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Use of advance care directives for individuals with dementia living in residential accommodation: A descriptive survey

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Abstract

Background: End-of-life decision-making for individuals living with a dementia needs to be addressed because as dementia progresses, individuals need support to make decisions about their health care, living arrangements and end-of-life care changes. Advance care directives (ACDs) provide an opportunity for individuals living with a dementia to communicate their wishes about these important issues. **Aim:** The aim of this study was to understand how Australian registered nurses (RNs) use ACDs for individuals with a dementia living in residential accommodation. **Methods:** Two hundred and thirty eight RNs working in Australian residential accommodation were recruited via social media, professional organisations and organisations providing residential accommodation. Respondents completed an online survey delivered via Survey Monkey. **Findings:** 59.7% of respondents reported commencing discussions around ACDs within the first month of individuals living with a dementia relocating to residential accommodation. However, 42.4% never or rarely completed ACDs. Only 59.3% stated that ACDs for individuals living with a dementia were always or often regularly reviewed. 53.8% identified that ACDs were always adhered to when an individuals' circumstances changed. 62.6% felt that understanding among families about ACDs was sometimes, or often, a barrier to using ACDs. **Conclusion:** The implementation of ACDs in Australian residential accommodation for those living with a dementia remains sub-optimal. This study has demonstrated that ACD documentation and policies describing how they should be used exist, but gaps remain around the practical implementation of ACDs. Strategies to promote communication and collaboration between residential facilities, general practitioners and carers / families could also assist in providing cohesive, high quality care.

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Use of Advance Care Directives for Individuals with Dementia

Living in Residential Accommodation: A descriptive survey

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Abstract

Background: End-of-life decision-making for individuals living with a dementia needs to be addressed because as dementia progresses, individuals need support to make decisions about their health care, living arrangements and end-of-life care changes. Advance care directives (ACDs) provide an opportunity for individuals living with a dementia to communicate their wishes about these important issues.

Aim: The aim of this study was to understand how registered nurses (RNs) use ACDs for individuals living with a dementia within Australian residential accommodation.

Methods: Two hundred and thirty eight RNs working in Australian residential accommodation were recruited via social media, professional organisations and organisations providing aged care. Respondents completed an online survey delivered via Survey Monkey.

Findings: 59.7% of respondents reported commencing discussions around ACDs within the first month of individuals living with a dementia relocating to residential accommodation. However, 42.4% never or rarely completed ACDs. Only 59.3% stated that ACDs for individuals living with a dementia were always or often regularly reviewed. 53.8% identified that ACDs were always adhered to when the circumstances of individuals changed. 62.6% felt that understanding among families about ACDs was sometimes, or often, a barrier to using ACDs.

Conclusion: The implementation of ACDs in Australian residential accommodation for those living with a dementia remains sub-optimal. This study has demonstrated that ACD documentation and policies describing how they should be used exist, but gaps remain around the practical implementation of ACDs. Strategies to promote communication and collaboration between residential facilities, general practitioners and carers / families could also assist in providing cohesive, high quality care.

Summary of Relevance

Problem or Issue

As the population ages, dementia is a growing health issue. Over time, living with a dementia has an effect on the capacity of individuals' to independently ensure their life preferences are met. Writing an advanced care directive is one way in which individuals can record their wishes and preferences and ask families and health professionals to ensure these are adhered to when their capacity to do this independently is compromised.

What is Already Known

For individuals living with a dementia, developing an advanced care directive as soon as possible optimizes the potential to capture their wishes and ensure that their families and health professionals can enact their wishes. Despite various interventions, the writing of advanced care directives is sub-optimal internationally.

What this Paper Adds

Evidence is provided about the experiences of registered nurses in Australia using advanced care directives with individuals living with a dementia in residential accommodation. It emphasises areas of practice where gains could be made in using advanced care directives to capture and enact the wishes of individuals living with a dementia.

