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After the Liverpool Care Pathway – development of heuristics to guide end of life care for people with dementia

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3 **After the Liverpool Care Pathway – development of heuristics to guide end of life care**
4 **for people with dementia**
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ABSTRACT

Introduction: End of life care guidance for people with dementia is lacking and this has been made more problematic in England with the removal of one of the main end of life care guidelines which offered some structure, the Liverpool Care Pathway. This guidance gap may be eased with the development of heuristics (rules of thumb) which offer a fast and frugal form of decision making.

Objective: To develop a toolkit of heuristics (rules of thumb) for practitioners to use when caring for people with dementia at the end of life.

Method and analysis: A mixed method study using a co-design approach to develop heuristics, in three phases. In phase one we will conduct at least six focus groups with family carers, health and social care practitioners from both hospital and community care services, using the ‘think-aloud’ method to understand decision-making processes and to develop a set of heuristics. The focus group topic guide will be developed from the findings of a previous study of 46 interviews of family carers about quality end of life care for people with dementia and a review of the literature. A multidisciplinary development team of health and social care practitioners will synthesise the findings from the focus groups to devise and refine a toolkit of heuristics. Phase two will test the use of the heuristics in practice in five sites: one general practice, one community nursing team, one hospital ward and two palliative care teams working in the community. Phase three will evaluate and further refine the toolkit of heuristics through group interviews, online questionnaires and semi-structured interviews.

Ethics and Dissemination: This study has received ethical approval from a local NHS research ethics committee (Rec ref: 15/LO/0156). The findings of this study will be presented in peer reviewed publications, national and international conferences.

Strengths and limitations

- This study places a high emphasis on family carers and will utilise their experience and knowledge to develop heuristics through a process of co-design
- Heuristics offer a novel approach to decision making at the end of life
- The heuristics developed in this study will be tested in a range of settings

INTRODUCTION

At present no treatment can alter the course of any form of dementia. Estimated average survival from when the person with dementia first notices symptoms is between 4 and 5 years¹ and from receiving a diagnosis is 3.5 years.² End of life care is therefore rapidly becoming one of the major priorities for dementia care. There are currently more than 670,000 family members and friends caring for people with dementia in the UK.³ These carers often provide the majority of health and social care, especially earlier in the course of dementia, and without them the professional health and care system would be likely to collapse.⁴

In England the government's End of Life Care Strategy defines end of life care as the last 12 months of life⁵ but this can be a problem when supporting people with dementia and those caring for them because it is often not possible to know how their dementia will progress and how other illness may affect the dementia⁶. For this study the researchers take the view that end of life care is not a period of time limited to the final days, hours or weeks of life, but more a period when the person, their family or practitioners recognise that they are dying⁷ and this will vary for individuals.

Guidance for practitioners on end of life care in England is currently specific guidance only for end of life care for people with cancer and not for other conditions, such as dementia.⁸ One of the main documents referred to by practitioners at the end of life was the Liverpool Care Pathway which offered a way for practitioners to plan care for someone who was at the very end of their life, often the final 48 hours. The Liverpool Care Pathway involved the withdrawal of unnecessary medication and interventions, and emphasised attention to the personal needs of the dying patient.

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3 Growing media attention highlighted concern about the ways in which end of life care was
4 being delivered within England. This culminated in an independent review of the Liverpool
5 Care Pathway.⁹ As a consequence, the government announced it would gradually phase out
6 the Liverpool Care Pathway. Many of the media reports were from family members who felt
7 their older relatives were abandoned or treated differently because of their age. Practitioners'
8 criticisms of the failings of the Liverpool Care Pathway included its over emphasis on 'paper
9 work' which led to a lack of attention to care. Many considered that these problems were
10 exacerbated by a misinterpretation of many of the key features of the Liverpool Care
11 Pathway, including nutrition, and hydration, together with a lack of training about its
12 implementation.⁹⁻¹¹

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21 Some practitioners argue that quality care for people with dementia at the end of life is
22 inhibited by its lack of clear structure.¹² The Liverpool Care Pathway provided some support
23 and a structure to guide care practitioners. Its withdrawal following the public criticisms has
24 resulted in a potential 'guidance gap' as well as a potential decline in confidence among
25 practitioners.^{13 14} The removal of the Liverpool Care Pathway coincided with the publication
26 of the European Association for Palliative Care's white paper which defined optimal
27 palliative care for people with dementia and their families.¹⁵ This potentially provides the
28 first set of guidance specific for dementia end of life care for practitioners but lacks policy
29 endorsement and the controversy over the Liverpool Care Pathway may affect its reception.

