

# Being Present and Meaningful Engagement for Aged Care Residents Living With Dementia: A Mixed-Methods Evaluation of Australian Care Worker's Experiences

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## Abstract

**Background and Objectives:** Meaningful engagement is essential for aged care residents living with dementia. Our knowledge pertaining to caring presence for residents living with dementia is limited. This study aims to understand care workers' experiences of providing care to residents, the challenges they face in being present with residents and support that enable them to be more present and provide person-centered care.

**Research Design and Methods:** A mixed-methods approach using surveys and semi-structured interviews with care workers from three Australian residential aged care homes was adopted. Surveys were analyzed using descriptive statistics. Open-ended survey responses and interviews were analyzed using thematic analysis.

**Results:** Twenty-six care workers completed surveys and a subset ( $n = 8$ ) participated in interviews. Survey participants were largely positive about their role and reported that they loved caring for and making a difference in the lives of residents. Three themes emerged from interviews: (a) trust, connection, and the complexities of maintaining engagement; (b) time as gift and challenge; (c) organizational culture, structure and resources, and enabling carer presence.

**Discussion and Implications:** Care workers in our study expressed their desire to be present with residents and stated that enablers such as meaningfully engaging with residents was one of the most enjoyable aspects of their work. Barriers such as staff shortages, competing demands of the role, and time-related impediments to being present were reported. Addressing challenges to being present with residents living with dementia is key to help avoiding poor care practices and resident outcomes.

**Keywords:** Dementia, Long-term care, Person-centered care, Presence, Residential aged care workers

## Background and Objectives

Being present (also referred to as *nursing presence* or *presence*) is widely considered to be one of the most important aspects of quality health care (Boeck, 2014). Many authors have discussed the concept of presence particularly in the context of nursing (Boeck, 2014; Doona et al., 1999; Kostovich & Clementi, 2014; Mohammadipour et al., 2017; Smith, 2001) arguing that presence is a multidimensional, complex, contextual, and circular concept with a number of interconnected attributes.

Boeck (2014) reviewed the concept of presence from diverse viewpoints (such as spiritual, literary, psychological,

and nursing literature) and defines that “*genuine nursing presence consists of being with another individual, deeply listening, not conditional on what to do or say next, while remaining in the intimacy of the moment. Presence implies that the nurse permits oneself to be open and vulnerable to their patient, their patients' families and fellow nurses ... Presence in nursing is an integral and mutual exchange among nurses and patients that involves attentiveness, empathy, and the mature recognition of the nurse's and the patient's holistic needs.*” Boeck further described the value of interconnectivity of attributes through a presence model that had four circular

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interconnected domains: (a) patient demonstrates needs (e.g., physical/emotional/spiritual); (b) openness to experience (e.g., reciprocity/rapport/connection); (c) improved well-being for nurse and patient (empowerment/mutuality/renewal); and (d) nurse willing to enact (e.g., empathy/compassion/maturity/authenticity).

Mohammadipour et al. (2017) also studied the concept of presence using a combination of theoretical, field work, and analytical approaches and define nursing presence as “*co-constructed interaction identified by deliberate focus, task-oriented/patient-oriented relationship, accountability, clarification, and ubiquitous participation. Nursing presence requires clinical competence, self-actualization, reciprocating openness, and conducive working environment. Worthwhile communications, balance/recovery, and growth and transcendence are the main consequences of this concept.*”

Although multiple definitions are attached to nursing presence, there is still some ambiguity and overlap with similar concepts, a lack of consensus on defining nursing presence and a lack of research focused explicitly on care worker presence. These definitions underpin our understanding of presence and help disseminate its education, research, and practice (Engqvist et al., 2010; Iseminger et al., 2009; McMahon & Christopher, 2011; Tavernier, 2006). Further research will help disentangle these concepts.

Both meaningful engagement and person-centered care are two of the many inter-related attributes within the broad concept of presence. Although presence encapsulates these attributes as key pillars, presence requires further than meaningful engagement and person-centered care. Kemp et al. (2021) found that certain approaches successfully promoted meaningful engagement across all levels of residents living with dementia and state that “*facilitating positive engagement experiences among residents with dementia required observation, attentiveness, and person- and relationship-centered approaches. These approaches included: (a) knowing the person; (b) connecting with the person and meeting them where they are; (c) being in the moment; and (d) viewing all encounters as opportunity.*” Kitwood’s (1997) definition of person-centered care rejects the reliance on medical approach to caring for people with dementia and focusses on the needs of the people living with dementia using psychological attributes such as love, comfort, attachment, inclusion, occupation, and identity. Meaningful engagement and person-centered care approaches have the potential to facilitate nurses and aged care staff to find better ways of fully meeting their patients’ needs.

Several improvements in clinical and social outcomes for patients have been reported in the literature as a direct result of nursing presence programs or interventions. Nursing presence programs used a variety of techniques focused on relationship building, being respectful, empathetic, truthful, patient-centered, and provision of holistic care (Kostovich & Clementi, 2014) including using practical techniques such as smiling and emoting positive energy, mindfulness meditation, active listening, and looking for nonverbal communication (An & Jo, 2009; Penque & Kearney, 2015). Nursing presence programs have also been shown to decrease incidence of falls and pressure ulcers (Kostovich & Clementi, 2014), improved stress and cortisol levels (An & Jo, 2009); improved healing process (Engqvist et al., 2010; Iseminger et al., 2009; Kostovich & Clementi, 2014); and patient satisfaction (Negarandeh et al., 2014; Penque & Kearney, 2015). Lack of

nursing presence has been linked to increased patient aggression, violent behaviors, loneliness, and anxiety (Engqvist et al., 2010; McMahon & Christopher, 2011). Some research studies exploring patient perspectives on quality of care have reported that patients perceive nursing presence as an important caring behavior and an indicator of quality of nursing care (Atashzadeh Shoorideh et al., 2012; Negarandeh et al., 2014). We acknowledge that none of the earlier benefits and outcomes were exclusively reported for care worker presence. However, given that residents spend most of their day with care workers (Australian Institute of Health and Welfare, 2023; Personal Social Services Survey of Adult Carers in England, 2017) it is prudent to expect similar benefits to those reported for nursing presence.

