Exploring Consumer Vulnerability in the Funeral Market

Rapid Evidence Assessment

NatCen

Social Research that works for society

Date: June 2020

Prepared for: The Competition and Markets Authority (CMA)

Authors: Karen Windle, Sokratis Dinos, Alexander Martin, Frances Shipsey and Imogen

Martin.

At NatCen Social Research we believe that social research has the power to make life better. By really understanding the complexity of people's lives and what they think about the issues that affect them, we give the public a powerful and influential role in shaping decisions and services that can make a difference to everyone. And as an independent, not for profit organisation we're able to put all our time and energy into delivering social research that works for society.

NatCen Social Research 35 Northampton Square London EC1V 0AX T 020 7250 1866 www.natcen.ac.uk

A Company Limited by Guarantee Registered in England No.4392418. A Charity registered in England and Wales (1091768) and Scotland (SC038454) This project was carried out in compliance with ISO20252

NatCen Social Research 2

Contents

1	Executive Summary	1
2	Background	4
3	Research Questions	5
4	Methodology	6
Sta	ge 0: Scoping phase including pilot search and identification	
	ge 1: Evidence Identification	
	ge 2: Evidence selection, screening and weighting	
รเล 5	ge 3: Narrative synthesis and information integration Findings	
	be and extent of included papers	
	e nature and scale of the effect (if any) of recent grief and bereavemen	
con	sumers' decision-making capacity and purchasing behaviour	
	Impact of grief/bereavement on decision-making capacity	
	Contextual factors that impact on decision-making in the funeral indu	-
	Outcome of cognitive and contextual factors on decision-making and	
	choice in the funeral industry	
Cor	mparable emotional states on decision-making capacity and purchasin	g
	naviour	
	erventions to mitigate deficits in decision-making capacity and purchas	_
ber	naviour 'Institutional' interventions	
	Relational interventions	
	Individual interventions	
6	Observations on the research	
7	Implications of the research	
8	References	
	pendix A: Search strings for database searches	
	1 Research questions 1 and 3	
Λι.	A1.1.1 Scopus	
	A1.1.2 MEDLINE(R) and In-Process & Other Non-Indexed Citations	
	Daily (Ovid) <1946 to January 07, 2020>	
	A1.1.3 PsycINFO (Ovid) <1806 to December Week 5 2019>	33
A1.	2 Research guestions 2 and 3	34

NatCen Social Research

Appendix B: Search terms for grey-literature searches . :	36
Appendix C: Inclusion/exclusion criteria for title and	
abstract screening	37
Appendix D: Full text screening and Weight of Evidence	!
(WoE)	38
Appendix E: Round table slide-pack, presentation and	
prompt questions	39
Appendix F: Data extraction tool	56

NatCen Social Research 2

1 Executive Summary

- 1.1 NatCen, an independent social research agency, was commissioned by the Competition and Markets Authority (CMA) to undertake a Rapid Evidence Assessment (REA) as part of the CMA's evidence-gathering for the Funerals Market Investigation. This REA, which was conducted between December 2019 and March 2020, was undertaken to provide a structured and objective synthesis of literature relating to the impact (if any) of grief/bereavement on the decision-making and purchasing behaviours of funeral consumers (those arranging an 'at need' funeral).
- 1.2 The funeral arrangement process, whilst being a part of supporting and progressing the grieving process, can be particularly challenging. Decision-making may be affected by the individual's emotional vulnerability, whilst knowledge around planning (and paying) for a funeral may be limited.
- 1.3 A four-stage Rapid Evidence Assessment (REA) was carried out to respond to three research questions: (1) the nature and scale of the effect (if any) of recent grief/bereavement on consumers' decision-making capacity and purchasing behaviour; (2) the nature and scale of the effect (if any) of comparable emotional states on decision-making capacity and purchasing behaviour; and (3) what interventions have been used to address/remedy deficits in consumers' decision-making capacity and purchasing behaviours caused by grief/bereavement or comparable emotional/mental states.
- 1.4 Of those papers extracted (n=39), five were directly related to the funerals sector, whilst the remaining papers discussed the impact of grief and bereavement on decision-making across a range of transferable contexts including, for example, end-of-life hospital treatment, organ donation, miscarriage and still-birth as well as a selection of welfare and social care services at a time of crisis.
- 1.5 Drawing on all papers extracted, there is an overarching consensus that the psychological effects of grief or bereavement make it challenging (if not impossible) for consumers to make informed decisions.
- 1.6 From the evidence that discusses the impact of grief and bereavement on decision-making it seems that, overall, individuals will struggle to make logical and rational choices and actions whilst experiencing bereavement or likely bereavement.
- 1.7 Individuals living with grief or 'anticipatory grief' (i.e. prior to the expected death of their relative) may take mental short-cuts, demonstrate poorer overall problemsolving ability, avoid decisions, be locked into 'uncertainty angst', attempt to delay any decision, show a preference for the 'status quo', or transfer any decision-making to someone else: 'What would you do?'.
- 1.8 An individual's ability to cognitively process information and make decisions on behalf of their relative was not only reduced, but it was found that higher measures of anticipatory grief increased impulsivity and carelessness.
- 1.9 Alongside the impact of death on cognitive processing and subsequent decision-making, the situational impact of the funeral *per se*, as well as the context of the bereavement (where, when and how the relative died), will additionally impact on an individual's choices and purchasing-behaviours.
- 1.10 For many individuals, the grief and shock of bereavement is compounded by a lack of knowledge around the process of choosing and purchasing a funeral, as well as the short-time frame in which often this needs to be carried out.
- 1.11 When arranging a funeral, individuals may not put in place the normal checks and balances that would be applied when acting as a consumer, i.e. shopping around, checking costs, identifying the value of different 'packages' that may be available.

- 1.12 Evidence suggested that few individuals made active 'choices' about the funeral home they used. Individuals will contact a funeral home that had supported them at a previous bereavement or had been used before by a family member or friend.
- 1.13 Few (if any) consumers will be guided by financial (price) information in making their choice of funeral provider, avoiding price comparisons owing to the perceived sacred nature of the funeral. Research participants perceived that searching for the lowest price disturbs the ritual adherence (e.g. wishes of the deceased) to holding the funeral and 'insults' the deceased.
- 1.14 Research participants were likely to report that 'financial tension' between themselves and the funeral provider was an unfavourable aspect of their interaction.
- 1.15 Many of the papers alluded to the 'risks' consumers face as a consequence of the impact of grief and bereavement on decision-making, highlighting prior papers around over-charging, lack of control and reliance on the 'expert' in order to make a decision.
- 1.16 Decisions made at a time of crisis, in fear or in a high emotional state were likely to have a long-term impact with the possibility of regret, guilt and distress for months or even years afterward.
- 1.17 There is a limited evidence-base identifying the impact of grief (or comparable emotional states) on decision-making and purchasing behaviour which relates directly to arranging a funeral. However, where available, the evidence-base suggests that no considered decisions can generally be made at, or shortly prior to, bereavement, that there is little shared decision-making between the consumer and the funeral arranger, and individuals are (in the main) making purchases lacking information and financial understanding. All such factors are likely to result in increased consumer vulnerability.
- 1.18 There is limited exploration in the research literature of potential interventions to mitigate the effects of grief following bereavement on consumers' decision-making behaviour when purchasing a funeral. Collectively, the literature focused on arranging a funeral, as well as those studies undertaken within transferable contexts, proposes potential interventions or innovations across three elements: institutional interventions; relational interventions; and individual interventions. In the main, these identified interventions were neither fully implemented nor evaluated in the reported studies, limiting the evidence available to comment on their effectiveness.
- 1.19 Those interventions identified in the literature that explored individuals' experiences following bereavement, including that of purchasing a funeral, encompassed institutional, relational and individual approaches. These recommendations (1.20 to 1.22) were drawn from qualitative research alongside bereaved individuals which was, in part, focused toward participants identifying what interventions they perceived may have been of support following their bereavement, rather than any empirically tested provision.
- 1.20 It was recommended that a centralised agency or 'go-to' organisation be put in place that could provide support and advice, not only on the organisation and purchase of the funeral, but on the myriad of practical tasks (e.g. probate) that individuals needed to address following bereavement.
- 1.21 Appropriate relationship management training of funeral staff should be delivered, encompassing psychological support and empathy. Whilst this recommendation was not directly related to improving decision-making when purchasing a funeral, it may improve the overall consumer experience.
- 1.22 A transparent and clear dialogue needed to be undertaken between funeral staff and the consumer, underpinned by sincerity and respect. As many needs and wishes of individuals were (often) unexpressed in any emotion-driven dialogue, it was essential that staff were proactive in asking individuals what actions they would wish to undertake and give them appropriate time to think about possible options. However,

this was an untested recommendation and the evidence around how this may take place or how it may impact on the customer is absent.

- 1.23 The research literature relating to transferable contexts similarly highlighted those interventions that may be applicable to support funerals-related decision-making and purchasing behaviours (1.24 to 1.25). Whilst these studies detailed supportive interventions relevant to health and social care (as opposed to purchasing a funeral) and at different 'life' and time points, there was limited evidence on the detail of the proposed interventions (e.g. of the shape or focus), or their effectiveness.
- 1.24 In exploring individual interventions that may support decision-making and purchasing behaviour, two recurrent themes were identified in the transferable literature: the need for clear information, and advance care planning. Further investigation is necessary to demonstrate the efficacy of these interventions when applied to the funeral industry.
- 1.25 Targeted and clear information is essential to guide and support decision-making and consequent actions. Those effective interventions drawn from the health and social care literature include Decision-Support Intervention tools (e.g. advance care directives) and face-to-face problem-solving techniques delivered by a care coordinator. Further research would be necessary to identify if these mechanisms to support decision-making are as effective when implemented alongside the purchase of funerals or within the funeral industry.

2 Background

- 2.1 NatCen, an independent social research agency, was commissioned by the Competition and Markets Authority (CMA) to undertake a Rapid Evidence Assessment (REA) as part of the CMA's evidence-gathering for the Funerals Market Investigation.
- 2.2 It is recognised that bereavement will necessarily be personal to each individual, with limited universality of experience. For example, the type and extent of grief may differ if people are facing the death of a young child when compared with that of a grandparent who dies in old age following a life 'well-lived'. Similarly, there may be differences in experience if individuals are facing the sudden death (e.g. by suicide or accident) of a family member, rather than an 'expected' death in which there may have been space and time to hold end-of-life conversations.
- 2.3 Whatever the experience of death, the funeral process can be challenging. Whilst some families/individuals may hold pre-paid plans, funeral 'insurance'^{4,5} or have directed their needs and wants through an 'Advance Care Plan',⁶ this is by no means universal and is available only to some families.⁷ A further pressure on the bereaved individual is the cost of any funeral, burial or cremation, which has risen substantially in recent decades.^{8,9}
- 2.4 This REA was commissioned to provide a structured and objective synthesis of literature relating to the impact (if any) of grief/bereavement on the decision-making and purchasing behaviours of funeral consumers (those arranging an 'at need' funeral¹⁰). A key question for the CMA was whether funeral consumers can be said to be inherently vulnerable, that is, that the cognitive/psychological impact of bereavement, and/or the need to make decisions under several different pressures (i.e. the peculiar circumstances of arranging a funeral) is such that it creates a vulnerability for many funeral consumers (whether they are aware or this or not). This REA, conducted between December 2019 and March 2020, provides a response to this area of enquiry.

 $\underline{\text{https://www.artshealthandwellbeing.org.uk/sites/default/files/bereavement-and-bereavement-care-literature-review.pdf}$

¹ Joanna Briggs Collaborating Centre for Evidence-based Multi-professional Practice. (2006) *Literature Review on Bereavement and Bereavement Care*. Faculty of Health and Social Care: The Robert Gordon University, Aberdeen. Available at:

² Krosch, D. J., and Shakespeare-Finch, J. (2017). Grief, traumatic stress, and posttraumatic growth in women who have experienced pregnancy loss. *Psychological Trauma: Theory, Research, Practice, and Policy*, *9*(4): 425–433.

³ Shields, C., Kavanagh, M., Russo, K. (2017) A Qualitative Systematic Review of the Bereavement Process Following Suicide. *Journal of Death and Dying*, 74(4): 426-524.

⁴ Woodthorpe, K., Rumble, H., Valentine, C. (2013) Putting 'The Grave' into Social Policy: State Support for Funerals in Contemporary UK Society. *Journal of Social Policy*, 43 (3): 605 – 622.

⁵ Corden, A. and Hirst, M. (2015) *The Meaning of Funeral Poverty: an exploratory study*. Social Policy Research Unit, Working Paper WP2668. York, University of York. Available at: https://pure.york.ac.uk/portal/files/48237572/FUNERALpoverty.pdf

⁶ Fried, T.R., Redding, C.A., Robins, M.L., Paiva, A., O'Leary, J.R., Iannone, L. (2010) Stages of Change for the Component Behaviors of Advance Care Planning. *Journal of the American Geriatric Society*, 58: 2329 – 2336.

⁷ Foster, L. and Woodthorpe, K. (2013) What cost the price of a good send off? *Journal of Poverty and Social Justice*, 21 (1): 77 – 89.

⁸ Competition and Markets Authority (2018) *Funerals market study: Interim Report and Consultation*. London, CMA. Available at:

 $[\]underline{\text{https://assets.publishing.service.gov.uk/media/5bffb9d5ed915d11965a199d/Funerals_market_study_interi}\\ \underline{\text{m report and consultation.pdf}}$

⁹ Bickerton, R. and Morelli, C. (2019) Funeral Poverty in Dundee: Funeral Link Evaluation, Final Report. Dundee, University of Dundee. Available at:

https://www.dundee.ac.uk/media/dundeewebsite/schoolofbusiness/discussionpapers/Funeral-Link-Final-Report-July-2019.pdf

¹⁰ An 'at need' funeral is one where the funeral arrangements are made and paid for at the time someone dies. It is not a funeral that the deceased arranged and paid for in advance of their death by purchasing a pre-paid funeral plan.

3 Research Questions

- 3.1 We conducted a Rapid Evidence Assessment (REA) to consider the peerreviewed and grey literature comprehensively and, critically evaluate the evidence identified. The REA explored the following research questions (RQs):
 - 1. RQ1: What is the nature and scale of the effect (if any) of recent grief/ bereavement on consumers' decision-making capacity and purchasing behaviour?
 - 2. RQ2: What is the nature and scale of the effect (if any) of comparable emotional states (e.g., grief-related emotional states including anxiety, depression and mourning) on decision-making capacity and purchasing behaviour?
 - 3. RQ3: What interventions have been used to address/remedy deficits in consumers' decision-making capacity and purchasing behaviour caused by grief/bereavement or comparable emotional states (e.g., grief-related emotional states including anxiety, depression, mourning and temporal incapacity)?