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38 Robust scientific conclusions derived from randomised controlled trials or epidemiological
39 studies are too scarce to inform practitioners' decision-making in many areas of practice and
40 many guidelines are not sufficiently based on evidence and are of low quality.¹⁶ Instead
41 heuristics ('rules of thumb' or 'mental short-cuts') are widely employed to address everyday
42 problems.¹⁷ Typically, heuristics are used in situations of uncertainty, may rely on first
43 impressions, and can occur effortlessly as a form of fast and frugal decision-making that
44 frequently gets the right answer.¹⁸ However, they are also prone to multiple biases and can
45 easily provide the wrong answer; they are assumed by many in healthcare to give second-best
46 outcomes.¹⁹ Nevertheless heuristics may well be the only solution to managing poorly
47 defined problems where no robust evidence exists and speedy decisions are needed. When
48 uncertainty is high, decision-makers need to use the minimal amount of relevant information
49 – in these circumstances less is more.²⁰ Fast and frugal heuristics have also been shown to be
50 more accurate than more complex and sophisticated prediction tools.²¹ Heuristics are
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3 important to practice, but to reduce errors and avoid biases they should be discussed,
4 criticised, refined and taught.¹⁷
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8 'FAST' is an example of a well-known heuristic designed to guide responses to stroke
9 symptoms (standing for Facial drooping, Arm weakness, Speech difficulties, Time to call
10 emergency services). FAST has demonstrated increased accuracy of the identification of
11 stroke patients.²² Similarly, PAID may be useful for practitioners trying to understand the
12 causes of challenging behaviour in people with dementia (standing for Pain, Aggravation,
13 Intrinsic to dementia (e.g. wandering), Depression/Delusions. The heuristics that general
14 practitioners use in making clinical decisions appear to shape performance more powerfully
15 than any form of formal training.²³
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23 End of life care for dementia can be very difficult for many reasons, not least because of the
24 difficulty communicating verbally many people with dementia have towards the end of life.
25 Many practitioners lack the confidence and skills to provide end of life care for someone with
26 dementia, both practitioners from palliative care backgrounds but also practitioners
27 experienced in dementia care²⁴ such as those working in care homes where resources, staffing
28 levels, and regulatory requirements are limited, and their support from the wider health care
29 systems is variable. End of life care for people with dementia is for these reasons often poor,
30 with improvement needed in many areas.²⁵ There is still limited access to end of life care
31 services for people with dementia^{5 26 27}, with a lack of the recognition of pain often
32 highlighted^{28 29} some even believing that people with dementia do not experience pain.³⁰
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41 The challenge remains how best to improve end of life care in the light of the recent
42 Liverpool Care Pathway review, family and practitioner anxieties and media controversy.⁹
43 One critically important resource is those people close to the person with dementia, often
44 family members. However, rarely have the views and experiences of family carers in their
45 own right been elicited³¹ and little is known about the experiences of carers about end of life
46 care.^{26 31 32} The recent descriptions of poor end of life care surrounding the Liverpool Care
47 Pathway have created an urgent need for health and social care practitioners to make more
48 use of the experiences of families, some of whom experience the dilemmas of care on a daily
49 basis.
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3 The removal of the Liverpool Care Pathway has left a gap in the guidance for practitioners
4 which may need to be filled, as suggested by claims that some organisations are finding it
5 hard to adapt to the Pathway's removal and suspicions that some are simply using it under a
6 different name.³³ We have proposed that this gap could be filled with the assistance of the
7 families of people with dementia, some of whose experiences were similar to those that
8 brought about the demise of the Liverpool Care Pathway. There remains little practice related
9 training in end of life care for people with dementia, with dementia apparently still often not
10 being accepted as an illness which will lead to death, sometimes requiring specialist end of
11 life care input.³⁴

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13 Starting with data from 46 interviews with family carers about end of life care for people with
14 dementia as a foundation,³⁵ collected and funded as part of the IMPACT study,³⁶ our three-
15 phase study described in this paper aims to:
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1. Conduct focus groups with family carers both current and former, as well as health and
social care practitioners to understand decision making at the end of life. Data collected
from the focus groups, literature and the previous interviews will be synthesised to
produce heuristics. These novel heuristics will be discussed, criticised, and refined in an
iterative process involving experts by training and experts by experience, as
recommended by McDonald.¹⁷
2. Test the use of heuristics with practitioners in five real settings including; one general
practice, one community nursing team, one hospital ward and two community palliative
care teams.
3. Evaluate the use content, and further refine the toolkit of heuristics through individual
interviews, group interviews, and online questionnaires.

METHODS AND ANALYSIS

Design: This study will use mixed methods and will comprise three phases: phase one will use input from interviews with families plus findings from focus groups with families and practitioners and a rapid appraisal literature review to develop a collection of heuristics; phase two will test the feasibility of the developed heuristics in real settings; phase three will evaluate the heuristics using semi-structured interviews and group interviews, finishing by synthesising the learning from all sites to create the final heuristics. Figure 1 shows the project's flow path.

