

Balancing compliance and care in dementia practice

Simon Biggs and **Ashley Carr** discuss the strategies used by aged care organisations and care workers to manage the demands of dementia care within a regulated environment. How they do this, while still allowing room for innovation, is of interest to aged care providers, care practitioners, care-users, policy makers and regulators

approaches to regulation, measures have also been proposed to increase regulation and focus regulatory attention towards care activities and facilities considered higher risk. Much of the latter emerged as a consequence of the Oakden Report and the subsequent independent *Review of National Aged Care Quality Regulatory Processes*, conducted by Kate Carnell and Professor Ron Paterson, and released by the Australian Government in October 2017. A key outcome of the review was that for residential care facilities in particular the market alone proved “an inadequate mechanism to ensure the safety and wellbeing of highly vulnerable residents”. The report argues that government regulation, including a rigorous accreditation process, should remain, as a means to ensure quality care standards and the protection of residents.

The Aged Care Act 1997 sits at the centre of Australia’s regulatory system, and includes 17 principles covering areas such as care standards, requirements for approval, allocation of care places, fees and payments, sanctions, record-keeping, prudential requirements and care recipient rights. State legislation deals with other areas related to care, such as building certification, medication management and aspects of food provision. There are currently more than six independent or semi-independent regulatory agencies, including the Aged Care Complaints Commissioner, the Australian Aged Care Quality Agency (see box p29), the Aged Care Funding Authority, as well as national and state authorities covering food, building and training/skills. State and federal courts of law provide another source of regulatory influence.

Our policy and literature reviews found very few regulations specific to dementia within the Act and other relevant regulations. As a result, the implementation of formal regulatory



Australia’s aged care regulatory system is complex, with duplication and overlap occurring at the Commonwealth, state and local government levels and between different regulatory agencies

requirements within organisational settings, and their integration within daily dementia care emerged as an area of critical concern. We began by examining ‘soft’ regulation, which is one means by which ‘hard’ forms of regulation, such as laws and legislation, are implemented within organisational and care settings. These soft forms of regulation, which include guidelines, organisational policies, practices and procedures, and care protocols, are what providers and professionals use to help translate legislation into everyday compliance (Heimer 2013).

The process of translating hard regulation into everyday practice via soft regulation suggested a middle ground, which leaves significant room for flexibility and manoeuvre (Huising & Silbey 2011). It also means that standardised regulatory controls can be adapted to the specific care needs of people living with dementia, though this was an ongoing challenge for care providers.

Regulation ‘clusters’

We found that the distribution of regulation throughout the system and in care settings was uneven. From this we

developed the idea of ‘regulatory clusters’ to show how regulation tended to collect around particular points along a care pathway, for example, at care transition points, such as the move into residential care. This type of clustering suggests where additional support services might be needed to assist care users negotiating multiple regulatory demands, including eligibility requirements, care assessments and income/financial assessments.

Another form of clustering was used to show how regulation collects around particular daily care activities of residential care and not others. A continuum of regulation was proposed, indicating how activities like medication management are subject to high levels of regulatory control and prescriptive rules, whereas morning routines appear the least affected by regulation.

As our report states: “Care workers are able to exercise flexibility around certain care activities, but may be more constrained around others. Once these clusters of risk and control are understood, it is much easier to identify areas where innovation can be quickly achieved and where regulation may create a risk-averse response.” We identified an ongoing need for organisations to provide support and guidance to help care workers balance discretion, best practice and caring relationships amidst regulatory control.

Organisational responses to regulation

We found that care providers adopted particular strategies as a way to cope with regulation. These proved important for balancing care principles, such as the creation of a homelike environment or the promotion of resident choice, with different regulatory demands, some of which were experienced as intrusive.

We categorised the strategies, all of

Care user views on regulation

Five people living with dementia currently accessing community care services and five carers or advocates were interviewed as part of this project. Findings emphasise the increasing importance of user-voice, plus the need to ensure that residents' rights and choices are maintained in care settings. They highlighted the following themes:

Rights and entitlements: regulation was important for supporting rights and entitlements in a fair and accessible way, and for determining the level and type of care that care users were entitled to. Failure to ensure rights and entitlements, including the right to choose and self-determine within facilities, was viewed as a cause of inadequate regulatory control or non-compliance by care organisations and their workers.

Regulation and care quality: regulation was often associated with high-quality care. While many observed the various other inputs that contribute to care, such as staffing levels and staff training/education, these were often assumed to be controlled by formal regulatory requirements and the responsible regulatory agencies, such as the Aged Care Quality Agency, rather than the care provider.

