in the Pacific. During the placement students were required to spend time within a mental health unit at an island's hospital to gain clinical experience. The mental health unit catered for people in acute mental health crisis as well as providing permanent residential care for people living with dementia. The environmental conditions within the mental health unit were confronting and extremely impoverished.
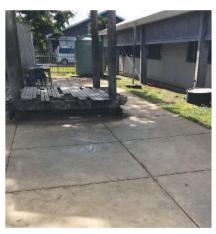
The physical environment was set as an institution as Goffman (1961) established, located away from the main hospital and socially isolated from the island community. Overcrowding was an immediate issue with only 28 beds for 41 people. Many slept without mattresses or bedding, and resorted to sleeping on the ground with no linen. Strict rules were imposed by medical, nursing and security teams. Day-to-day care within the institution was rule-bound with layers of surveillance. The institution set the order of the day. Tasks were performed at the same time in the same manner and care work was controlled through the dominance of

tasks. Nursing staff wore white uniforms and security guards wore black with padded vests and carried batons. The staff instilled order with a regimented administration of set times for medications, meals and staff-to-resident interaction.

Sense of community

Initially, the impoverished environment and overall disciplined administration of care made me incensed. Seeing shared living spaces for people with dementia and those experiencing acute mental health issues brought to the fore ethical issues of risk and safety. After a few weeks however, I started to notice that those living within the unit created their own routine. A sense of community and home was formed by one another rather than the organisation. I started to consider this institution and care for people living with dementia differently.

Instead of holding on to my expectations of what best practice should be, I started to let go of my moral expectations. I began to deliberate about what was really going on between residents. I looked beyond what was immediately in front of me and started to think about, as Goffman (1959) espoused, "the definition of the situation". What was the driving force behind people living together as a collective group? How was this group of individuals creating a sense of self,

Above: The unit's communal outdoor area

community and collaboration? What was really going on aside from the organisational structure and rigid rules?

Connections and negotiations

I began to focus on understanding interactions and collective action between individuals. Once considered in this light, as Meltzer and colleagues (1975) inform, I noticed connections and negotiations between individuals. What was evident behind the wire fence of this institution was the collectivism between the short-term patients and long-term residents.

This secure institution was a home for many, created by those living within, rather than by staff dictating and delivering a fixed organisation of care. To explain further, and to provide an example, within the institution was a man of 22. He was diagnosed with a mood disorder and had a complicated history of violence, abuse and drug dependence. This young man took it upon himself to support the residents living with dementia by helping them with personal care and meals. He would carry those that were unable to walk and covered in faeces on the floor to the shower block and gave essential personal care.

He was not the only one to do so; many would support those who were dependant on others for their care needs. Other people living in the unit created safe spaces inside the larger living area to initiate group discussions and memory support groups. If a person living with dementia had a fall or experienced incontinence, it was the fellow individuals within the institution that understood and delivered person-centred care.

It was at this point I recognised that it was the collective action of fellow residents towards the dependent care group that espoused a person-centred approach towards one another. This all occurred against squalid living conditions, an appalling impersonal environment and away from the hierarchy and bureaucracy of nursing teams and security guards.

The routine of enabling an

Left: The entrance to the unit for people living with dementia, part of the Pacific island mental health unit. Within this confronting and extremely impoverished environment, it was the patients and residents who created a sense of community and home, rather than the organisation. Right: Overcrowding was an issue, with only 28 beds for 41 people. Many slept without mattresses or bedding, or on 'overflow' beds in this outdoor area

individualised, person- centred approach was created through flexibility in caring for one another through collective action.

Residents hold the key

Let's pause for a moment and consider the reality of care practice in Australian residential aged care facilities. We are bound by strict accreditation rules and hierarchal systems. What if, rather than imposing a person-centred approach through complicated practice change programs, residents were provided with more opportunity to support each other? As Kitwood (1997) states, giving is part of living.

In other words, those living within the facility hold the key to creating a collective and caring environment by supporting one another. Shared collective actions, as Gongaware (2012) affirms, sets identity-making against the structure of an organisation. This means, as Klandermand (2004) explains, collective action is created by everyone working together.

