

# Journal of Palliative Care

## Deathbed Etiquette – The Guide: A qualitative study exploring the views of practitioners on its introduction into end-of-life care settings

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| Abstract:        | <p>Objectives. It is common for relatives to feel uncertain about what to expect at the bedside of a dying loved one. The Centre for [anonymous] together with clinical, academic and communications experts created a 'Deathbed Etiquette' guide offering information and reassurance to relatives. This study explores the views of practitioners with experience in end-of-life care on the guide and how it might be used. Methods. Three online focus groups and nine individual interviews were conducted with a purposive sample of 21 participants involved in end-of-life care. Participants were recruited through hospices and social media. Data was analysed using thematic analysis. Results. Discussions highlighted the importance of effective communication that normalises experiences of being by the bedside of a dying loved one. Tensions around the use of the words 'death' and 'dying' were identified. Most participants also expressed reservations about the title, with the word 'deathbed' found to be old-fashioned and the word 'etiquette' not capturing the varied experiences of being by the bedside. Overall, however, participants agreed that the guide is useful for 'mythbusting' death and dying. Conclusion. There is a need for communication resources that can support practitioners in having honest and compassionate conversations with relatives in end-of-life care. The 'Deathbed Etiquette' guide is a promising resource to support relatives and healthcare professionals by providing them with suitable information and helpful phrases. More research is needed on how to implement the guide in health care settings.</p> |
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## Abstract

**Objectives :** It is common for relatives to feel uncertain about what to expect at the bedside of a dying loved one. The Centre for [anonymous] together with clinical, academic and communications experts created a 'Deathbed Etiquette' guide offering information and reassurance to relatives. This study explores the views of practitioners with experience in end-of-life care on the guide and how it might be used. **Methods :** Three online focus groups and nine individual interviews were conducted with a purposive sample of 21 participants involved in end-of-life care. Participants were recruited through hospices and social media. Data was analysed using thematic analysis. **Results :** Discussions highlighted the importance of effective communication that normalises experiences of being by the bedside of a dying loved one. Tensions around the use of the words 'death' and 'dying' were identified. Most participants also expressed reservations about the title, with the word 'deathbed' found to be old-fashioned and the word 'etiquette' not capturing the varied experiences of being by the bedside. Overall, however, participants agreed that the guide is useful for 'mythbusting' death and dying. **Conclusion :** There is a need for communication resources that can support practitioners in having honest and compassionate conversations with relatives in end-of-life care. The 'Deathbed Etiquette' guide is a promising resource to support relatives and healthcare practitioners by providing them with suitable information and helpful phrases. More research is needed on how to implement the guide in healthcare settings.

**Keywords:** bereavement, palliative care, support, communication, death, dying

## Introduction

Being by the bedside of a loved one who is dying can be challenging, as relatives juggle a multitude of practical problems, emotional difficulties as well as an uncertainty about what to expect.<sup>1-3</sup> Existing research shows that relatives seek jargon-free and honest information and communication as well as compassionate care that will help them to understand what to expect before, around the time of death, and immediately after.<sup>2-6</sup> This includes practical information about looking after their loved one in those final days or hours, exploring fears and dispelling any myths, being prepared for the physical process of dying, and given opportunities to say goodbye.<sup>2,3,7</sup> Yet, research shows that relatives' information and communication needs are not always met<sup>3,8</sup>, and when this happens, relatives may feel isolated, disillusioned, frustrated and distressed.<sup>9-10</sup> This makes the need for explicit, honest and understandable information and communication ever more urgent.<sup>11</sup>

In response to relatives' need for jargon-free and honest communication at the end-of-life of their loved one, the Centre for [anonymous] at University A, in collaboration with University B and Hospice A, created a guide called 'Deathbed Etiquette' – an A4 sized sheet with 15 short statements, offering guidance and gentle reassurances about being by the bedside during the last days or hours of someone's life.<sup>12</sup> The guide, designed by a group of clinicians, academics and communications experts, was first released in 2019, and another for when relatives cannot be present released in 2020 in response to the Covid-19 pandemic. Both versions have received widespread media coverage, including the Financial Times, The Guardian and the BBC, amongst others.<sup>13-18</sup>

The aim of this study was to explore the views of healthcare practitioners on the guide and how it might be used within end-of-life care. Providing an account of their views will

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2  
3 contribute to the evidence base needed to develop effective information and communication  
4  
5 for relatives at the end of life.  
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## 8 **Methods**