Advocacy: the ability to advocate for oneself or others was seen as a necessary part of formal care, and one that could be enhanced through regulation, such as formal processes related to complaints, co-creation and substitute decision-making.

Managing transitions and navigating a complex system: care users may be confused and frustrated by complex regulatory requirements when navigating the system and managing transition between service systems. Assistance with navigating the system appears to improve their experience of care.

Autonomy: In a best-case scenario regulation should form a secure background that allows people with dementia to simply get on with their lives.

Care users made a number of suggestions for improvement around regulation, including:

- More care staff, particularly in residential settings, and more time spent caring to enhance person-to-person interactions in formal care.
- More stringent accreditation and care quality processes.
- Improved integration of care services at the system and organisational levels.
- Limits to the intrusiveness of regulatory processes.
- More attention to a care user perspective on rights and entitlements.

Reference

Carr A, Biggs S (2018) *The organisation of risk: how do dementia care providers adapt to regulation?* Victoria: Brotherhood of St Laurence.

which were adopted by the organisations in our study to varying degrees, as follows:

- **Above and beyond:** using regulation as minimum standards which the organisation seeks to exceed. Examples include providing training; including dementia-specific training beyond the minimum mandated topics; and a strict dysphagia management regime for all staff to follow.
- **Pushing back:** challenging regulations, regulatory decisions and regulators in the perceived interests of the organisation, its workers and clients. Examples include rejecting specific regulatory decisions, such as a requirement to have both hot and cold taps coloured yellow, excessive food labelling requirements and advice on

food cooking times that restricts resident choice; and challenging assessor expectations where these were not thought to be in the interests of quality care.

- **System-based:** developing systems that translate regulation into action, especially around the admission process, care planning and food provision. This approach aimed to 'engineer out' problems before they became critical. Examples include risk management systems for monitoring, detecting patterns and reporting emerging risks.
- **Organising space:** we observed the following approaches towards organising space to minimise the effect of regulation that might confuse residents or lead to misunderstanding:

- Building planning/facility design (co-creating building design with architects, providers and consumers).
- The use of open and restricted spaces (frontstage/backstage) – for example placing items such as fire safety equipment and notices in service corridors rather than living environments; dividing space into high- and low-risk areas (eg high-risk areas such as medicines management or large cooking areas were separated from living areas to reduce intrusiveness and the feeling of an institution and maintain the normality of everyday living spaces).
- Environmental cues: sensory prompts such as visual cues, smells and sounds were used to attract residents to certain areas at certain times or reduce interest in thoroughfares and specialist equipment.

Overall, a key challenge identified in the report is for aged care service providers to ensure that the specific needs of people with dementia are accommodated within a generic system of compliance and that it is not just a box-ticking exercise.

How care workers respond to regulation

Care workers expressed different views about the role and effects of regulation. On the one hand, regulation was recognised as important for the protections it provided to workers and residents, and for the sense of order it could potentially provide. On the other hand, through reporting and documentation requirements, regulation was seen to increase workload, and the presence of multiple requirements could be experienced as confusing.

Care workers sought a balance between prescriptive rules and the ability to exercise some judgment and discretion, both of which were considered important for effectively relating to residents. As such, regulation was perceived as most effective where it provided a broad framework of limits that also left room for meaningful interaction and interpersonal communication. Indeed, the majority of care workers valued this aspect of their role and desired to spend more time interacting with residents. However, most felt that strict routines, workload, staffing and rostering, and reporting requirements could prevent this from occurring.

An important part of providing care within a regulated environment was for

New commission to oversee aged care regulation

The Federal Government will establish a new and independent quality and safety commission from 1 January 2019 to bring together aged care regulation, compliance and complaints handling – measures recommended by the Carnell-Paterson review.

The move, announced by Aged Care Minister Ken Wyatt in April, is in response to the Carnell-Paterson review into failures at South Australia's Oakden Older Persons' Mental Health Service, which found Australia's current aged care regulatory framework is fragmented and does not adequately provide the assurance the community expects.

The new Aged Care Quality and Safety Commission will bring together the functions of the current Australian Aged Care Quality Agency, the Aged Care Complaints Commissioner and the aged care regulatory functions of the Department of Health.

care workers to determine which of the internal regulations had to be followed to the letter and which permitted flexibility. While more experienced care workers knew where points of flexibility existed and could pass on this knowledge to new workers, organisational policies and procedures could support care workers in daily decision-making and enable more time and opportunity for flexibility and resident engagement.

