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Care to the end. A retrospective observational study of Aged Care Facility residents transferred to hospital in the last day of life.

Abstract:

Aim: Whilst transfer of Aged Care Facility ACF) residents to an acute hospital is sometimes necessary, for those at end-of-life this can cause fragmented care and disruption. This study explores the characteristics of ACF residents transferred to hospital in the last 24hours of life and factors that may influence this decision, including access to medical review, advance care planning and pre-emptive symptom management prescribing; an area not previously researched.

Methods: A retrospective observational audit of ACF residents transferred to a metropolitan hospital between 2012 to 2017 who died within 24 hours of transfer.

Results: 149 patients met the criteria. The median age was 87, 63(42%) were male. 83(56%) were transferred 'out-of-hours', the majority (71%) having no medical review in the 24hours prior. 43(29%) died within 4hours of arrival. The commonest reasons for transfer were dyspnoea (46%) and altered conscious state (32%), and commonest cause of death was pneumonia (37%). Some form of advance care planning documentation was available in 48%. Of the 86 (58%) patients who required injectable opioid for symptom management in hospital, only 7(8%) had this pre-emptively prescribed on their ACF medication chart.

Conclusions: Appropriate decision making around hospital transfers and end-of-life care for ACF residents may be influenced by access to professionals able to diagnose dying and access to appropriate symptom management medications. Advance care planning is important, but often requires the aforementioned to be enacted. Further research is needed to better inform how we can identify and meet the end-of-life care needs of this cohort.

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INTRODUCTION

Residential aged care facilities (RACF) play an important role in the care of people at the end of life. Fifty-four percent of Australians die in hospitals and 32 percent die in residential care (1). As such, it is critically important that RACFs are able to identify and manage end-of-life care well. The Grattan Institute's report, *Dying Well* highlighted that as more people die in older age, there is greater opportunity to help people plan for dying in home or home-like environments, "supported by family, friends and effective services"(1 p2).

Despite this, many aged care residents are transferred to hospital in their final days of life (2, 3). This results in fragmentation of care at end-of-life, with care provided by unfamiliar medical and nursing staff in an unfamiliar environment. Reasons for transfer to hospital are complex and varied, and include patient/family wishes, clinician opinions, facility resources and capacity to provide the care required (4-6). Advance care planning (ACP) is promoted as important for ensuring the person's preferred care is provided, reflecting the intersection of personal values and medical conditions, and has been shown to improve end-of-life care and satisfaction for both patients and their families (7). However, ACP documents are only one part of the equation.

This study aimed to identify and describe factors relating to residents of RACFs who were transferred to hospital within the last 24 hours of life. The presumption was that these patients were not expected to survive at the time of transfer. By better understanding some of the factors that contributed to transfer of this cohort,

there is potential for identifying opportunities to improve care within RACFs and avoiding unwanted or non-beneficial transfers for this vulnerable population.

Method

This was a retrospective cross-sectional study using patient file audit, and approved as a quality improvement audit by Northern Health Research Ethics. Participants were patients transferred from RACFs to an outer metropolitan Emergency Department (ED) during a five-year period (2012-2016 inclusive), and who died within 24 hours of arrival. The audit was of patient hospital files only. This included information contained within correspondence sent from the transferring RACF, as well as ambulance notes, but excluded aged care facility records. The health service has 49 facilities within its catchment area, representing about 2800 residents. Demographics, medical conditions, reason for and time of transfer, pre-hospital medical review and cause of death (ICD-10) were collected (table 1). Availability of ACP documents and end-of-life care needs following transfer were also recorded, including: any form of advance care planning documentation; patient appointed substitute decision maker (SDM); anticipatory prescription of symptom-management medications on the RACF medication chart; and administration of symptom management medications in hospital. An ACP document for the purpose of this study was defined as: (i) documentation of a resident's instructions, preferences or values for future medical treatment, written by the resident; or (ii) a statement of instructions, preferences or values written on behalf of the resident, usually by a family member. This audit occurred prior to introduction of the Victorian *Medical Treatment Planning and Decisions Act (2016)* that re-defined ACP document terminology.