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11 The study was designed for developing a deep and accurate understanding of the views of  
12  
13 healthcare practitioners on the guide, hence the case study design was selected.<sup>19</sup> The study  
14  
15 was approved by the Research Ethics Committee in the Faculty of Health and Medicine at  
16  
17 Lancaster University (reference number: FHMREC 20078 1 Feb 2021).  
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## 20 **Sample and Recruitment**

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22  
23 The study was carried out in the UK. A purposive sample of hospice staff working in one of  
24  
25 three participating hospices was selected as well as a purposive sample of practitioners with  
26  
27 experience in end-of-life care who had previously commented on the guide on social media.  
28  
29 Sampling and data collection continued until data saturation. The inclusion criteria for the  
30  
31 participants were: a) working in a UK health or social care setting in a role that primarily or  
32  
33 partly encompasses support for patient at the end of life and their families, b) aged 18+, and  
34  
35 c) English speaking.  
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38  
39 Potentially eligible hospice staff were approached via email by hospice site staff and invited  
40  
41 to take part. Other practitioners with experience in end-of-life care who had previously  
42  
43 commented on the guide on social media were approached by a member of the research team  
44  
45 using contact details available in the public domain. Other eligible practitioners were also  
46  
47 recruited via social media channels. An online recruitment flyer was distributed via Twitter  
48  
49 and Facebook, and eligible practitioners were invited to contact the research team. All  
50  
51 participants were informed about the aim and objectives of the research. Consent was  
52  
53 obtained from all participants before the start of data collection.  
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## 58 **Data Collection**

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3 Semi-structured focus groups were conducted online, and individual semi-structured  
4  
5 interviews were conducted either online or over the phone. When data collection took place  
6  
7 online, a secure digital video conferencing software was used. A topic guide was used to  
8  
9 guide the discussions (available in the supplemental material) and to ensure consistency  
10  
11 across focus groups and interviews. The same topic guide was used for focus groups and  
12  
13 individual interviews. Focus groups were conducted by LD, MF and KS, and interviews were  
14  
15 conducted by LD and MF, all with previous experience of conducting focus groups or  
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17 interviews. Focus groups lasted approx. 1 hour and on average, the interviews lasted 40  
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19 minutes (range 30-50 minutes). They were digitally recorded, anonymised and transcribed  
20  
21 verbatim. Data was collected between February and April 2021.  
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## 26 **Data Analysis**

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29 Data was analysed inductively using thematic analysis.<sup>19</sup> Following familiarization with the  
30  
31 data, transcripts were coded using Nvivo 12 Plus. An initial set of codes was generated and  
32  
33 developed into a coding scheme that was applied across the dataset. Comparison across the  
34  
35 dataset allowed regularities (themes) to be identified. MKF led on the data analysis with input  
36  
37 from LD, MF and AG, who had all read the transcripts. Emerging themes and findings were  
38  
39 discussed with the team on a bi-weekly basis.  
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## 44 **Results**

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47 Three focus groups (n = 5, 3, 4) and nine individual interviews were conducted. In total, 21  
48  
49 participants took part in the study, all with university/degree level education except the  
50  
51 healthcare assistant. See table 1 for further details on participants. Most of the participants  
52  
53 had not yet used the guide in a professional context, only two participants had.  
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56  
57 All participants were very positive and supportive of the guide, viewing it as a potentially  
58  
59 very effective tool in supporting relatives with advice and reassurance.  
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3 Three broad themes emerged from the discussions: the importance of normalising  
4 experiences of being by the bedside of a dying loved one; the guide as an important and  
5 effective training tool for healthcare practitioners; and participants' reflections on how best to  
6 introduce and implement the guide in practice.  
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### 13 **Normalising experiences of being by the bedside of a dying loved one**