Figure 1 near here

We will develop the heuristics using a standard, well-established developmental approach for creating decision-support guides.³⁷ We have successfully used this method to develop a decision-support system for dementia diagnosis and management,^{38 39} which was incorporated into the electronic medical records system EMIS (Egton medical Informatics System) after being shown to improve practice in a randomised controlled trial.⁴⁰ A co-design approach⁴¹ will be used to engage carers and practitioners in the identification of important aspects of end of life care where heuristics might usefully be applied and the subsequent operationalization of the heuristics.

Focus groups will be organised for carers and practitioners from different disciplines and the interaction within groups will be facilitated to promote professional creativity and debate around the usefulness and effectiveness of individual heuristics.⁴²

The findings from the focus groups and literature reviews will be synthesised, developed, and refined into heuristics using a modified nominal group technique with a development group. Nominal groups are potentially powerful learning and development tools.⁴³ They have a particularly useful role in analysing health care problems,⁴⁴ and can help bridge the gap between researchers and practitioners.⁴⁵ A nominal group approach designed for ill-structured problems will be used, to allow for disagreements over problem definition, and to produce potential solutions that overlap or vary widely in specificity. This will require the synthesis process to generate ideas, confirm that it is addressing the same problem, analyse the content of the heuristics, categorise and clarify them.⁴⁶

Participants and settings: The focus of the study is on end of life care for people with dementia in their own homes acknowledging that some may also classify a care home as their home (community), and on end of life care in general hospitals.

Phase 1 will aim to recruit:

1. Former family carers and family carers who are currently caring for someone with dementia.
2. Practitioners working with people with dementia at the end of life, including Admiral nurses (specialist dementia nurses), general practitioners, community nurses, hospital nurses, health care assistants, palliative care teams, social workers, psychiatrists, psychologists and geriatricians.

Phase 2 and 3 will take place in:

1. One hospital ward
2. One general practice
3. One community nursing team
4. Two palliative care community teams

Recruitment: Family carers for the first phase will be recruited through the Alzheimer's Society and other carers' organisations, such as a local Carers Service and the Carers Trust. We will also utilise the Patient and Public Involvement Forum and the clinical studies groups of the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) and the North Thames Dementia Registry. We will seek help from DeNDRoN co-ordinating centre, the Comprehensive Local Research Network (CLRN), the education sector, and Central North West London NHS Foundation Trust for recruitment of practitioners and social care employers in the same localities. For the second phase of the study we will make use of the above networks to recruit a community nursing team, a general practice which has care home responsibilities, and a hospital ward. We will seek advice from Marie Curie and members of the research team who have experience of successfully recruiting palliative care teams.

Procedure

This study has received ethical approval from both University College London (ID: 3344/003) and from the National Research Ethics Service (ID: 15/LO/0156).

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3 *Phase 1: Development and generation of heuristics using focus groups based on data from 47*
4 *interviews*

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6 At least six focus groups will be conducted with carers, practitioners and other experts.
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8 Family carers will be offered individual interviews if preferred. The focus groups will last
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10 between 1-1.5 hours and will be facilitated by a researcher with experience of group
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12 facilitation to include:

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15 **Group 1.** Up to five bereaved family carers discussing heuristics for hospital care
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17 **Group 2.** Up to five carers currently caring for someone with dementia discussing
18 heuristics for hospital care
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20 **Group 3.** Five – eight practitioners involved in end of life care for people with dementia
21 in hospital discussing heuristics for hospital care
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23 **Group 4.** Up to five bereaved family carers discussing heuristics for home care
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25 **Group 5.** Up to five carers currently caring for someone with dementia discussing
26 heuristics for home care
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28 **Group 6.** Five – eight practitioners involved in end of life care for people with dementia
29 at home discussing heuristics for home care
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33 The focus groups will use the ‘think aloud’ method⁴⁷ which encourages people to vocalise
34 their thought process when performing tasks or solving problems. Many have argued that
35 attention is needed to verbalizations of thought processes as this highlights an individual’s
36 cognitive behaviour and information stored in working memory.⁴⁷⁻⁴⁹
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41 Each group will be invited to follow the same four stage procedure to discuss and devise
42 heuristics:
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46 **Stage 1.** *Introduction (5min):* An introduction from the facilitator, explaining the
47 purpose of the study and the focus groups.
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49 **Stage 2.** *Opening the topic (5min):* The facilitator will introduce quality of care ideas
50 developed from the results of previous 46 in-depth interviews with family carers and a
51 review of the literature.
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53 **Stage 3.** *Discussion (think-aloud) (up to 70min):* Six topics of quality end of care
54 and/or possible topics of heuristics will be displayed on a screen individually for up to ten
55 minutes each and participants will be asked to discuss, think about their experience with
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3 this topic, what decisions need to be made, and finally what are the right decisions, whilst
4 verbalising their thought processes. The facilitator will record key ideas on a flip chart.