Emotional labour

The emotional labour involved in dementia care is not always recognised in the person-centred literature. It is, however, a critical aspect of care work. Not only is the display of particular emotions prescribed through 'soft' regulation, but care workers are also required, in the interests of personalised and relational care, to engage with residents at a deeper level. Knowing the person, relating to them and providing comfort in times of distress all require significant emotional input. In cases of advanced dementia, such input is not always reciprocated in conventional ways (Bailey *et al* 2015).

Our research identified two distinctive strategies commonly used by personal care workers to manage the competing demands of emotional engagement in the context of regulation. We have called these 'misattention' and the 'puzzle approach'. We hope that highlighting these may help personal care workers fine-tune their care strategy and see how others cope.

Misattention

A combination of regular reporting schedules, emotional stress and frequent regulatory visits can lead to a form of distancing termed 'misattention'. Here the individual loses contact with the intent behind regulation, replacing caring interaction and emotional engagement with residents with

mechanical, routine compliance, as bureaucratic tasks are given priority in the individual's care approach. Misattention occurs when such rule-following behaviours are mistakenly identified as the core purpose of a caring role. It attends to the letter rather than the spirit of risk avoidance.

Workers who feel that they are being negatively evaluated may then defend themselves against complexity and emotional connection to residents by relying on routine work and reporting practices. Such an approach was referred to by our interviewees as "box-ticking", "rule following" and "looking busy".

While regular, accurate reporting is a necessary part of aged care work, the problem here is that workers 'misattend' to performance by associating best practice with successful reporting on individual tasks rather than with positive and appropriate interaction with residents. This gives a feeling of task compliance but misses the key element of interpersonal connection, resulting in:

- individual staff behaviour that is routinised
- timetabling that fails to allow opportunities for interaction
- detailed attention to monitoring regimes that intrude upon residents' everyday behaviour
- an overly prescriptive approach towards 'soft' guidance
- introducing specifications that do not actually exist in the regulations.

A 'puzzle approach'

A more effective and rewarding approach towards the multiple demands of providing care is to see dementia and dementia care as a puzzle. In this approach good care becomes a process of finding and implementing solutions to such puzzles, in a way that is meaningful for both the worker and the person living with dementia. This approach usually occurred when the

organisational environment was more relaxed and supportive mechanisms were in place.

The puzzle motif suggests the complexity of individuals and the many factors that can contribute to their wellbeing or distress. This is consistent with feedback from facility managers and care workers who likened understanding people living with dementia to learning a different language, an approach that resonated with care workers from non-English speaking backgrounds.

In crafting solutions to people and behaviour as puzzles, knowledge is gleaned from other care workers, health professionals, experts and relatives. The approach empowers care workers to make certain care decisions and gain satisfaction from the care they provide. It allows the care worker to achieve a healthy balance between intimacy, curiosity and distance.

According to the care workers we interviewed, the dimensions of people as puzzles might include:

- Knowing the person's story, their likes / dislikes, and what activities they find meaningful.
- Attending to verbal and non-verbal communication to determine what causes or makes people feel good or bad.
- Watching for signs, such as when a resident looks tired or unsteady on their feet, to be ready to act in a pre-emptive or preventative fashion.
- Identifying basic physical causes, such as infections and pain, to explain distress or other responses.
- Modifying aspects of the physical environment that can foster wellbeing or reduce distress and confusion.

On further analysis we identified that the puzzle strategy used by care staff had three components: empathic understanding, professional distancing or detachment, and the adoption of a problem-solving approach.

Empathic understanding

The ability of care workers to empathise with residents is an important element of dementia care. The idea of seeing the world from a resident's perspective was expressed by care workers as the need to know the resident, leading many to cultivate a professional type of closeness. This involved knowing individual biographies and social identities, awareness of individual likes and dislikes, and attention to moods and feelings. From these elements care workers were able to put themselves in

the shoes of someone experiencing dementia and respond in more sensitive and effective ways.

Professional distancing

At times, for effective care to take place, care workers were required to distance themselves from the feelings evoked by residents and avoid emotionally-charged situations. Using their professional and practical experience care workers could stand back and assess the events, triggers and/or patterns that prompted particular responses. Through such distancing, otherwise confusing situations could be recognised as an understandable response to factors such as the physical environment or individual fears and anxieties. From this standpoint care workers were able to logically and reasonably assess the cause of particular behaviours, and potentially engage with individual residents more effectively.