4 Methodology

- 4.1 We carried out a REA which enabled robust and transferable collation, review and synthesis of relevant literature in the most efficient way. The aims and objectives of this REA were to:
 - Consider the electronic and print-based literature comprehensively, but within a timeframe that is in keeping with the statutory timescales in which the CMA must operate;
 - b. Integrate descriptive outlines of the evidence available on a specific topic;
 - c. Critically evaluate the evidence identified;
 - d. Identify, record and exclude evidence that is considered of poorer quality; and,
 - e. Summarise the information in its entirety, linked to project-specific research questions.
- 4.2 The REA was conducted in four stages, each of which is detailed below. For all stages of this REA, all activities were developed in partnership with (and approved by) the CMA.

Stage 0: Scoping phase including pilot search and identification

- 4.3 The first stage of our REA focused on a scoping phase to refine the research questions as well as co-produce, develop and deliver the detailed protocol and supporting documents, including the relevant inclusion and exclusion criteria for title and abstract screening.
- 4.4 We carried out a pilot stage of the REA. In this pilot stage, we tested all processes on Scopus, an academic database focused on social science journals. We applied the initial research questions as well as those processes detailed in each of the stages below, to create and test our developed search strings, inclusion and exclusion criteria, extraction sheet, screening and weighting.
- 4.5 Comparable mental states were determined by three processes. Firstly, we included those terms applied in the academic literature to describe grief (e.g. fear, shock, trauma, guilt, shame). Subsequently, an internal subject specialist (a NatCen colleague) and chartered psychologist was consulted to provide insight into comparable mental states. The results of this consultation were then discussed with the search specialist, who provided their expertise in identifying those synonyms that could capture these comparable states in the academic literature. Finally, the selected range of terms were discussed and agreed with the CMA.
- 4.6 Amendments to the different tools (i.e. search terms, inclusion/exclusion criteria, extraction sheet) were undertaken prior to the full search using the additional databases of PsycINFO and MEDLINE. These additions and changes were discussed and shared with the CMA as part of ongoing weekly catch-up meetings.
- 4.7 In addition, a range of shortened (or condensed) search terms were tested to identify relevant grey literature which similarly detailed the impact of recent grief/bereavement and/or comparable emotional states on decision-making capacity and purchasing behaviour. These were applied in a number of sources of high-quality grey literature, including GreyMatters and the OECD website (see Table 1, below).

Stage 1: Evidence Identification

4.8 Following the pilot stage and the finalisation of the tools, we identified the relevant evidence for the REA. The sources used and, processes applied are detailed below.

Database searches

- 4.9 Three academic journal databases were systematically searched to identify relevant published literature. These search terms were in the form of Boolean search strings that incorporated a range of key words and concepts into literature databases. Finalised search strings are included in Appendix A.
- 4.10 The following databases were searched using the finalised search strings:
 - a. MEDLINE;
 - b. PsychINFO; and
 - c. Scopus.

Grey literature searches

4.11 Grey literature repositories and websites were manually searched to identify relevant grey literature. These search terms were in the form of key words, as determined during the pilot stage (Stage 0, above). Finalised key words are included in Appendix B.

Table 1: Listing of grey literature repositories and websites

Repositories	Websites
Grey Matters	Age UK
OpenGrey	Carers UK
	Citizens Advice
	Fair Funerals Campaign
	GOV.UK
	Hospice UK
	Joseph Rowntree Foundation
	Macmillan Cancer Support
	Marie Curie
	Mind
	Money Advice Service
	Money and Pensions Service
	OECD
	Samaritans
	Social Care Institute for Excellence
	The Good Funeral Guide

Stage 2: Evidence selection, screening and weighting

Title and abstract screening

4.12 Following the searches in the databases and grey literature sources identified above, a process of screening the titles and abstracts of all the evidence against the inclusion and exclusion criteria (Appendix C) took place. At the title and abstract screening stage, studies that appeared to be relevant were included for full-text review. Title and abstract screening took place at source, i.e. papers were screened on the

website or repository to assess the type and extent of information that may be included in the paper or report. Title and abstract screening was completed using Abstrackr, an online database screening tool that applies artificial intelligence (AI) to prioritise the listing of papers dependent on the choices and selections made by the researcher. As the programme begins to 'learn' the type of papers that are being selected by the researcher, the listing of papers is continually reprioritised to 'move-up' those papers or reports likely to be of greater relevance. Sensitivity analyses of results generated by this AI programme has demonstrated that Abstrackr has the potential to reliably prioritise and identify relevant citations. In exploring this, a study¹¹ found that in two datasets, all relevant citations were identified, whilst in a further two datasets, only one relevant citation was missed.

4.13 Following title and abstract screening, any papers where inclusion (or exclusion) was unclear were discussed amongst the NatCen team. All inclusion decisions at the title and abstract screening stage were checked by a second reviewer.

Full-text screening

4.14 At full-text screening and extraction, information from each of the selected papers was charted (written) into an agreed framework (see Appendix D), with studies excluded if they did not meet the full-text inclusion and exclusion criteria. These inclusion and exclusion criteria were based on a scoring system developed with the CMA, building upon the inclusion and exclusion criteria used for title and abstract screening. Papers were scored by reviewers to identify the topics that each paper covered. Each paper could receive a maximum score of 18 points (incorporating both the thematic areas within the framework as well as the weight of evidence score). Papers were sorted by score and NatCen, following discussion with the CMA, determined a minimum score which each paper needed to obtain to be included in the review.

Weight of Evidence tool

- 4.15 Weight of Evidence (WoE) criteria were applied to score the evidence according to relevance and robustness (see Appendix D). The WoE analysis is based on the approach first developed by the EPPI-Centre (Evidence for Policy and Practice Information and Coordinating Centre) and has been applied in the analysis of both quantitative- and qualitative-based research 12. A WoE analysis explores each individual source in terms of quality and relevance to the overarching research aims and objectives, whilst providing a score of up to nine. Each study is weighted/scored based on:
 - a. Relevance;
 - b. Quality of design and methodology; and
 - c. Whether the research paper meets its stated aims and objectives.
- 4.16 A final assessment is made which considers these criteria and the source in its entirety, with scores for both relevance, insightfulness, and robustness.

¹¹ Rathbone J., Hoffman, T and Glasziou, P. (2015) Faster title and abstract screening? Evaluating Abstrackr, a semi-automated online screening program for systematic reviewers. *Systematic Reviews*, 4(80) DOI 10.1186/s13643-015-0067-6

¹² Gough, D. (2007) Weight of Evidence: a framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education*, 22(2): 213-28.

Proposed shortlist

- 4.17 A systematic process was applied to develop the proposed shortlist of papers for data extraction. Firstly, all papers with a Weight of Evidence (WoE) score of below eight (out of nine) were excluded, which resulted in 45 papers. Application of this score meant that all papers included in the shortlist demonstrated a valid, robust, reliable and (if a quantitative paper) transferable evidence-base, ensuring that any included findings were of high quality. All papers demonstrated: a clear statement of the aims and objectives of the research; a justified sampling strategy; the use of methods appropriate to examining the research question(s) posed; detailed ethics procedures and processes; clarity about funding sources; a justified data analysis technique; and, any conclusion reported stemmed from (i.e. did not go beyond) the presented evidence. From this pool of papers scoring eight and above on the WoE score, those additional papers with an evidence score of below two (out of nine) identified in the thematic framework (see 4.14, above) were excluded, which resulted in 27 papers. Subsequently, three of the thematic areas within the framework (see Appendix D) had a noticeable absence of papers; these were:
 - a. The nature and scale of the effect (if any) of recent grief/bereavement on decision-making behaviour;
 - b. The nature and scale of the effect (if any) of recent grief/ bereavement on purchasing behaviour;
 - c. The nature and scale of the effect (if any) of different emotional states or life events on purchasing behaviour.
- 4.18 To increase the number of papers in these areas and achieve a wider range of evidence, the WoE cut-off point was lowered to seven for the above three criteria. This ensured that the researchers were still satisfied with the strength of evidence of the papers included, as they met most of the criteria above, whilst recognising the importance of including papers which were relevant to less-explored areas. This resulted in six additional papers, with 33 papers being included in the proposed shortlist.

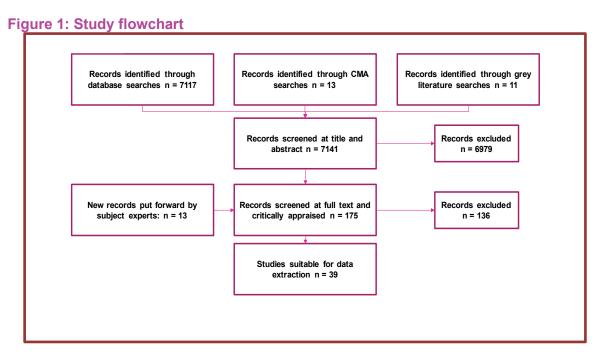
Round table discussion

4.19 Following the extraction of these 33 papers into the agreed framework (Appendix D), an early analysis was carried out and the interim findings presented at a round-table discussion on 4th March 2020. Taking place at the CMA offices in London, this half day discussion included the NatCen research team, representatives from the CMA, from the third sector (e.g. CRUSE) and two of the four subject matter experts (see 4.20). A presentation was provided that detailed the methods applied and highlighted the emerging findings against each of the three research questions (see 3.1). In addition, a range of prompt questions were prepared to support a wider discussion. These ensured appropriate feedback could be sought from participants, contradictions or gaps in the evidence could be discussed and further information provided by the stakeholders to the NatCen research team on the implications of the interim findings. The feedback received at this exercise was incorporated into the continuing further analysis and reporting. The slide-pack presentation and prompt questions can be found in Appendix E.

Subject matter experts

4.20 Following the screening process, a database was created of those papers selected for data extraction. This was shared with four subject matter experts at national and international universities. Our subject experts were:

- Darach Turley, Emeritus Professor of Marketing, Dublin City University Business School:
- Dr Julie Rugg, Senior Research Fellow, University of York;
- Dr Kate Woodthorpe, Senior Lecturer, Centre for Death and Society, Department of Social and Policy Sciences, University of Bath;
- Ruth McManus, Associate Professor, University of Canterbury, Christchurch, New Zealand, President of the Society for Death Studies (NZ).
- 4.21 The experts reviewed the database of screened papers to identify any relevant papers that they perceived should have been included in the extraction process. Feedback was received in two ways.
 - a. A number of papers that had been placed in the exclusion list were identified for reconsideration.
 - b. Further papers were recommended that had seemingly not been identified through the search terms.
- 4.22 In exploring these additional recommendations, the research team carried out a series of assessments. First, those papers that had been placed in the exclusion list (and recommended by our experts for inclusion) were re-scored by a further reviewer to assess if the exclusion of these papers had been appropriate. Second, additional recommended papers were scored applying our existing framework and WoE criteria. In bringing together these actions, an additional eight papers were included within the review. This resulted in a total of 39 included papers (see Figure 1, below).



Data extraction

- 4.23 On screening for final inclusion, core information about each paper was placed in an extraction sheet (see Appendix F) for internal analysis use in Stage 3 (below) and subsequent report development. The extraction sheet was refined in consultation with the CMA and included (amongst other areas):
 - a. Short summary of key findings.
 - b. Sample size and level of representation (e.g. is the study nationally representative).
 - c. Setting of the research (e.g. funeral service, hospital, palliative care unit).
 - d. Level of focus of the article on grief or bereavement and/or comparable mental health states.
 - e. Type of behaviour or decision-making
 - f. Impact (if any) of grief and bereavement on decision-making.
 - g. Main conclusions; and
 - h. Weight of Evidence (WoE) score.

Stage 3: Narrative synthesis and information integration

4.24 The literature that details consumer vulnerability in the funeral market was heterogeneous in terms of methodologies used (e.g. cross-sectional surveys, ethnography, observational, one-to-one interviews, focus groups). To bring these data together we used the extraction sheets to carry out a narrative synthesis. Research papers and 'grey literature' were analysed using a method analogous to qualitative data analysis. A line-by-line inspection of the studies was carried out on the area of interest in each paper, e.g. the results or discussion section. Different codes were attached and then organised into broader descriptive or conceptual themes, building complete models of concepts, outcomes or findings. Inferences were then drawn from across the papers and the information was organised into coherent narratives. In interpreting the data, we were also mindful of drawing out any differences in international examples that were more (or less) transferable to the UK context.

5 Findings

Type and extent of included papers

In applying the search terms and moving through the different stages of this REA (see above), a range of papers were extracted, focused toward grief following bereavement as well as a number of comparable emotional states, i.e. fear, emotional distress, shock, guilt and shame (paragraph 4.5 above describes how these were decided upon). Table 1 details the focus of the study, the authors, study type and number of participants. All these shortlisted papers have used robust research methods to investigate the research questions. There is a good mix of qualitative (including observational and ethnographic studies) and quantitative studies (surveys) as well as studies using a mixed methodology. As discussed, part of the scoring system included the type of methods applied in responding to the study research questions, allowing for a more conclusive discussion when considering the strength of the evidence presented. Quantitative studies (e.g. surveys) and the use of inferential statistical analyses allow for results to be generalised to the population being studied, whereas qualitative studies allow for an in-depth exploration of the questions and richness in the evidence provided. The shortlisted studies provide strong evidence using a variety of methodological tools.