1. Introduction

In excess of 44 million people are estimated to have dementia globally (Alzheimer's Disease International, 2013). It is predicted that the prevalence of dementia will rise to 76 million by 2030 and 135 million individuals by 2050 (Alzheimer's Disease International, 2013). Dementia is a chronic, progressive neuro-degenerative illness characterised by a number of cognitive deficits involving memory impairment and general functioning (American Psychiatric Association, 2013). Dementia has an impact on many aspects of health and well-being. Individuals living with a dementia experience personality changes, memory loss, decline in cognitive functioning and a decrease in independence in everyday function (Nicholas, Bynum, Iwashyna, Weir, & Langa, 2014). Due to the substantial economic and societal impact of dementia, it is important that best practice management is implemented to optimise outcomes and resource allocation (Australian Institute of Health and Welfare, 2012; Guideline Adaptation Committee, 2016).

End-of-life decision-making is an important issue for individuals living with a dementia (Sampson et al., 2018). This is an important concern because as dementia progresses, the capacity of individuals to make decisions about their health care, living arrangements and end-of-life care diminishes (Beck, McIlpatrick, Hasson, & Leavey, 2017). Advance care planning (ACP) is a collaborative process involving health professionals, individuals and their carers / families. An ACP aims to record desired health care options and develop a plan to convey the wishes of individuals (Stewart, Goddard, Schiff, & Hall, 2011). These wishes may also be legally recorded in Advance Care Directives (ACDs)(de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2011; Stewart et al., 2011). ACDs, or living wills, are

essentially written instructions regarding an individuals' preferences around their end of life care (de Boer et al., 2011). For ACDs to be recognised as a legal document, individuals must have had sufficient decision-making capacity at the time of writing (Advance Care Planning Australia, 2016). ACPs can be undertaken by families in collaboration with individuals when their physical or mental health has compromised their capacity to write an ACD or as a wholly proxy record of the wishes of an individual (Advance Care Planning Australia, 2016). This clearly has implications for those with dementia, whilst in some cases individuals living with a dementia are screened for cognitive capacity, the evidence for the usefulness of this screening is equivocal (Bezzina, 2009; Caplan, Meller, Squires, Chan, & Willett, 2006). Such uncertainties relating to ACDs in individuals living with a dementia serve to demonstrate the importance of discussing and developing ACDs as soon as possible after the dementia is diagnosed.

When individuals living with a dementia relocates to residential accommodation it is essential that health professionals are made aware of existing ACDs, or that on admission information is sought to inform the development of an ACD or ACP. Any subsequent changes in an individuals' health status should trigger discussions about amending these documents based on the changing circumstances. There is also need for proper documentation of ACDs by the residential care nurses and clear strategies for communicating ACDs / ACPs to all health professionals involved in the delivery of care.

ACDs were first introduced to residential accommodation in Australia in 1993 (Meller & Caplan, 2009). By 2001, a systematic approach using an educational intervention strategy had been adopted to promote the uptake of ACDs with individuals living with a dementia and their families (Meller & Caplan, 2009).

Despite the potential advantages and various strategies to promote implementation, the uptake of ACDs is reported to be sub-optimal internationally (Poppe, Burleigh, & Banerjee, 2013; Sinclair et al., 2017; Yapp, Sinclair, & Kelly, 2018).

In an Australian study, a baseline audit found that none of the 533 older people living across six nursing homes had an ACD (Potter, Fernando, & Humpel, 2013). The Guideline Adaption Committee Clinical Practice Guidelines and Principles of Care for People with Dementia (2016) confirmed a lack of evidence based recommendations in this area. Indeed, these Dementia practice guidelines based their recommendations for ACDs on what was called 'practice points' derived only from expert opinion because evidence based recommendations were absent (Guideline Adaptation Committee, 2016).

2. Aim

This study sought to understand how registered nurses (RNs) use ACDs with individuals living with a dementia in Australian residential accommodation.

3. Methods

3.1 Design

This was a descriptive, cross-sectional, online survey of RNs working with individuals living with a dementia within residential accommodation across Australia.

3.2 Sample

The online survey was made available to RNs working in residential accommodation across Australia. RNs were included regardless of whether they

had a clinical, management, education or administrative role within residential accommodation services. The precise number of RNs working in residential accommodation at the time of the survey was not possible to determine.