The Australian Government initiated the Royal Commission into Aged Care Quality and Safety as an important and major independent inquiry (2018–2021) into the quality and safety of the Australian aged care system. The 2019 Interim Report (titled “Neglect”) released by the Royal Commission (The Australian Royal Commission into Aged Care Quality and Safety, 2019) highlighted several challenges in providing care, including those related to care workers (e.g., education level, attrition rate, and role satisfaction of care workers in aged care). There is considerable evidence to suggest that health care workers can be absent rather than present and this intentional or unintentional absence can have significant implications on the types of care and forms of neglect that can emerge from a lack of intentional presence. Absence is not only a lack of presence or meaningful engagement but also avoidance and alienation. For example, the recent Australian Royal Commission into Aged Care Quality and Safety highlighted deliberate acts of abuse as well as significant problems within the culture of the aged care working environment leading to dangerous omissions from care, suggesting that staff were not engaging with aged care home residents in meaningful ways (Royal Commission into Aged Care Quality and Safety, 2021). The Commission reported harrowing accounts of aged care home residents living with dementia experiencing “substandard care,” “unkindness” and “neglect” (Royal Commission into Aged Care Quality and Safety, 2021).

Concerns about the appropriateness of care provided to residents living with dementia in residential aged care homes (RACHs) are not new and have been highlighted as such for some decades (Brody, Lawton, & Liebowitz, 1984). Of particular importance, the criticism the Royal Commission made, that many Australian RACHs were not providing sufficient meaningful engagement opportunities for residents living with dementia (Royal Commission into Aged Care Quality and Safety, 2021) to be able to provide quality care. However, it is important to note that cultural factors such as culturally inappropriate dementia services, language barriers, or poor attitudes (shame and discrimination) toward people with dementia (Chejor et al., 2022) could also inhibit the possibility of meaningful engagement of residents even when a care worker values and acknowledges the significance of meaningful engagement (McGrath et al., 2022). Further studies are needed to better understand cultural factors that could preclude meaningful engagement for aged care residents and hence practicing efficient and effective presence. Similarly, a recent literature review of the impact of the coronavirus disease 2019 (COVID-19) pandemic on people living with dementia has shown that isolation and other pandemic restrictions have negatively affected the cognitive as well as

psychological well-being of people with dementia (Paplikar et al., 2022). Lack of awareness of resident's needs as well as under-resourced aged care settings may present challenges for practicing presence and meaningfully engaging with residents. Further research is needed to understand factors that prevent staff practicing presence (Atashzadeh-Shoorideh et al., 2021).

Consideration needs to be given to ensure that RACH staff have the right skills to perform meaningful engagement with residents living with dementia. Past research has shown that RACH staff reported lack of time and poor training in dementia to be barriers for personalized care of residents living with dementia (Milte et al., 2016). For example, 90% of health care professionals in a survey conducted by Alzheimer's Australia indicated that additional training in dementia would be beneficial (Palliative Care Australia and Alzheimer's Australia, 2014) and 50% of staff at a RACH reported a lack of understanding of dementia (Robinson et al., 2014). Such findings warrant additional training programs/support for RACH staff to assist with their knowledge regarding dementia and caring for residents living with dementia. The practice of presence among care workers and how they gain knowledge, skills, and experience to demonstrate presence are not well understood. Previous work focused on nursing presence has shown that training and coaching related strategies such as introduction of presence concepts during staff onboarding or orientation, structured educational, and experiential interventions to improve nurse knowledge, skills, and confidence about being present (Crocco et al., 2023; Kostovich & Clementi, 2014; Penque & Kearney, 2015), ongoing professional development (Crocco et al., 2023; Penque & Kearney, 2015), shadowing or observing preceptors or role models (Crocco et al., 2023), mentoring (Penque & Kearney, 2015), and the use of organizational champions (O'Malley Tuomi, 2014) facilitate practicing nursing presence. Thus, ideally, information about being present, presence, and meaningful engagement should be part of the care worker staff onboarding, orientation, and continuous education programs.

There is a lack of studies on care worker presence and most of the literature is related to nursing presence. Thus, the purpose of this study is to explore the extent to which care workers at Australian RACHs were able to meaningfully engage, interact, and be present with residents living with dementia and understand opportunities for improving capacity for meaningful engagement with those residents. Specifically, this paper aims to understand: (a) care workers' experiences of providing care to residents living with dementia; (b) the challenges that care workers face in being present with residents living with dementia; and (c) the support mechanisms that enable care workers to be more present and provide person-centered care.

## Design and Methods

This study is an exploratory pilot study to understand the ability of care workers in a single aged care organization to be present and have meaningful engagement with residents living with dementia. A mixed-methods approach was adopted to study the experiences of care workers in providing care to residents living with dementia using survey (quantitative) and interview (qualitative) data. Initially, a short survey was administered to care workers at the participating RACH sites to understand aspects of care that they were doing well, challenges they face in providing care,

and resources or training that would assist them in caring for residents living with dementia. The survey questions were informed by input and feedback from residential aged care stakeholders, Royal Commission findings, and literature reviews (The Australian Royal Commission into Aged Care Quality and Safety, 2019; Turpin, 2014). Survey participants were asked to rate how strongly they agreed or disagreed with a set of statements about aspects of caring for residents living with dementia and how it affected them using nine-point Likert scales. Open-ended questions were included in the survey to seek detailed explanation or reasons for their ratings. The survey was followed by a series of semistructured interviews to explore the topics highlighted in the survey in greater detail to gain a deeper understanding of care workers' experiences and perceptions on being present when caring for residents living with dementia. An interview guide (see the [Supplementary Material](#)) was developed after being informed by the topics highlighted in the survey.