Descriptive statistical analysis used STATA statistical analysis software, version 15.1; with a two-sided p-value less than 0.05 indicated statistical significance. Chi-squared tests and Fisher exact tests were used to test for differences between groups for categorical data. Continuous variables were assessed for normality using

parametric tests (Student's t-test) and/or non-parametric tests (Mann-Whitney) where appropriate.

Results

One hundred and sixty-two potential participants were identified by the hospital records department. Thirteen were excluded as time to death was more than 24hours, giving a final number of 149 participants, who transferred from 45 facilities (range 1-10 transferred residents per facility) out of the 49 facilities in the area. Table 1 describes the demographic characteristics. It was a culturally diverse cohort with 46 percent (n=68) being of non-English speaking background (NESB) and a median age of 87.6 years. On admission to ED, the patient's preferred language is recorded in their medical file. Where the patient's preferred language is other than English, they were identified in this study to be from a non-English speaking background (NESB), recognising that they may also speak some English as well. The high percentage of NESB patients is consistent with the demographics of the area in which the ED is located, where a little over 40 percent of residents are born overseas and almost 50 percent speak a language other than English at home (8). Forty-two percent of participants (n=63) were male. Patients had a high median Charlson comorbidity score of 7 (Interquartile range: 5 to 8). Because of this high number of comorbidities, it is difficult to define a single major illness for many patients, hence the emphasis on numbers of co-morbidities. A minority of 23 (15.4%) patients had a malignancy comorbidity and only 3 (2.0%) were documented to have cancer as

contributing to their death. The median time to death from ED arrival was 8 hours. The distribution of times to death are shown in Figure 1 and it can be seen that many of the transferred patients died within a few hours after arrival in the Emergency Department.

Approximately half (n=83; 55.7%) of patients were transferred outside business hours (defined as Monday to Friday 9am – 5pm) and the majority (N106; 71.1%) had no documented evidence in their file, including transfer correspondence, of having seen a medical practitioner in the 12 hours prior. The most frequent reason for transfer was acute shortness of breath in 68 cases (45.6%), followed by altered conscious state in 47 cases (31.4%). This correlated with the most common causes of death, using ICD-10 classification: diseases of the respiratory system (N=62; 41.6%) most of which were pneumonia (n=55; 88.7%); followed by diseases of the circulatory system (N=34; 22.8%). One hundred and forty-two patient deaths (95.3%) were considered expected by the hospital, and one case was referred to the coroner.

Advance care planning documents

ACP documents were available for 62 patients (41.6%), the vast majority (n=52; 85.2%) having been completed by a substitute decision maker. If an ACP document was available, transfer to ED was consistent with or not stated in the ACPin 80.6% cases (n=50). In the 12 cases (8.1%%) where transfer was not consistent with the ACP document, only one case had the reason for this discrepancy documented. Only 35 residents (23.5%) had documentary evidence of an appointed substitute medical decision maker, known as the Enduring Power of Attorney Medical (MEPOA).

End-of-life care

Regarding provision of end-of-life care, 91/149 (61.0 %) patients required injectable opioids in hospital to manage symptoms. Of these, only 7/91 (8.0%) had anticipatory PRN injectable opioid prescribed on their RACF drug chart. Benzodiazepines were

required by 49/149 patients (33%) for symptom management, with only 7(15%) of these having anticipatory PRN benzodiazepine prescribed on their RACF drug chart. The presence of an ACP document was associated with a higher likelihood of having anticipatory prescribing for symptoms on the RACF drug chart (p=0.023) (see Table 2). Of interest, only 1 (8%) of the 12 patients who had an ACP indicating they did not want transfer to hospital (ie- transfer to ED was against their documented ACP), had anticipatory prescribing of either opioid or benzodiazepine on their RACF drug chart for requested palliative care in the event of deterioration.