An email inviting participation in the study was sent to aged care service providers (n=31) (public, private, for profit and not for profit) and key stakeholders (including; Department of Health & Ageing, Alzheimer's Australia, Aged Care Community Services Association, Aged Care Assessments Team, Dementia Collaboration Research Centre and Dementia Australia Training) across Australia. These groups were asked to disseminate information about the study to RNs within their organisations or groups. Additionally, study information was disseminated via email to personal networks, newsletters of professional organisations (Australian Journal of Dementia, Nurses & Midwifery Council, Nurses & Midwifery Association, Australian College of Mental Health Nurses) and social media (LinkedIn, Twitter and Facebook). This promotional information provided a direct link for potential participants to access the online survey.

Two reminder emails were sent to all initial contacts to increase response rates. At the same time, reminders were posted on social media sites.

3.3 Survey tool

As there was no pre-existing validated survey tool that addressed the objectives for this study, a new survey tool was developed by the investigators based on a comprehensive literature review and consultations with both survey and aged care experts.

The final survey tool consisted of 26 questions. The first 13 items asked about respondent demographics and their workplace setting. A further 8 items related to policy and practice about ACDs in the participants workplace. Three items asked

about participants' involvement and confidence in working with ACDs. Four of these items asked participants to rate statements on a four point Likert scale (1 - never to 4 – always) to indicate their impact on ACD implementation. The final two items asked about the barriers and enablers to ACD use in their workplace. These two items provided 10 factors which were rated by participants on a four point Likert scale (1 - never to 4 – always) to indicate their impact on ACD use. An 'other' response was included with an accompanying text box to provide participants with an opportunity to identify additional factors that impacted.

The online survey was pilot tested by 14 individuals, including RNs working in residential accommodation services and experts in survey design to test face validity. This pilot testing identified some issues with wording and formatting of response choices which were amended prior to the main data collection.

3.4 Data collection

The survey tool was delivered online using SurveyMonkey™ (2018) software. Invitations to participate included a direct link to the survey tool. The survey was open for a period of eight weeks. Reminder emails were sent and posts placed on social media to encourage response.

3.5 Data analysis

Data were downloaded from Survey Monkey™ (2018) into the Statistical Package for the Social Sciences (SPSS) version 21.0 (IBM Corp, 2012) for analysis. Data were cleaned and responses with significant missing data removed. Descriptive statistics, including frequencies, means, percentages, and standard deviations were calculated to describe the findings.

3.6 Ethical Considerations

This study was approved by the University of ##### Human Research Ethics Committee prior to the commencement of data collection (Approval No. ####/####).

4. Findings

4.1 Participants

Three hundred and eighteen respondents entered the survey, of which 80 responses (25.2%) were incomplete, leaving 238 responses for analysis. The demographics of respondents are outlined in Table 1. The majority of respondents were female (n=218, 91.6%) and most were aged over 50 years (n=166; 62.8%). Respondents had significant work experience, with most having 30 years or more experience as an RN (Mean 16 years) and 10-20 years' experience working in aged care (Mean 27 years).

4.2 Workplace Demographics

Although respondents worked in six Australian States / Territories, most reported working in NSW (n=167; 70.2%) (Table 2). The distribution of respondents across urban, regional, rural and remote areas likely reflects the workforce distribution in these areas. Most respondents reported working in not for profit services (n=146, 61.3%) and in a setting with a specialist dementia service (n=180, 75.6%).

Table 1: Participant demographics

Characteristic	n (%)
Gender	
Female	218 (91.6)
Age	
21 to 30yrs	13 (5.6)
31 to 40yrs	29 (12.6)
41 to 50yrs	44 (19.0)
51 to 60yrs	108 (46.8)
61 yrs and over	37 (16.0)
Highest Qualification	
Bachelor's Degree	84 (35.3)
Diploma	14 (5.9)
Hospital certificate	36 (15.1)
Post Graduate Diploma/ Certificate	74 (31.1)
Master's Degree	30 (12.6)
Employment Classification	
Registered Nurse	106 (44.5)
Manager	92 (38.7)
Advanced Nurse	40 (16.8)
Experience As Registered Nurse	
0-10yrs	46 (19.3)
11-20yrs	27 (11.3)
21-30yrs	43 (18.1)
31-40yrs	95 (39.9)
41-46yrs	26 (10.9)
Experience In Aged care	
0-10yrs	93 (39.2)
11-20yrs	71 (30.0)
21-30yrs	51 (21.5)
31-40yrs	19 (8.0)
41-43yrs	3 (1.3)