## Recruitment and Sample

Three RACHs from a large, not-for-profit aged care provider in New South Wales, Australia, were recruited to participate in the study. RACH-1 was a large facility (over 100 beds) with about 40% being dementia specific, while RACH-2 and RACH-3 were each under 100 beds but with all beds being dementia specific. RACH-3 was a regional site, while the other two sites (RACH-1 and 2) were in metropolitan Sydney. During the study period, the three study sites employed approximately 350 care workers across the three locations.

## Inclusion and Exclusion Criteria

All RACH staff providing care to residents living with dementia from the participating sites (RACH-1, RACH-2, and RACH-3) who were available to participate in surveys and/or interviews during the study period were eligible to participate. Exclusion criteria included not working within the RACHs where the study was conducted and nil experience working with residents living with dementia.

A purposive sampling approach was used to target participants from the three RACH sites and inform them about the opportunity to participate in a survey and/or interview. The study was introduced by the site managers during their regular RACH staff meetings. It was made clear that participation was voluntary. Care workers with any queries about the study were referred by site managers and team leaders to the research team. Posters explaining the study were placed in staff common areas. A contact number and email were available to interested care workers to allow them to ask any questions about the study.

Any eligible and interested care worker from the three RACHs was able to complete an anonymous survey. Care workers interested in participating in an interview were able to register their interest on a page on the end of the survey by providing their first name and a contact telephone number. Potential interview participants were approached by the research assistant. The research assistant had no previous relationship with potential participants. Potential participants were sent an information letter and consent form by mail or email, depending on their preference. Once written consent form was completed and returned to the research assistant via email, a mutually convenient time was negotiated for the interview.

## Data Collection

Completion of survey and participation in interview was optional. Participant information sheets, anonymous paper-based surveys, and secure survey boxes were placed in the staff tea rooms at each of the study sites and were available during March 2020—May 2021 for staff to complete. There was no reimbursement offered to participants who completed the anonymous survey.

Semistructured individual interviews were conducted via telephone (due to COVID-19 pandemic), by a single interviewer (a research assistant with a master's level qualitative researcher experienced in conducting interviews and focus groups) during October 2020—May 2021. Before commencing the interview, the interviewer answered any questions from participants about the study. All interviews were audio-recorded and transcribed verbatim. No one other than the researcher and the participant were present during the interview. The interview guide was not piloted due to resources and time constraints during the COVID pandemic.

There were challenges to recruitment due to the COVID-19 pandemic including stressed, overworked aged care staff, and workforce staff shortages due to isolation requirements. Only participants who had responded to the expression of interest to attend interview section in the survey were contacted by the researcher regarding participation in interviews. The research assistant contacted the participating site managers requesting them to remind potential participants at their sites about the study and details of researchers to contact if they were interested in participating in the study.

## Data Analysis

All surveys were collated, and data were analyzed using descriptive statistics. Open-ended survey responses were analyzed for themes. The interview data were transcribed and de-identified by the research assistant (interviewer) and only de-identified transcripts were shared with other team members for data analysis and interpretation. Audio recordings of the interviews were stored electronically on a secure password-protected server only accessible to the research team members. All study data will be destroyed seven years postcompletion of the study. Interview transcripts were analyzed inductively using steps proposed by Braun and Clarke's thematic analysis framework (familiarization with data, generation of codes, searching for themes across codes, review of themes, defining and naming themes, and writing up the analysis; Braun & Clarke, 2006). Only de-identified transcripts were shared with the research team for analysis. Interview data were thematically coded and reviewed iteratively by two experienced qualitative researchers (research assistant, J. S.). Research assistant and J. S. coded the transcripts independently. The codes were discussed and collated to form categories. These categories were combined to develop a list of potential themes. Further discussions among the research team with expertise in restorative care and aged care (research assistant, C. P.), nursing (J. S.), qualitative research (research assistant, J. S., C.P.), and dementia (T. M., M. A.) resulted in re-coding of themes, reviewing/relabeling of themes and an agreement on interpretation and analysis was confirmed resulting in a final list of themes. No member checking of transcripts was conducted with interviewees due to tight project timelines and potential burden for health care professionals during COVID-19 pandemic.

Data saturation was discussed given the small sample size. Taking into consideration discussion in Guest et al. (2006) and emergence of no new major themes after the last interview, an agreement was reached by the research team that data saturation was reached. Additionally, S. V. N. (experienced qualitative researcher with a doctoral degree) also reviewed the transcripts and noted agreement with the list of themes developed. Credibility of this study is achieved through detailed description of study analysis and results supported by participant quotes, presentation of demographics of study participants, and discussion of study strengths and limitations.

## Ethical Considerations

Ethical approval was obtained from the University of New South Wales Human Research Ethics Committee (HC190990). Submission of the completed anonymous survey was taken as consent for the survey component of the study. All interview participants gave their written informed consent to participate.

## Results

### Surveys

Twenty-six participants from three sites completed surveys ( $n = 6$  [RACH-1],  $n = 12$  [RACH-2], and  $n = 8$  [RACH-3]). Demographic characteristics of survey participants are presented in Table 1. Ten participants (38.5%) had more than 5 years' experience working as a care worker. Over a third of the participants ( $n = 10$ ; 38.5%) had previous working experience as a care worker at another organization and had been a carer for a family member living with dementia ( $n = 9$ ; 34.6%). See Table 2 for further details. The mean number of months caring for residents living with dementia was 41 ( $SD = 22.3$ ) at RACH-1, 15.7 ( $SD = 16.6$ ) at RACH-2, and 87.6 ( $SD = 69.5$ ) at RACH-3. The mean number of months caring for residents living with dementia collectively for the three sites was 44.8 ( $SD = 51.3$ ) with a median of 36 months. The mean score for the survey item "I feel proud of the work I do caring for residents with dementia" is 6.9 ( $SD = 1.3$ ) at RACH-1, 8.1 ( $SD = 1$ ) for RACH-2, and 8.0 ( $SD = .9$ ) for