Discussion

This study highlighted some of the issues surrounding provision of care towards end-of-life for residents in RACFs. In this study the residents transferred to ED, and who subsequently died within 24 hours, presented with an acute and distressing change in medical condition, often shortness of breath or altered conscious states, leading to rapid death following transfer. In general, these were not patients being transferred for gradual and progressive decline over weeks to months, a common pattern of dying in older people (9, 10), where there is more time to make decisions and put in place resources for end-of-life care. Whilst these patients made up only a small minority of the total number of visits by RACF residents to the study hospital's ED for assessment (149/ 28349; 0.5%), it should be noted that they did make up a significant number of RACF residents who ultimately died in hospital (149/505; 30%) over the 5 year study period. Further this does not include the number of patients who died in ambulances during transfer, and may be an underestimate.

Advance care planning has been shown to reduce hospitalisation rates from nursing home by 9-26% (11). Despite this, Australia wide, 52% of aged care facility residents have no ACP document (12). The population serviced by this hospital is culturally

diverse, with a high incidence of poor health literacy and people whose preferred language is not English (8). Research has identified cultural difference in uptake of ACP and acceptance of treatment limitation (13-15)**.** Low health literacy has also been associated with lower acceptance of ACP and treatment limitation (1, 16)**.** Perhaps this is reflected in the low rates of ACP documentation of 42% seen in this study. However, potential inclusion bias in this cohort may mean that it does not accurately reflect the actual rate in the RACFs of the area. It should be noted that for 80% of transferred patients, this transfer was not inconsistent with their advance care planning document; advance care planning can also be for the purposes of requesting more or maximal medical treatment, rather than for limiting treatment.The difficulties of applying ACP documents at a time of resident deterioration has been well reported and was apparent in this study (17, 18). Whilst the transfer in the majority of cases to the acute hospital was technically 'in keeping' with the documented ACP, and recorded as such in our data, many of the ACPs contained comments along the lines of "I would like comfort care in the facility if it is felt I am dying and not likely to recover". An inference can be made that the challenge in applying this depends on 'who' has the skills to make the diagnosis of 'dying'? Many residents may have been transferred in order to obtain this skilled medical assessment and to assess the possibility of reversing the deterioration. This means that those who would have wanted to remain in the RACF if dying,unfortunately then miss the opportunity to have their wish to die in their RACF, which is their home. Indeed, the majority of patients in this study did not have a medical review in the 12 hours prior to transfer, perhaps reflecting the very rapid clinical deterioration seen, and the lack of timely access to skilled clinicians able to determine if there was a reversible deterioration for which the patient would have wanted treatment, or whether the patient was not expected to survive. Lack of availability of medical review prior to transfer has previously been demonstrated to increase emergency department use (4) and may represent a potential area for improvement, and thus facilitate provision of care more consistent with a resident's ACP documentation, should they want to avoid transfer, if dying.

A further issue that was highlighted in this study was the difference between a hospital and an RACF in providing timely access to medications for managing symptoms when a resident is dying. Only a small minority of the patients who received symptom management medications in hospital had ready access to this in their RACF (ie- anticipatory medications were already prescribed on their RACF medication chart) even if dying had been diagnosed. The overwhelming majority of aged care facilities serviced by this hospital do not have a medication 'imprest'. This means that once a medical practitioner prescribes medications, these need to be dispensed and delivered by an external pharmacy before they can be administered. Practically, this process takes several hours which is an unacceptable delay to treating suffering being experienced by an imminently dying person in distress. If the prescription is written after-hours, this delay may be well over 12 hours. Knowing that the median time to death of this cohort of patients was 8 hours, this is an issue that needs addressing. In this cohort of patients who have deteriorated very rapidly, transfer to hospital may currently be the only way to ensure appropriate access to symptom management medications at end-of-life. As mentioned previously, residents who had an ACP document were more likely to have anticipatory prescribing in the aged care facility, again reinforcing the benefits of ACP for this cohort. However, this preparation for palliative care and for dying was sometimes lacking for patients who had requested palliative care in the event of deterioration,