Table 2: Focus of included papers

Study focus	Bereavement or 'transferable' paper	Authors	Methods	Country	Participant numbers
Funerals (services,	Bereavement	Aoun et al., 2019	Cross-sectional postal survey	Australia	n=1139
bereavement support, poverty and debt)	upport, overty and	Corden and Hirst, 2015	Workshop and one interview (both face to face)	United Kingdom	n=20
		Drenten et al., 2017	Photo-analysis and online ethnography	United States	180 photos
		Halpenny, 2013	Cross-sectional online survey and face to face interviews	Ireland	Survey, n=50 Interviews, n=3
		Korai and Souiden, 2017	Interviews (9 face to face, 1 via email)	Canada	n=10
		McCarthy, 2016	Face to face interviews	United Kingdom	n=18
		McManus and Schafer, 2014	Online cross- sectional survey and face to face interviews	New Zealand	Survey, n=105 Interviews, n=12
		McQuaid, 2013	Interviews (mode not stated)	United States	n=46

Study focus	Bereavement	Authors	Methods	Country	Participant
	or 'transferable' paper				numbers
Bereavement and Grief	Bereavement	Bellamy et al., 2014	Telephone interviews	New Zealand	n=28
		Blackburn and Bulsara, 2018	Interviews (face to face, telephone & Skype)	Australia	n=24
		Glick et al., 2018	Cross-sectional survey (paper questionnaire completed in the hospital)	United States	n=50
		Stevenson et al., 2016	Interviews (mode not stated)	Canada	n=21
Decision- making in financial planning	Transferable	Joseph Rowntree Foundation, 2017	Systematic literature review	United Kingdom	n=266 papers
End-of-life care	Transferable	Dionne-Odom et al., 2015	Interviews (face to face & telephone)	United States	n=19
		Forbes et al., 2000	Focus groups (face to face)	United States	n=28
		Gerber et al., 2019	Face to face interviews	Australia	n=17
		Monaro et al, 2014	Interviews (face to face and telephone)	Australia	Patients n=11 Carers n=5
		Price et al., 2014	Face to face interviews	United Kingdom	n=45
		Yamamoto et al., 2017	Cross-sectional postal survey	Japan	n=700
Care (other)	Transferable	Bern-Klug, 2008	Secondary analysis of qualitative data (mode not stated)	Spain	n=44
		Baxter and Glendinning, 2013	Interviews (mode not stated)	United Kingdom	n=52
		Chiu et al., 2015	Randomised control design applying a survey (data collected in person & over the phone)	Canada	Intervention group, n=23 Control group, n=24
		Lambert et al., 2005	Interviews (mode not stated)	United States	n=9
		Wolfs et al., 2012	Focus groups (face to face)	Netherlands	n=29

Study focus	Bereavement	Authors	Methods	Country	Participant
	or 'comparable' paper				numbers
Organ donation	Transferable	de Groot et al., 2016	Secondary analysis of qualitative data (face to face interviews and one letter)	Netherlands	n=24
		Lopez et al., 2018	Cross-sectional paper survey	Spain	n=421
		Sque et al, 2007	Interviews (face to face & telephone)	United Kingdom	n=26
Midwifery and Paediatric	Transferable	Hallstrom et al., 2002	Observational (in person)	Sweden	Parents = 35 Children =24
(stillbirth, miscarriage,		Horey et al., 2012	Focus groups (face to face)	Australia	n=17
child hospitalisation		Meaney et al., 2015	Face to face interviews	Ireland	n=10
and medication)		Oleson et al., 2015	Interviews (mode not stated)	Denmark	n=11
		Taylor et al., 2006	Interviews (face to face and telephone)	Australia	n=33
Mental health (depression, service use, social exclusion and post-	Transferable	Britain Thinks, 2018	Ethnographic (face to face) and record analysis (online)	United Kingdom	n=48
traumatic stress disorder)		Britain Thinks, 2018a	Ethnography (face to face and online)	United Kingdom	n=48
		Citizen's Advice, 2004	Cross-sectional survey, case studies and interviews (modes not stated)	United Kingdom	n~510
		van Randenborgh et al., 2010	Cross-sectional paper survey (completed in lab settings)	Germany	n=85
		Regehr and LeBlanc, 2017	Cross-sectional paper survey (completed in lab settings) and assessed simulated scenarios across four studies	Canada	n=315
Critically ill patients	Transferable	Bernat-Adell et al., 2012	Observational (face to face)	Spain	n=29
Cancer care	Transferable	Lifford et al., 2015	Secondary analysis of qualitative interviews (face to face)	United Kingdom	n=35

The nature and scale of the effect (if any) of recent grief and bereavement on consumers' decision-making capacity and purchasing behaviour

Impact of grief/bereavement on decision-making capacity

- Overall, there was a limited number of academic papers or grey literature that detailed the impact of grief or bereavement on decision-making capacity or purchasing behaviours directly relating to arranging a funeral. Of those papers extracted (n=39), five were found to be specific to the research questions (Halpenny, 2013; McQuaid, 2013; McManus and Schafer, 2014; Korai and Souiden, 2017; Aoun et al., 2019). However, the impact of grief and bereavement on decision-making at different life points was discussed in a range of transferable papers focusing on comparable emotional states, further exploring and informing the research questions (see Table 1, above). Each highlighted the impact of grief or bereavement on making decisions around, for example, end-of-life hospital treatment (e.g. Sque et al., 2008; de Groot et al., 2016), organ donation (e.g. Lambert et al., 2005; Dionne-Odom et al., 2015; Lifford et al., 2015; Glick et al., 2018; Lopez et al., 2018), miscarriage and still-birth (e.g. Horey et al., 2012; Olesen et al., 2015), as well as choosing welfare and social care services at a time of crisis (e.g. Baxter and Glendinning, 2013; Price et al., 2014).
- 5.3 The definition of decision-making that we adopt in this REA was drawn from a study (systematic literature review) by the Joseph Rowntree Foundation that explored how poverty impacts on people's decision-making processes. In this study, decision-making was defined as "The thought process of selecting a choice or action from a set of available options" (JRF, 2017: 45). Three core areas emerge from this definition. First, any individual needs to be able to cognitively process choices, to compare what is being suggested, and to think about any wider context to understand what action should be taken. Secondly, individuals need to have options from which to choose (i.e. having one available option does not allow choice). Finally, they need to be able to financially and emotionally act on those choices. Limited cognitive capacity will constrain those choices as well as the ability to act.
- 5.4 Drawing on all papers extracted, there is an overarching consensus that the psychological effects of grief or bereavement make it challenging of for consumers to make informed decisions (Korai and Souiden, 2017; Aoun et al., 2019). In addition, where discussed, it was identified that few individuals made an active choice as to the funeral home they selected, or the type and extent of the funeral package purchased (McQuaid, 2013). Those papers that discussed grief and bereavement outside of the funeral industry were able to provide some insight into how these emotions impacted on the cognitive process of making decisions.
- 5.5 Lopez et al. (2018) explored how (and why) bereaved individuals make decisions around organ donation. From a cross-sectional survey with relatives of deceased people (n=421), they were able to highlight that cognitive processes 'shrank' to fit the situation. Mental 'short-cuts' were taken, with only the most relevant factors (e.g. wishes of their relative as opposed to discussions with health professional) considered whilst others were ignored or obscured. The application of such mental short-cuts was reflected in the actions of the family members. That is, in their state of grief, and particularly if they had increased emotional reactions, they would supersede the stated wish of their relative. That is, even if this individual had agreed and wished to donate their organs, their relatives were less likely to consent to any organ extraction

and donation. The bereaved individual or family were seemingly unable to process the wider context of making any decision, including that of the wishes and wants of their relative who had died.

- An individual's decision-making capacity or cognitive processes will also 5.6 seemingly be affected prior to the death of their relative. 'Anticipatory grief' (i.e. grief before the actual death of the individual) and/or 'uncertainty angst' (a state of simply not knowing what decision should be made) were also referred to in studies where the death of a relative was either anticipated or the most appropriate decision was not clear. One paper (Glick et al., 2018) identified that 'anticipatory grief' impaired problemsolving. In applying the Social Problem-Solving Index¹³ to explore how well (or not) individuals (n=50 across seven intensive care units) were able to make decisions for their critically ill relative (i.e. undertaking surrogate decision-making), the papers found high levels of impairment across problem-solving. Higher levels of anticipatory grief were significantly associated with poorer overall problem-solving ability. An individual's ability to cognitively process information and make decisions on behalf of their relative was not only reduced, but it was found that higher measures of anticipatory grief increased impulsivity and carelessness. In addition, for some participants, the decisionmaking capacity was seemingly 'closed-down': individuals choosing to avoid decisionmaking, handing over responsibility to the clinical 'experts'.
- 5.7 Avoidant decision-making was also seen across a number of papers throughout different 'life events' such as end-of-life care, miscarriage and welfare support (Baxter and Glendinning, 2013; Dionne-Odom et al., 2015, Olesen et al., 2015). Dionne-Odom et al. (2015), as well as highlighting the impact of 'anticipatory grief' on decision-making, also identified that relatives (n=19) of dying patients (resident in an intensive care unit) were affected by 'uncertainty angst'. The papers highlighted that avoidant decision-making was triggered in several cases by not knowing what their relative would have wanted, as well as a lack of clarity or information around the medical situation of the patient.
- Such findings were underpinned by Baxter and Glendinning (2013). In exploring the role of emotions in the process of making choices and decisions about social care provision (e.g. admission to residential care), this paper linked such avoidant decision-making to overarching theories around emotion-focused coping (Folkman and Lazarus, 1988, cited by Baxter and Glendinning, 2013: 440). That is, in coping with negative emotions, individuals will simply attempt to avoid any unwanted emotion (e.g. grief, shock). This resulted in either reducing the amount of thought devoted to the choice that was being made (similar to the mental short-cuts highlighted by Lopez et al., 2018), or delaying any decision. In addition, Baxter and Glendinning (2013) detailed that such behaviours may result in a preference for the status quo or the transfer of permission to make core decisions to someone else.
- 5.9 This latter point was similarly found by Olesen et al. (2015) in a study that explored the decision-making process of women experiencing miscarriage. All the women in this study (n=11) identified as suffering from fear, emotional distress, shock, guilt and shame and it was argued that all found their ability to process and apply treatment information to be severely impaired. Reflecting the findings of Baxter and Glendinning (2013), the papers found that women did not just avoid decision-making, but moved the responsibility for deciding on their treatment path to clinicians or healthcare practitioners, asking 'what would you do'? As a further paper highlighted when discussing surrogate decision-making for carers of people living with dementia: "Because of the emotional demands, some people navigated only part of the journey.

-

¹³ This is a 25-item questionnaire that examines problem orientation across five elements of decision-making to address problems (positive, negative, rational, impulsive, careless and avoidant).

forcing others to take over. Some, either actively or passively, allowed providers, nursing facility personnel, to become the decision-makers" (Forbes et al., 2000: 256).

Contextual factors that impact on decision-making in the funeral industry

- 5.10 Alongside the impact of death on cognitive processing and subsequent decision-making, the situational impact of the funeral *per se*, as well as the context of the bereavement (where, when and how the relative died) will additionally impact on an individual's choice and purchasing-behaviours (McManus and Schafer, 2014). For example, where the death is perceived as 'natural', e.g. in old age and outside of hospital or hospice care, the experience of bereavement and grief by any individual or family may be different from that of a parent whose child has died suddenly. In short, bereavement is necessarily individual to the person experiencing the death. The type and extent of decisions, choices and acts we are able (or not able) to make will be linked to our own understanding of death and illness, underpinned by the myriad of life experiences encompassing spiritual, emotional and social perceptions and beliefs (Lambert et al., 2005).
- 5.11 Where discussed, all papers identified that a lack of knowledge around planning or purchasing funerals impacted on an individual's decision-making (Forbes et al., 2000; Corden and Hirst, 2015; McCarthy, 2016; Aoun et al., 2019):
 - "Oh my God, how do I bury my husband?' I had no knowledge that he stayed in the mortuary and the funeral director picked him up, and the funeral director arranged the death certificate. I didn't know what happened [...] the nurse said, 'You need to organize a funeral director' and I went 'Oh, how much time do I have?' you know, like do I have to do it tonight? Do I do it tomorrow? When do you do this? (Blackburn and Bulsara, 2018: 629)
- As this quote reflects, for many individuals, the grief and shock of any bereavement is compounded by lack of knowledge around the process of planning and purchasing a funeral, as well as the time-frame in which this needs to be carried out. Corden and Hirst (2015), in a qualitative study (n=20 interviews) exploring funeral poverty, reported that some family members emphasised that their inexperience in organising a funeral required them to make decisions outside of any prior experience or knowledge. They detailed they may never have attended a funeral previously, have no or low awareness of the range of options that could be available and, as a result, were completely reliant on the funeral director. Such findings were mirrored by Aoun et al. (2019). Through a cross-sectional survey (n=1,139) exploring bereaved individuals' experience of funeral providers, the papers found that many respondents reported unfamiliarity with the processes or the demands of planning (and purchasing) a funeral, relying on the funeral director to navigate them through the experience by the provision of appropriate and timely information. McQuaid (2013), in a qualitative interview study (n=56, 31 consumers and 26 funeral directors) that explored how buyers and sellers in the funeral market interacted, similarly reflected the above findings, finding that consumers were unaware of how to go about arranging a funeral, unable to 'assess the competence' of the funeral director to deliver appropriate services, or to infer trustworthiness (McQuaid, 2013: 210).
- 5.13 This naivety and inexperience of many individuals at the point of choosing or purchasing a funeral was similarly affected by the perception that they only have a small window of opportunity in which to decide arrangements as well as "consider and deal with costs" (Corden and Hirst, 2015: 19). This additional pressure, requiring immediacy of decision when cognitive processing was necessarily difficult, was again reflected by Aoun et al. (2019) who identified that "In addition to emotional disruption,

bereavement affects decision-making capacity at times when an individual may need to deal with immediate, unfamiliar demands." (Gentry, Kennedy, Paul & Hill, 1995, cited by Aoun et al., 2019: 619).

- 5.14 A further contextual factor that needs to be understood when exploring how and why individuals make (or do not make) decisions around funeral purchasing is the impetus to keep the dying or dead person 'safe' (Sque et al., 2007). This paper, drawn from the transferable literature, drew on qualitative interviews (n=23) with individuals who had declined to donate their relative's organs and tissues. In exploring their decision-making (and rationale) for this stance, it was found across 15 interviews that the core perception informing decision-making was not knowledge of the person's wishes (at times, superseding what their relative might have wanted), but the need to protect the "integrity and wholeness" (140) of their relative's body.
- 5.15 This drive to keep the body 'safe' and to reduce or control any further violation or desecration of the body was reflected and extended in those papers that directly explored the funeral industry. McManus and Schafer (2014) carried out a mixed methods study (survey n=150, qualitative interviews n=12) to understand why individuals may take on funeral debt. The paper argues that purchasing and arranging a funeral necessarily encompasses a range of socio-emotional processes, including the need to do the 'best' for their loved one. Similarly, McQuaid (2013), found that controlling costs of the funeral (e.g. by purchasing the least expensive casket available) was perceived as "insulting to the deceased and a sign to the community that the deceased was not valued" (McQuaid, 2013: 49). There was seemingly an overarching need to ensure that the 'value' of the deceased relative was reflected in the funeral ornamentation as well as the process.

