Acceptability and feasibility of end-of-life care pathways in Australian residential aged care facilities

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ABSTRACT

Objectives: To investigate the acceptability and feasibility of using end-of-life (EOL) care pathways in residential aged care facilities (RACFs).

Design, setting and participants: Multistage action research approach involving interviews, surveys and prospective audits of deaths and EOL care pathway use among residents and staff of RACFs and associated general practitioners from 14 RACFs in Victoria and South Australia between April 2009 and July 2010.

Intervention: Introduction of EOL care pathways.

Main outcome measures: Evidence of acceptability was determined by the rate of pathway use in RACFs and through feedback from RACF managers, staff and GPs. Evidence of feasibility was determined by reductions in transfers to hospital for symptom management before death, length of time on pathways, and whether care was consistent with best practice at EOL.

Results: The use of EOL care pathways across the RACFs fell into low-, moderate- and high-uptake groups (for 10%, 34% and 68% of all deaths at the facility, respectively). Feedback from RACF staff and GPs indicated that acceptability was critical to successful implementation. The use of EOL care pathways demonstrated improvements in care, sometimes over extended periods. There were fewer unnecessary admissions to hospital before death, although not all RACF staff and GPs were aware of the project.

Conclusion: EOL care pathways are feasible strategies for delivering EOL care consistent with best practice. However, their introduction into Australian RACFs needs to include strategies to facilitate acceptability by RACF staff and GPs.

Introduction

End-of-life (EOL) care pathways are specialised integrated care pathways for the terminal phase of palliative care. Traditionally associated with cancer care, EOL care pathways aim to support quality palliative care by improving symptom management, documentation and assessment.[1,2] Evidence of effectiveness from randomised controlled trials is not yet available,2 although other study types from several countries consistently support the use of EOL care pathways.[3-6] They are increasingly used internationally and are appearing in Australian residential aged care facilities (RACFs)[7,8] as active documents that provide guidance on different aspects of terminal care.[9]

Effectiveness is just one requirement of evidence-based practice. Acceptability by those receiving and providing care and feasibility in the particular clinical and social context are also critical.10 These criteria have particular importance in complex care environments such as RACFs where care is provided by a mix of nursing and allied health staff, personal care assistants and general practitioners.[11] EOL care pathways support multidisciplinary care teams to document decisions, actions and observations[12] and may also be useful quality markers of care at the end of life.[13]

EOL care pathways were introduced to 14 RACFs in Victoria and South Australia through *A good death in residential aged care: optimising the use of medicines to manage symptoms in the end-of-life phase* (the Good Death project). The Good Death project

used a modified version of the widely used Liverpool Care Pathway for the Dying Patient,[14] adapted and evaluated for use in Australian RACFs.[15] We aimed to examine the acceptability and feasibility of using EOL care pathways in RACFs in Australia.

Methods

The Good Death project involved a consortium of partners across Victoria and South Australia led by the North East Valley Division of General Practice, Victoria. It included two other Divisions of General Practice, 14 RACFs with a total of 1033 resident places, pharmacists, specialist services, and research staff from La Trobe University, Melbourne. There was considerable heterogeneity across the RACFs (Table 1).

The project used a multistage action research design that collected both qualitative and quantitative data from a range of sources. Data were obtained each month from the 14 participating RACFs by project staff using purpose-designed tools. Data sources included interviews with RACF staff and GPs, RACF manager surveys, and the prospective audits of deaths and EOL care pathway use. RACF staff reviewed retrospective records of residents over the last 28 days of life to examine if common signs of transition to death were evident. All RACF managers14 were surveyed at the start of the project in April 2009 and again in July 2010. Baseline and post-implementation interviews were conducted with 28 GPs (21 at baseline and seven post-implementation) and 42 RACF staff members (17 registered nurses, seven enrolled nurses, 14 personal care workers and four allied health workers).

EOL care pathways were introduced to the RACFs from June 2009 and prospective audits of all deaths in participating RACFs were undertaken from 1 November 2009 to 31 July 2010. The audit sought details about each death, including information about hospital transfers, use of EOL care pathways, actions recorded in pathways, and the initiators and signatories of pathway actions.