Of the 62 patients who had an ACP document, 12 (19.4%) were transferred to hospital against the directions within their document. The retrospective nature of this study made determining the rationale for this discrepancy difficult to determine. Given 91% of patients transferred against their ACP had no anticipatory symptom management prescribing, it could be hypothesised that at least one factor leading to transfer may be lack of timely access to these medications in the event of rapid deterioration, making a resident's preference to die in their RACF difficult to honour. It is also possible that staff at the residential homes felt ill-equipped to manage dying

patients, be that through: lack of skill to diagnose dying; difficult symptom management, complex care needs or educational gaps (19).

Appropriately, there is an increased focus on advance care planning by residents of RACFs, however, many residents will already lack capacity to complete an ACP document by the time they are admitted to the facility. Forward planning is particularly important in the event of rapid deterioration in a resident's medical condition, as seen in this patient cohort. However, ACP alone is not sufficient to prevent a resident's unwanted transfer to hospital at end-of-life. Several other factors must also fall in to place, namely: rapid access to clinicians skilled to diagnose the reason for deterioration and to diagnose dying; staff skilled at managing end-of-life care; anticipatory prescribing and timely access to comfort care medications; and effective communication about dying with family members both prior to and during deterioration. Future research is needed to explore these factors and barriers further.

Limitations of this study include lack of generalisability - a single centre which services a culturally diverse demographic. The variability of resources available in aged care facilities, including access to emergency medical review, also limits generalisability. Being a retrospective file audit, determining the rationale for transfer compliance with ACP documents is dependent on the quality of documentation which is known to be incomplete. It was also difficult to interpret the application of some ACP documents retrospectively, potentially resulting in errors in allocation. Finally, this research was only assessing residents who were transferred to hospital and who died within 24 hours; for a complete picture, research involving residents who are not transferred at end of life should be included, together with a comparison of those who were transferred but did not die within this time frame.

Conclusion

A small, but significant number of RACF residents were transferred to the hospital emergency department in the last 24 hours of their life. Thisstudy identifies a number of requirements for dying patients to remain in the aged care facility: skilled and timely assessment of deterioration; skilled management of dying; skilled communication with family; and timely access to medications for management of symptoms.

These residents, whose health deteriorates rapidly, are likely to always represent a challenging cohort for providing best end-of-life care within RACFs, if that is the patient's preference. This is a vulnerable patient cohort for whom the aged-care-facility is their home. Like those who live in their own homes, and prefer to die in their own homes, these residents deserve the best of end-of-life care within the aged care facility if this is their preferred location of death.

Bibliography

1. Volandes A, Paasche-Orlow M, Gillick M, Cook E, Shaykevich S, Abbo E, et al. Health literacy not race predicts end-of-life care preferences. Journal of Palliative Medicine. 2008;11(5):754-61. DOI: 10.1089/jpm.2007.0224
2. Menec V, Nowicki S, Blandford A, Veselyuk D. Hospitalizations at the end of life among long-term care residents. Journal of Gerontology A Biol Sci Med Sci. 2009;64A(3):395-402. doi:10.1093/gerona/gln034
3. Temkin-Greener H, Zheng N, Xing J, Mukamel D. Site of death among nursing home residents in the united states: changing patterns 2003-2007. Journal of the American Medical Directors Association. 2009;14(10):741-8. doi.org/10.1016/j.jamda.2013.03.009
4. Dwyer R, Stoelwinder J, Gabbe B, Lowthian J. Unplanned transfer to the emergency departments for frail elderly residents of aged care facilties: a review of patient and organisational factors. Journal of the American Medical Directors Association. 2015;16(7):551-62. doi.org/10.1016/j.jamda.2015.03.007
5. Houttekier D, Vandervoort A, Van den Block L, Van der Steen J, Stichele R, Deliens L. Hospitalizations of nursing home residents with dementia in the last month