Table 2: Workplace demographics

Workplace Characteristic	n (%)
State/ Territory	
Australian Capital Territory	5 (2.1)
New South Wales	167 (70.2)
Queensland	29 (12.2)
Victoria	26 (10.9)
South Australia	8 (3.4)
Western Australia	3 (1.3)
Practice Location	
Urban/ Metropolitan	107 (45.0)
Regional	85 (35.7)
Rural	43 (18.1)
Remote	3 (1.3)
Size of Service (Bed Licences)	
0-50	59 (24.8)
51-100	89 (37.3)
101-199	64 (26.9)
200+	21 (8.8)
Multiple Sites	4 (1.7)
Other	1 (0.4)
Funding of Service	
For profit	41 (17.2)
Not for profit	146 (61.3)
Funded by State/ Territory government	47 (19.7)
Unsure	4 (1.7)
Specialist Dementia Services	
Yes	180 (75.6)
No	51 (21.4)
Unsure	7 (2.9)

4.3 Introducing ACDs

Whilst three quarters respondents (n=179; 75.2%) reported having policies in their workplace on ACDs, several respondents indicated that they were unsure if such policies existed (n=18; 7.6%). One hundred and forty two respondents (59.7%) identified that they commenced discussions with individuals living with a dementia around ACDs within the first month of individuals relocating to residential accommodation (Table 3). Most of these discussions were reported to be initiated by RNs (n=178; 74.8%), with fewer initiated by care managers / care coordinators (n=19; 8.0%), directors / deputy directors of nursing (n=7; 2.9%), general practitioners (GPs)(n=8; 3.4%) or families (n=7; 2.9%). Many respondents indicated that individuals living with a dementia and/or families are always (n=142; 59.7%) and often (n=70; 29.3%) involved in discussions about the ACDs. There was a mixed response about the use of formal face-to-face education sessions, printed brochures and/or DVDs about ACDs, with 51.6% (n=123) indicating that such resources were rarely or never provided.

Table 3: Timing of ACD discussion

RN discussions about ACD	n (%)
First month after relocation to residential accommodation	142 (59.7)
Between 2-6 months after relocation into residential accommodation	37 (15.5)
Between 6-12 months after relocation to residential accommodation	7 (2.9)
When the physical health of an individual deteriorates	32 (13.4)
When the mental health of an individual deteriorates	3 (1.3)
Never	17 (7.1)

4.4 Completing ACDs

Despite the significant role RNs play in initiating ACD discussions, just under half of the respondents reported that they never (n=37; 15.5%) or rarely (n=64; 26.9%) assisted individuals living with a dementia and/or their families to complete ACDs. Only 14.3% (n=34) of respondents described GPs as always attending face-to-face meetings with individuals living with a dementia and/or families about ACDs. Some 59.6% (n=142) respondents stated that GPs rarely or never attended such face-to-face meetings.

Most respondents indicated that the outcomes from discussions about ACDs with individuals living with a dementia and/ or families are always (n=143; 60.1%) or often (n=58; 24.4%) recorded on paper or online. Over half of the respondents (n=129; 54.2%) reported that individuals living with a dementia and/or their families are always given a form by the facility to structure the ACDs. However, 48 (20.2%) respondents reported that this never or rarely occurred. Most respondents (n=173; 72.7%) agreed that the ACDs used in their workplace were easy to complete. The majority of respondents also described that facility staff often (n=80; 33.6%) or always (n=96; 40.3%) initiate follow-up with families regarding the return of completed ACDs.

There was a lack of agreement amongst respondents as to whether GPs sign the ACDs in their workplace. Whilst 39.9% respondents (n=95) described GPs as always signing ACDs, many respondents identified that in their workplace GPs rarely (n=51; 21.4%) or never (n=30; 12.6%) signed the ACDs.