Outcome of cognitive and contextual factors on decisionmaking and choice in the funeral industry

- 5.16 From the evidence that discusses the impact of grief and bereavement on decision-making, it seems that, overall, individuals will struggle to make logical and rational choices and actions whilst experiencing bereavement or likely bereavement. They may employ mental 'short-cuts', avoid or delay decisions, show preference for the status quo and/or attempt to pass the decision onto someone else (Baxter and Glendinning, 2013; Dionne-Odom et al., 2015; Olesen et al., 2015; Glick et al., 2018; Lopez et al., 2018). These challenges to cognitive processing are compounded by the perception (upon bereavement) that purchasing a funeral must take place as quickly as possible (Corden and Hirst, 2015; Aoun et al., 2019). In addition, the majority of individuals are inexperienced in purchasing (and arranging) funerals, demonstrably uncertain as to what actions they should be undertaking (Forbes et al., 2000; McQuaid, 2013; Corden and Hirst, 2015; McCarthy, 2016; Aoun et al., 2019). Bringing these factors together results in individuals seemingly not putting in place the normal checks and balances that would be applied when acting as a consumer, i.e. shopping around, checking costs, identifying the value of different 'packages' that may be available.
- 5.17 Where discussed, it was identified that few individuals made active 'choices' about the funeral home they used (Halpenny, 2013; McQuaid, 2013; Korai and Souiden, 2017). McQuaid (2013) highlighted that despite consumer uncertainty, the bereaved individual will simply contact the funeral home that had either supported them at a previous bereavement or had been used before by a family member or friend: "She said that she had always known that if anything were to happen to her or her husband they would go to Lamont's, because as she said, 'my mother was there, my father was there'. I don't know'." (McQuaid, 2013: 92). Two further papers reflected this finding and, in addition, detailed that for many, the choice of the funeral home may be simply

based on the ease of location, reducing stress and travel times (Halpenny, 2013; Korai and Souiden, 2017).

- Few papers provided further rationale as to why the impact of grief and bereavement may result in individuals stepping out of any consumer behaviours they might normally demonstrate. Whilst McQuaid (2013) argued that "The majority of funeral consumers' purchases are unreflexive and therefore not to be thought of choices at all" (McQuaid, 2013: vii), his wider analysis would seem to reject the argument that it is the impact of grief and bereavement on decision-making that results in chaotic or careless behaviour in making choices and taking actions around funeral purchasing. Rather, consumers simply avoid price comparison owing to the perceived sacred nature of the funeral. Searching for the lowest price disturbs that ritual adherence to this sacred nature of the funeral and 'insults' the deceased. To some extent, this assessment was supported by McManus and Schafer, 2014. Although the paper recognised the intensity of emotions that are present whilst making decisions about funeral purchasing, bereaved individuals and families will ignore any pricing owing to the need to 'do the best' for their loved one. "A funeral is an important occasion. I feel that a small debt would be better than the regret one would feel if a loved one did not receive an appropriate funeral" (McManus and Schafer, 2014: 389).
- Many of the papers alluded to the 'risks' consumers face as a consequence of the impact of grief and bereavement on decision-making, highlighting prior papers around over-charging, lack of control and reliance on the 'expert' in order to make a decision (e.g., McQuaid, 2013; McManus and Schaefer, 2014). However, only one paper (Aoun et al., 2019) explored the consequences of this suspension of normal consumer practice. In exploring bereaved individuals' experiences of funeral service providers, some study participants perceived funeral providers as professional, providing appropriate instrumental and emotional support in organising the funeral. However, when there were difficulties in the relationship and the delivery of the funeral, these were "described as emotionally detrimental" (Aoun et al., 2019: 623). In particular, although reported experiences were, on average, divided between those who had good and those who had poor outcomes, the majority of participants reported that discussion of costs between the bereaved individual or family and the funeral director resulted in a "financial tension" and was perceived by the majority of participants as an "unfavourable aspect of their interaction with funeral providers" (Aoun et al., 2019: 623). The reasons for the financial tensions were related to challenges of meeting payment deadlines, the lack of transparency of costs as well as perceiving financial policies as "inconsiderate" and "exorbitant" (Aoun et al., 2019: 623).

Comparable emotional states on decisionmaking capacity and purchasing behaviour

- 5.20 In exploring the impact of comparable emotional states, we incorporated fear, emotional distress, shock, guilt and shame (Hallstrom et al., 2002; Baxter and Glendinning, 2013; Lifford et al., 2015; Meaney and Gallagher, 2015; Dionne-Odom et al., 2019; Gerber et al., 2019). As we have discussed, the rationale for incorporating these terms can be found in paragraph 4.5 above. In addition, it will be noted that in discussing the impact of grief and bereavement on decision-making, a number of papers cited were drawn from this wider health and care literature as many of these mirrored the existing (small) literatures on the challenges of decision-making during grief and bereavement.
- 5.21 Each paper identified (perhaps not surprisingly) that these negative emotions (i.e. fear, emotional distress, shock and shame), more than positive emotions, impact on cognitive processes and, in consequence, the decision-making process (Lifford et

- al., 2015; Olesen et al., 2015; Dionne-Odom et al., 2019). Gerber et al., (2019), in their qualitative interview study (n=17 individuals, eight patients and nine care-givers), explored how terminally ill patients and their family caregivers reach a decision about the location of end-of-life care. It was found that processes of decision-making during this time are underpinned by uncertainty as to their suitability (Gerber et al., 2019).
- 5.22 As we have reported, the study by Baxter and Glendinning (2013), focusing on decision-making and choice in social care, identified that many participants at a crisis point reduced the amount of thought devoted to any choice, avoided the decision altogether, delayed any decision, accepted the status quo and/or passed this decision onto someone else: "I wasn't really thinking straight at the time, I don't know what I was thinking in fact. Was I thinking, was I able to think? It was just instinctive" (Baxter and Glendinning, 2013: 445). Such incoherent decision-making was reflected in a further study. Meaney and Gallagher (2015) explored decision-making processes in parents who had experienced stillbirths and who had consented to, or declined, an autopsy. For many parents, decision-making was "incoherent and fuelled by emotion" (3165) with some admitting that any decision around autopsy was solely "an emotional decision rather than based on any fact" (3166).
- 5.23 In addition, a number of these papers highlighted that decisions made at a time of crisis in fear or in a high emotional state had long-term impact. For example, Dionne-Odom et al. (2015) carried out a qualitative study (n=19 interviews) to identify and describe the underlying psychological processes of individuals when making medical or treatment decisions for their relative during the latter's admission to an intensive care unit. In their study, they highlighted that participants were having to make decisions during a time of anticipatory grief (prior to the death of their relative), uncertainty angst (an inability to know what decision should be made) and empathetic distress (the vicarious distress felt when seeing the pain and suffering of their loved one), as well as a lack of knowledge as to what the individual may have wanted. Whilst these emotional states reduced decision-making efficacy, it was found that decisions made under these emotions had resulted in long-term individual ramifications, with the possibility of regret, guilt and distress for months or even years afterwards as to whether the right decision had been made.

Interventions to mitigate deficits in decisionmaking capacity and purchasing behaviour

'Institutional' interventions

5.24 A number of studies recognised that people living with grief as a result of bereavement (McQuaid, 2013; Bellamy et al., 2014; Price et al., 2014) or comparable emotional states (Baxter and Glendinning, 2013) may need greater institutional support (e.g. be part of the remit of a local or health authority department to implement). Whilst these studies highlighted the necessary institutional support in the context of decision-making and carrying out a range of practical activities, no single paper discussed such support in the context of purchasing behaviour. Similarly, whilst papers identified that some form of institutional response would support individuals, none of the papers provided concrete details of the focus of such institutional responses (e.g. as part of the role and remit of any particular local or health authority department). For example, one study that explored older people's views, experiences and sources of support following the death of a relative, highlighted the "value of adopting a public health-based approach as a way of optimising bereavement support" (Bellamy et al., 2014: 101). Unfortunately, at no point is it clear what this approach might entail, how it may be

developed and what further partnerships (e.g. with community organisations) need to be put in place.

- 5.25 A further paper reflected this absence of any clear pathway to identifying and developing an institutional response. Blackburn and Bulsara (2018) carried out a qualitative interview study (n=24) exploring participants' experiences in dealing with practical matters following bereavement (e.g. obtaining the death certificate, notifying a range of utility companies, moving into probate). Participants identified a range of challenges in managing the post-bereavement process (e.g. an overwhelming amount of paperwork and the need to make multiple contacts with organisations) and expressed a wish for a centralised agency "or allocated 'go to' person, with up to date knowledge, experience, and practices in relation to bereavement, particularly in relation to dealing with the deceased's estate and other practical matters" (Blackburn and Bulsara, 2018: 631). Again, it was unclear where this centralised agency should be located or who should take responsibility for supporting individuals following any bereavement.
- 5.26 As part of their analysis, Blackburn and Bulsara (2018) identified that, alongside this centralised agency, consideration should be given to changing bereavement legislation to account for the range of decisions and actions individuals face on the death of a relative, extending statutory bereavement leave. The role of legislation in supporting an individual's decision-making was similarly highlighted by Forbes et al. (2000). This qualitative study (four focus groups, n=28) explored the experiences of those family members who were making decisions on behalf of their relative living with severe dementia. Participants identified the challenges of decision-making when admitting their relative to residential care or to end-of-life care and the consequent "overwhelming burden and undying guilt" (Forbes et al., 2000: 253). This study (drawn from the US), identified the importance of fully enacting and applying existing legislation to support individuals' decision-making. They highlighted that whilst the Patient Self-Determination Act (1991) requires institutions "to inform patients of their right to participate in medical decision making and complete an advance directive" (Forbes et al., 2000: 252), fewer than 20% of the population are seemingly aware of, or completing, such directives. The use of advance care directives is discussed in more detail further below (see 5.4.3).
- 5.27 In discussing the type of institutional support that should be provided for decision-making, a number of studies identified the need for appropriate staff training across a range of organisations in the funeral industry, health and social care. Korai and Souiden (2017) in their qualitative interview study with funeral staff (n=10) explored the central characteristics of funeral services. The paper identified that owing to "consumers' lack of competency" in purchasing funerals (247), the emotion-driven nature of the purchase, and that consumers were seeking emotional connection with the funeral provider, specific "consumer relationship management training" (256) should be undertaken. Whilst the paper recognised that some existing training in consumer relationships was available (e.g. Funeral Industry Development Australia and College Notre-Dame de Foy, Quebec) they made strong recommendations that any inhouse or external training for funeral staff should incorporate psychological support and empathy if the emotion-driven nature of the purchase were to be appropriately managed and supported.
- 5.28 In those papers that explored grief as well as comparable emotional states (e.g. fear, shock, guilt, emotional distress) across the health and care sector, it was highlighted that the emotional states of individuals were often not considered in relation to decision-making (Olesen et al., 2015). Whilst papers alluded to necessary further organisational staff support (e.g. Baxter and Glendinning, 2013), there was, again, little detail on the type and extent of training that was perceived as necessary.

5.29 One paper that did provide partial recommendations in exploring this area, applied a mixed-method response of surveys and simulated critical incident scenarios (n=315) to examine the effects of critical incident exposure (e.g. death of a child, death of an adult client, assaults and threats) on the decision-making of emergency workers (i.e. police officers, paramedics and child protection workers). Identifying that acute stress was associated with performance deficits in cognition, memory and assessment of risk, the paper recommended that any training delivered to support decision-making in the field should be delivered via simulation and/or led by patient engagement (Regehr and Le Blanc, 2017).

Relational interventions

- 5.30 As we have discussed above, the impact of grief following bereavement, as well as the comparable emotional states (fear, shock, guilt, emotional distress), all result in some form of avoidant cognitive processes and decision-making. Whilst for many of the purchases we make, no (or few) personal relationships are required (because they consist of simple instrumental transactions), planning and purchasing a funeral may involve a more personal and emotive type of communication (McQuaid, 2013). For example, in purchasing a pint of milk it is unnecessary to have a relationship with the individual at the check-out (instrumental transaction). In contrast, many consumers would seem to demand a more meaningful and/or informative interaction when purchasing a funeral. Analogous to healthcare procedures (from check-ups to operations as well as personal care), there would seem to be a need to develop some form of (trusted) relationship with those who are perceived as 'experts' (Olesen et al., 2015).
- 5.31 Many papers highlighted that support for decision-making was dependent on the type of relationship between the staff member (e.g. within the funeral industry as well as health, social and third sector care) and the consumer, patient or user (e.g. see Hallstrom et al., 2002; Olesen et al., 2015; de Groot et al., 2016; Dionne-Odom et al., 2016; Stevenson et al., 2016; Glick et al., 2018; Lopez et al., 2018;). As with much of the literature in this field, there were few concrete recommendations as to the type of relational interactions that were necessary to mitigate challenges in decision-making (or purchases), with even fewer identifying how relational interaction could be carried out in a high-pressure environment during a single appointment or discussion. For example, Baxter and Glendinning (2013) highlighted that a "lack of support made people feel isolated during choice-making processes" (444), going on to stress that if the negative aspects of emotion-laden choices were to be mitigated, individuals needed to be supported in their decision-making. However, there are no concrete recommendations that identified who should provide that support (e.g. social worker, personal care worker, residential care manager) or when it should be provided.
- 5.32 Where discussed, there was some indication that a transparent and clear dialogue between individuals and families and the 'experts' (e.g. funeral or health and care providers) was essential if appropriate decision-making was to be supported. Bernat-Adell et al. (2012), in a qualitative interview study with patients admitted to an intensive care unit (n=29), identified that most patients would like to be provided with clear information (as well as bad news) and to be included in any decision-making process. Such decision-making should be underpinned by "mutual respect and sincerity" (421).
- 5.33 Such mutuality in decision-making (or shared decision-making) was reflected in further papers. Each highlighted that where transparency of information or a dialogue was not in place, the resulting challenges were perceived by consumers as emotionally detrimental. Participants surveyed or interviewed as part of the study by Aoun et al. (2019), identified that clear communication led to positive outcomes: *"They listened"*

carefully to what we wished and provided exactly that" (623). In contrast, where communication broke down, participants found this hurtful: "We told the [funeral director] no religious stuff. He didn't listen. He asked us did we want a crucifix on the coffin? No, we didn't! He should have listened" (623). Similarly, Lopez et al. (2018) in their study exploring the rationale underpinning decision-making in organ donation found that whilst clear information was essential, mutuality (emotional support and a positive relationship) was fundamental if organ donation was to take place.