of life: Results from a nationwide survey. Palliative Medicine. 2014;28(9):1110-7. doi: 10.1177/0269216314535962
6. Trahan L, Spiers J, Cumming G. Decisions to Transfer Nursing Home Residents to Emergency Departments: A Scoping Review of Contributing Factors and Staff Perspectives. Journal of the American Medical Directors Association. 2016; 17(11):994-1005. doi.org/10.1016/j.jamda.2016.05.012
7. Detering K, Hancock K, Reade M, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ. 2010;340(7751):c1345. doi.org/10.1136/bmj.c1345
8. Australian Bureau of Statistics. 2016 Statistics Quickstats: Whittlesea demographics. https://quickstatscensusdataabsgovau/census_services/getproduct/census/2016/quickstat/LGA27070?opendocument (accessed 21/07/202). 2016.
9. Oliver D. Progressive dwindling, frailty, and realistic expectations. BMJ. 2017;358(8120):j3954. doi.org/10.1136/bmj.j3954
10. Lynn J, Adamson D. Living well at the end of life: Adapting health care to serious chronic illness in old age. RAND Corporation, California. 2003;https://www.rand.org/pubs/white_papers/WP137.html.
11. Martin R, Hayes B, Gregorevic K, Lim W. The effects of advance care planning interventions on nursing home residents: A systematic review. Journal of the American Medical Directors Association. 2016;17(4):284-93. doi.org/10.1016/j.jamda.2015.12.017
12. Buck K, Detering K, Sellars M, Sinclair C, Whilte B, Kelly H, et al. Prevalence of advance care planning documentation in Australian health and residential aged care services. Advance Care Planning Australia, Melbourne. 2019;https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/report-national-acd-prevalence-study-2019.pdf.
13. Hayes B, Fabri A, Coperchini M, Parkar R, Austin-Crowe Z. Health and death literacy and cultural diversity: insights from hospital-employed interpreters. BMJ Supportive & Palliative Care. 2017;10:e8. doi:10.1136/bmjspcare-2016-001225
14. Yap S, Chen K, Detering K, Fraser S. Exploring the knowledge, attitudes and needs of advance careplanning in older Chinese Australians. Journal of Clinical Nursing. 2017;27:3298-306. DOI: 10.1111/jocn.13886
15. Ohr S, Jeong S, Saul P. Cultural and religious beliefs and values, and their impact onpreferences for end-of-life care among four ethnic groups ofcommunity-dwelling older persons. Journal of Clinical Nursing. 2016;26:1681-9. doi: 10.1111/jocn.13572
16. Ladin K, Buttafarro K, Hahn E, Koch-Weser S, Weiner D. “End-of-Life Care? I’m not Going to Worry About That Yet.” Health Literacy Gaps and End-of-Life Planning Among Elderly Dialysis Patients. The Gerontologist. 2018;58(2):290-9. doi:10.1093/geront/gnw267
17. Clemency B, Cordes C, Lindstrom H, Basior J, Waldrop D. Decisions by Default: Incomplete and Contradictory MOLST in Emergency Care. Journal of the

American Medical Directors Association. 2017;18:35-9. doi.org/10.1016/j.jamda.2016.07.032
18. Street M, Ottman G, Johnstone M-J, Considine J. Advance care planning for older people in Australia presenting to the emergency department from the community or residential aged care facilities. Health and Social Care in the Community. 2015;23(5):513-22. doi.org/10.1111/hsc.12162
19. Dening K, Greenish W, Jones L, Mandal U, Sampson E. Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study. BMJ Supportive & Palliative Care. 2012;2:103-7. doi:10.1136/bmjspcare-2011-000178