**Table 1.** Characteristics of Survey Participants ( $n = 26$ )

Characteristics	Number of participants (%)
Experience working as care worker	
0–1 year	6 (23.05%)
1–3 years	6 (23.05%)
3–5 years	4 (15.4%)
5 + years	10 (38.5%)
Worked as a care worker prior to current employment	
Yes	10 (38.5%)
No	16 (61.5%)
Carer for a family member with dementia	
Yes	9 (34.6%)
No	16 (61.5%)
Invalid response	1 (3.9%)

**Table 2.** Survey Responses of Participants in Study Sites on Aspects of Caring for Residents Living With Dementia

Survey items	Statistics	
	Mean (SD) or %	Median
1a. "How long have you been caring for people with dementia at this site?" (months?)	44.8 (51.3)	36.0
1b. "Have you provided care at another site or provider?"	42.3% Yes	N/A
1b.2. "If yes, how long?" (months)	43.3 (62.3)	21.0
1c. "Have you ever provided care to a relative or friend with dementia in a personal capacity?"	35% Yes	N/A
3a. "I feel proud of the work I do caring for residents with dementia"	7.8 (1.1)	8.0
4a. "I find the work I do rewarding"	7.5 (1.5)	8.0
5a. "I find caring for residents with dementia challenging"	6.8 (1.7)	7.0
6. "I am comfortable being around, and caring for residents with dementia"	8.0 (1.4)	8.0
7. "I find it easy to communicate and interact with residents with dementia"	6.8 (1.5)	7.0
8. "I have a good understanding of the needs of residents with dementia"	7.2 (1.3)	7.0
9. "I sometimes find interacting with residents' families challenging"	5.6 (2.2)	6.0
10. "I often have to focus on my tasks and jobs rather than the residents I am caring for"	4.4 (2.9)	3.0
11. "I often form connections with the residents I am caring for"	7.2 (1.9)	8.0
12. "I form connections with the families of residents I am caring for"	6.7 (1.9)	7.0
13. "I never have enough time to spend with the residents I am caring for"	5.2 (3.0)	6.0
14. "I find myself thinking about my role even when I am not at work"	6.3 (2.2)	7.0

Notes: N/A = not applicable; SD = standard deviation.

RACH-3, and collectively for all three sites is 7.8 ( $SD = 1.1$ ). The mean score for the survey item "I form connections with the families of residents I am caring for" is 6.7 ( $SD = 1.5$ ) at RACH-1, 6.5 ( $SD = 2.4$ ) at RACH-2, and 7 ( $SD = 1.3$ ) for RACH-3 and collectively for all three sites is 6.7 ( $SD = 1.9$ ). Qualitative feedback about suggestions for improvements was elicited using open-ended questions.

### Interviews

Of the survey respondents, eight participants took part in interviews. Seven of the eight participants were female. Their years of experience in aged care ranged from seven months to 15 years. The semistructured interviews lasted on average 57 min (range: 32–73 min). See Table 3 for interviewees' characteristics. Three major themes were identified. Table 4 lists the three themes with sample quotes.

#### Theme 1: Trust, connection, and the complexities of maintaining engagement

Participants highlighted that performing the role successfully was predicated on establishing meaningful relationships with the residents. Forming connections and building trust with residents, participants stressed, was not a straightforward matter. Care workers spend a considerable time reading through the residents' care plans, getting to know their habits, preferences, needs, and triggers. At the heart of the caring task is the issue of trust. If new staff fail to establish those bonds, the residents' attentions would be directed to those care workers they already trusted; placing further demands upon a small number of staff. For example, one care worker participant stated that it was important for all care workers working with a resident to know what the resident's preferences are (e.g., enjoys a shower in the morning rather than at night). Forming bonds of reciprocal trust not only helps staff know the residents and their preferences but it also reinforces connection, engagement, and helps ensure that the workload is fairly shared.

**Table 3.** Interview Participant Demographics

Participant	Experience working in aged care (years)	Residential aged care home (RACH) site
P1	7	1
P2	<1	2
P3	15	2
P4	1	2
P5	<1	2
P6	10	2
P7	6	3
P8	>12	3

Notes: P1 = Participant 1; P2 = Participant 2; P3 = Participant 3; P4 = Participant 4; P5 = Participant 5; P6 = Participant 6; P7 = Participant 7; P8 = Participant 8.

Staffing and responsibilities (see Theme 3 for further information) were recognized as key issues for the ability of all staff to be present. Participants were aware of the need for connection with residents living with dementia, but they were also aware that dementia can be a source of disconnection. Participants said that residents often live with physical and emotional pain, where sometimes they are disoriented by their condition and can feel a deep sense of loneliness and loss for the lives they previously led. This loneliness is exacerbated by the fact that family were not always able to visit residents as much as they would like. Moreover, residents who were unsettled by the physical and psychological pain associated with their frail and failing bodies were also limited by their inability to communicate their discomfort to staff. The understandable communicational challenges of dementia combined with difficulties in empathizing with respective care needs that cannot be articulated can make the experience of being present highly complicated and perhaps