Although most respondents indicated that completed ACDs are always (n=157; 66.0%) accessible online or printed by RNs, a small group of respondents indicated that RNs were rarely (n=13; 7.6%) or never (n=21; 8.8%) able to access

ACDs. In terms of the accessibility of ACDs to individuals living with a dementia and/or families, most respondents indicated a copy of the ACDs was often or always provided to individuals or their families (n=148; 62.2%) and that completed ACDs are often or always accessible by individuals and their nominated family representatives in within the facility (n=195; 81.9%).

4.5 Content of ACDs

The frequency of various issues being included in ACDs is presented in Table 4. As can be seen from this table, whilst most respondents reported that each of these issues was often included a number of respondents reported that the issues were rarely or never addressed.

Table 4: Content of ACDs

Characteristics	Never n (%)	Rarely n (%)	Sometimes n (%)	Often n (%)	Mean
Artificial Feeding/ Hydration	10 (4.2)	9 (3.8)	25 (10.5)	193 (81.4)	3.69
End of Life Considerations	8 (3.4)	11 (4.7)	31 (13.2)	184 (78.6)	3.67
Palliative Care Wishes	7 (3.0)	12 (5.1)	38 (16.0)	180 (75.9)	3.65
Pain Management Choices	8 (3.4)	14 (5.9)	35 (14.8)	179 (75.8)	3.63
Wishes Around Hospital Transfer	7 (3.0)	16 (6.8)	41 (17.4)	172 (72.9)	3.60
Use of medications in acute illness	11 (4.6)	18 (7.6)	41 (17.3)	167 (70.5)	3.54
Things that matter most to residents	13 (5.6)	20 (8.5)	34 (14.5)	167 (71.4)	3.52
Funeral Options	18 (7.6)	17 (7.2)	37 (15.7)	164 (69.5)	3.47

4.6 Reviewing ACDs

Just over half of respondents (n=141; 59.3%) stated that ACDs for individuals living with a dementia were always or often reviewed at regular intervals. The majority of respondents, however, stated that ACDs for individuals living with a dementia were always (n=82; 34.5%) or often (n=104; 43.7%) reviewed when the

circumstances or health of individuals changes. RNs were identified by respondents as most frequently initiating reviews of ACDs for individuals living with a dementia (n=152; 63.9%). Few respondents identified that reviews of ACDs were initiated by either GPs (n=12; 5.0%) or families (n=6; 2.5%).

4.7 Enacting ACDs

When asked whether ACDs are adhered to when the circumstances or health of individuals changes, 53.8% (n=128) respondents stated always, whilst 18 (7.6%) respondents described that they were never or rarely adhered to.

Most respondents identified that families want to follow ACDs when the circumstances or health of individuals changes (n=143; 60.1%). However, 26.1% respondents (n=62) identified that when the circumstances or health of individuals changes families often do not want to follow ACDs. Most respondents (n=154; 64.7%) stated that the wishes of families rarely or never override established ACDs.

4.8 Knowledge and Confidence

When asked how confident they felt in assisting individuals living with a dementia and/or families to complete ACDs, most respondents reported feeling confident (n=91; 38.2%) or very confident (n=82; 34.5%). However, some 18 respondents (7.6%) reported not feeling confident in this role.

Most respondents (n=110; 46.2%) reported that they felt that they had adequate knowledge about ACDs for those with dementia. Only 66 respondents (27.7%) reported a high level of knowledge and 12 respondents (5.0%) reported insufficient knowledge.

4.9 Barriers and Facilitators in the use of ACDs

There was limited agreement about the barriers to ACD use for individuals living with a dementia living in residential accommodation (Table 5). The only issue that most respondents felt was sometimes or often a barrier to ACDs use was perceptions / understandings of families about ACDs (n=142; 62.6%). For all other issues, more than half of the respondents (59.5%-78.4%) described them as never or rarely a barrier to ACD use.

In contrast, most respondents (80.6%-60.8%) agreed that all of the identified facilitators sometimes or often enhanced ACD use. Over three quarters of respondents felt that workplace support (n=183; 80.6%), confidence among RNs (n=177; 78.0%) and knowledge among RNs (n=178; 78.5%) sometimes or often facilitated the use of ACDs.