- A further challenge to mutuality or shared-decision-making was that many 5.34 decisions made during a time of grief or comparable emotional states are seemingly often unexpressed. The main finding drawn from one study exploring decision-making at or following miscarriage was that "women's choices were often based on unspoken emotional considerations" (Olesen et al., 2015: 389). The paper goes on to recommend that if appropriate decision-making is to be supported, healthcare practitioners first need to uncover these 'hidden' considerations. In short, staff need to ask the patients what actions (if any) they want to take and, give them the time to think about the options. For example, if patients were perceived as not being able to process information, staff may encourage women to go for a walk and consider the options. Such a technique perhaps also allowing time to think about further questions that may be able to be asked. A further paper partially reflected this finding, identifying that the extent to which parents were involved in decision-making following admission of their child to hospital was dependent on a dvadic interaction: "how explicitly parents explained their needs and how sensitive staff were in identifying the parents' needs" (Hallstrom et al. 2002: 212).
- 5.35 It was discussed that a relational interaction was challenging in an environment where decisions have to be made in a short-time frame and when the consumer may never previously have met the 'expert' (e.g. funeral staff member, health or social care clinician or professional). In one qualitative study (workshop, n=19, interview=1) that explored the concept of funeral poverty, it was identified that it may be important to challenge the assumptions that the funeral needed to be held as soon as possible, overcoming "the idea that people had only a small window of opportunity to consider and deal with costs" (Corden and Hirst, 2015: 19). If individuals are able to 'slow the process down', this may give them more time to discuss the funeral with 'experts', building that important relational interaction.
- 5.36 Where identified, it would seem to be clear from the literature that this relational aspect is important to consumers when making emotion-laden decisions (either in the funeral industry or health). Aoun et al. (2019) found that compassion, care and empathy necessarily had to be in place if the funeral process was to be perceived as 'successful'. In addition, for some participants a temporal aspect to care was essential, with follow-up contact from the funeral director perceived as "additional emotional support" (623). Where this was absent, participants perceived that staff at the funeral home may lack care, simply "just doing their job" (623). A further paper, which highlighted the importance of mutuality as well as temporality, reflected some of these findings. Parents whose child had spent months in hospital prior to death reported a double-loss: "that of their child and of their supportive relationships with staff" (Stevenson et al., 2016: 655). As one parent reported: "It wasn't just the loss of [their child]. We got to know people at the hospital over many years, a third of our working life was spent there. You see the same people, get to know the same people, then from one day to the next it finishes there" (Stevenson et al., 2016: 655-656).

Individual interventions

- 5.37 In exploring those individual interventions that may support decision-making and purchasing behaviour, two recurrent themes were identified in the literature: the need for clear information, and advance care planning.
- A number of papers identified that it was essential to provide targeted and clear information and guidance to support decision-making, ensuring that the different choices made (and consequences) were transparent (e.g., Baxter and Glendinning, 2013; Olesen et al., 2015; de Groot et al., 2016; Lopez et al., 2018). In discussing how this information should be presented and at what time point it should be provided, again, concrete recommendations were scarce. Some papers simply identified that information would be expected to relate to more positive outcomes, without detailing whether this should be delivered verbally in a face-to-face meeting, provided in a written format, talked through with the consumer or patient or simply given as a 'leaflet' that could be taken away. For example, one study identified that "[q]ualified and clear information about donation" would result in positive outcomes without specifying the type, extent, structure of this information or how it would be delivered to patients (Lopez et al., 2018: 41). Similarly, whilst Baxter and Glendinning (2013) highlighted that participants identified a level of regret if they had "stumbled upon" information about choices or found information was too limited to support decision-making (445); no recommendations are made around the type of information necessary.
- 5.39 In the study by McQuaid (2013), exploring the interaction between funeral providers and consumers, it was highlighted that whilst the range of information necessary to make decisions and choices about purchasing a funeral (e.g. how and where the body is stored) was limited, US federal regulation had ensured all consumers were able to access specific price information. Following this requirement (enacted in 1984), funeral homes were mandated to provide a general price list to anyone who requested this, as well as a specific price of funeral packages. "As such, any consumer with a phone can survey the prices of every funeral home in his or her area in a matter of minutes. While funeral consumers theoretically face uncertainty about many aspects of the funeral arrangement process, price uncertainty could easily be managed in funeral markets" (McQuaid, 2013: 80).
- 5.40 Only two papers in this review explored how information could (or should) be provided to support decision-making. Lifford et al. (2015) carried out a secondary analysis of qualitative interviews with older women with breast cancer (aged 75 and over) to understand their needs for information and support as well as the type and extent of information that would ensure their involvement in the decision-making process. In particular, these secondary analyses enabled the development of a Decision-Support Intervention (DSI) tool. This DSI was produced in a 'grid' form with the first page summarising treatment options as well as details on, for example, side-effects and likely outcomes. The next pages provided a fuller, expanded options grid on each type of treatment available. The paper argued that "The dual approach of a concise and expanded DSI format may support fast, intuitive emotional responses as well as more deliberative, cognitive responses to information about treatment options" (Lifford et al., 2015: 11).
- 5.41 The second paper that provided insight into how decision-making could be supported was a study by Chui et al. (2015). This research carried out a small, randomised trial (n=47, 23 in the intervention group and 24 in the control group) to assess the impact of an intervention to provide problem-solving techniques to unpaid carers of people living with dementia. Those carers in the intervention group received three one-hour visits from a care co-ordinator who had received training in advanced problem-solving techniques. The outcomes from this short intervention were positive. Those in the intervention group "significantly improved task-orientated coping, mastery

and competence", whilst reducing carer burden and stress (937). It is recognised that whilst this intervention was directed toward unpaid carers of people living with dementia, such a model could be adapted prior to or at bereavement. For example, there are myriad courses around retirement and many individuals are supported by carer organisations. This problem-solving technique approach could be adopted (and adapted) to support individuals to make decisions when planning or purchasing a funeral.

- 5.42 The application of advance care planning or advance care directives to support decision-making was highlighted in a number of papers (e.g. Forbes et al, 2000; Yamamoto et al., 2017; Blackburn and Bulsara 2018). Advance care planning (ACP) has been adopted in a range of organisations (residential or nursing homes, hospices as well as at hospital end-of-life care) to, initially, enable patients to identify the type and extent of treatment that they would wish, should they be unable to make decisions for themselves. Such clear documentation, usually discussed with the wider family, ensures clarity of decision-making in intense, often urgent, situations (Lambert et al., 2005). However, such tools are, at present, under-utilised. Lambert et al., 2015, drawing on data from the US, highlighted that it is estimated that more than 50% of those individuals entering nursing facilities have no "formal or informal directives in place at the time of admission" (626).
- 5.43 A number of papers in this review suggested that not only should ACPs be more common and all individuals hold one along with their care givers and/or healthcare team (Forbes et al. 2000; Yamamoto et al., 2017), but also discussed that these could be extended to incorporate funeral planning and purchasing. Blackburn and Bulsara (2015), in their qualitative interview study (n=24) exploring the experiences of bereaved individuals in dealing with practical matters, argued that adopting a proactive approach through completion of an ACP, "may mitigate adverse psychological impacts in bereavement" (633).

6 Observations on the research

- 6.1 This systematic rapid review ensured appropriate extraction and weight-of-evidence (WoE) scoring for those 39 papers identified. This latter measure (WoE) ensured that we included only those papers that were robust, developing the evidence-base in this important field. However, there are three areas that need to be highlighted.
- 6.2 It has been discussed that there is a limited number of papers (either peer-reviewed or drawn from the grey-literature) that provide sole insight into the impact of grief on decision-making and purchasing behaviour (n=5). To ensure that further detail was available to provide additional understanding in this complex area, a range of transferable papers were included (see Table 1, above). We would argue that each has provided further information, ensuring a multi-disciplinary lens in responding to each research question. However, it will be noted that these discuss decision-making in different areas and at different 'life' and time points.
- 6.3 The identification of comparable emotional states was carried out across the research team and with the CMA. These included fear, guilt, shame, emotional distress and mental health challenges (albeit excluding severe mental health states). From our analysis, these are analogous to grief as well as, at times, integral to any grief reaction (e.g. see Stevenson et al., 2017; Blackburn and Bulsara, 2018). Similarly, all transferable papers incorporated within those emotional states, some form of 'stress', either due to decisions having to be made in an urgent environment (e.g. within an intensive care unit) or due to 'anticipatory grief' (e.g. when making decisions about organ donation, still-birth and miscarriage). As Bellamy et al. (2014) reported, "Previous research suggests that bereavement and particularly the death of a spouse can be one of the most stressful life events for older people and is related to a decline in both physical and mental health (Fitzpatrick, 1998)" (97). It may be that given the complexity around emotional states and the individual nature of conceptualisation emotions (e.g. one individual may perceive a 'feeling' as anxiety, whilst another identifies this as stress), inclusion of further emotional states may have added greater insight.
- 6.4 This REA included four systematic steps, appropriate extraction and WoE scoring. However, this was necessarily a short piece of work (three months) requiring a 'cap' on the number of papers included. The round-table discussion (see 4.19) and the involvement of subject experts ensured an external quality appraisal process along with the addition of further papers. Whilst the final number of papers extracted (n=39) is large for such a short process, there may be substantive (and seminal) papers that could not be identified or discussed.

7 Implications of the research

- Within this analysis, it seems clear that grief and comparable emotional states impact negatively on cognitive processes and on any decision-making capacity. It was highlighted across the clear majority of papers that individuals will struggle to make appropriate decisions whilst experiencing bereavement or likely bereavement. Individuals living with grief or 'anticipatory grief' will necessarily have to take mental short-cuts (Lopez et al. 2018), demonstrate poorer overall problem-solving ability (Glick et al., 2018), avoid decisions (Olesen et al., 2018), be locked into 'uncertainty angst' (Dionne-Odom et al. 2018), attempt to delay any decision, show a preference for the 'status quo' and/or transfer any decision-making to someone else: 'What would you do?' (Olesen et al., 2018). In addition, it was found that the context of bereavement was important in affecting what decisions (if any) an individual was capable of making at the time of, or prior to, bereavement. For example, it was highlighted that many individuals had never purchased a funeral and knew little (if anything) about how one was arranged or purchased. Similarly, it was perceived by many bereaved individuals that the funeral needed to be undertaken 'quickly', limiting in-depth consideration of either selection of a funeral package or provider (Corden and Hirst, 2015).
- 7.2 Owing to such "bounded rationality" (Simon, 1955, cited Baxter and Glendinning, 2013: 440), as well as the overarching context of bereavement, it was found that "The majority of funeral consumers' purchases are unreflexive and therefore not to be thought of choices at all" (McQuaid, 2013: vii). This finding was underpinned by two further papers which identified that, in the main, the 'choice' of any funeral provider (or package) was based on ease of location, reducing stress and travel times (Halpenny, 2013; Korai and Souiden, 2017).
- 7.3 To mitigate these deficits in decision-making (and purchasing) around the funeral process, a number of interventions were proposed, although few papers provided concrete recommendations on the shape or focus of any innovation. Two papers identified that there should be a centralised agency or 'go-to' organisation that could provide support and advice, not only on the organisation and purchase of the funeral, but on the myriad practical tasks (e.g. probate) that individuals needed to address following bereavement (Bellamy et al., 2014, Blackburn and Bulsara, 2018). In addition, Blackburn and Bulsara (2014), as well as McQuaid (2013), highlighted that legislation could be a tool in supporting decision-making. The authors of the former paper perceived that lengthening statutory bereavement leave may enable appropriate time (and space) in which to make decisions. Similarly, McQuaid (2013) flagged that federal regulations in the US demand that funeral providers provide transparent pricing lists to anyone that requests this information.
- 7.4 Any institutional response was seen as necessarily including appropriate training of funeral staff. Korai and Souiden (2017) identified that owing to consumers' lack of competency in purchasing funerals and that such a purchase was taking place in an emotional environment, either in-house or external "consumer relationship management training" should be available (256). The paper argued that any such training should focus on psychological support and empathy, identifying two educational courses (in Australia and Quebec) that were delivering on this area. No further concrete data was provided on the content of such training, or where (or by whom), this should be delivered. One training innovation that may be suitable for adaptation within this field was that recommended by Regehr and Le Blanc (2017). In exploring the effects of critical incident exposure on the decision-making of emergency workers, the study tested (and recommended) that training should be provided by virtual simulation and/or led by 'experts by experience' (i.e., those users or patients who had been involved in the death of a child or relative).

- 7.5 A range of papers highlighted that the ease (or otherwise) of making appropriate decisions (and choices) was dependent on the type of relationship between the staff member and consumer, patient or user. It was discussed that a transparent and clear dialogue between individuals needed to be undertaken, underpinned by mutuality and respect (Bernat-Adell et al., 2012). In addition, as it was found that needs and wishes of individuals were (often) unexpressed in any emotion-driven dialogue, it was essential that staff asked individuals what actions they would wish to undertake and give them appropriate time to think about any proposed options. One paper suggested that one technique to give time for consideration was to suggest a 'time-out' was taken, e.g. either through the individual going for a walk or, if a telephone conversation, to break off and then have a further conversation to discuss the proposed options (Olesen et al., 2015).
- 7.6 Individuals will only be able to make a 'choice' around options if they have knowledge of the different options from which they can choose. Targeted and clear information was seen as essential to guide and support decision-making and consequent actions. However, again, there was a limited data as to how this information should be presented, to whom it should be provided and at what time or life point (e.g. should 'leaflets' be provided in doctors' surgeries along with public health information or provided as part of any retirement discussion). Where details were available, these were drawn from transferable papers focusing on healthcare. Lifford et al. (2015) identified that a Decision-Support Intervention tool could support deliberative, cognitive responses in decision-making. They identified that the design of the tool tested was that of a "grid form". The first page provided an overarching summary of each treatment option, and supporting information (e.g. side-effects, likely outcomes) whilst, further pages detailed each type of treatment available. In addition, there was an indication that existing courses run by a range of organisations (e.g. retirement, unpaid caring) could incorporate problem-solving techniques to support decision-making during this difficult time (Chui et al., 2015).
- 7.7 The evidence-base identifying the impact of grief (or comparable emotional states) on decision-making and purchasing behaviour within the funeral industry is limited. Collectively the papers suggest that no considered decisions can generally be made at, or shortly prior to be eavement, that there is little shared decision-making between the consumer and the funeral industry and, individuals are (in the main) making purchases lacking information and financial understanding. All such factors are likely to result in increased consumer vulnerability.

8 References

Aoun, S.M., Lowe, J., Christian, K.M. and Rumbold, B. (2019) Is there a role for the funeral service provider in bereavement support within the context of compassionate communities? *Death studies*, *43*(10): 619-628.

Baxter, K. and Glendinning, C. (2013) The role of emotions in the process of making choices about welfare services: the experiences of disabled people in England. *Social Policy and Society*, *12*(3): 439-450.

Bellamy, G., Gott, M., Waterworth, S., McLean, C. and Kerse, N. (2014) 'But I do believe you've got to accept that that's what life's about': older adults living in New Zealand talk about their experiences of loss and bereavement support. *Health & social care in the community*, 22(1): 96-103.