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6 **Stage 4.** *Summary and close (10min):* The facilitator will round up the group discussion
7 with a summary of the key topics and thoughts from the group.
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11 A separate development group consisting of ten health and social care practitioners as well as
12 family carer representatives, will be formed and begin to meet regularly after the first focus
13 group. They will assist with the synthesis of the results and construction of a set of heuristics,
14 acting as a think tank and providing a validation process using a nominal group process as
15 described above.
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20 21 *Phase two: Feasibility of heuristics*

22 Practitioners will be asked to use the heuristics as a framework and basis when providing end
23 of life care for up to ten people with dementia for a period of six months, in each setting.
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28 *Phase 3: Evaluation of heuristics*

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30 *3 month questionnaire and group interviews:* Up to five practitioners from each site will be
31 asked to complete an online questionnaire about their use of the heuristics. This will act as an
32 early indication of the use of heuristics and will enable the research team to identify and
33 address any major concerns, and reinforce the use of heuristics to guide care. We will also
34 undertake group interviews at each site consisting of 5-8 participants, with practitioners to
35 gain a better understanding of whether the heuristics are working, and if not why. Group
36 interviews keep staff time to a minimum and collect a variety of ideas whilst allowing for
37 interaction and discussion of these ideas. They will be conducted using nominal group
38 methods (see above).
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47 *6 month interviews:* Following phase two semi-structured interviews will be conducted with
48 the use of a topic guide on a one to one basis with practitioners (5-8 per site) who have
49 applied the heuristics in practice. This will inform the final iterations of the heuristics with
50 the research development team.
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55 **Analysis**

56 Interviews will be transcribed verbatim and thematic analysis methods will be used to analyse
57 the data. Coding will be led by one researcher and checked by two further researchers who
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3 will meet regularly to discuss emerging themes to enhance reliability and rigour.⁵⁰⁻⁵² The
4 development group will be convened and invited to discuss the evaluation and discuss the
5 final set of heuristics using nominal group procedures.
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8 9 10 **ETHICS AND DISSEMINATION**

11 The output of this study will be a series of heuristics (rules of thumb) developed using carers'
12 experiences and views, as well as practitioner experiences and opinions, and which have been
13 tested with practitioners caring for people with dementia at end of life in various settings.
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17 The findings from this study will be presented in peer-reviewed journals both within
18 palliative care and dementia care journals to target audiences a wide audience which this
19 study will be relevant for. Findings will be presented at national and international
20 conferences, and professional press such as Journal of Dementia Care will be utilised to
21 increase the spread of knowledge generated. Finally, a study website will be developed and
22 social media such as twitter and blogs will be used to disseminate findings.
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28 29 30 **CONTRIBUTION TO KNOWLEDGE AND PRACTICE**

31 The diversity of end of life care provision has prompted a search for a common language to
32 describe it,⁷ whilst there is greater acknowledgement of the importance of capturing the
33 complexities of provision.⁵³ End of life care for people with cancer is relatively well
34 developed, in terms of its conceptual framework and evidence base.⁵⁴ The evidence base to
35 guide practice in end of life care for people with dementia is less well developed, although
36 now evolving.⁵⁵ This study will contribute to the common language, and to the development
37 of practice. The heuristics it develops and tests may help fill the gap left by the departure of
38 the Liverpool Care Pathway.
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46 **Authors' contributions:** ND and SI are the Principal investigators for the funding. JM and
47 ELS are co-applicants and all contributed to the development of the study design. ND drafted
48 the manuscript and all authors have provided comments and approved the final manuscript.
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- **PRELIMINARY STUDY:** 47 interviews with family carers about quality end-of-life care for dementia (Completed)
- **PHASE 1: Generation of heuristics of care:** Validation of themes from preliminary study with opportunities for refinement using co-design with focus groups
Synthesis of results by multidisciplinary development group including carers using nominal groups
- **PHASE 2: Feasibility** of heuristics in real settings (GP surgery, community nursing team, and hospital ward)
- **PHASE 3: Evaluation** of heuristics through interviews, group interviews and online questionnaires
Synthesis of results by research development group and heuristics refined using nominal group
- **OUTCOME: Toolkit** to guide the delivery of end-of-life care for practitioners, presented at a symposium for all involved

Figure 1. Overview of project

BMJ Open

After the Liverpool Care Pathway – development of heuristics to guide end of life care for people with dementia: Protocol of the ALCP study

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2015-008832.R1
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Primary Subject Heading:	Geriatric medicine
Secondary Subject Heading:	Palliative care, Qualitative research
Keywords:	Dementia < NEUROLOGY, PALLIATIVE CARE, end of life care, decision making, heuristic

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3 **After the Liverpool Care Pathway – development of heuristics to guide end of life care**
4 **for people with dementia: Protocol of the ALCP study**
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37 **Key words:** Dementia, decision making, heuristic, end of life care, palliative care
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ABSTRACT

Introduction: End of life care guidance for people with dementia is lacking and this has been made more problematic in England with the removal of one of the main end of life care guidelines which offered some structure, the Liverpool Care Pathway. This guidance gap may be eased with the development of heuristics (rules of thumb) which offer a fast and frugal form of decision making.