On the island, residents created their own sense of identity and a collective movement towards a more person-centred care approach. They were able to

find a sense of purpose and build a person-centred environment through their interactions, thus producing collective action to support others. Collectivism, as Melucci (1995, 1996) notes, symbolises unity. Hence those living within the unit negotiated care giving through collective action to produce their own definition of person-centredness. In this instance, against the harsh realities of living in an appalling institution, individuals overcame adversity to deliver care and understanding towards each other as was highlighted through their collective group action.

Take a step back?

At this point I would like to reiterate my proposed argument for further thought and consideration. If we focus on interactions and collective actions of groups within RACFs against the structure of the organisation, this may provide another way of thinking about achieving a person-centred approach. In other words, interactions within our facilities create the home and a sense of belonging, aside from the overlaying organisation.

It is at this point we need to stop and

look at the situation of what is really going on with the interactions and collective actions of residents. Currently, organisations promote a person-centred approach at every opportunity. Managerial hierarchies impose one-line mantras about person-centeredness as a model or a representation of practice that does not align with everyday care.

We know that person-centeredness is an approach rather than a model and need to ponder further on whether the millions of dollars being spent by care providers to impose culture change to create a more person-centred reality is really working.

Maybe the answer is already in front of us. What if we provided an opportunity for residents to create their own collective action? What if we, the care givers, managers, and organisational hierarchy, just take a step back and learn from those who have achieved this in the most undesirable circumstances? For example what if, as on the island, the concept of time was irrelevant and care came from a more organic paradigm? What if personal care, such as a shower, was delivered when the individual was ready; food was given by others when wanted; food

Can residents be given more opportunities to create a caring environment by supporting one another? Photo: Eberhard Grossgasteiger, Unsplash

preparation was a whole-of-facility operation?

Bound by the clock

In Australia care is bound by the clock. Time is the dominant force over when and how care is provided. Time and temporality (meaning past, present and future of how things are done) dictates. The dominance of time and routine is privileged over actual person-centeredness and collective action. The current situation of practice does not align with the needs of people living with dementia. I propose if we remove the dominance of when a task should be completed we may be able to recreate a more collective home environment.

What if we do not turn the lights on at 6.30am or 7am when the morning shift comes on for the day? What if we leave the lights off until people wake naturally; staff do a morning handover, then a quiet round to check who is awake and who is asleep. People wake when ready; breakfast is available on demand. Personal care is not dominated by time and is offered when the person is ready; medication delivery is prescribed at times to match the individual's unique cycle (within reason. Time is removed from the day.

Currently, in practice for most morning shifts, 11am is the golden hour for care staff discussions. This is the time that staff orientate and judge whether their work is 'falling behind' or not. Their work is time-based and removes opportunity for collective action. Time has become the socially bound representative over collective care actions. Of course, managers, those in

hierarchical positions and care staff alike reject that a preference for routine exists, but reality demonstrates the opposite.

I suggest that for a true person-centred approach to align with the person living with dementia we must remove time-based routines. We need to consider a move to a more collective and person-centred focus requiring a whole-of-organisation culture change movement. For example, a facility could focus on one wing of the RACF to trial changes to care.

Education sessions would be required to inform the residents living with dementia, their families and all staff and to explain, discuss and negotiate proposed temporal changes to care delivery: the morning shift staff would not routinely turn on lights, start medication rounds and bring people to the dining room for a communal breakfast. The kitchen would be affected due to variances in meal delivery and meal times. Cleaning staff would need to alter cleaning routines, and noisy cleaning activities would be moved to times that did not disturb others. Staff meal break times would change so they were available to provide individualised care as residents awoke during the morning.

Time for change?

Changes to care provision need to be gradual. As with all change, this can bring uncertainty and stress to all involved, so planning is vital. Of course these changes may not be suitable for all people living with dementia as some individuals require care routines because of their dependency on help with

personal care, toileting and nutrition.

This is just one suggestion to change care practice. This article suggests an alternate view and offers many avenues for further discussion.

Postscript

After my trip to the Pacific island I made a presentation to the Australian High Commission on the island to raise awareness about the impoverished environment and appalling living conditions within the mental health unit and the desperate need for improvement.

Since then, a recent report has identified some improvements for the residents with dementia: a new built environment has been proposed, to be paid for with international funding. At the time of writing the overcrowding issue had been resolved, with each person now having their own bed; people living with dementia and older adults are no longer admitted to the mental health unit and are now cared for in a designated ward within the main hospital. ■

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