Bernat-Adell, M.D., Ballester-Arnal, R. and Abizanda-Campos, R. (2012) Is the critical patient competent for decision taking? Psychological and psychopathological reasons of cognitive impairment. *Medicina Intensiva (English Edition)*, 36(6): 416-422.

Bern-Klug, M. (2008) The emotional context facing nursing home residents' families: A call for role reinforcement strategies from nursing homes and the community. *Journal of the American Medical Directors Association*, 9(1): 36-44.

Blackburn, P. and Bulsara, C. (2018) "I am tired of having to prove that my husband was dead." Dealing with practical matters in bereavement and the impact on the bereaved. *Death studies*, *42*(10):627-635.

Britain Thinks (2018) Essential service markets and people with mental health problems. London, Citizens Advice Bureau. Available at:

https://www.citizensadvice.org.uk/Global/CitizensAdvice/Energy/The%20Energy%20Market%20and%20people%20with%20mental%20health%20problems CitizensAdviceBritainThinksFINAL%20(1).pdf (Accessed 23.03.2020)

Britain Thinks (2018a) *The energy market and people with mental health problems*. London, Britain Thinks. Available at: https://britainthinks.com/pdfs/Essential-service-markets-and-people-with-mental-health-problems Report-from-BritainThinks-Final.pdf (Accessed 23.03.2020)

Chiu, M., Pauley, T., Wesson, V., Pushpakumar, D. and Sadavoy, J. (2015) Evaluation of a problem-solving (PS) techniques-based intervention for informal carers of patients with dementia receiving in-home care. *International psychogeriatrics*, *27*(6): 937-948.

Citizens Advice Bureau (2004) *Out of the picture: CAB evidence on mental health & social exclusion.* London, CAB. Available at:

https://www.citizensadvice.org.uk/Global/Migrated Documents/corporate/outofthepicture.pdf (Accessed 23.03.2020)

Corden, A. and Hirst, M. (2015) *The meaning of funeral poverty: an exploratory study.* London, Marie Curie. Available at:

https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/march-2016/meaning-of-funeral-poverty-exploratory-study.pdf (Accessed, 23.03.2020)

de Groot, J., van Hoek, M., Hoedemaekers, C., Hoitsma, A., Schilderman, H., Smeets, W., Vernooij-Dassen, M. and van Leeuwen, E. (2016) Request for organ donation without donor registration: a qualitative study of the perspectives of bereaved relatives. *BMC medical ethics*, *17*(1): 38 - 45

Dionne-Odom, J.N., Willis, D.G., Bakitas, M., Crandall, B. and Grace, P.J. (2015) Conceptualizing surrogate decision making at end of life in the intensive care unit using cognitive task analysis. *Nursing outlook*, *63*(3): 331-340.

- Drenten, J., McManus, K. and Labrecque, L.I. (2017) Graves, gifts, and the bereaved consumer: a restorative perspective of gift exchange. *Consumption Markets & Culture*, 20(5): 423-455.
- Forbes, S., Bern-Klug, M. and Gessert, C. (2000) End-of-life decision making for nursing home residents with dementia. *Journal of Nursing Scholarship*, 32(3) 251-258.
- Gerber, K., Hayes, B. and Bryant, C. (2019) 'It all depends!': A qualitative study of preferences for place of care and place of death in terminally ill patients and their family caregivers. *Palliative medicine*, *33*(7): 802-811.
- Glick, D.R., Motta, M., Wiegand, D.L., Range, P., Reed, R.M., Verceles, A.C., Shah, N.G. and Netzer, G. (2018) Anticipatory grief and impaired problem solving among surrogate decision makers of critically ill patients: A cross-sectional study. *Intensive and Critical Care Nursing*, 49 (4): 1-5.
- Halpenny, J. (2013) *An exploration of consumer decision making processes in the Funeral Industry* (Doctoral dissertation, Dublin, National College of Ireland).
- Hallström, I., Runeson, I. and Elander, G. (2002) An observational study of the level at which parents participate in decisions during their child's hospitalization. *Nursing Ethics*, 9(2): 203-214.
- Horey, D., Flenady, V., Conway, L., McLeod, E. and Yee Khong, T. (2014) Decision influences and aftermath: parents, stillbirth and autopsy. *Health Expectations*, *17*(4): 534-544.
- Korai, B. and Souiden, N. (2017) Rethinking functionality and emotions in the service consumption process: the case of funeral services. *Journal of Services Marketing*, 31(3): 247-264
- Joseph Rowntree Foundation (2017) *How poverty affects people's decision-making processes*. York, JRF. Available at:
- https://www.jrf.org.uk/file/49906/download?token=gE5-D8 z&filetype=full-report (Accessed, 23.03.2020)
- Lambert, H.C., McColl, M.A., Gilbert, J., Wong, J., Murray, G. and Shortt, S.E. (2005) Factors affecting long-term-care residents' decision-making processes as they formulate advance directives. *The Gerontologist*, *45*(5): 626-633.
- Lifford, K.J., Witt, J., Burton, M., Collins, K., Caldon, L., Edwards, A., Reed, M., Wyld, L. and Brain, K. (2015) Understanding older women's decision making and coping in the context of breast cancer treatment. *BMC medical informatics and decision making*, 15(1): 45.
- Linnet Olesen, M., Graungaard, A.H. and Husted, G.R. (2015) Deciding treatment for miscarriage—experiences of women and healthcare professionals. *Scandinavian journal of caring sciences*, 29(2): 386-394.
- López, J.S., Martínez, J.M., Soria-Oliver, M., Aramayona, B., García-Sánchez, R., Martín, M.J. and Almendros, C. (2018) Bereaved relatives' decision about deceased organ donation: An integrated psycho-social study conducted in Spain. *Social Science & Medicine*. 205: 37-47.
- McCarthy, J., (2016) Closing the casket: professionalism and care amongst funeral directors in the Republic of Ireland. *Mortality*, 21(4): 305-321.
- McManus, R. and Schafer, C. (2014) Final arrangements: examining debt and distress. *Mortality*, *19*(4): 379-397.
- McQuaid, J., 2013. *Mortuaries, markets, and meaning: the social context of funeral expenditures* (Doctoral dissertation).

- Meaney, S., Gallagher, S., Lutomski, J.E. and O'Donoghue, K. (2015) Parental decision making around perinatal autopsy: a qualitative investigation. *Health Expectations*, *18*(6): 3160-3171.
- Monaro, S., Stewart, G. and Gullick, J. (2014) A 'lost life': coming to terms with haemodialysis. *Journal of clinical nursing*, 23(21-22): 3262-3273.
- Price, D., Bisdee, D., Daly, T., Livsey, L. and Higgs, P. (2014) Financial planning for social care in later life: the 'shadow' of fourth age dependency. *Ageing & Society*, 34(3): 388-410.
- Regehr, C. and LeBlanc, V.R. (2017) PTSD, acute stress, performance and decision-making in emergency service workers. *Journal of American Academy Psychiatry Law*, *45*(2): 184-192.
- Stevenson, M., Achille, M., Liben, S., Proulx, M.C., Humbert, N., Petti, A., Macdonald, M.E. and Cohen, S.R., 2017. Understanding how bereaved parents cope with their grief to inform the services provided to them. *Qualitative health research*, *27*(5) 649-664.
- Sque, M., Long, T., Payne, S. and Allardyce, D. (2008) Why relatives do not donate organs for transplants: 'sacrifice' or 'gift of life'? *Journal of advanced nursing*, *61*(2): 134-144.
- Taylor, M., O'Donoghue, T. and Houghton, S. (2006) To medicate or not to medicate? The decision-making process of Western Australian parents following their child's diagnosis with an attention deficit hyperactivity disorder. *International Journal of Disability, Development and Education*, *53*(1): 111-128.
- van Randenborgh, A., de Jong-Meyer, R. and Hüffmeier, J. (2010) Decision making in depression: differences in decisional conflict between healthy and depressed individuals. *Clinical psychology & psychotherapy*, *17*(4): 285-298.
- Wolfs, C.A., de Vugt, M.E., Verkaaik, M., Haufe, M., Verkade, P.J., Verhey, F.R. and Stevens, F. (2012) Rational decision-making about treatment and care in dementia: a contradiction in terms? *Patient education and counseling*, 87(1): 43-48.
- Yamamoto, S., Arao, H., Masutani, E., Aoki, M., Kishino, M., Morita, T., Shima, Y., Kizawa, Y., Tsuneto, S., Aoyama, M. and Miyashita, M. (2017) Decision making regarding the place of end-of-life cancer care: the burden on bereaved families and related factors. *Journal of pain and symptom management*, *53*(5): 862-870.

Appendix A: Search strings for database searches

A1.1 Research questions 1 and 3

These search strings are designed to capture papers related to research questions 1 and 3, focusing on the experiences of grief, bereavement and funeral planning, including interventions relating to these experiences. All searches were run on 9th January 2020.

A1.1.1 Scopus

(TITLE-ABS-KEY ((death* W/3 (arrang* OR plan* OR organis* OR organiz*))OR funeral* OR cremat* OR burial* OR undertaker* OR disposition)) AND (TITLE-ABS-KEY (consumer* OR customer* OR buy* OR purchas* OR spend* OR expenditure OR pay OR payment* OR cost* OR financ* OR bill OR bills OR debt* OR budget* OR regulat*)) AND (TITLE-ABS-KEY (australia OR austria OR belgium OR canada OR chile OR "czech republic" OR denmark OR estonia OR finland OR france OR germany OR greece OR hungary OR iceland OR ireland OR ulster OR israel OR italy OR japan OR latvia OR lithuania OR luxembourg OR mexico OR netherlands OR "new zealand" OR norway OR poland OR portugal OR slovakia OR slovenia OR "south korea" OR spain OR sweden OR switzerland OR turkey OR "united kingdom" OR uk OR britain OR england OR scotland OR wales OR "united states" OR usa)) AND (LIMIT-TO (SUBJAREA, "SOCI") OR LIMIT-TO (SUBJAREA, "PSYC") OR LIMIT-TO (SUBJAREA, "ECON") OR LIMIT-TO (SUBJAREA, "MULT") OR LIMIT-TO (SUBJAREA, "DECI")) AND (LIMIT-TO (PUBYEAR, 2020) OR LIMIT-TO (PUBYEAR, 2019) OR LIMIT-TO (PUBYEAR, 2018) OR LIMIT-TO (PUBYEAR, 2017) OR LIMIT-TO (PUBYEAR, 2016) OR LIMIT-TO (PUBYEAR, 2015) OR LIMIT-TO (PUBYEAR, 2014) OR LIMIT-TO (PUBYEAR, 2013) OR LIMIT-TO (PUBYEAR, 2012) OR LIMIT-TO (PUBYEAR, 2011) OR LIMIT-TO (PUBYEAR, 2010) OR LIMIT-TO (PUBYEAR,2009) OR LIMIT-TO (PUBYEAR,2008) OR LIMIT-TO (PUBYEAR,2007) OR LIMIT-TO (PUBYEAR, 2006) OR LIMIT-TO (PUBYEAR, 2005) OR LIMIT-TO (PUBYEAR, 2004) OR LIMIT-TO (PUBYEAR, 2003) OR LIMIT-TO (PUBYEAR, 2002) OR LIMIT-TO (PUBYEAR, 2001) OR LIMIT-TO (PUBYEAR, 2000)) - 656 hits (limited to subject categories: Social Sciences (505); Psychology (93); Economics & Finance (68); Multidisciplinary (43); Decision Sciences (15)

A1.1.2 MEDLINE(R) and In-Process & Other Non-Indexed Citations and Daily (Ovid) <1946 to January 07, 2020>

- 1 ((death* adj3 (arrang* or plan* or organis* or organiz*)) or funeral* or cremat* or burial* or undertaker* or disposition).ti,ab,kw. (41426)
- 2 funeral rites/ or funeral homes/ or burial/ or cremation/ (1743)
- 3 or/1-2 (42322)
- 4 (consumer* or customer* or buy* or purchas* or spend* or expenditure or pay or payment* or cost* or financ* or bill or bills or debt* or budget* or regulat*).ti,ab,kw. (2583187)

- 5 Consumer Behavior/ (21011)
- 6 Financing, Personal/ (5477)
- 7 decision making/ or choice behavior/ (120531)
- 8 or/4-7 (2701670)
- 9 (australia or austria or belgium or canada or chile or "czech republic" or denmark or estonia or finland or france or germany or greece or hungary or iceland or ireland or ulster or israel or italy or japan or latvia or lithuania or luxembourg or mexico or netherlands or "new zealand" or norway or poland or portugal or **slovakia** or slovenia or "south korea" or spain or sweden or switzerland or turkey or "united kingdom" or uk or britain or england or scotland or wales or "united states" or usa).ti,ab,kw. (1354981)
- 10 exp canada/ or mexico/ or exp united states/ or chile/ or israel/ or turkey/ or exp "republic of korea"/ or austria/ or belgium/ or estonia/ or latvia/ or lithuania/ or czech republic/ or hungary/ or poland/ or slovakia/ or slovenia/ or exp france/ or exp germany/ or exp united kingdom/ or greece/ or ireland/ or exp italy/ or luxembourg/ or netherlands/ or portugal/ or exp denmark/ or finland/ or iceland/ or exp norway/ or sweden/ or spain/ or switzerland/ or exp australia/ or japan/ or new zealand/ (2984211)
- 11 or/9-10 (3554967)
- 12 3 and 8 and 11 (1096)
- 13 limit 12 to yr="2000 -Current" (881)

A1.1.3 PsycINFO (Ovid) <1806 to December Week 5 2019>

- 1 ((death* adj3 (arrang* or plan* or organis* or organiz*)) or funeral* or cremat* or burial* or undertaker* or disposition or grief or grieve* or grieving or bereave*).ti,ab. (28756)
- 2 death rites/ or "death and dying"/ or death attitudes/ or grief/ or bereavement/ (41400)
- 3 or/1-2 (56813)
- 4 (consumer* or customer* or buy* or purchas* or spend* or expenditure or pay or payment* or cost* or financ* or bill or bills or debt* or budget* or regulat*).ti,ab. (416650)
- 5 consumer behavior/ or consumer ethics/ or consumer protection/ or behavioural economics/ or consumer satisfaction/ or customer relationship management/ or consumer psychology/ or coping behavior/ or Financing, Personal/ or decision making/ or choice behavior/ (164944)
- 6 or/4-5 (534671)
- 7 (australia or austria or belgium or canada or chile or "czech republic" or denmark or estonia or finland or france or germany or greece or hungary or iceland or illuster or israel or italy or japan or latvia or lithuania or luxembourg or mexico or netherlands or "new zealand" or norway or poland or portugal or **slovakia** or slovenia

or "south korea" or spain or sweden or switzerland or turkey or "united kingdom" or uk or britain or england or scotland or wales or "united states" or usa).ti,ab,lo. (783607)

- 8 3 and 6 and 7 (1546)
- 9 limit 8 to yr="2000 -Current" (**1432**)

A1.2 Research questions 2 and 3

These search strings are designed to capture papers related to research questions 2 and 3, focusing on the experiences of purchasing under comparable emotional or mental states, including interventions related to the same.

