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## Designing a nurse-delivered delirium bundle: what ICU staff, survivors and their families think

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1 Designing a nurse-delivered delirium bundle: what ICU staff, survivors and  
2 their families think

3 **ABSTRACT**

4 Background. Implementation of quality improvement interventions can be enhanced by exploring  
5 the perspectives of those who will deliver and receive them. We designed a non-pharmacological  
6 bundle for delirium management for a feasibility trial and we sought to obtain the views of Intensive  
7 Care Unit (ICU) staff, survivors and families on the barriers and facilitators to its implementation.

8 Objective: To determine the barriers and facilitators to a multi-component bundle for delirium  
9 management in critically ill patients comprising [1] education and family participation, [2] sedation  
10 minimisation and pain, agitation and delirium (PAD) protocol, [3] early mobilisation and [4]  
11 environmental interventions for sleep, orientation, communication and cognitive stimulation.

12 Methods: Nine focus group interviews with ICU staff (n=68) in 12 UK ICUs. Three focus group  
13 interviews with ICU survivors (n=12) and their family members (n=2). Interviews were digitally  
14 recorded, transcribed and thematically analysed using the Braun and Clarke framework.

15 Results: Overall, staff, survivors and their families agreed the bundle was acceptable. Facilitating  
16 factors for delivering the bundle were staff and relatives' education about potential benefits and  
17 encouraging family presence. Facilitating factors for sedation minimisation were evening ward  
18 rounds, using non-verbal pain scores and targeting sedation scores. Barriers identified by staff were  
19 inadequate resources, poor education, relatives' anxiety, safety concerns and ICU culture. Concerns  
20 were raised about patient confidentiality when displaying orientation materials and managing  
21 resources for early mobility. Survivors cited that flexible visiting and re-establishing normality were  
22 important factors; and staff workload, lack of awareness and poor communication were factors that  
23 needed to be considered prior to implementation.

24 Conclusion. Generally, the bundle was deemed acceptable and deliverable. However, like any  
25 complex intervention, component adaptations will be required depending on resources available to  
26 the ICU; in particular, involvement of pharmacists on the ward round and physiotherapists in  
27 mobilising intubated patients.

28

## 29 **INTRODUCTION**

30 Critically ill patients have an increased risk of developing delirium during their intensive care stay.  
31 Delirium is a common and devastating syndrome characterised by inattention and associated with  
32 increased mortality and morbidity <sup>(1, 2, 3)</sup>. Pharmacological therapies remain the popular choice for  
33 delirium management in United Kingdom (UK) Intensive Care Units (ICUs) despite the publication of  
34 recent studies and guidelines that indicate that there is insufficient evidence to support their use <sup>(4, 5,</sup>  
35 <sup>6)</sup>. A multi-component non-pharmacological intervention may reduce incidence and severity of  
36 delirium by targeting known risk factors such as sensory deprivation, sleep deprivation and  
37 immobilisation in critically ill patients. Non-pharmacological interventions for delirium management  
38 have been effective in non-ICU populations but whether they are effective for critically ill patients  
39 has not been adequately researched <sup>(7, 8)</sup>.

40 We conducted a systematic review of studies evaluating non-pharmacological interventions for  
41 delirium management in critically ill patients to determine which interventions were most effective  
42 for reducing the incidence and/or duration of delirium <sup>(9)</sup>. Findings indicated a number of effective  
43 interventions, some that could be delivered singly or in combination <sup>(11 – 19)</sup>. These findings were  
44 presented to a panel of international, multidisciplinary delirium experts for agreement at the 2016  
45 Intensive Care Society State of the Art meeting in London. Following discussion with the panel, a  
46 delirium bundle based on best evidence was designed to be tested in a feasibility study. The bundle  
47 comprised four components [1] education and family participation, [2] sedation minimisation and

48 Pain Agitation and Delirium (PAD) protocol, [3] early mobilisation and [4] environmental  
49 interventions.

50 Translating knowledge to practice for healthcare professionals can be more successful if it is  
51 informed by an assessment of the barriers and facilitators <sup>(20)</sup>. Therefore, the aim of this study was to  
52 elicit the perspectives of ICU staff, survivors and families about the barriers and facilitators to  
53 delivering and receiving this delirium bundle that would inform design, delivery and implementation.

## 54 **METHODS AND MATERIALS**

### 55 **Research approach**

56 The research approach was guided by the Medical Research Council framework for the development  
57 of complex interventions <sup>(21)</sup> and a systematic review of key factors affecting intervention  
58 implementation <sup>(22)</sup>. This approach enabled us to examine deliverability and acceptability of the  
59 components in the bundle using focus group interviews. We elicited the perspectives of ICU staff,  
60 survivors and their families using focus group interviews conducted between July and September  
61 2016.

62 Semi-structured questions in the interview guide were framed around the key findings from Durlak's  
63 systematic review <sup>(22)</sup> (see appendix 1 for interview schedule). The study was approved by an NHS  
64 research ethics committee (OREC/16/EM/0208). The standards for reporting qualitative research  
65 (SRQR) were applied <sup>(23)</sup>.

### 66 **Setting**

67 Staff interviews took place in 12 NHS adult general ICUs in England, Scotland, Wales and Northern  
68 Ireland. We used a sampling matrix to ensure inclusion of units from all four devolved nations of the  
69 UK and staff with a range of experience from less than one year to ten years and over. ICUs ranged  
70 in size from seven beds to 52 beds with a range of specialties including medical, surgical, trauma and  
71 burns. Interviews with ICU survivors and their families were conducted face to face at ICUsteps

72 group meetings in England and Northern Ireland and online using Skype technology with each  
73 participant in their own home <sup>(24)</sup>.