Problem-solving

By combining empathic understanding and professional distancing, care workers were able to develop a problem-solving approach to the puzzle that dementia presents. Solutions to puzzles came from a range of sources, including:

- clinical practice
- modifying the physical environment
- flexible work schedules
- personal biographies and social identities, plus information gleaned from families and friends.

Care workers played a key role in contributing, trialling and refining solutions, and could experience the puzzle approach as rewarding. While most participants acknowledged the impossibility of arresting the progress of dementia, much could be done to engage with its effects, even though the solutions to particular puzzles could change from day to day and from individual to individual.

The 'puzzle' approach leading to problem solving that takes into account the feeling as well as the thinking elements of the care task holds considerable promise for future training for dementia care staff.

Conclusion

The policy and practice of regulation emerged from this research as both complex and nuanced, and not a uniform phenomenon.

We recommend that a national review of the aged care regulations is needed to identify the intent of current regulations and simplify areas of operational

overlap. Such a review would build on the work of Kate Carnell and Professor Ron Paterson (see box p29), which sought to determine the effectiveness of regulatory arrangements on quality care. It would specifically aim to (1) re-state the intent of regulation, including relevant regulations beyond the Aged Care Act 1997, and (2) identify ways to reduce the duplication and overlap that exists between aged care regulations and other regulated areas.

Examples might include identifying areas where the work of Quality Agency assessors overlaps with or duplicates the work of other regulatory bodies, such as in building design, fire safety, food safety and workplace health and safety. In such instances, we suggest that specific technical assessments are collated by an overview agency in what could be called a 'specialism and overview' model. This would have the advantage of reducing the number of inspections in some areas, and enable bodies like the Quality Agency to focus more on overall care quality.

The three key findings of our research are summarised below.

- First, regulation clusters around particular activities or transitions. Sometimes this reflects risk, but clustering also occurs for administrative reasons or through an overlap of multiple authorities on the same issue. An analysis of clustering may help to target services and identify areas requiring review of their efficiency and effectiveness. It may also be used to identify areas where innovation may be more easily or more difficult to achieve.
- Second, provider organisations respond to the demands of regulation through a process of interpretation, cultural preference and specialisation by organisational level. Organisations spend a lot of time and resources translating formal regulation into everyday practice through guidance, training, monitoring and environmental design. As part of this, they would seek a workable balance between care principles, resident and worker wellbeing and compliance.
- Third, an analysis of everyday practice identified two distinctive staff approaches toward dementia care: misattention and a puzzle approach, with the latter considered an effective and novel approach to dementia care, particularly in balancing emotional connection and professional distance in staff-resident interactions.

Care workers are not simply

constrained by regulation, but use it as a means to cope with the uncertainty of dementia care and the emotional demands of care work. As such, positive regulatory cultures allow for problem-solving innovation while containing the emotional demands of dementia care.

Finally, viewing regulation as an interpretative process reveals significant areas of flexibility, particularly at the organisational and practice levels, and how such flexibility might be used to enhance dementia care.

We will be doing further work this year based on these research findings and their impact on aged and dementia care policy and practice. ■

The organisation of risk: how do dementia care providers adapt to regulation? by Ashley Carr and Simon Biggs (2018) is freely available to download at: <https://bit.ly/2ruu0J2> and www.bsl.org.au/research/

References

- Bailey S, Scales K, Lloyd J, Schneider J, Jones R (2015) The emotional labour of health-care assistants in inpatient dementia care, *Ageing & Society* 35(2) 246-269.
- Carr A, Biggs S (2018) *The organisation of risk: how do dementia care providers adapt to regulation?* Victoria: Brotherhood of St Laurence
- Heimer C (2013) Resilience in the middle: contributions of regulated organisations to regulatory success. *The ANNALS of the American Academy of Political and Social Sciences* 649(1) 139-156.
- Huising R, Silbey S (2011) Governing the gap: forging safe science through relational regulation. *Regulation & Governance* 5(1)



■ Simon Biggs (left) is Professor of Gerontology and Social Policy in the School of Social and Political Sciences, University of Melbourne and in the Brotherhood of St Laurence Research and Policy Centre. Ashley Carr is a Research Fellow in the School of Social and Political Sciences, University of Melbourne. To follow up on this article, contact Ashley at: ashley.carr@unimelb.edu.au