The 12-month reports from RACF managers before and after implementation provided two comparable periods to assess hospital transfers and were used to determine feasibility. The death audits confirmed that use of the EOL care pathways was consistent with best-practice care and were used to determine acceptability.

The EOL care pathway used in the Good Death project had five main sections: (i) commencing a pathway; (ii) medical interventions and advance care planning; (iii) care staff interven-tions, including care management, daily comfort care chart and further care action sheet; (iv) multidisciplinary communication sheet; and (v) after-death care. The care team, including the GP, decided whether it was appropriate to commence a resident on the pathway or to reconsider its continuance.[16] The pathway could be initiated by a GP or a registered nurse and local protocols were developed. As only non-identifying data were collected, patient consent was not required. Our study was approved by the La Trobe University Human Ethics Committee.

Measures

Acceptability is associated with preferences and values. Evidence of the acceptability of EOL care pathways was determined a priori to be demonstrated by the rate of pathway use and through feedback from RACF managers, staff and GPs. We sought views regarding changes to the approach to people who were dying, including perceptions of the involvement of residents and families in decision making, staff confidence in managing care, and collaboration between staff and GPs.

Feasibility is associated with practical implementation. Evidence of the feasibility of using EOL care pathways was determined a priori to be demonstrated by reductions in transfers to hospital for symptom management before death, length of time on

pathways, and whether care was consistent with best practice at EOL as determined by national guidelines.[17,18]

Data analysis

Consistent with an action research approach, we generated data to meet evaluation objectives and undertook quantitative and qualitative analyses. All quantitative data were coded as either dichotomous or categorical variables and entered into PASW Statistics, version 17 (SPSS Inc, Chicago, Ill, USA). We calculated simple descriptive statistics and set significance at 0.05 for all analyses. Mantel–Haenszel χ^2 summary statistics were calculated for reported death data from all RACFs. This procedure adjusts for confounding from different mortality rates to give a measure of the average strength of association between variables.

We collected the major sources of qualitative data by telephone interviews, and transcribed and imported the data into NVivo, version 8 (QSR International, Melbourne, Vic). These data were subject to qualitative content analysis, which identified core consistencies to generate a comprehensive analysis informed by the project objectives.[19]

Results

Acceptability

Over the 9-month death audit period, of a total 1033 RACF resident places, 175 (17%) residents died; equivalent to an annual death rate of 23%. Pathways were used 63 times (36% of all deaths and 43% of deaths when sudden deaths not on pathways were excluded). Pathways were considered for another four residents not on a pathway when they died. Three other residents received care from community palliative care services and were not on a pathway.

There were three levels of uptake of EOL care pathways across the 14 RACFs. A high-uptake group (four RACFs) used pathways for 68% of all deaths (93% of deaths when sudden deaths not on pathways were excluded); a moderate-uptake group (six RACFs) used pathways for 34% of all deaths (41% when sudden deaths not on pathways were excluded); and a low- or no-uptake group (four RACFs) used pathways for 10% of all deaths (11% when sudden deaths not on pathways were excluded). The difference between the groups was highly significant ($P < 0.0001$) and remained when sudden deaths not on pathways were excluded. Heterogeneity across the RACFs was also apparent across the groups, and uptake was not associated with any known factors.

Registered nurses initiated most EOL care pathways (57/63, 90%). GPs initiated five of 63 pathways (8%) and were signatories to about half the pathways (31, 49%) in 10 of the 14 RACFs. RACF staff reported verbal support from some GPs unable to attend the RACF in person. The initiator of one pathway was not recorded.

Feedback from RACF managers in the high-uptake group indicated pathway use was incorporated into policy and had become routine care, and two RACFs linked pathway use to their auditing processes. One manager reported staff "enthusiasm to start pathways". No managers from moderate-uptake RACFs described policy changes related to the pathway. Low uptake of pathways was attributed to either few deaths in the audit period, so little opportunity to use them, or the lack of an electronic version.