Table 5: Barriers and Facilitators in the use of ACDs

	Never n (%)	Rarely n (%)	Sometimes n (%)	Often n (%)	Mean
Barriers					
Family perceptions/ understandings	9 (4.0)	76 (33.5)	120 (52.9)	22 (9.7)	2.68
Nurses Knowledge about ACDs	41 (18.1)	94 (41.4)	73 (32.2)	19 (8.4)	2.31
Time to Complete	52 (22.9)	79 (34.8)	77 (33.9)	19 (8.4)	2.28
Legal Implications	43 (18.9)	97 (42.7)	71 (31.3)	16 (7.0)	2.26
Confidence in using ACDs	50 (22.0)	99 (43.6)	63 (27.8)	15 (6.6)	2.19
Scope of practice	47 (20.7)	106 (46.7)	58 (25.6)	16 (7.0)	2.19
GP Support for ACD's	62 (27.3)	85 (37.4)	61 (26.9)	19 (8.4)	2.16

Facilitators					
Workplace Support for ACD's	94 (41.4)	70 (30.8)	44 (19.4)	19 (8.4)	1.95
Policy Availability	104 (45.8)	74 (32.6)	32 (14.1)	17 (7.5)	1.83
Workplace support for ACDs	9 (4.0)	35 (15.4)	85 (37.4)	98 (43.2)	3.20
Nurses Confidence in using ACDs	6 (2.6)	44 (19.4)	98 (43.2)	79 (34.8)	3.10
Nurses Knowledge about ACDs	6 (2.6)	43 (18.9)	100 (44.1)	78 (34.4)	3.10
GP support for ACDs	11 (4.8)	47 (20.7)	91 (40.1)	78 (34.4)	3.04
Policy Availability	18 (7.9)	42 (18.5)	82 (36.1)	85 (37.4)	3.03
Time to complete	13 (5.7)	50 (22.0)	97 (42.7)	67 (29.5)	2.96
Scope of practice	10 (4.4)	54 (23.8)	100 (44.1)	63 (27.8)	2.95
Family perceptions / understandings	6 (2.6)	62 (27.3)	103 (45.4)	56 (24.7)	2.92
Legal Implications	14 (6.2)	75 (33.0)	86 (37.9)	52 (22.9)	2.78

5. Discussion

Given that most of the related literature is published from studies undertaken within the USA and Europe (Beck et al., 2017), this was an important study for understanding the use of ACDs in residential accommodation within Australia. A recent international literature review on the topic reiterated the lack of uptake by individuals living with a dementia for writing ACDs, even when specific quality initiatives aimed at improving this were implemented (Beck et al., 2017; Jethwa & Onalaja, 2015). Over three quarters of respondents felt they had sufficient, or higher, levels of knowledge about and confidence in the use of ACDs which was a positive finding and reflected a high level of awareness about the importance of ACDs for individuals living with a dementia living in residential accommodation. This finding could reflect the concerted efforts in Australia by various groups to promote awareness of ACDs. These resources were developed for use by wider population groups (NSW Office for Ageing NSW Trustee and Guardian and NSW

Public Guardian, ND) and targeted for individuals living with a dementia and their families (Alzheimer's Australia, ND) and information help sheets and interactive tools to help consumers, families and practitioners develop and use ACDs. It was reassuring that findings demonstrated that most respondents reported that individuals living with a dementia and / or their families were always or often involved in discussions to develop an ACD. However, the 11% who did not perceive that clients and consumers were not involved in discussions to develop ACDs should not be ignored. If we are to provide person-centered care, it is vital that strategies are developed to ensure individuals living with a dementia and family carers are never excluded from discussions around end of life care.

A range of potential solutions to address the short comings in the use of ACDs were suggested in the findings from this study, including the implementation of work based education programmes. Other studies have similarly found that role play activities were successful for improving the use of ACDs (Herrington., 2011) and could be replicated more widely. As only just over half of the respondents had participated in education about ACDs, this represents an area for practice improvement and focus for future professional education.

The content of future education and role play sessions would be informed by the findings from this study and address the gaps identified in clinical practice by RNs working in residential accommodation. In particular, improving the findings from this study that less than half of respondents never initiated discussions about ACDs with individuals living with a dementia or their families or involved GPs in this discussion because only 14% of respondents reported GPs being present. Previous literature suggests that GPs may not recognise dementia as a terminal condition which could contribute to them not recognising the importance of ACDs

for this group (Beck et al., 2017; Luckett et al., 2017; Pond et al., 2018). It is important to explore in more detail why GPs have this perception and their current management strategies for individuals living with a dementia as the views of GPs have so far been largely overlooked in studies exploring ACD use (Beck et al., 2017; Pond et al., 2018).