#### 14 *A need to talk about death and dying*

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16 Participants discussed how they often see relatives not knowing what to do or say at the  
17 bedside, and participants were therefore very supportive of the guide in its aim to normalise  
18 the need to talk about death and dying. The guide was described as giving relatives the words  
19 to talk about death and dying with participants commending its short sentences and simple  
20 language for being 'extremely reassuring'.  
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30 *I know there are lots of books and textbooks and there are some generalised*  
31 *resources which are okay, but I think I love the simplicity of this material. (P7)*  
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35 Yet, a tension around the use of the words 'death' and 'dying' was identified. On the one  
36 hand, participants felt that the words can be harsh sounding and expressed worry about  
37 upsetting relatives, yet on the other hand, they agreed that it is important to tell it as it is, and  
38 not speak in codes, as doing so can lead to confusion and relatives not realising that their  
39 loved one is in their final days or hours of life.  
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47 Many participants expressed concerns about the word 'deathbed' and its connotations,  
48 especially how it would be perceived by the public. They described the word as old-  
49 fashioned and not commonly used and expressed concern about some people possibly not  
50 understanding what it means. Some did not like the bluntness of the phrase, viewing it as  
51 'quite harsh in its sounding' (P17) and 'a mouthful' (P4). Others did not mind the word, but  
52 still commented on its unusualness, 'it just sounds odd' (P6). The discussions highlighted a  
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3 need to have a shared vocabulary for talking about death and dying that should be familiar  
4  
5 and accessible to everyone.  
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8 *No rules for how to behave*  
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11 Participants felt that it was important to convey how experiences of being by the bedside can  
12  
13 be varied and that what is right for one person is not necessarily right for another. Some  
14  
15 participants therefore did not like the word 'etiquette' in the title.  
16  
17

18 *I think sometimes people think 'my relative is dying so now I have to hold a bedside*  
19 *vigil and wait for them to die', and that is really difficult, I think, so I think*  
20 *sometimes giving people that acceptance that we wouldn't expect that, there's no*  
21 *judgement, we won't judge you, whether you're here or you're not here, because you*  
22 *need to do what's right for you. (P8)*  
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30 The discussions highlighted a need for the guide to not set up certain expectations for how to  
31  
32 behave, especially since end-of-life situations can potentially be very difficult experiences  
33  
34 for relatives. Participants spoke about relatives struggling to accept that their loved one is  
35  
36 dying and about relatives who find the death of their loved one very distressing. They  
37  
38 therefore thought that the guide should be portrayed and introduced as a supportive guide,  
39  
40 and therefore suggested using a different title.  
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45 *De-medicalising end-of-life*  
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47  
48 Participants shared a concern with death in general being too medicalised. They therefore  
49  
50 expressed a dislike with the image that many of them thought looked 'medicalised', and  
51  
52 not realistically representing what death and dying is like, describing the image as 'very  
53  
54 hospital focused' (P16) and 'too clinical' (P15). They worried about false expectations and  
55  
56 unnecessary worry on behalf of relatives.  
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3 *There's, like, a drip hook, which you wouldn't have with somebody necessarily who*  
4 *was actively dying. That's another thing that we have lots of conversations around*  
5 *the ward. (P16).*  
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10 The discussions highlighted a need for 'mythbusting' death and dying. Participants agreed  
11 that the text did that very well with its focus on the social nature of death and dying, but that  
12 more could be done to de-medicalise the image.  
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### 18 **Guide to support practitioners in having conversations with relatives**

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20 Discussions highlighted the importance of the guide being used to support healthcare  
21 practitioners and students in having conversations with relatives, either in person or over the  
22 phone. This includes new and less experienced practitioners as well as those who do not feel  
23 confident or comfortable having conversations with relatives of a dying person.  
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30 *There is a massive need for this across the board really, not just with nurses and*  
31 *doctors and certainly not just with palliative care [...] GPs, district nurses, they all*  
32 *need this. (P4)*  
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### 38 *Providing an end-of-life language*

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40 The guide was described as providing practitioners with ideas on what to say, including a  
41 'repertoire of phrase' (P8), and helping them to think about 'hints and tips' for how to  
42 support families (P4). It was thought to give practitioners the reassurance that 'having a kind  
43 heart' and 'just presence and being there' can make a big difference to relatives (P12). This  
44 was considered important, especially since some participants expressed the view that there  
45 still exists an unease amongst practitioners about talking about death and dying.  
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55 *Now it's a bug bear with me that people who work with the dying don't like having*  
56 *these sort of conversations [...] We're supposed to be the specialists of dying and we*  
57 *won't talk about dying, which I do find quite frustrating sometimes. (P4)*  
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3 Others commented on the need for ‘getting the language right’ (P3), and not ‘talking in  
4  
5 euphemisms’ (P5) that can lead to misunderstandings, and how the guide could help address  
6  
7 this need.  
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### 10 *The guide as a training tool*