Search string one (research questions one and three)

(TITLE-ABS-KEY ((death* W/3 (arrang* OR plan* OR organis* OR organiz*))OR funeral* OR cremat* OR burial* OR undertaker* OR disposition)) AND (TITLE-ABS-KEY (consumer* OR customer* OR buy* OR purchas* OR spend* OR expenditure OR pay OR payment* OR cost* OR financ* OR bill OR bills OR debt* OR budget* OR regulat*)) AND (TITLE-ABS-KEY (australia OR austria OR belgium OR canada OR chile OR "czech republic" OR denmark OR estonia OR finland OR france OR germany OR greece OR hungary OR iceland OR ireland OR ulster OR israel OR italy OR japan OR latvia OR lithuania OR luxembourg OR mexico OR netherlands OR "new zealand" OR norway OR poland OR portugal OR slovakia OR slovenia OR "south korea" OR spain OR sweden OR switzerland OR turkey OR "united kingdom" OR uk OR britain OR england OR scotland OR wales OR "united states" OR usa)) AND (LIMIT-TO (SUBJAREA, "SOCI") OR LIMIT-TO (SUBJAREA, "PSYC") OR LIMIT-TO (SUBJAREA, "ECON") OR LIMIT-TO (SUBJAREA, "MULT") OR LIMIT-TO (SUBJAREA, "DECI")) AND (LIMIT-TO (PUBYEAR, 2020) OR LIMIT-TO (PUBYEAR, 2019) OR LIMIT-TO (PUBYEAR, 2018) OR LIMIT-TO (PUBYEAR, 2017) OR LIMIT-TO (PUBYEAR, 2016) OR LIMIT-TO (PUBYEAR, 2015) OR LIMIT-TO (PUBYEAR,2014) OR LIMIT-TO (PUBYEAR,2013) OR LIMIT-TO (PUBYEAR,2012) OR LIMIT-TO (PUBYEAR, 2011) OR LIMIT-TO (PUBYEAR, 2010) OR LIMIT-TO (PUBYEAR,2009) OR LIMIT-TO (PUBYEAR,2008) OR LIMIT-TO (PUBYEAR,2007) OR LIMIT-TO (PUBYEAR, 2006) OR LIMIT-TO (PUBYEAR, 2005) OR LIMIT-TO (PUBYEAR, 2004) OR LIMIT-TO (PUBYEAR, 2003) OR LIMIT-TO (PUBYEAR, 2002) OR LIMIT-TO (PUBYEAR, 2001) OR LIMIT-TO (PUBYEAR, 2000))

Search string two (research question two)

(TITLE-ABS-KEY (anxiety OR depression OR "reactive depression" OR emotion* OR stress* OR OR fear* OR panic* OR "OR worr* OR mood OR helpless* OR anger OR angr* OR hostility OR aggress* OR "temporal incapacity" OR grief OR grieve OR grieving OR bereave* OR mourn*)) AND (TITLE-ABS-KEY (australia OR austria OR belgium OR canada OR chile OR "czech republic" OR denmark OR estonia OR finland OR france OR germany OR greece OR hungary OR iceland OR ireland OR ulster OR israel OR italy OR japan OR latvia OR lithuania OR luxembourg OR mexico OR netherlands OR "new zealand" OR norway OR poland OR portugal OR slovakia OR slovenia OR "south korea" OR spain OR sweden OR switzerland OR turkey OR "united kingdom" OR uk OR britain OR england OR scotland OR wales OR "united states" OR usa)) AND (TITLE-ABS-KEY (consumer* OR customer* OR buy* OR purchas* OR spend* OR expenditure OR pay OR payment* OR cost* OR financ* OR bill OR bills

OR debt* OR budget*) W/5 (decision* OR "cognitive process*" OR "critical think*" OR judgement* OR judgment* OR choice* OR choos* OR reason* OR (problem* W/2 (solv* OR assess* OR evaluat*)))) AND (LIMIT-TO (SUBJAREA, "SOCI") OR LIMIT-TO (SUBJAREA, "BUSI") OR LIMIT-TO (SUBJAREA, "PSYC") OR LIMIT-TO (SUBJAREA, "PSYC") OR LIMIT-TO (SUBJAREA, "DECI")) AND (LIMIT-TO (PUBYEAR, 2020) OR LIMIT-TO (PUBYEAR, 2017) OR LIMIT-TO (PUBYEAR, 2018) OR LIMIT-TO (PUBYEAR, 2017) OR LIMIT-TO (PUBYEAR, 2016) OR LIMIT-TO (PUBYEAR, 2015) OR LIMIT-TO (PUBYEAR, 2014) OR LIMIT-TO (PUBYEAR, 2013) OR LIMIT-TO (PUBYEAR, 2010) OR LIMIT-TO (PUBYEAR, 2011) OR LIMIT-TO (PUBYEAR, 2010) OR LIMIT-TO (PUBYEAR, 2009) OR LIMIT-TO (PUBYEAR, 2008) OR LIMIT-TO (PUBYEAR, 2005) OR LIMIT-TO (PUBYEAR, 2004) OR LIMIT-TO (PUBYEAR, 2003) OR LIMIT-TO (PUBYEAR, 2001) OR LIMIT-TO (PU

Appendix B: Search terms for greyliterature searches

The following search terms were used for the grey-literature searches.

- Funeral
- Death
- Cremation
- Grief
- Bereavement
- Decision
- Judgement
- Thinking
- Consume
- Buy
- Spend
- Purchase

Appendix C: Inclusion/exclusion criteria for title and abstract screening

Vulnerabil	ity in the Funerals Market (CMA): Title and Abstra	ct Screening Tool							
All papers must feature one inclusion factor from each row in rows 1-5									
Criteria	Inclusion factors Australia, Austria, Belgium, Canada, Chile	Exclusion factors							
1. Country focused in research (OECD member states)	All other countries								
2. Date of publication	January 2000 – December 2019	Published outside of these dates							
3. Publication language	English	Languages other than English							
4. Evidence type	All types of evaluative studies (where available): systematic literature reviews (including scoping reviews, rapid evidence assessments, meta-analyses, narrative analyses), randomised control trials, quasi-experimental studies (including cohort and pragmatic trials, case and observational studies. Grey literature (those publications or policies not published in peer reviewed journals).	Protocols, opinion pieces, popular media (e.g., blogs, social media feeds and/ or newspaper articles).							
5. Methodology	All paradigms (i.e., quantitative, qualitative, mixed methods).	Where methods are unclear, do not respond to the research question and/ or are of low-quality (excluding grey literature).							
All papers <u>must</u> featur	e one inclusion factor from at least one of rows 6-	8							
Criteria	Inclusion factors	Exclusion factors							
6. Substantive topic: effect of bereavement/grief on purchasing	Research features the nature and scale of the effect (if any) of recent grief/ bereavement on consumers' decision-making capacity and purchasing behaviour.	Research features decision- making (i.e., outside of grief/ bereavement). Purchasing decisions (i.e., outside of grief/ bereavement).							
7. Substantive topic: effect of emotional states on purchasing	Research features the nature and scale of the effect of comparable emotional states on consumers' decision-making capacity and purchasing behaviour.	Research features decision- making (i.e., outside of emotional states). Purchasing decisions (i.e., outside of emotional states).							
8. Substantive topic: interventions to support decision making	Research features those interventions that may support decision-making for those individuals living with grief/ bereavement or comparable emotional states.	Research features interventions that support decision-making for individuals outside of grief/bereavement or comparable emotional states.							

Appendix D: Full text screening and Weight of Evidence (WoE)

Full text screening consisted of recording article information, substantive criteria marking, and WoE scoring.

Please see below for the article information recorded:

Search strir	g Article ID	Article Title	Article Author (all names)	Screened by	Year of publication	Country	Evidence type (drop-down list)
--------------	--------------	---------------	----------------------------	-------------	---------------------	---------	--------------------------------

Please see below for the substantive criteria each paper was marked against:

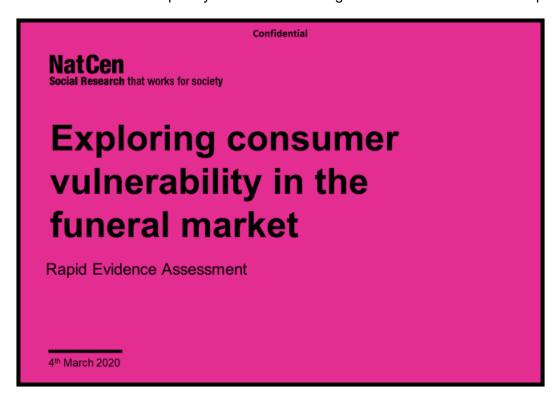
Article discussed	Article discussed	Article discussed	Article discussed	Article discussed	Article discussed	Article discusses	Article discusses	Article focuses on
the nature and	the nature and	the nature and	the nature and	the nature and	the nature and	interventions,	interventions to	funeral industry
scale of the effect	scale of the effect	scale of the effect	including	support decision-				
(if any) of recent	(if any) of recent	(if any) of recent	(if any) of different	(if any) of different	(if any) of different	theoretical	making,	
grief/	grief/	grief/	emotional states	emotional states	emotional states	interventions, to	purchasing	
bereavement on	bereavement on	bereavement on	or life events on	or life events on	or life events on	support decision-	behaviour or other	
decision-making	purchasing	other types of	decision-making	purchasing	other types of	making, purchasing	behaviour for	
behaviour	behaviour	behaviour	behaviour	behaviour	behaviour	behaviour or other	individuals in	
						behaviour for	different	
						individuals with	emotional states	
						recent grief/	or following major	
						bereavement	life events	

Please see below for the WoE each paper was scored against:

Is there a clear	Do the study authors justify	Is the method of	Do the researchers	Is the paper or research team	Are the methods	Are there any	Is sufficient data/
statement of the	their sampling strategy (or	data collection	identify ethical	explicit about sources of	for data analysis	concerns regarding	evidence
aims and	data selection strategy if not	clearly described	issues involved in	funding for the project? (Yes	justified as being	accuracy (e.g.	presented to
objectives and/or	collecting primary data) as	by the researchers	the study design	and it's the funeral or	appropriate for the	discrepancies	support the
clear research	representative and/or	as being	and explain steps	funeral-related industry = 1,	aims/objectives	within the report)?	discussion/
questions? (Yes =	appropriate for the research	appropriate to	to address these?	Yes and non-funeral industry	and/or research	(Yes = 0; No = 1)	conclusions? (Yes
1; No = 0)	questions/aims? (Yes = 1; No	answer the aims/	(Yes = 1; No = 0)	= 2, No = 0)	questions? (Yes =		= 1; No = 0)
	= 0)	research			1; No = 0)		
		questions? (Yes =					
		1; No = 0)					

Appendix E: Round table slide-pack, presentation and prompt questions

The slides below were used to present interim findings from the REA to the CMA and stakeholders at a half-day round table on 4th March 2020. As discussed in section 4.19 above, these slides outline NatCen's preliminary findings only; extensive further work was undertaken subsequently to inform the findings in full as described in this report.



For the avoidance of doubt, the content of these slides should not be interpreted as the CMA's or the Inquiry Group's views. These slides should not be circulated any further without the express permission of NatCen and the CMA.

NatCen Social Research

1

Contents

Aims and Research Questions

- Rationale and aims
- · Research questions

Methods

- Inclusion and exclusion criteria
- · Search strategy
- · Study inclusion flowchart
- Data extraction and weight of evidence

Main findings

- Impact of grief/ bereavement on decision-making capacity and purchasing behaviour
- · Impact of comparable emotional states on decision-making capacity and purchasing behaviour
- Interventions that may support decision-making following grief/ bereavement or comparable emotional states

Conclusive remarks

- Gaps/Limitations
- Future directions
- · Implications



Aims and Research Questions

1

Background

Arranging and purchasing a funeral is challenging and impacted by:

- · Individual psychological vulnerability (Rosenblatt, 2018);
- Pressures to make a 'quick decision' (Kemp and Kopp, 2014);
- Overall cost of the funeral. (Bickerton and Morelli, 2019; McManus and Schafer 2015); and
- Purchase inexperience, low (or no) knowledge of the funeral sector.

Essential to understand the impact of grief on decision-making and purchasing behaviour as well as how this may be mitigated.



Overarching research questions

- 1. What is the nature and scale of the effect (if any) of recent grief/ bereavement on consumers' decision-making capacity and purchasing behaviour?
- What is the nature and scale of the effect (if any) of comparable emotional states (e.g., grief-related emotional states including anxiety, depression and mourning) on decision-making capacity and purchasing behaviour?
- 3. What interventions have been used to address/remedy deficits in consumers' decision-making capacity and purchasing behaviour caused by grief/bereavement or comparable emotional states (e.g., grief-related emotional states including anxiety, depression, mourning and temporal incapacity)?

5

NatCen Social Pessarch



Rapid Evidence Assessment

- Consider the electronic and print-based literature comprehensively, but within necessarily tight timescales.
- Integrate descriptive outlines of the evidence available on a specific topic.
- · Critically evaluate the evidence identified.
- Identify, record and exclude evidence that is considered of poorer quality.
- Summarise the information in its entirety.
- · Four stages:
 - Scoping phase, including pilot search and identification;
 - Evidence identification;
 - Evidence selection, screening and weighting;
 - Narrative synthesis and information integration.