In this study, nearly two thirds of respondents reported that families do not follow the ACD when the health of individuals living with a dementia changes. This concurs with the findings of Shanley et al. (2011) who identified that, in many cases, families are concerned when a deteriorating individual is not transferred to an acute care setting. This is somewhat in contrast to previous literature which highlights the positive impact of open communication with families around care wishes and future prognosis that accompanies the ACD development (Johnson, Singer, Masso, Sellars, & Silvester, 2015; Stewart et al., 2011). These findings highlight the need to ensure that ACD development is accompanied by open and honest communication between health professionals and families around the implications of care wishes and future care. This is important work for RNs to undertake to reduce the distress the experienced by families who feel unable to make difficult decisions on behalf of individuals living with a dementia even when there is an ACD explicitly stating the wishes of individuals. Governments have a role to play in managing the legal processes around ACDs and cultural shifts are needed to enhance acceptance of the wishes of individuals recorded in ACDs as being legitimate even when the cognitive capacity of an individual is compromised. Additionally, the importance of the specific needs of families from culturally and linguistically diverse communities may be different and further work is required to

understand how cultural influences impact on end of life care wishes (Shanley et al., 2009).

Future research should include qualitative investigations to better understand why the factors which promote and prevent the use of ACDs in residential accommodation occur. Another important extension of this study is with community practitioners to understand how we can better enable individuals living with a dementia as soon as dementia is recognised to develop ACDs with their families (Pond et al., 2018). This work could reduce the need to rely on proxy views of families about the wishes of individuals living with a dementia with advanced cognitive impairment and reduced capacity for decisions about healthcare treatments if their health deteriorates. The study found that three quarters of respondents had workplace policies and procedures in place for ACDs so our focus now needs to be on improving the implementation of these policies and procedures by RNs working in residential accommodation with individuals living with a dementia and their families.

Limitations

This study used an investigator developed tool to capture the current experiences of RNs working in residential accommodation around ACD use. As such the data was both descriptive and self-report. While the face and content validity of the tool were evaluated prior to data collection no formal psychometric analysis was conducted.

Given the potential numbers of RNs employed in residential accommodation, the sample size was small. However, the recruitment of participants from various residential accommodation settings across Australia increases the diversity of

responses and provides a level of confidence that the data provides a description of current experiences in this setting.

This study was exploratory and provided new insights not previously available from RNs about their use and implementation of ACDs with individuals living with a dementia in residential accommodation in Australia. Future research will build on this new knowledge to explore the issues raised by this work.

6. Conclusions and relevance to practice

As the global population ages and the prevalence of dementia continues to rise, research on ACDs with individuals living with a dementia continues to be crucial for providing effective healthcare and ensuring the best quality of life is promoted for individuals living with a dementia and their families. This study provides a deeper understanding of RNs experiences in developing and implementing the ACDs for individuals with a dementia in residential accommodation. It highlights areas of practice where strategies could improve the application of ACDs and the quality of health care provided.

Future initiatives to implement the use of ACDs need to actively involve practitioners in knowledge translations strategies to ensure that the use of ACDs becomes common practice. Future initiatives by aged care organisations need to trial strategies which provide role modelling activities where practitioners practice challenging conversations with individuals living with a dementia and their families to develop an ACD and amend existing ones when the circumstances and health needs of individuals change. The findings from this study demonstrated that ACD documentation and policies describing how they should be used exist but the practical implementation of ACDs is where the gaps lay. If future research and

quality improvements in the area of ACDs focus on enabling practitioners to have difficult conversations about developing a new ACDs or amending existing ACDs would benefit individuals living with a dementia, family carers and practitioners. The quality of life of individuals living with a dementia would be enhanced by their end-of-life wishes being adhered to through the enactment of their ACD, family carers would experience less distress by knowing they are doing their best for individuals living with dementia and practitioners would have enhanced work satisfaction by being enabled to implement best practice care.

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