**Table 4.** Interview Participant Quotes for Themes 1–3

Theme	Sample quotes
(1) Trust, connection and the complexities of maintaining engagement	<p><i>to build that trust with a resident, and knowing the resident is a major part, of them having a good day basically.</i> (P6, Site 2)</p> <p><i>make sure ... they can trust you. If not, you do something, and they feel, "oh I can't trust them," they'll just come to the old staff they know and be like, "I don't want this person in my room, I don't trust them," or that. So we just want to make sure if someone comes in new [staff], they know the residents.</i> (P1, Site 1)</p> <p><i>a huge thing because, you know, say the resident enjoys a shower first thing in the morning, to get them ready for the day. If you start giving them a shower at night it's going to put them off, and it's you know, their day is probably not going to go quite as well because they've been in that routine of shower first thing in the morning, but if there is not that consistency of care, of the same care workers in the same apartment, with the same resident, they usually don't have time to go and read that person's care plan before they go and give them personal care and see them for the first time in the morning and stuff.</i> (P6, Site 2)</p> <p><i>they wake up every day to strangers. You just go to their room early in the morning and you're a stranger. They don't, ... know who you are. And that's very uncomfortable, if you go in there and they keep asking you, "who are you, what are you doing here?."</i> (P1, Site 1)</p> <p><i>a totally different time of their life, where they can't, can't do the same things, [ ... ] like he was like a neurosurgeon, or a cardio, cardiologist, and you're know, like oh whao, he can't, he can't really put a sentence together anymore, like it's pretty upsetting.</i> (P4, Site 2)</p> <p><i>I put myself in their position most of the time, and if I'm there my family are not visiting me, you know, it'd be sad. Because you've known them all your life, and I don't know these strangers, I don't know who they are, so if I'm sitting there with them I'm not seeing their faces, the faces that I've always been seeing all my life.</i> (P1, Site 1)</p> <p><i>able to do anything, because we've got some who are really sick, even though they are sick, they're in pain, but you can't really help, you don't know how, how to help them, if you are giving them medication and all that, they need and it's not working, and they can't tell you, "I'm in pain, I have pain here, or I have pain there" it's really challenging, like it's a lot for them and I think it's a lot for us, as this carers as well. So I think that's really challenging.</i> (P1, Site 1)</p>
(2) Time as gift and challenge	<p><i>when you get to spend quality time with residents, and have a chat, ... hear about their day or whatever, ... or play a game. That's like, that's the best part, or go for a walk or something, where you know, you are sort of making them smile or, making their day a bit better</i> (P4, Site2)</p> <p><i>I just did the one-on-one with her, dealing with her nails, and she doesn't show a lot of affections, but she actually come and cuddled me and said "thank you," [ ... ] she doesn't do that very often, [ ... ] I couldn't believe it, I lapped that up.</i> (P8, Site 3)</p> <p><i>between personal care and like medication I'd be like, the prime times that I get to have a chat with a resident or a couple of residents. Or just maybe at mealtimes I'd be like, they'd be sitting at the table, and I'd be maybe in the kitchen, and just like, trying to have a chat across ... the way. And then I suppose a little bit, ah, like this isn't ... this isn't great.</i> (P4, Site 2)</p> <p><i>if you are with someone, and another person is screaming, [ ... ] I got, I got punched in my face last year because we start at 7 o'clock, and then I came in, and two of them were screaming really loudly and I didn't know who to go to first, because both of them sound really cranky, so I went to the loudest one [ ... ] "I'm sorry I just came in, but I had to go to someone else." She threw water at me and she punched me in the face, for not being there on time. So if we had enough staff on that shift, someone else could have gone to her or something.</i> (P1, Site1)</p> <p><i>depending on what the incident is and how serious it is. Obviously there are reporting obligations that go along with that, and a lot of paperwork, and there's, and then it's monitoring, you know, that one resident for the rest of the shift, to you know, make sure it doesn't happen again, ... so then obviously the care staff don't get to do some of those tasks that are expected of them in the morning because it does take, you know, sometimes even up to an hour just to get this paperwork done, when an incident happens.</i> (P6, Site 2)</p> <p><i>I know we need more staff here, but nobody's actually applying at the moment.</i> (P6, Site 2)</p> <p><i>someone just doesn't come, or someone calls sick, then we become really busy and I think, and I know, I'm sure you know, whenever staff are short we don't get the chance to give the resident the care they need.</i> (P1, Site 1)</p> <p><i>I feel like for a lot of the care staff that are on visas, it's more of a stepping stone sometimes, to get to where they actually want to be so sometimes the care isn't 100% there because it's just a stepping stone, while they study to get to where they need to be.</i> (P6, Site2)</p>
(3) Organizational culture, structure and resources, and enabling carer presence	<p><i>everybody who's there [RACH] isn't getting better, like everyone's, in a way like probably declining, either, like quite slow or fast, but you don't just, you know stay for some time and then like "oh I'm better and I'm going back to my family," like, you know, they're like, I guess seeing out their days there.</i> (P4, Site 2)</p> <p><i>I can see them like light up and, [residents], they don't remember my real name, but they'll like call me a name or whatever, like, [ ... ] Goldilocks or something, [ ... ] I'm like, pretty excited to see them too. I mean they're genuinely excited to see me, yeah. Yeah, it goes both ways.</i> (P4, Site 2)</p>

Table 4. Continued

Theme	Sample quotes
	<p>... you know because they have so many tasks to do within the ... 7.5 hours that they're here ... they don't always get that time to sit down and engage, you know, and that's when we do, call upon our volunteers and things, to spend time then, with the residents. ... so that is a challenge for the care staff, is that they are sometimes don't have enough time to do that. (P7, Site 3)</p> <p>some carers become very task orientated, instead of you know, leaving that task for later and spending that one on one, which then becomes a challenge, they don't do that, then with, then you see your array of behaviors and things like that. (P7, Site 3)</p> <p>three of us there, it kept them more engaged, what was going on, it wasn't just the one thing going, "oh, let's sit and listen to music." It was like you know, helping making the cupcakes, helping doing the dishes, playing the checkers, it wasn't just the one thing. Three of us had three different things going on, and in that cottage, it just kept them really engaged, to where you know, one resident all she does is call out, well she didn't call out once, Not the whole time. And when I sat and did nail-care with her today I said "did you enjoy yesterday afternoon playing checkers?," she said "I loved it." (P8, Site 3)</p> <p>in high-demand that there should be some sort of leniency on certain you know, especially with the aged-care, with their visas, that should be you know, some sort of allowances or certain things, because they are needed here. It's not like they are needed, you know, just in remote locations, when we need them here as well. (P6, Site 2)</p> <p>Everybody is different, everybody has different needs, wants. Wants are actually included rather than just their needs. (P6, Site 2)</p> <p>...two faces in there at one time, apart from the residents and families that visit obviously. So then you can have ... that connection with the resident, and get to know the resident, and you are doing absolutely everything for them, rather than them seeing so many different faces ... you don't want, you know, six care staff in there doing everything, because you don't have that at home. (P8, Site 3)</p>

Notes: P1 = Participant 1; P2 = Participant 2; P3 = Participant 3; P4 = Participant 4; P5 = Participant 5; P6 = Participant 6; P7 = Participant 7; P8 = Participant 8.

for some impossible. The temptation for withdrawal is obvious for staff.