Objective: To develop a toolkit of heuristics (rules of thumb) for practitioners to use when caring for people with dementia at the end of life.

Method and analysis: A mixed method study using a co-design approach to develop heuristics, in three phases. In phase one we will conduct at least six focus groups with family carers, health and social care practitioners from both hospital and community care services, using the ‘think-aloud’ method to understand decision-making processes and to develop a set of heuristics. The focus group topic guide will be developed from the findings of a previous study of 46 interviews of family carers about quality end of life care for people with dementia and a review of the literature. A multidisciplinary development team of health and social care practitioners will synthesise the findings from the focus groups to devise and refine a toolkit of heuristics. Phase two will test the use of the heuristics in practice in five sites: one general practice, one community nursing team, one hospital ward and two palliative care teams working in the community. Phase three will evaluate and further refine the toolkit of heuristics through group interviews, online questionnaires and semi-structured interviews.

Ethics and Dissemination: This study has received ethical approval from a local NHS research ethics committee (Rec ref: 15/LO/0156). The findings of this study will be presented in peer reviewed publications, national and international conferences.

Strengths and limitations

- This study places a high emphasis on family carers and will utilise their experience and knowledge to develop heuristics through a process of co-design
- Heuristics offer a novel approach to decision making at the end of life
- The heuristics developed in this study will be tested in a range of settings

INTRODUCTION

At present no treatment can alter the course of any form of dementia. Estimated average survival from when the person with dementia first notices symptoms is between 4 and 5 years¹ and from receiving a diagnosis is 3.5 years.² End of life care is therefore rapidly becoming one of the major priorities for dementia care. There are currently more than 670,000 family members and friends caring for people with dementia in the UK.³ These carers often provide the majority of health and social care, especially earlier in the course of dementia, and without them the professional health and care system would be likely to collapse.⁴

In England the government's End of Life Care Strategy defines end of life care as the last 12 months of life⁵ but this can be a problem when supporting people with dementia and those caring for them because it is often not possible to know how their dementia will progress and how other illness may affect the dementia⁶. For this study the researchers take the view that end of life care is not a period of time limited to the final days, hours or weeks of life, but more a period when the person, their family or practitioners recognise that they are dying⁷ and this will vary for individuals.

Guidance for practitioners on end of life care in England is currently specific guidance only for end of life care for people with cancer and not for other conditions, such as dementia.⁸ One of the main documents referred to by practitioners at the end of life was the Liverpool Care Pathway which offered a way for practitioners to plan care for someone who was at the very end of their life, often the final 48 hours. The Liverpool Care Pathway involved the withdrawal of unnecessary medication and interventions, and emphasised attention to the personal needs of the dying patient.

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3 Growing media attention highlighted concern about the ways in which end of life care was
4 being delivered within England. This culminated in an independent review of the Liverpool
5 Care Pathway.⁹ As a consequence, the government announced it would gradually phase out
6 the Liverpool Care Pathway. Many of the media reports were from family members who felt
7 their older relatives were abandoned or treated differently because of their age. Practitioners'
8 criticisms of the failings of the Liverpool Care Pathway included its over emphasis on 'paper
9 work' which led to a lack of attention to care. Many considered that these problems were
10 exacerbated by a misinterpretation of many of the key features of the Liverpool Care
11 Pathway, including nutrition, and hydration, together with a lack of training about its
12 implementation.⁹⁻¹¹

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21 Some practitioners argue that quality care for people with dementia at the end of life is
22 inhibited by its lack of clear structure.¹² The Liverpool Care Pathway provided some support
23 and a structure to guide care practitioners. Its withdrawal following the public criticisms has
24 resulted in a potential 'guidance gap' as well as a potential decline in confidence among
25 practitioners.^{13 14} The removal of the Liverpool Care Pathway coincided with the publication
26 of the European Association for Palliative Care's white paper which defined optimal
27 palliative care for people with dementia and their families.¹⁵ This potentially provides the
28 first set of guidance specific for dementia end of life care for practitioners but lacks policy
29 endorsement and the controversy over the Liverpool Care Pathway may affect its reception.