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12  
13 Participants saw the guide as an important training tool helping practitioners to understand  
14  
15 and communicate what is happening at the very end of life. Participants discussed several  
16  
17 approaches for its introduction such as including the guide as part of training packages, for  
18  
19 example, as part of e-learning modules on end-of-life care or induction sessions for new staff  
20  
21 and students. A personal introduction was thought to be the best and most effective approach  
22  
23 to engage staff, for example, introducing the guide at training days that would allow people to  
24  
25 discuss the guide and ask questions, rather than emailing the guide to staff.  
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29  
30 While most agreed an introduction to the guide is needed, other participants thought it was  
31  
32 best to incorporate the guide into ad hoc training on the wards. Some suggested using  
33  
34 ‘champions’ or ‘ambassadors’, who could have a chat with each staff member. They could  
35  
36 individualise its introduction, taking into account each person’s experiences and be attentive  
37  
38 to any reluctance that could hinder its uptake in practice. Leaving the guide as a poster in the  
39  
40 staff room, as another participant had suggested, was therefore thought to be ineffective.  
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45 Despite disagreement on how best to introduce the guide, most participants agreed that the  
46  
47 guide needs to be introduced to staff and into clinical practice for it be effective.  
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### 49 **Implementation of the guide in practice**

#### 50 51 *Timely introduction of the guide to relatives*

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54 Participants agreed that the guide must be introduced in a timely and compassionate way.  
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56  
57 Rather than leaving the guide to be picked up by relatives themselves or the guide becoming  
58  
59 ‘a tick box thing’ (P21), most participants thought it best to introduce the guide to relatives  
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3 following an initial conversation with a healthcare practitioner about their loved one dying.

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5 Some suggested that the guide could be introduced once relatives start to ask questions.

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8 Getting to know the relatives and building up rapport with them were highlighted as  
9  
10 important in order to assess when to introduce the guide. Introducing the guide too soon  
11  
12 could potentially be distressing. Tailoring its introduction to the needs of each family was  
13  
14 therefore felt to be important.  
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17  
18 *[S]ometimes some people aren't ready to hear those things or don't want to hear*  
19  
20 *those things even though they are happening right in front of them. And so I think it is*  
21  
22 *getting to know the family, the relatives, and sort of using it sort of bespoke to that*  
23  
24 *person who needs it. (P12)*  
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27  
28 Participants agreed that the guide should be introduced by the person who will have that  
29  
30 initial conversation about their loved one dying. Being able to answer questions about the  
31  
32 process was seen as crucial, and delivery would therefore be challenging for practitioners  
33  
34 who cannot provide an answer.  
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## 36 37 **Discussion**

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40 The study findings highlight several potential benefits of using the guide to Deathbed  
41  
42 Etiquette in end-of-life care, particularly how the guide with its simple, yet impactful  
43  
44 messages and format was seen to provide relatives with a language and reassurances to talk  
45  
46 about death and dying. Our findings thus support existing research on the importance of  
47  
48 effective information and communication for relatives at the end of life.<sup>2-3,5-6,8-9,11,20-23</sup> This  
49  
50 includes research that evidences the benefits of using information pamphlets in end-of-life  
51  
52 care for relatives' experiencing bereavement.<sup>24-26</sup> Other benefits highlighted by the study  
53  
54 include the guide's effort to de-medicalise death and dying, thus contributing to a growing  
55  
56 trend emphasizing the social nature of death and dying.<sup>27-28</sup> Although, our findings show that  
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3 more could be done to de-medicalise the image used in the guide, making it appear less  
4  
5 clinical.  
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8 The guide was also described as a potentially important training tool that can support  
9  
10 healthcare practitioners in having conversations with relatives, giving them the confidence  
11  
12 and language to talk to relatives.<sup>29</sup> As existing research has found that death and dying within  
13  
14 the healthcare profession remain challenging and difficult topics with practitioners feeling  
15  
16 inadequately trained for having such conversations,<sup>20,30-31</sup> the guide to Deathbed Etiquette  
17  
18 could potentially play an important role in addressing this unmet need. This is crucial since  
19  
20 existing research has found that a willingness to discuss death and dying at the end of life is  
21  
22 one of the most important needs of relatives.<sup>2,32</sup>  
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27 In terms of the guide's effective introduction to relatives, the findings highlight a need for  
28  
29 introducing the guide in a timely and compassionate way and following an initial  
30  
31 conversation with relatives about their loved one entering their final days or hours of life. It is  
32  
33 worth noting that the guide may need adapting and evaluating for different cultural contexts,  
34  
35 something which the discussions only briefly touched upon. While the guide has been  
36  
37 adapted for different religious groups,<sup>12</sup> more research is needed to explore its cultural  
38  
39 appropriateness, including whether it could be introduced effectively through a mobile  
40  
41 application.  
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46 Challenges were also identified, particularly in relation to the title of guide. Concerns were  
47  
48 raised about the public perception of the word 'deathbed', which was thought to be blunt as  
49  
50 well as unfamiliar to many, and the word 'etiquette', which was thought to not fit with the  
51  
52 aim of the guide to offer support and guidance to relatives in a way that does not set up  
53  
54 certain expectations for how to behave. Existing research on the taboo associated with death  
55  
56 and dying could help explain the negative connotations connected to the word 'deathbed'.  
57  
58 This includes a discomfort with dying's physicality as well as difficulties explaining or  
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3 relating to ‘deathbed visions’,<sup>33-34</sup> but also more generally, the thesis that we live in a death-  
4 denying society, spurred on by the medicalisation of death and the individualism of the 20th  
5 Century,<sup>35</sup> and which has since been embraced as public knowledge and become  
6 normalised.<sup>36-37</sup> That the word ‘etiquette’ is found to be problematic could be explained by  
7 practitioners’ familiarity with clinical etiquette as taught in medical school and practiced in  
8 healthcare as a way to maintain politeness and integrity.<sup>38-39</sup>  
9