### Theme 2: Time as gift and challenge

Participants consistently cited their experiences of being fully present with residents as some of the most enjoyable and rewarding aspects of the role. Practicing presence and spending focused time with residents helped care workers to see different aspects in residents who were regarded as difficult to care for. Taking the time to be present helps carers to move beyond what they might assume and discover things that may surprise them as described by one care worker. However, care workers indicated that they could experience numerous time related impediments to being present.

Meeting the needs of people living with advanced dementia is a complex undertaking, that is carried out within an intricate system of care. Participants recounted that it was not uncommon for their plans to go awry, often caught between competing demands and lack of time to interact with and be fully present with residents living with dementia. They understand that residents require practical care and meaningful human engagement, but the former takes time, leaving them with limited opportunities for meaningful engagement with residents. Situations in which residents are not fully engaged, can give rise to them experiencing distress, becoming aggressive toward other residents or staff, having falls, or withdrawing into themselves. Resolving such situations takes time and can impact on other aspects of care and can impinge upon carers' ability to be present with residents.

### Theme 3: Organizational culture, structure and resources, and enabling carer presence

Participants were largely aware of the nature and importance of their role. *First*, participants recognized dementia

as a deteriorating condition which required specialized care and residents entrusted to them would, likely, be spending the remainder of their lives in their care. This was hard for families and friends who found themselves unable to continue to meet the needs of their loved ones in the community leading to permanently placing the person with dementia into a RACH. Participants felt that the service they provided was not limited to the individuals in their care, but also extended to the families, friends, and communities from which they came. In this sense care workers saw their work as an essential aspect of dementia care for the individual and their family. *Second*, care workers would play a large part in making the residents' remaining time as meaningful and enjoyable as possible within the limits of their situation. This was something that care workers took seriously. Participants articulated the joy they felt engaging residents, and how the residents themselves appreciated those moments of engagement with staff. *Third*, meeting those needs in a way that reflects the humanity and personhood of residents necessitates staff going beyond basic aspects of care provision. It requires them to be fully present with residents to engage with them in activities and interactions that resonate with them. However, problems arose when the pressures of the work environment militate against such presence. Participants reported that one way of dealing with stressful work environments is to focus on tasks. Study participants were clearly well motivated and consistently articulated that establishing positive, meaningful, and enduring relationships with residents and their families was not only rewarding but also essential for successfully undertaking their role.

The participating RACH sites had a model of care which was predicated on knowing the resident and partnering in care with residents and their families. This model recognizes the distinct personhood of each resident and is intended to

encourage individualized care. Applying this model necessitated care workers doing more than just meeting the basic care needs of residents. Normally, there are two care workers providing care for 9–14 residents in the cottages or apartments. Nurses, pastoral care workers, and volunteers provide additional assistance as needed. The organization structures staffing ratios to maintain the homelike and intimate feeling of the apartments. It seemed clear that, at least in principle, the structure, organization, and mission intentions of the RACH sites were conducive to encouraging care worker presence. Participants felt that government funding provisions sometimes limited the amount of care that could be provided, especially when the funding tool did not adequately recognize a resident's needs.

The shortage of staff is exacerbated by three factors: (a) finding staff to work in RACHs is not easy; (b) COVID-19 pandemic (staff restricted to work if they are ill); and (c) dependence on a transient workforce of international students as care workers bound by visa restrictions (including relocation to regional areas postgraduation) resulting in loss of knowledge of, and connection with, the residents. Staffing levels and staff turnover can thus be seen to be a significant, but complex factor in enabling or disabling presence.

Participants suggested that resident engagement could be improved by addressing the *practical* time constraint (see Theme 2 for further information), by having additional staff on shift. One participant offered the example of the difference she noticed in resident engagement when she was an additional person on a two-person shift due to being on reduced duties following an injury. Participants at the other sites concurred, saying that they had similar experiences (including reduction in behaviors associated with dementia) when there was extra help available. The *structural* issue of addressing staff attrition is a little more complex and sometimes largely out of the organization's hands. Losing experienced staff (e.g., foreign-born care workers) because of their visa regulations has, participants stressed, serious implications for the care residents receive.

## Discussion and Implications

Presence is a multidimensional and complex concept comprising of several interconnected attributes (Boeck, 2014; Doona et al., 1999; Kostovich & Clementi, 2014; Mohammadipour et al., 2017; Smith, 2001). Despite the abundance of literature on presence, there is still a lack of consensus in relation to its definition, description, and measurement (Turpin, 2014). Meaningful engagement (Kemp et al., 2021) and person-centered care (Kitwood, 1997) are two of the many attributes of presence. However, our understanding of presence in the context of care workers is still limited. This study is, to the best of our knowledge, the first published study that discusses the Australian care worker's experience and challenges in being present with aged care residents living with dementia. There are two key findings. First, meaningful engagement with residents requires establishing a connection of trust, which is then maintained through reliable relationships with residents. However, caring for residents living with dementia is complex and this presented several challenges for maintaining engagement. Second, care worker presence requires appropriate organizational structure, supporting resources, and adequate staffing levels to ensure that care workers were able to pay attention to both the individual resident and their community.