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38 Robust scientific conclusions derived from randomised controlled trials or epidemiological
39 studies are too scarce to inform practitioners' decision-making in many areas of practice and
40 many guidelines are not sufficiently based on evidence and are of low quality.¹⁶ Instead
41 heuristics ('rules of thumb' or 'mental short-cuts') are widely employed to address everyday
42 problems.¹⁷ Typically, heuristics are used in situations of uncertainty, may rely on first
43 impressions, and can occur effortlessly as a form of fast and frugal decision-making that
44 frequently gets the right answer.¹⁸ However, they are also prone to multiple biases and can
45 easily provide the wrong answer; they are assumed by many in healthcare to give second-best
46 outcomes.¹⁹ Nevertheless heuristics may well be the only solution to managing poorly
47 defined problems where no robust evidence exists and speedy decisions are needed. When
48 uncertainty is high, decision-makers need to use the minimal amount of relevant information
49 – in these circumstances less is more.²⁰ Fast and frugal heuristics have also been shown to be
50 more accurate than more complex and sophisticated prediction tools.²¹ Heuristics are
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3 important to practice, but to reduce errors and avoid biases they should be discussed,
4 criticised, refined and taught.¹⁷
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8 'FAST' is an example of a well-known heuristic designed to guide responses to stroke
9 symptoms (standing for Facial drooping, Arm weakness, Speech difficulties, Time to call
10 emergency services). FAST has demonstrated increased accuracy of the identification of
11 stroke patients.²² Similarly, PAID may be useful for practitioners trying to understand the
12 causes of challenging behaviour in people with dementia (standing for Pain, Aggravation,
13 Intrinsic to dementia (e.g. wandering), Depression/Delusions. The heuristics that general
14 practitioners use in making clinical decisions appear to shape performance more powerfully
15 than any form of formal training.²³
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23 End of life care for dementia can be very difficult for many reasons, not least because of the
24 difficulty communicating verbally many people with dementia have towards the end of life.
25 Many practitioners, both those from palliative care backgrounds and those with experience in
26 dementia care, lack the confidence and skills to provide end of life care for someone with
27 dementia.²⁴ This includes practitioners working in care homes where resources, staffing
28 levels and regulatory requirements are limited, and support from the wider health care system
29 is variable. End of life care for people with dementia is for these reasons often poor, with
30 improvement needed in many areas.²⁵ There is still limited access to end of life care services
31 for people with dementia^{5 26 27}, with a lack of the recognition of pain often highlighted^{28 29}
32 some even believing that people with dementia do not experience pain.³⁰
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41 The challenge remains how best to improve end of life care in the light of the recent
42 Liverpool Care Pathway review, family and practitioner anxieties and media controversy.⁹
43 One critically important resource is those people close to the person with dementia, often
44 family members. However, rarely have the views and experiences of family carers in their
45 own right been elicited³¹ and little is known about the experiences of carers about end of life
46 care.^{26 31 32} The recent descriptions of poor end of life care surrounding the Liverpool Care
47 Pathway have created an urgent need for health and social care practitioners to make more
48 use of the experiences of families, some of whom experience the dilemmas of care on a daily
49 basis.
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3 The removal of the Liverpool Care Pathway has left a gap in the guidance for practitioners
4 which may need to be filled, as suggested by claims that some organisations are finding it
5 hard to adapt to the Pathway's removal and suspicions that some are simply using it under a
6 different name.³³ We have proposed that this gap could be filled with the assistance of the
7 families of people with dementia, some of whose experiences were similar to those that
8 brought about the demise of the Liverpool Care Pathway. There remains little practice related
9 training in end of life care for people with dementia, with dementia apparently still often not
10 being accepted as an illness which will lead to death, sometimes requiring specialist end of
11 life care input.³⁴

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13 Starting with data from 46 interviews with family carers about end of life care for people with
14 dementia as a foundation,³⁵ (collected and funded as part of the IMPACT study³⁶) our three-
15 phase study described in this paper aims to:
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1. Conduct focus groups with family carers both current and former, as well as health and
social care practitioners to understand decision making at the end of life. Data collected
from the focus groups, literature and the previous interviews will be synthesised to
produce heuristics. These novel heuristics will be discussed, criticised, and refined in an
iterative process involving experts by training and experts by experience, as
recommended by McDonald.¹⁷
2. Test the use of heuristics with practitioners in five real settings including: one general
practice, one community nursing team, one care of the elderly hospital ward and two
community palliative care teams.
3. Evaluate the use content, and further refine the toolkit of heuristics through individual
interviews, group interviews, and online questionnaires.

METHODS AND ANALYSIS

Design: This study will use mixed methods and will comprise three phases: phase one will use input from interviews with families plus findings from focus groups with families and practitioners, and a rapid appraisal literature review to develop a collection of heuristics; phase two will test the feasibility of the developed heuristics in real settings; phase three will evaluate the heuristics using semi-structured interviews and group interviews, finishing by synthesising the learning from all sites to create the final heuristics. Figure 1 shows the project's flow path.

