

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

Emily West [1], Kirsten Moore [1], Nuriye Kupeli [1], Elizabeth L Sampson [1,3], Pushpa Nair [2], Narin Aker [2], Nathan Davies [1,2]

1 Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, London, UK
 2 Department of Primary Care and Population Health, University College London, London, UK
 3 Barnet, Enfield and Haringey Mental Health Liaison Service, North Middlesex University Hospital NHS Trust, London, UK.



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].

If an older person becomes unwell, rapid decisions may have to be made concerning place of care, social distancing, availability of services and which treatments a person may or may not need to receive. 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.]. These decisions will often be left for the family to make with practitioners if the older person becomes unwell and/or loses capacity.

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.

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, 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.

We adopted a narrative synthesis approach using tabulation and thematic analysis. Themes were generated based on several major categories – namely care settings, disease groups, study population, decision-making approach (formal approaches such as advanced care planning, as well as informal modes such as conversations) and decision-making role (whether informational, supportive etc.). These themes were devised iteratively throughout the review process by one author and ratified by the wider team.

Included Papers

We identified 533 papers from database searches up to April 22 2020, and eliminated 39 duplicates. Four further papers were found through reference searches and 46 papers were included for full-text review. Nineteen were excluded for not having a clear focus on older adults, four for not explicitly considering place of care and/or place of death and seven for not fitting the eligibility criteria of this review. The 10 papers included for data extraction were published between 2005 and 2020.

Articles included for analysis approached the research question from different standpoints. The evidence primarily spanned North America and Europe, although as included papers were themselves systematic reviews there was considerable variation within papers.

	Hosell	Huor	Gomes	Costa	Tepeler	Hoban	Debonza	Kwak	Goodman	McCaffrey
Preference PdC / PdC	x	x	x	x	x	x	x	x	x	x
Actual PdC / PdC		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

Results

In performing data extraction, a split in the focus of papers emerged between those that primarily concerned the process of decision-making and those that concerned outcomes. This two-theme approach was devised iteratively as data extracted showed a split between papers that looked at decision-making as something that had already taken place, and those where decision-making was a process in progress or a hypothetical future scenario.

Decision-making process

Five papers focussed on the process aspect of decision-making – papers included in this table focus on factors such as service design, access to care, advance directives and the process of making decisions. Four themes were identified in this section: Factors affecting decisions, emotional aspects of decision-making, capacity in decision-making and minority experience in decision-making.

Decision-making outcomes

The remainder of the papers explored the subject of decision-making in terms of outcomes – where people expressed preferences to be cared for and to die, and factors influencing these decisions. Often, the line between place of death and place of care was not clear, with respondents and researchers using the terms interchangeably. In this section, three sub-themes were identified: place of death, decision over time and what affects decisions made.

Discussion

This rapid review was undertaken to explore the range of factors affecting decision-making concerning place of care and place of death amongst older adults. In the current context of the global COVID-19 pandemic, such decisions are both more acute – as the disease more severely affects those who are older or have multiple comorbidities– and more heightened in the sense that health care systems are working with ever-shifting allocation and triage needs. Literature included in this review explored a diverse breadth of issues, both in terms of outcomes and the process of making such decisions. Decision-making for older adults at the end of life is a complex process which can be affected by myriad factors, and sometimes competing or conflicting priorities.

Place of care, and place of death

Place of care and place of death, both actual and preferred, proved to be a key theme 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. This has immediate effects on caregiver wellbeing, and potentially ability to cope. However, 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. Patients who lack capacity may require proxy decision-makers, whether familial or legal, to be involved in care decisions. Xie, in exploring end-of-life decision-making models in people living with dementia, highlighted a lack of current tools that allow values and preferences to be incorporated in decision-making and a lack of sensitivity to cultural variance. 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

Though advance care planning is seen as aspirational, care must be taken to ensure that access to advance care planning services and interventions is culturally appropriate. Advance care planning should be an iterative process, based on patient values rather than set treatment options, integrated across the illness trajectory and continually reviewed [Ahluwalia SC, Bekelman DB, Huynh AK et al.; Llewellyn R, Jaye C, Egan R et al.]. During the COVID-19 pandemic, advance care plans may need to be renegotiated and reconsidered as care options change – for example, a person who wants to die in hospice may reconsider this decision in light of visitors not being allowed. Thus the continual review element of advance care planning is particularly important within the COVID-19 context.

Conclusions

The process and outcomes of decision-making for older people are affected by many factors – all of which have the potential to influence both patients and caregivers experience of illness and dying. 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.