Care workers articulated that meaningfully engaging with residents living with dementia was one of the most enjoyable aspects of what is, in many respects, a very demanding role. Care workers also highlighted practical (e.g., competing work demands limiting opportunities for meaningful engagement with residents living with dementia) and structural barriers (e.g., staff shortages) when caring for residents living with dementia. The care environment, participants responded, is often dynamic, unpredictable, and even volatile. These issues can limit carers' opportunities for being present and meaningfully engaging with residents living with dementia.

Meaningful engagement explored in this study, is an intrinsic aspect of our shared humanity (Christakis, 2019; Marmot, 2004), but is something that is sadly absent in some Australian RACHs (Royal Commission into Aged Care Quality and Safety, 2021). Effective caring is about more than meeting the physical needs of residents in these RACHs. Research suggests that a paucity of social engagement is deleterious to residents' physical and mental well-being (Cacioppo et al., 2009; Holt-Lunstad et al., 2015). As our participants noted, dementia may have impacted many aspects of the residents' lives, but it did not, for the most part, diminish their willingness to connect and engage with other residents and staff. People living with dementia are still relational beings, capable of agency, sentience and engaging with the world, and are no less deserving of the dignity and respect of their peers, despite their condition (Brooker, 2003; O'Sullivan, 2013; Swinton, 2012). Further, residents living with dementia, like their peers in the community, require consistent, reliable relationships to flourish. Therefore, care workers or staff presence is vital for delivering best practice dementia care.

RACHs, like the societies they reside in, are systems of care for a population with very specific, and often complex, needs. Applying a systems lens (Meadows, 2008) to the study sites allowed us to identify the practical and structural issues and challenges care workers face in the role. Most importantly, staff said they had limited time to be present with residents living with dementia. As such, time with residents is predicated and focused on completing the basic care tasks that must be undertaken at the sites. As our participants highlighted, the profile of residents entering RACHs is changing; they are increasingly older and frailer. This correlates with similar findings in comparable countries, such as the USA, Germany, and Canada (Eagar et al., 2019). Our participants acknowledged that with limited staff on per shift, meeting the basic care needs of frailer residents now requires more of their time and attention; the corollary of which is they have less time for engagement. Engagement, as participants highlighted, is extremely important for the residents' mental and physical well-being (Du Toit et al., 2019; Wood et al., 2009). Practical tools such as the Preferences for Everyday Living Inventory (PELLI; Van Haitsma et al., 2013) assists with capturing strongly held personal psychosocial preferences of older adults including residents living with dementia (Preference Based Living, 2020) and provides valuable information to care providers to not only understand their client preferences but also deliver customized person-centered care.

Residents living with dementia have their lives circumscribed by the condition (Kolanowski et al., 2006), and as our participants noted, it is further circumscribed by the capacity of their loved ones to care for them in the community. The personal and professional resources that carers in the community can avail themselves of are, for many, limited (Brodsky



& Cumming, 2010; Harkin et al., 2020) and our participants were acutely aware that although often reluctant, the only realistic option for many family carers is placing care-recipients into permanent care to properly meet the health needs of both members of the dyad.

Finally, the lives of people living with dementia are circumscribed by the resources that society is willing to expend on not just meeting their basic physical care needs, but also on providing them with a comfortable and dignified life. Given the growing number of people living with dementia, and the resources required to meet their care needs, the societal impact are expected to increase markedly over the coming decades (Committee for Economic Development of Australia, 2021; Winblad et al., 2016).

Participant responses in this study suggest that staffing arrangements are shaped by both the model of care maintaining a “homelike” environment as well as by the prevailing funding model. There is a growing body of research that has shown that people living with dementia experience better consumer rated quality of care outcomes in settings that are more intimate, less institutional, and more familiar (Gnanamanickam et al., 2019; Harkin et al., 2020). Although improving quality of care is a key goal of the institution, underpinning its model of care, funding is also a consideration. Funding models must accurately reflect the real world case-mix of residents in RACHs (Eagar et al., 2019). Recent initiatives such as the Australian National Aged Care Classification (AN-ACC) funding model aims to address this issue through provision of customized funding to RACHs based on the type of service and individual residents’ care needs (Department of health and aged care, 2022). But as the participants themselves note, it is important that funding models also reflect the changing of individual resident’s care needs over time.

Consistency in staff training, and strategies to promote high staff retention rates, are key practices to ensuring consistent reliable relationships between residents living with dementia and those who care for them. However, participants in the study recognized that several external factors could influence both practices. First, research has highlighted that Australian RACHs face considerable challenges in recruiting staff, with an expected shortfall of 110,000 by 2030 if current projections of need are realized (Committee for Economic Development of Australia, 2021). Aged care is labor intensive, and staff shortages are not limited to Australia (Frank & Weiss, 2012; Winblad et al., 2016). Overseas students undertaking training in Australia, often in health-related fields, can make welcome additions to the labor pool. This benefits both providers and students because they can practically deploy their newly acquired skills, and RACHs can avail themselves of a well-educated workforce. Indeed, RACH-1 and RACH-2 reportedly engaged a number of overseas students, and while they were highly regarded by colleagues, they also presented challenges. Care workers on student visas, as participants indicated, have conditions which limit their hours (20 hr per week) and duration of employment. They are also required to re-locate to regional areas at the completion of their studies. These conditions have, one participant commented, significant impacts upon hiring, training, retention of institutional knowledge and, of particular concern to this study, disrupt meaningful, established relationships with residents living with dementia.