Figure 1 near here

We will develop the heuristics using a standard, well-established developmental approach for creating decision-support guides.³⁷ We have successfully used this method to develop a decision-support system for dementia diagnosis and management,^{38 39} which was incorporated into the electronic medical records system EMIS (Egton medical Informatics System) after being shown to improve practice in a randomised controlled trial.⁴⁰ A co-design approach⁴¹ will be used to engage carers and practitioners in the identification of important aspects of end of life care where heuristics might usefully be applied and the subsequent operationalization of the heuristics.

Focus groups will be organised for carers and practitioners from different disciplines and the interaction within groups will be facilitated to promote professional creativity and debate around the usefulness and effectiveness of individual heuristics.⁴²

The findings from the focus groups and literature reviews will be synthesised, developed, and refined into heuristics using a modified nominal group technique with a development group. Nominal groups are potentially powerful learning and development tools.⁴³ A nominal group process is a structured meeting which seeks to facilitate group or team decision making about a given problem (generation of heuristics), from a group who are experts in the given field. The process involves an introduction from the facilitator, silent generation of ideas by individuals, group discussion of generated ideas, and ranking of ideas to the problem being discussed (in this case heuristics).⁴⁴ They have a particularly useful role in analysing health care problems,⁴⁴ and can help bridge the gap between researchers and practitioners.⁴⁵ A nominal group approach designed for ill-structured problems will be used, to allow for

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3 disagreements over problem definition, and to produce potential solutions that overlap or
4 vary widely in specificity. This will require the synthesis process to generate ideas, confirm
5 that it is addressing the same problem, analyse the content of the heuristics, categorise and
6 clarify them.⁴⁶
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11 **Participants and settings:** The focus of the study is on end of life care for people with
12 dementia in their own homes acknowledging that some may also classify a care home as their
13 home (community), and on end of life care in general hospitals.
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18 *Phase 1 will aim to recruit:*
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- 20 1. Former family carers and family carers who are currently caring for someone with
21 dementia.
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- 23 2. Practitioners working with people with dementia at the end of life, including Admiral
24 nurses (specialist dementia nurses), general practitioners, community nurses, hospital
25 nurses, health care assistants, palliative care teams, social workers, psychiatrists,
26 psychologists and geriatricians.
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31 *Phase 2 and 3 will take place in:*
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- 33 1. One care of the elderly hospital ward
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- 35 2. One general practice
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- 37 3. One community nursing team
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- 39 4. Two palliative care community teams
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43 **Recruitment:** Family carers for the first phase will be recruited through the Alzheimer's
44 Society and other carers' organisations, such as a local Carers Service and the Carers Trust.
45 We will also utilise the Patient and Public Involvement Forum and the clinical studies groups
46 of the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) and the
47 North Thames Dementia Registry. We will seek help from DeNDRoN co-ordinating centre,
48 the Comprehensive Local Research Network (CLRN), the education sector, and Central
49 North West London NHS Foundation Trust for recruitment of practitioners and social care
50 employers in the same localities. For the second phase of the study we will make use of the
51 above networks to recruit a community nursing team, a general practice which has care home
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responsibilities, and a hospital ward. We will seek advice from Marie Curie and members of the research team who have experience of successfully recruiting palliative care teams. All participants will receive a verbal explanation of the study as well as a written copy of the information sheet, and will be given the opportunity to ask any questions. An experienced researcher (ND) will collect informed consent from all participants and the lead site manager/director prior to study participation.

Procedure

This study has received ethical approval from both University College London (ID: 3344/003) and from the National Research Ethics Service (ID: 15/LO/0156).

Phase 1: Development and generation of heuristics using focus groups based on data from 46 interviews

At least six focus groups will be conducted with carers, practitioners and other experts. Family carers will be offered individual interviews if preferred. The focus groups will last between 1-1.5 hours and will be facilitated by a researcher with experience of group facilitation to include:

- Group 1.** Up to five bereaved family carers discussing heuristics for hospital care
- Group 2.** Up to five carers currently caring for someone with dementia discussing heuristics for hospital care
- Group 3.** Five – eight practitioners involved in end of life care for people with dementia in hospital discussing heuristics for hospital care
- Group 4.** Up to five bereaved family carers discussing heuristics for home care
- Group 5.** Up to five carers currently caring for someone with dementia discussing heuristics for home care
- Group 6.** Five – eight practitioners involved in end of life care for people with dementia at home discussing heuristics for home care

The focus groups will use the ‘think aloud’ method⁴⁷ which encourages people to vocalise their thought process when performing tasks or solving problems. Many have argued that attention is needed to verbalizations of thought processes as this highlights an individual’s cognitive behaviour and information stored in working memory.⁴⁷⁻⁴⁹

Each group will be invited to follow the same four stage procedure to discuss and devise heuristics:

- Stage 1.** *Introduction (5min):* An introduction from the facilitator, explaining the purpose of the study and the focus groups.
- Stage 2.** *Opening the topic (5min):* The facilitator will introduce quality of care ideas developed from the results of previous 46 in-depth interviews with family carers and a review of the literature.
- Stage 3.** *Discussion (think-aloud) (up to 70min):* Six topics of quality end of care and/or possible topics of heuristics will be displayed on a screen individually for up to ten minutes each and participants will be asked to discuss, think about their experience with this topic, what decisions need to be made, and finally what are the right decisions, whilst verbalising their thought processes. The facilitator will record key ideas on a flip chart.
- Stage 4.** *Summary and close (10min):* The facilitator will round up the group discussion with a summary of the key topics and thoughts from the group.

A separate development group consisting of ten health and social care practitioners as well as family carer representatives, will be formed and begin to meet regularly after the first focus group. They will assist with the synthesis of the results and construction of a set of heuristics, acting as a think tank and providing a validation process using a nominal group process as described above.

Phase two: Feasibility of heuristics

Practitioners will be asked to use the heuristics as a framework and basis when providing end of life care for up to ten people with dementia for a period of six months, in each setting.

Phase 3: Evaluation of heuristics

3 month questionnaire and group interviews: Up to five practitioners from each site will be asked to complete an online questionnaire about their use of the heuristics. This will act as an early indication of the use of heuristics and will enable the research team to identify and address any major concerns, and reinforce the use of heuristics to guide care. We will also undertake group interviews at each site consisting of 5-8 participants, with practitioners to gain a better understanding of whether the heuristics are working, and if not why. Group interviews keep staff time to a minimum and collect a variety of ideas whilst allowing for

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3 interaction and discussion of these ideas. They will be conducted using nominal group
4 methods (see above).
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8 *6 month interviews:* Following phase two semi-structured interviews will be conducted with
9 the use of a topic guide on a one to one basis with practitioners (5-8 per site) who have
10 applied the heuristics in practice. This will inform the final iterations of the heuristics with
11 the research development team.
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14 15 16 **Analysis**

17 Interviews will be transcribed verbatim and thematic analysis methods will be used to analyse
18 the data. Coding will be led by one researcher and checked by two further researchers who
19 will meet regularly to discuss emerging themes to enhance reliability and rigour.⁵⁰⁻⁵² The
20 development group will be convened and invited to discuss the evaluation and discuss the
21 final set of heuristics using nominal group procedures.
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28 **ETHICS AND DISSEMINATION**

29 The output of this study will be a series of heuristics (rules of thumb) developed using carers'
30 experiences and views, as well as practitioner experiences and opinions, and which have been
31 tested with practitioners caring for people with dementia at end of life in various settings.
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36 The findings from this study will be presented in peer-reviewed journals both within
37 palliative care and dementia care journals to target a wide audience which this study will be
38 relevant for. Findings will be presented at national and international conferences, and
39 professional press such as Journal of Dementia Care will be utilised to increase the spread of
40 knowledge generated. Finally, a study website will be developed and social media such as
41 twitter and blogs will be used to disseminate findings.
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48 **CONTRIBUTION TO KNOWLEDGE AND PRACTICE**

49 The diversity of end of life care provision has prompted a search for a common language to
50 describe it,⁷ whilst there is greater acknowledgement of the importance of capturing the
51 complexities of provision.⁵³ End of life care for people with cancer is relatively well
52 developed, in terms of its conceptual framework and evidence base.⁵⁴ The evidence base to
53 guide practice in end of life care for people with dementia is less well developed, although
54 now evolving.⁵⁵ This study will contribute to the common language, and to the development
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3 of practice. The heuristics it develops and tests may help fill the gap left by the departure of
4 the Liverpool Care Pathway.
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8 **Authors' contributions:** ND and SI are the Principal investigators for the funding, JM and
9 ELS are co-applicants and all contributed to the development of the study design. ND drafted
10 the manuscript and all authors have provided comments and approved the final manuscript.
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12

13
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26 **Competing interests:** None declared
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PRELIMINARY STUDY: 46 interviews with family carers about quality end-of-life care for dementia (Completed)

PHASE 1: Generation of heuristics of care: Validation of themes from preliminary study with opportunities for refinement using co-design with focus groups

Synthesis of results by multidisciplinary development group including carers using nominal groups

PHASE 2: Feasibility of heuristics in real settings (GP surgery, community nursing team, and hospital ward)

PHASE 3: Evaluation of heuristics through interviews, group interviews and online questionnaires

Synthesis of results by research development group and heuristics refined using nominal group

OUTCOME: Toolkit to guide the delivery of end-of-life care for practitioners, presented at a symposium for all involved

Figure 1. Overview of project

Figure 1 Overview of project
200x78mm (300 x 300 DPI)