### 17 **Strengths and limitations**

20 The strength of the study is its inclusion of a variety of healthcare practitioners with  
21 experience in end-of-life care, including nurses and doctors, chaplains, allied health  
22 professionals, and managers that allowed for rich data on their views on the guide and its  
23 introduction into practice. Practitioners with less extensive experience in non-hospice  
24 settings, however, may respond differently to this resource. The study findings are also  
25 limited by focusing on professional views. Understanding the perspective of relatives and  
26 other loved ones, including differences in settings (ICU patients versus hospice and ward  
27 patients) will be paramount for further development and implementation of the guide.  
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### 39 **Conclusion**

42 Exploring the views of practitioners with experience in end-of-life care, the study found that  
43 the guide to Deathbed Etiquette could potentially be an effective tool in supporting relatives  
44 as well as practitioners in end-of-life care. Key findings demonstrate the importance of  
45 normalising experiences of being by the bedside of a dying loved one, including the need to  
46 talk about death and dying. Having honest and compassionate conversations with relatives  
47 about death and dying is crucial, and the guide was found to potentially contribute to this aim  
48 with its simple messages and reassuring language. Further research is needed on relatives’  
49 views on the guide, ensuring that broad perspectives are captured. There is also a need for  
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3 more research on how to implement the guide in healthcare settings, which will include  
4 exploring the suitability of different terminology and language around death and dying, and  
5 how communication resources can be designed and implemented in settings where  
6 practitioners and patients are likely to have different preferences regarding language.  
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## 12 **Supplemental material**

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16 A. Interview topic guide  
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**Table**

| Participant | Job role                     | Setting   | Type        |
|-------------|------------------------------|-----------|-------------|
| P1          | Clinical manager             | Hospice   | Interview   |
| P2          | Consultant                   | Hospice   | Interview   |
| P3          | Senior nurse                 | Hospital  | Interview   |
| P4          | Chaplain                     | Hospice   | Interview   |
| P5          | End of life care facilitator | Community | Interview   |
| P6          | Nurse                        | Hospital  | Interview   |
| P7          | Chaplain                     | Hospice   | Interview   |
| P8          | Registrar/specialty trainee  | Hospice   | Interview   |
| P9          | Clinical manager             | Hospital  | Interview   |
| P10         | Clinical nurse specialist    | Hospice   | Focus group |
| P11         | Consultant                   | Hospice   | Focus group |
| P12         | Bereavement nurse            | Hospice   | Focus group |
| P13         | Bereavement nurse            | Hospice   | Focus group |
| P14         | Clinical nurse specialist    | Hospice   | Focus group |
| P15         | Healthcare assistant         | Hospital  | Focus group |
| P16         | Occupational therapist       | Hospital  | Focus group |
| P17         | Senior nurse                 | Hospital  | Focus group |
| P18         | Senior nurse                 | Hospice   | Focus group |
| P19         | Senior nurse                 | Hospice   | Focus group |
| P20         | Senior nurse                 | Hospice   | Focus group |
| P21         | Clinical manager             | Hospice   | Focus group |

Table 1: Study participant details

## Interview Topic Guide

### Exploring the views of health and social care professionals on using the Deathbed Etiquette guide in end-of-life care settings