GP involvement appeared influential to the level of uptake. High uptake RACFs were more likely to have pathways signed by a GP than moderate-uptake RACFs (20/24 [83%] v 9/32 [28%]; $P<0.001$). In the initial interviews with 21 GPs, nine were satisfied with how EOL care was managed at the RACFs they attended, although their views tended to be qualified or concerned the competence of particular staff. Three GPs raised

concerns about variability in EOL care and the timeliness of their involvement. During the project, GPs in 10 of the 14 RACFs were directly involved in implementing EOL care pathways. In addition, five of the seven GPs interviewed at the end of the project commented positively about their experience. The other two GPs were unaware of the project or pathways. One GP felt the project provided a catalyst for discussion about death among doctors, nursing staff, and family and relatives. He also noted the RACFs' expectation that GPs manage the care of dying residents more scientifically, using their pharmacological and medical skills.

Another GP commented on other beneficial effects, such as easier dose management and more streamlined care. Two GPs with wide palliative care experience noted positive effects among RACF staff and an improved understanding of the dying process. One reflected that staff were more aware of the principles and plans involved, which increased staff confidence in how they cared for patients and also enabled them to voice any concerns. He observed that the pathway is part of an education process, "where most people go from trying to salvage people no matter what, to a process whereby people are allowed to die peacefully".

Feasibility

Indications of important practice change were evident in RACF managers' reports of transfers to hospital in the period before death. The proportion of deaths in hospital and RACFs remained constant in pre- and post-implementation manager surveys, but significantly fewer residents were transferred to hospital and subsequently returned to the RACF at the end of the project (Table 2).

The audit confirmed the reported mortality rates and place of death by the managers, including the important reduction in unnecessary hospital transfers. The proportion of deaths in hospital remained comparable to baseline data, but only one of the 18 people in the audit group transferred to hospital returned to the RACF. One resident on a pathway was transferred to hospital for pain management and subsequently died there.

The median length of time on an EOL care pathway for residents was 5.5 days (SD, 25.3). RACF managers reported that before the introduction of pathways, their reviews of resident records revealed that little was written about the care provided. The pathways encouraged documentation, and the audits demonstrated that care for residents on pathways was consistent with best practice at EOL, regardless of an RACF's level of pathway uptake. Table 3 shows how aspects of care promoted by the project were implemented. Almost all people on a pathway had appropriate medicines ordered as needed. Nonessential medicines were discontinued for 76% of those on pathways, and inappropriate interventions and observations were discontinued for 60% of those on pathways.

Approach to care was raised in most post-implementation interviews with RACF staff (25/42, 60%). One in four reported no change. However, most reported improvements, such as more holistic or improved quality of care (13, 31%); increased focus on EOL and palliative care (19, 45%); more consistent care (15, 36%); more timely care (11, 26%); more systematic care (11, 26%); and more informed decision making (3, 7%). Greater consistency in the approach to care was evident in several comments. One nurse commented that it is a "a more holistic approach, not just looking at the person and their needs, but going through all the needs". A manager observed that previously, "it all relied on [an] individual nurse's knowledge to make an assessment, and put things in place, and now there is a … more structured approach".

The use of EOL care pathways demonstrated improvements in care, sometimes over extended periods, and fewer unnecessary admissions to hospital before death were noted, although not all RACF staff and GPs were aware of the project.

Discussion

When introducing EOL care pathways in Australian RACFs, acceptability and feasibility are important considerations to ensure that quality EOL care is sustained in practice. Our measures for acceptability and feasibility are consistent with studies of EOL care pathways in acute settings, which found positive responses from nurses associated with increased confidence and better relationships with medical staff;20 audits of EOL care pathway use showed improved EOL care.[3]

We used the rate of uptake of EOL care pathways as part of our measure of acceptability, recognising that pathways are not suitable for every death. The significant differences in uptake across the 14 RACFs were associated with acceptability of pathways by RACF staff and GPs. This indicates that acceptability is crucial to successful implementation of EOL care pathways.