Mindful of the vulnerability of residents to COVID-19, RACHs stopped volunteers coming onsite for long periods of

time during the pandemic. Although judicious from an infection control perspective, it further limited residents’ opportunities for social engagement. Providers have highlighted that border closures associated with COVID-19 have also exacerbated staff shortages (Knaus, 2021). In response, the Australian Government relaxed some visa work conditions to relieve staffing pressures (Department of Home Affairs, 2021), but the fact remains that staffing is a particular vulnerability in aged care; and the aging population and demand for RACH places in the coming decades will likely remain unless serious steps are taken to address it (Committee for Economic Development of Australia, 2021). Although increasing staff would seem like the most obvious way to increase carer presence, as we reflect on the results of this study, we can see that the issue is much more complex. Appropriate staffing levels may be necessary, but they are not sufficient to ensure effective carer presence. Additionally, there is some evidence from nursing presence literature that suggests a combination of education, training, and coaching strategies can assist with preparation of nurses by providing them knowledge, skills, and practical experience of using presence (Crocco et al., 2023; Kostovich & Clementi, 2014; Penque & Kearney, 2015). Doona et al. (1997) state that self-awareness, openness, flexibility, and willingness to embrace another person’s situation are key attributes (Anderson, 2007) that nurses need to develop to establish and practice presence. Nurses who participated in a structured educational intervention program (which covered definition, benefits for patients and nurse, and behaviors to practicing presence) reported increases in their preparedness and confidence in their ability to use presence in their professional practice (Crocco et al., 2023) posteducation intervention. Penque & Kearney (2015) reported that use of focused training including theory and intentional use of presence techniques with patients supported practicing presence and meaningful engagement with patients. While some care workers may have personal traits that support practicing presence as part of their routine practice, we believe that developing experience to practicing presence on an ongoing basis is key for sustainable practice of presence in busy and very demanding residential aged care settings. This could be facilitated through integration of reminders about practicing presence during routine workflow activities such as communication about being present with residents living with dementia during shift handovers, inclusion of being present concepts in continuous education programs and use of local champions as a role model to motivate peers to be present and meaningfully engage with residents living with dementia for successful implementation of care worker presence. Future studies should address these areas of research in the context of care workers.

Past research has suggested that making effective changes in workplace culture is often complicated, but it is easier when those that are the subject of the change are included in the process (Parmelli et al., 2011). Further when the workplace environment is properly understood and changes are implemented in an inclusive manner, benefits accrue to staff, residents, and family members (Koren, 2010; Lopez et al., 2013).

The competing demands of the role, to varying degrees, limit care workers opportunities for engaging meaningfully with residents. Although staff to resident ratios, particularly in relation to registered nurses, is a topic of considerable debate (Eagar et al., 2019; Royal Commission into Aged Care Quality and Safety, 2021) it is the care workers that are the

focus of this study. Residents, as participants attest, are very happy engaging with the care workers they see in their everyday lives. Participants highlighted that having some extra “hands on-deck,” even for a limited time, would increase the opportunities for meaningful engagement with residents living with dementia and reduce behaviors and psychological symptoms of dementia (BPSD). Future research should consider the impact of increased care worker presence on BPSD and quality of life in this population.

Our study has taken the first important step toward developing a good understanding of Australian care workers perspectives of being present while working with residents living with dementia. The study employed a mixed-methods approach using a comprehensive survey with follow-up interviews for further exploration of key topics raised by survey participants.

This study has some limitations. Because participants (care workers) were self-selected and only came from few (three) RACHs of a single aged care provider, the study findings may not provide a complete representation of the issues related to care worker presence with residents living with dementia in other aged care homes. The pilot and exploratory study design along with the challenges to recruitment during the pandemic resulted in small sample sizes for the survey responses and interviews. There is also a small possibility that data saturation may have not been achieved given the small sample size of interviewees and the complexity of the topics the study sought to explore. Seven out of eight interviewees were female. This may have implications of a gender bias in contextualizing or understanding the concept of being present. Additionally, aged care and dementia experience of participants were self-reported. As the data were collected from Australian RACHs, the applicability of study findings to international long-term care or other care settings (e.g., home care, hospital) is uncertain. These limitations indicate that the findings may not be representative or transferable to all RACHs. Large-scale studies are needed to address these study limitations and confirm transferability of findings to similar RACH settings nationally or internationally.

Our study provides evidence to suggest that care workers in RACHs perceive presence and its enablers such as meaningful engagement with residents living with dementia to be an important aspect of their role. Our findings suggest that care worker presence has the potential to contribute to both the physical and emotional health and well-being of residents living with dementia, and to the well-being of the staff that care for them. Regulatory bodies, governments, community groups, and RACHs need to collaborate and cooperate with each other to ensure residents living with dementia experience meaningful engagement and appropriate funding and resources are available to enable care workers in RACHs to be more present and provide person-centered care.

## Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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## Conflict of Interest

None.

## Data Availability

The datasets generated and/or analyzed during the current study are not publicly available because the participant consent form stated that only the research team would access the data. This study was not preregistered.

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## Author Contributions

John Swinton (Conceptualization [Lead], Formal analysis [Lead], Funding acquisition [Equal], Investigation [Lead], Methodology [Lead], Project administration—Supporting, Supervision [Lead], Writing—original draft [Lead], Writing—review & editing [Equal]). Srivalli Vilapakkam Nagarajan (Formal analysis [Supporting], Project administration [Supporting], Validation [Supporting], Writing—original draft [Lead], Writing—review & editing [Equal]). Mustafa Atee (Formal analysis [Supporting], Project administration [Supporting], Supervision [Supporting], Validation [Supporting], Writing—original draft [Supporting], Writing—review & editing [Equal]). Thomas Morris (Formal analysis [Equal], Project administration [Supporting], Supervision [Supporting], Validation [Supporting], Writing—original draft [Supporting], Writing—review & editing [Supporting]). Christopher Poulos (Conceptualization [Supporting], Formal analysis [Supporting], Funding acquisition [Equal], Investigation [Supporting], Methodology [Supporting], Project administration [Lead], Supervision [Lead], Writing—original draft [Supporting], Writing—review & editing [Equal]).

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