Table 1: Demographics of cohort, n (%) unless otherwise indicated

Factor	Overall
N	149
Age in years, median (IQR)	87 (80, 90)
Sex (male)	63 (42.3%)
NESB	68 (45.6%)
Charlson comorbidity score, median (IQR)	7 (5, 8)
Transfer out of hours	83 (55.7%)
Any review within 12-hours of transfer	
No	106 (71.1%)
Yes	39 (26.2%)
Unknown	4 (2.7%)
Time to Death, median (IQR)	8 (4, 14)
Reason for transfer	
Shortness of Breath	68 (45.6%)
Altered conscious state	47 (31.5%)
Poor oral intake	5 (3.4%)
Abdominal pain	10 (6.7%)
Fall	7 (4.7%)
Vomiting	5 (3.4%)
Other	7 (4.7%)
Cause of Death (ICD-10-AM)	
Disease of respiratory system	62 (41.6%)
Disease of circulatory system	34 (22.8%)
Disease of Nervous System	11 (7.4%)
Other	42 (28.2%)
Advance Care Plan (ACP)	
ACP not in place/no evidence of plan	87 (58.4%)
ACP present, transfer consistent with plan	50 (33.6%)
ACP present, transfer inconsistent with plan	12 (8.1%)

Evidence of Medical Power of Attorney document	35 (23.6%)

NB: Non-English speaking background; ICD: International Classification of Diseases; IQR: interquartile range

Figure 1: Frequency Distribution of Time to Death (0 – 24 hours)

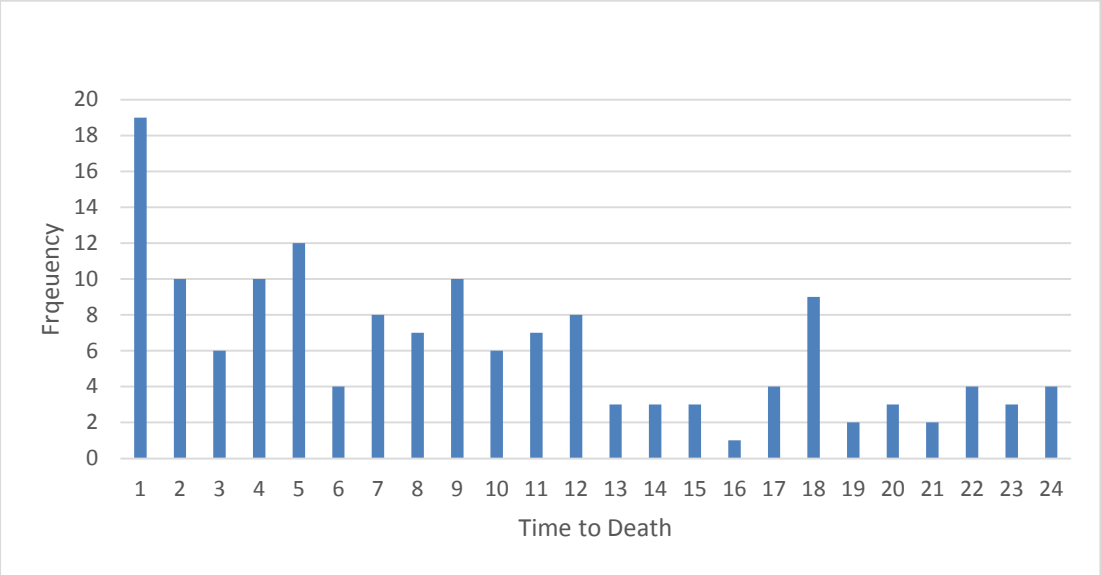

Table 2: End-of-Life-Care and ACP

	Any anticipatory prescribing (benzodiazepine/injectable morphine)		
Advance Care Plan (ACP)	**No**	**Yes**	p= 0.008
ACP not in place/no evidence of plan	76 (87.3%)	11 (12.6%)	
ACP, transfer consistent with plan	33 (66.0%)	17 (34.0%)	
ACP, transfer inconsistent with plan	11 (91.6%)	1 (8.3%)	

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Abstract

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Key words: Aged Care Facility, End-of-life-care, dying, advanced care plan, palliative care, Nursing home

This work is not under active consideration for publication, has not been accepted for publication nor has it been published, in full or in part.
I confirm the study has been approved by the Northern Health Ethics Committee, an institutional ethics committee.

Dr Hannah Brownstein
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