We found a similar level of uptake to that found among six Queensland RACFs.[8] Reymond and colleagues attributed higher uptake to greater support from management and GPs based on anecdotal accounts from RACF staff, consistent with our notion of acceptability. The Queensland study also reported that retention of a common link nurse throughout the project to be an important factor for uptake. As ongoing sustainability was our goal, we did not introduce additional staff into the RACFs. We found higher uptake to be related to reported change in RACF policies. Our study provided evidence of feasibility in using EOL care pathways in RACFs consistent with best practice at EOL. There was appropriate anticipatory planning of medicines and discontinuation of nonessential medications, interventions and observations when pathways were used across all RACFs, regardless of level of uptake.

Our study limitations include the bias of all observational studies. Participating RACFs were self-selected and clustering was likely. Experiences in using an EOL care pathway may affect subsequent decisions about its use, although this would apply both for and against uptake. There is no consensus on the best measures for acceptability and feasibility of pathway use in RACFs, but we selected a mix of quantitative and qualitative parameters to enable our assessment and chose these a priori to minimise bias.

EOL care pathways are feasible mechanisms for delivering EOL care consistent with best practice. Strategies to facilitate acceptability by RACF staff and GPs include incorporating EOL care pathways into existing standards and practices, and promoting awareness, education and accessibility. Acceptability of EOL care pathways could be achieved by establishing a national program to support their use (including support for training, implementation and monitoring); developing an electronic version; obtaining endorsement from the Royal Australian College of General Practitioners; emphasising their use in RACF accreditation; and incorporating them into advance care planning discussions.

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Table 1: Heterogeneity in Residential Aged Care Facilities in the Good Death project*

Area of difference	Type of difference	N
Level of care	High care only	2
	Low care only	1
	Mix of high and low care (including ageing in place)	11
Size (number of places)	30-134 places per facility	
Location	Urban;	12
	outer metropolitan/rural	2
Cultural specificity	Ethno-specific (Greek, Italian)	2
	Mono-cultural	4
	Mix of ethnic backgrounds	8
Profit status	For-profit	4
	Not-for-profit	10
RACF Provider	Single privately owned	6
	Part of multi-chain	7
	Co-located with public hospital	1
Staff profile	Staff to resident ratios; nurse to carer ratios; full-time to part-time staff ratios	
GP involvement	3-39 GPs per RACF, Mean patients per GP=5.7 (range 1-65)	
Medication Imprest system†	5/5 SA RACFs with Medication Imprest System ; 2/9 Victorian RACFs with Medication Imprest System	
Access to specialist palliative care and other services	In Victoria: • Community Palliative Care Services provide clinical support and education to RACFs including specialist nurses to work with local RACFs and GPs. • Hospital outreach provides care to RACF residents and support staff to prevent unnecessary transfers to emergency departments (ED). In South Australia: Extended Care Paramedic Program (ECPs), joint initiative of SA Health and SA Ambulance Service (SAAS) manages and treats people in their usual residence.	

* *A good death in residential aged care: optimising the use of medicines to manage symptoms in the end-of-life phase.*
†A specified range of medicines, for which there is an anticipated need, stored on a licensed site and restocked regularly

Table 2: Number and place of resident deaths and transfers to hospital for previous 12 months reported by RACF managers at baseline and post-implementation

	Baseline*	Post-implementation#	Mantel-Haenszel χ^2
Resident deaths in previous 12 months (n, % 1033 beds)	267 (26)	274 (27)	
Deaths in RACF (n, % all deaths)	229 (86)	232 (85)	
Resident deaths in hospital (n, % all deaths)	38 (14)	42 (15)	
Transfers to hospital (n, % all deaths)	52 (19)	44 (16)	
Transferred to hospital prior to death and returned to RACF (n, % all deaths)	14 (5)	2 (1)	9.581 p=0.002

*April 2008-April 2009, #June 2009-June 2010

Table 3: Impact of Pathway on End-of-Life care by rate of uptake

	High uptake N (%)	Moderate uptake N (%)	Low uptake N (%)	All N (%)
PRN Medicines ordered	25 (100)	33 (97)	4 (100)	62 (98)
Non-essential medicines discontinued	19 (76)	26 (77)	3 (75)	48 (76)
Inappropriate interventions & observations discontinued	16 (64)	19 (56)	3 (75)	38 (60)