#### Pre-recording:

- Make sure have copy of the guides to look at/refer to.
- Focus group needs to have at least 3 participants. If fewer than three people join, then send one participant a separate invite (check they can access their emails) and then wait until that arrives in their inbox before splitting off into individual interviews. [alternatively – call them directly using their email addresses]
- Check everyone has consented to take part in the study. Explain that expect FG to last an hour.
- **Focus group ground rules:** Everyone's perspective is equally valid, different views, negative as well as positive comments are just as important to the evaluation process. All discussions taking place in the focus group should not be discussed outside that focus group. There are some limits to confidentiality: if what is said makes the research team think that you, or someone else, is at significant risk of harm, they will have to break confidentiality and report this to the research lead and possibly other relevant parties. If possible, you will be informed about this.
- Check can use hand function to indicate want to speak or raise hand.
- Check if anyone has any questions about the study or consent form etc beforehand

*Switch recording on (including second recorder if using), state the date of interview and name of participant.*

#### Opening questions

Can you describe your role? (or for group: can you introduce yourself and briefly explain your role?)

Why you are interested the guide?

What are your experiences of the guide? What do you know about the guide already?

1  
2  
3 Give group opportunity to lead the discussion and clarify if they want to talk about the  
4 COVID or non-COVID version of the guide. May be useful to allow a few minutes to look at  
5 the guide if they haven't had chance yet.  
6  
7

8 For those who were already aware of the guide, can you describe what your initial thoughts  
9 were upon coming across it for the first time?  
10

11 For those who have only just read through the guide, perhaps you'd like to talk about your  
12 initial reaction to it? What are your first thoughts?  
13  
14

15 *Further prompts:*

16  
17 Are there some parts of the deathbed etiquette guide that stand out to you as particularly  
18 important? Why?  
19

20 Is there anything you don't like about the guide?  
21

22 Is there anything you think is missing/ should be added?  
23  
24

25 **Probe: What would you do differently?**

26  
27 Practical/process  
28

29 How do you use/might you use this guide in the settings where you work?  
30  
31

32 *Further prompts:*

33  
34 Would you use it for every patient, select patients, leave by bed, only give as part of a  
35 conversation?)  
36

37 How do you imagine the guide being incorporated into the care and support you and your  
38 colleagues provide to patients and families?  
39  
40

41 **Probe: At what point would it be appropriate to introduce the guide? At the point of**  
42 **breaking bad news?**  
43

44 **Probe: How would you manage the patient/family dynamics when using or introducing of**  
45 **the guide? E.g. in the hospital setting? In the patients home?**  
46

47 What might hold you back from using the guide? Or if guide is available have you held back  
48 from using the guide and why?  
49

50 Can you see any limitations to using the guide in end-of-life care?  
51  
52

53 How might use of the guide vary depending on the healthcare setting?  
54  
55

56 What preparation/training, if any, do you feel you may need before using the guide? Those  
57 who have used the guide, did you receive any training about it?  
58

59 COVID-19 guide  
60

1  
2  
3 The guide was revisited in light of the COVID pandemic. Having read this version of the  
4 guide, what are your thoughts on it?  
5

6  
7 For those who have used this guide, can you describe your experiences of doing so?  
8

9 Those who have not used the guide, how useful do you think it might be for loved ones of  
10 patients dying from COVID-19?  
11

12 What might you want to change or add to this? Do you have any concerns about using it for  
13 those affected by COVID-19?  
14

### 15 Closing questions 16

17  
18 Are there any further thoughts you'd like to share about the guide?  
19  
20  
21  
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## 26 **Distress protocol** 27 28 29

### 30 **Participant shows signs of distress:** 31

- 32 • Stating that they are distressed or upset
- 33 • Showing physical signs such as uncontrolled crying, incoherence, shaking  
34

### 35 **Stage 1 Response:** 36

- 37 • Stop the interview or focus group
- 38 • Ask the participant how they are feeling:  
39 "What are you feeling right now?"  
40 "Do you feel able to go on about your day after this interview?"  
41  
42  
43

### 44 **Review:** 45

- 46 • If the participant feels happy to continue then resume the focus group or interview
- 47 • If the participant would like to pause before continuing, take a break or offer to  
48 reschedule the interview. If they are taking part in a focus group, offer them to take  
49 part in an interview at a different time
- 50 • If the participant is unable to carry on go to Stage 2  
51  
52  
53

### 54 **Stage 2 Response:** 55

- 56 • With permission, withdraw the participant from the study
- 57 • Signpost participant to further resources (e.g. wellbeing support at their  
58 organisation)  
59  
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**Follow up:**

- With permission, follow up the participant with a courtesy call

For Peer Review