

# Decision-making for place of care and death in older people: A rapid review of current evidence, and implications for COVID-19

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## Introduction

The coronavirus pandemic (COVID-19) has affected the functioning and delivery of health and social care worldwide. Care must still be provided amidst the wider surge of demand for services, and rapidly changing needs for triage and service allocation, navigated within the context of rapidly changing situations and guidelines [Downar J, Seccareccia, D].

COVID-19 has disproportionately affected older adults, including those living with dementia. There have also been significant effects on the functioning of healthcare systems. In this context, decision-making surrounding place of care and place of death involves significant new challenges.

Difficult contexts are being navigated, such as a lack of visiting opportunities for families in certain care settings [Olivier, D], decision-making around resuscitation and informational awareness of the current situation. Many older people will not have an advance care plan or have discussed their end of life care preferences prior to the pandemic [Moore KJ, Sampson EL, Kupeli N et al.].

Our review aimed to explore key factors that influence place of care and place of death decisions in older people, including the choice of where people may be cared for and die. A secondary aim was to investigate key factors that influence the process and outcome of these decisions in older adults. Findings from this review are then explored through the context of healthcare challenges during COVID-19.

## Methods

A rapid review of reviews was undertaken using guidance from the WHO. Ten papers published between 2005-2020 were included for data extraction. Data extracted was synthesised using narrative synthesis, with thematic analysis and tabulation.

Papers included were systematic and narrative reviews, including meta-analyses. Papers focussed on older people –over the age of 65, professionals, caregivers and the general population who were concerned with caring for people over the age of 65, and decisions surrounding care and place of care/place of death.

We searched two databases (MEDLINE [1966–2020] and Embase [1980–2020]) as well as grey literature. The search strategy comprised terms for end-of-life and palliative care, as well as older adults, care settings and decision-making. We identified and screened the reference lists of relevant identified reviews and consulted experts in this field.

## Results

Papers were split into two groups dependent on their approach to considering decision-making. Five papers focussed on the process aspect of decision-making – papers included in this group focus on factors such as service design, access to care, advance directives and the process of making decisions. The remainder of the papers explored decision-making in terms of outcomes – where people expressed preferences to be cared for and to die, and factors influencing these decisions.

	Howell	Hoare	Gomes	Costa	Tejedor	Hudson	DeSouza	Kwak	Goodman	McCaffrey
Preference PoD / PoC	x	x	x	x	x	x	x	x	x	x
Actual PoC / PoD		x	x	x	x	x			x	
Home care / death	x	x	x	x	x				x	x
Hospital care / death	x	x		x	x	x			x	x
Hospice care / death		x								x
Nursing home care / death		x		x				x	x	
Cancer	x	x	x	x		x		x		x
Non-cancer		x	x	x		x		x		x
Dementia								x	x	
Patient views		x	x	x	x	x	x	x	x	
Caregiver views		x	x	x	x	x	x	x	x	
General Population		x	x							
BME focus							x	x		
Conversations					x		x	x		
Decision-making	x	x	x		x		x	x	x	
ACP / AD				x	x		x	x	x	
Specialist PC	x			x	x				x	x
Service design / access	x			x		x			x	x
Information						x				
Support						x				
Capacity					x				x	

Table 1 – Matrix of Included Themes

## Key Lessons

- Preparedness and a sense of control were found to be important for both patients and their families in making decisions.
- Decisions should be considered continually over time, as illnesses progress and priorities and capacities change.
- Appropriate multidisciplinary professional involvement can aid both good decision-making and facilitate patients and families to achieve their stated goals in terms of place of care and place of death.
- Appropriateness of available information in terms of cultural, language and access needs, was shown to be key in empowering family caregivers to cope well with decision-making and caring at home—should this be the preference.
- Sensitivity to cultural appropriateness is especially important in issues surrounding capacity and the role of proxies.

## Discussion

### Place of care, and place of death

Place of care and place of death, both actual and preferred, was key in decision-making amongst older adults. Home death was strongly favoured across papers, though this was contingent on factors such as having a caregiver and that caregiver's ability to cope [Costa V, Earle CC, Esplen MJ et al].

In the context of COVID-19, caregivers may also be balancing multigenerational caregiving responsibilities, economic insecurity and a lack of usual support networks. Strict and rapidly-changing guidelines around local lockdowns and visiting guidelines may also put pressure on decisions concerning place of death and place of care.

### The role of family and culture

The role of family or other proxy decision-makers is key when considering decisions around care at the end of life. A one-size-fits-all approach to end-of-life planning and decision-making is not effective for patients or caregivers [De Souza J, Gillett K, Froggatt K et al. ] and individuality and diversity must be taken into account to serve patients and their families best.

COVID-19 has resulted in disproportionately higher mortality in minority ethnic communities. Thus, culturally-tailored decision-making interventions and approaches are particularly important in order to enable diverse patients and caregivers to plan and make good care and end-of-life decisions.

### Advance Care Planning

Care must be taken to ensure that access to advance care planning services and interventions are culturally appropriate. Advance care planning should be an iterative process, integrated across the illness trajectory and continually reviewed [Ahiwalla SC, Bekelman DB, Huynh AK et al.; Llewellyn R, Jaye C, Egan R et al.].

During COVID-19, advance care plans may need to be renegotiated and reconsidered as care options change. Thus the continual review element of advance care planning is particularly important within COVID-19.

## Conclusions

Within the context of COVID-19, such decisions may have to be made rapidly and be reflexive to changing needs. These include needs of systems themselves, such as modified triage and service allocation, as well as individual and family desires.

Advance care planning and decision-making aids can help to facilitate patients and caregivers to make choices around issues such as modified visiting rules, availability and appropriateness of domiciliary care, multigenerational caring needs and rapid changes of circumstance.

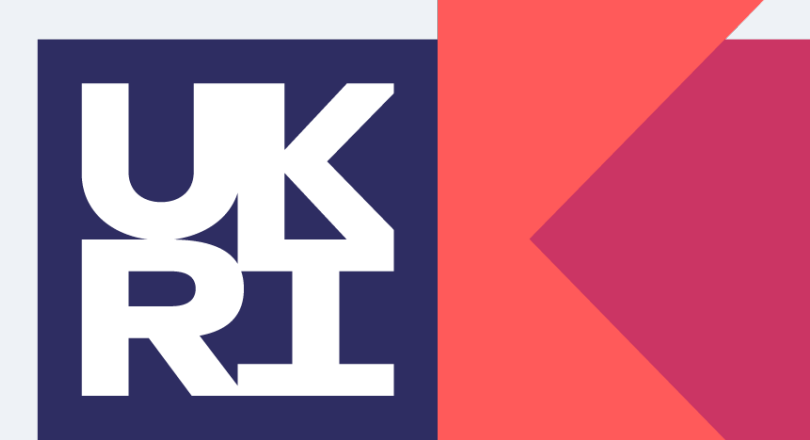
The combination of the current pandemic context, and lessons-learned from non-pandemic care planning has a number of implications for future best-practice.



FUNDED BY



National Institute for Health Research



Economic and Social Research Council