NatCen Social Research

7

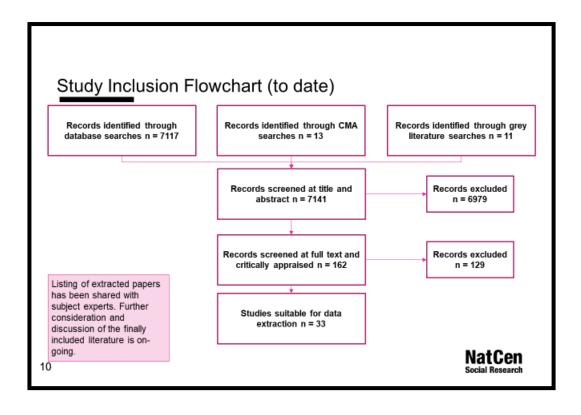
Inclusion and exclusion criteria

Area	Inclusion criteria	Exclusion criteria
Alea	inclusion criteria	Exclusion chiena
Date of publication	January 2000 – December 2019	Published outside of these dates
Location of study	All OECD countries	Non-OECD countries
Language	English	Languages other than English
Literature type	Academic and high-quality grey literature	Low-quality grey literature, including opinion pieces, popular media (e.g., blogs, social media feeds and/ or newspaper articles).
Type of study	All types of evaluative studies; systematic literature reviews (including scoping reviews, rapid evidence assessments, meta-analyses, narrative analyses), randomised control trials, quasi-experimental studies (including cohort and pragmatic trials, case and observational studies. Grey literature (e.g., publications not published in peer-reviewed journals).	Protocols, opinion pieces, popular media (e.g., blogs, social media feeds and/ or newspaper articles).
	reviewed journalej.	MotCon

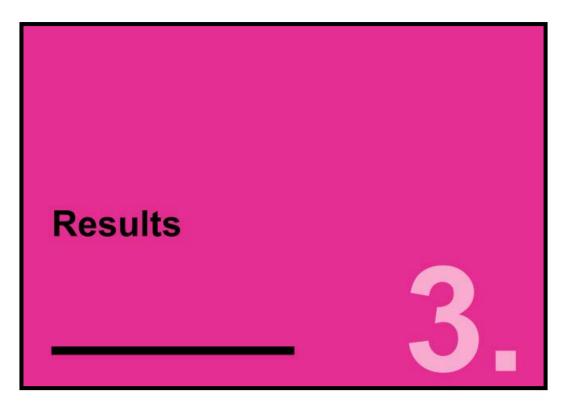
8

NatCen Social Research









Type and extent of included papers

- Impact of grief/ bereavement (as well as comparable emotional states) on decision-making and purchasing behaviour (e.g., Korai and Souiden, 2017; Halpenny, 2013; McManus and Schafer, 2014).
- Transferable research including, for example, decision-making at different 'life' points and in varied locations:
 - Bereavement per se (e.g., Blackburn and Bulsara, 2018; Bellamy et al., 2014; Drenten et al., 2017; Corden and Hirst, 2015);
 - At hospitalisation, end of life care, organ donation, or serious diagnoses (e.g., Lopez et al., 2018; Glick et al., 2018; de Groot et al., 2016; Dionne-Odom et al., 2015; Lifford et al., 2015; Sque et al., 2007; Lambert et al., 2005);
 - Choosing welfare services including home care, residential or day service provision (e.g., Price et al., 2014 Baxter and Glendinning, 2013); and,
 - Maternity provision including experiences of treatment following miscarriage and/ or still-birth (e.g., Oleson et al., 2015; Horey et al., 2012).

13

NatCen Social Research

RQ1: What is the nature and scale of the effect (if any) of recent grief and bereavement on consumers' decision-making capacity and purchasing behaviour?

"The process of organising a funeral depends on how and where [as well as when] a person died" (McManus and Schafer, 2014: 382).

- Decision-making: "The thought process of selecting a <u>choice</u> or <u>action</u> from a set of available options" (JRF, 2017: 45).
- Decision-making in this area is linked to our own experiences with death and illness with decisions based on a myriad of experiences: spiritual, emotional and social factors (Lambert et al., 2005).
- Understanding the context of the bereavement is crucial if the impact of grief and bereavement on purchasing decisions is to be understood (i.e., temporal considerations must be incorporated).

14

NatCen Social Research

Impact of grief/ bereavement on decisionmaking capacity

- Strong evidence that grief and bereavement impacts on decisionmaking capacity in purchasing funerals as well as at challenging life events:
 - Mental 'short-cuts' are taken, only what seems to be the most relevant factor is considered and others obscured (Lopez et al., 2018);
 - Anticipatory grief (grief before the mourned death of the individual) impairs problem-solving. Higher measures of anticipatory grief were found to be significantly associated with a reduction in overall problem-solving ability leading to increased impulsivity, carelessness and avoidance problem solving (Glick et al., 2018)
 - 'Uncertainty angst' may be present; a general state of simply not knowing what to do (Dionne-Odom et al., 2015);
 - Individuals may avoid decisions, delay decisions or show preference for the status quo (Baxter and Glendinning, 2013); and,
 - Individuals will also attempt to pass the decision onto someone else

 'What would you do?' (Oleson et al., 2015).

15

NatCen Social Research

Contextual factors that impact on decision-making

- Funeral services are "characterized by their strong emotiveness, nonrecurrence, irreversibility, uncommonness, high level of symbolism and personalization and emotional control of the service provider" (Korai and Souiden, 2017: 247)
- Bereaved individual/ family have a lack of knowledge of the environment in which they are operating. They may never attended a funeral previously, have no or low awareness of the range of options and are completely reliant on the funeral director (Corden and Hirst, 2015).
- Inadequate support from relatives or other professionals (de Groot et al., 2016);
- Huge impetus to keep the dying or dead person 'safe', keeping the integrity and wholeness of the relative (Sque et al., 2007) and to do 'the best' for their loved one (McManus and Schafer, 2014).
- Timeliness: the perception that people only have a small window of opportunity to decide arrangements, as well as 'consider and deal with costs' (Corden and Hirst: 19).

NatCen Social Research

Outcome of cognitive and contextual factors on decision-making

- Most bereaved families have two criteria at the beginning of the funeral process:
 - Finding the most conveniently located funeral services;
 - Making the purchase decision as quickly as possible (Korai and Souiden, 2017).
- Individuals will select the funeral home and package based on 'ease', reducing stress and travel times (Halpenny, 2013).

17

NatCen Social Research

RQ2: Comparable emotional states on decisionmaking capacity and purchasing behaviour.

"I wasn't really thinking straight at the time, I don't know what I was thinking in fact. Was I thinking, was I able to think? It was just instinctive." (Baxter and Glendinning, 2013: 445)

- Comparable emotional states linked to dealing with a death (whether expected or sudden) as well as the different stages of grief and grieving include: fear, shock, guilt, shame (Gerber et al., 2019; Chui et al., 2015; Dionne-Odom et al., 2015; Hallstrom et al., 2002), acute stress and posttraumatic stress disorder (Regehr and Le Blanc, 2017).
- Overall, cognitive processing is impaired by negative emotions: avoidance, delayed decisions and processing of only the most important information (e.g., Oleson et al, 2015; Baxter and Glendinning, 2013; Hallstrom et al., 2002).
- Decision-making is further impacted by the individual's awareness that they are making decisions that are not thoroughly considered (Corden and Hirst, 2015) resulting in the possibility of guilt and distress for months or even years afterward as to whether the 'right' decision had been made (Dionne-Odom et al., 2019).



RQ3: Interventions to mitigate deficits in decisionmaking capacity and purchasing behaviour

"To assume that grief always warrants a professional response may be to introduce iatrogenic effects and marginalise the support available [to the individual/ family] through their local community".

(Aroun et al., 2012 citied Bellamy et al., 2014:14)

NatCen Social Research

19

RQ3: Interventions to mitigate decisionmaking capacity and purchasing behaviour

- Emotional states are not (always) considered by staff in relation to decision-making (Oleson et al., 2015).
- No one paper discussed concrete interventions that could support consumer purchasing in the funeral market.
- Recognised that people needed greater support when making choices; no clarity on who should provide this support, where it should be provided or its structure.
- A range of interventions that could support decision-making and purchasing were identified:
 - Institutional;
 - Relational; and/ or
 - Individual.

NatCen Social Research

'Institutional' interventions

- A centralised agency with knowledge and support of bereavements and practical matters (Blackburn and Bulsara, 2018).
- Public health-based approach to optimising bereavement support may be necessary alongside community and third sector organisations (Bellamy et al., 2014)
- Appropriate training of funeral staff e.g., Funeral Industry Development Australia, Collège Notre-Dame de Foy (Korai and Souiden, 2017).
- Training should include 'simulation' exercises and be led by individual/ family (Regehr and Le Blanc, 2017).
- Completion of 'Advance Care Directives' should be encouraged (and extended) across health and social care (Lambert et al., 2015).
- Institutional support should be on-going, reflecting the grief pathway (Baxter and Glendinning, 2013).

 NatCen

21

Relational interventions

- Nature of the relationship between staff and relatives is seen as essential for decision-making (de Groot et al., 2016).
- Understanding different options and choices that are being faced is essential and there is a need for shared decision-making with 'experts' (Oleson et al., 2015).
- Transparent dialogue between individuals/ families and experts from the funeral industry is essential (Stevenson et al., 2016).
- Staff need to respond transparently and appropriately to questioning.
 Failure on the part of professionals or clinicians to answer questions from the bereaved individual/ family is perceived by that individual or group as one of the greatest stressors in any process (Bernat-Adell et al., 2012).
- Staff need to be guided to ask 'what the individual would have wanted' (Glick et al., 2018; Dionne-Odom et al., 2016; Lopez et al., 2018).
- Individuals need to be supported to be explicit about their needs and staff need to be empathetic and sensitive to what those needs might be (Hallstrom et al., 2002).
- Appropriate engagement and time with the individual and family is necessary (Glick et al., 2016).

NatCen Social Research

Individual interventions

"Parents noted that during the phase of acute grief, they had difficulty reading long texts or actively seeking resources and tools to address their grief." (Stevenson et al., 2016: 659)

- Essential to provide targeted and clear information and guidance that ensures different choices (and consequences) are transparent (Lopez et al., 2018; Oleson et al., 2015; Baxter and Glendinning, 2013; de Groot et al., 2016).
- There is a need to address the 'norm' of deciding the funeral as soon as possible; challenging the idea that people have only a small opportunity to consider and deal with costs (Corden and Hirst, 2015).
- Decision-support interventions (DSI) designed as an options grid could help individuals/ families to reach decisions. "The dual approach of a concise and expanded DSI format may support fast, intuitive emotional responses as well as more deliberative, cognitive responses to information about [treatment] options" (Lifford et al., 2015: 11).
- Extend existing effective 'courses', e.g., Problem-solving therapy. Focused toward carers of people living with dementia, three one hour face-to-face sessions over three weeks demonstrated improved task-orientated coping, mastery and competence (Chui et al., 2015).

 NatCe

23

Concluding remarks 4

Implications of the research

- Decision-making is affected by emotional states as well as wider contextual factors, including socio-economic factors (JRF, 2017; Bellamy et al., 2017; McManus and Schaefer, 2014).
- The necessarily focused choices (conveniently located funeral home and need to make the purchasing choice as quickly as possible) may leave the bereaved individual/ family vulnerable to 'overselling'.
- Consideration of a 'national' response to support choice and decisionmaking.
- It is essential to develop a range of targeted information that highlights each option alongside outcomes (e.g., Decision-Support Grid), recognising the idiopathic nature of bereavement.
- Relation between funeral staff and bereaved individual/ family needs to be developed to encompass shared-decision making.
- · Appropriate training of staff needs to be designed and delivered.

NatCen Social Research

25

Gaps and limitations in the research

Lack of acceptance of the relative's death and extreme emotional reactions hinder the decision-making process (Lopez et al., 2018).

- Limited research on the impact of emotional states on purchasing behaviours.
- Unclear as to the impact of specific types (or extent) of emotional states on purchasing, although some indication that 'fear' will underpin chaotic decision-making.
- Whilst there is a clarity in the literature that the type of bereavement has implications for choices and decision-making, there is no stratification of those that may be more (or less) vulnerable.
- Discussion around the type and extent of support necessary (institutional, relational and individual) is broad, limiting implementation and understanding of who needs what support.
- Whilst the 'comparable emotional states' were appropriately discussed across the research team, alongside subject experts and the CMA, questions remain as to whether the 'translated' data can be appropriately applied to the funeral industry.
- Rapid Evidence Assessment necessarily limits the extent and type of included research.

NatCen

Round-Table Discussion points

5.

Resonance of findings

- Do the findings seem 'sensible', do they have meaning?
- Do the findings provide any 'new' insight to the subject area or are the findings well-known?
- Are there any findings that appear to be unexpected and how should these be included within any reporting?
- What does the group identify as core findings from the review?

NatCen

Gaps and challenges in the research evidence

- Are literature gaps in the research questions identified?
- Do we have a 'spread' of interventions that may be applicable or, do we have limited data?
- Are you aware of any papers or data that may mitigate perceived gaps in the evidence?

29

NatCen Social Research

Implications of the research

- How can these findings be applied to developing interventions to guide decision-making and purchasing within the funerals market? For example:
 - What is the impact of giving the bereaved more time to make decisions? Is evidence from other contexts e.g. organ donation relevant?
 - When should information be given to the bereaved?
 - What type of information should be given? Is evidence from other contexts e.g. NHS treatment grids relevant?
 - Who should/can support the bereaved (role of FD / LA staff etc.)?
 - Potential for different remedies to be effective in the funerals market?
- · What further evidence is needed (if any)?



Contact

Dr Karen Windle: Karen.Windle@natcen.ac.uk, 0207 549 7005

Dr Sokratis Dinos: Sokratis.Dinos@natcen.ac.uk, 0207 549 7129

Alexander Martin: Alexander.Martin@natcen.ac.uk, 0207 549 7036

NatCen Social Research that works for society

Appendix F: Data extraction tool

The data extraction tool recorded the same article information as the full text screening tool (see appendix D). Data was extracted relevant to the themes outlined below:

Short summary	Sample size and	Does the article	Does the article	What type of	What setting	Does the article	Effect, if any, of	Effect, if any, of	Effect, if any, of
of key findings	comment as to	focus on grief or	focus on a	behaviour or	did the research	focus on an	grief/	grief/bereavement	comparable
	whether	bereavement	comparable	decision-making	take place in?	intervention?	bereavement	on purchasing	emotional
	nationally		mental state? If	does the article			on decision-	behaviours	states on
	representative		so, please say	focus on?			making		decision-making
			what this is.						
Effect, if any, of	If applicable,	If applicable, to	If applicable,	Does the article	What were the	Any further	(Emerging)	(Emerging) Theme	(Emerging)
Effect, if any, of	If applicable,	If applicable, to	If applicable,	Does the article	What were the	Any further	(Emerging)	(Emerging) Theme	(Emerging)
comparable	please give a	what extent	what facilitators	propose any	learnings and	comments/	Theme 1	2	Theme 3
mental states	brief	was the	and/or barriers	type of	recommendations?	? notes			
on purchasing	description of	intervention a	did the	intervention? If					
behaviour	the intervention	success	intervention	so, what does					
			have	this look like?					