#### 74 **Participant Recruitment**

75 ICU staff were recruited from the membership of the British Association of Critical Care Nurses  
76 (BACCN): the professional organisation for critical care nurses in the UK that has representation in  
77 the majority of UK ICUs. The ethos of the association promotes engagement in research for patient  
78 benefit, which is why I chose this method. Approval was granted by BACCN to post a study  
79 advertisement on the website and in the newsletter. Interested members discussed potential  
80 participation with staff in their ICUs; received approval from the ICU managers; and recruited staff to  
81 attend focus group interviews. Interviews took place in a hospital or university meeting room.

82 Inclusion criteria were staff with more than 6 months experience working in critical care and  
83 purposeful sampling method was encouraged to ensure a range of professions and experience  
84 within the focus group (Table 1).

85 ICU survivors and families were recruited from ICUsteps, a charity that supports survivors of critical  
86 illness and their families. Approval was received by ICUsteps to circulate study information via the  
87 ICUsteps newsletter and website: potential participants then contacted an investigator (LB) directly.  
88 Inclusion criteria were that ICU survivors had to have been cared for in ICU for greater than 48  
89 hours.

#### 90 **Data Collection**

91 Focus groups interviews were approximately 60 - 90 minutes in length and conducted by LB with  
92 experience in critical care nursing and research. The interview was preceded by a PowerPoint  
93 presentation of the multicomponent delirium bundle to initiate the discussion. Interviews were  
94 recorded using a WS-831 Digital Voice Recorder (Olympus Imaging Corp, Tokyo, Japan) and

95 transcribed verbatim by an independent transcriber. Interviews continued until data saturation was  
96 obtained which was judged by no new data arising in the interviews <sup>(25)</sup>.

## 97 **Data Analysis**

98 The transcripts were reviewed by the interviewer (LB) and compared with the voice recordings and  
99 the handwritten notes taken during discussions to reduce the risk of errors and missing information.

100 The corrected transcripts were thematically analysed using the Braun and Clarke thematic analysis  
101 framework to identify barriers and facilitators to the multicomponent bundle <sup>(26)</sup>.

102 To enhance confirmability of the results a random sample of 15% of the transcripts were  
103 independently analysed by a second investigator (JMG). Interpretations were discussed until  
104 consensus was reached to reduce the influence of personal characteristics on interpretation and  
105 bias.

106

## 107 **RESULTS**

108 Results are presented separately for (1) staff and (2) survivors and family members outlining generic  
109 (to the interventions as a whole) and specific (for each component of the intervention) barriers and  
110 facilitators to delivery and acceptability of the bundle. Quotes from transcripts have been used to  
111 support the themes arising for each participant group.

112 Twelve focus group interviews were conducted, nine involved staff (n = 68) and three involving ICU  
113 survivors (n = 12) and family members (n = 2). Tables 1 and 2 present a summary of participant  
114 characteristics.

### 115 **ICU staff perceptions of the multicomponent bundle**

#### 116 Acceptability of the intervention

117 Staff from all focus groups felt that this multicomponent intervention comprising education,  
118 sedation minimisation, early physical therapy and environmental interventions was feasible and  
119 acceptable to implement for delirium management in critically ill patients. Concerns were expressed  
120 about the feasibility of pharmacy involvement on the ward round and early physical activity of  
121 mechanically ventilated patients without an improvement in current staffing levels.

122 *“I think there’s lots of elements that we are already working on and we can definitely do*  
123 *some things better.” [FG3, ICU nurse, M].*

124 *“ there are limitations; chairs and staff, coordinating time.’ [FG11, ICU nurse, F]. [speaking*  
125 *about early physical activity].*

126 There were two generic factors that staff perceived would facilitate their use of this bundle:

127 1. Family presence was perceived as creating a sense of familiarity and safety for patients. Staff felt  
128 that families were an underutilised resource in ICU and could be used to assist with communication,  
129 orientation, personalising music selection and personal care if appropriate training and support was  
130 available. Family presence could be encouraged by facilitating more flexible visiting hours.

131 *“I’ve seen people who I thought were tipping into delirium actually end it in a much shorter*  
132 *period because of the presence of familiarity and safety around them” [FG8, Clinical*  
133 *Psychologist, F]*

134 2. Education for staff about delirium in ICU was deemed important for challenging existing cultures  
135 of deep sedation and excessive noise at night and would improve staff engagement with the delivery  
136 of the interventions. They suggested that education programmes should include some formal  
137 feedback from patients about their experiences in the ICU. Additionally, staff reported that  
138 education for relatives might help address their anxiety, although timing in the patient’s illness  
139 trajectory would be crucial to enable retention of information.

140 Specifically focusing on individual components of the bundle, factors that would facilitate the  
141 orientation and communication component were use of picture boards and photographs. Factors  
142 that would facilitate the sedation minimisation component, particularly for less experienced staff,  
143 were protocols, guidelines, targeted sedation, non-verbal pain scores and identifying suitable  
144 patients for a sedation break in an evening ward round on the previous day. Use of a Richmond  
145 Agitation Sedation Score (RASS) for monitoring sedation scores is standard practice in ICU however  
146 targeting a specific score for example, 0 alert and orientated, is not part of this practice but  
147 participants believed this helped reduce the amount of sedation administered overall. The use of a  
148 pain tool such as Critical Care Pain Observation Tool (CPOT)<sup>(27)</sup> for non-verbal patients is not  
149 standard practice however staff participants reported that the use of this tool facilitated sedation  
150 minimisation by avoiding the need for higher sedation due to better controlled pain. Staff reported  
151 that communication training and availability of tools would be useful for helping to meet patients'  
152 pain and care needs.

153

154 There were five generic barriers perceived by staff as barriers to successful delivery of the bundle:

155 1. Staff cited limited resources, in terms of personnel, equipment and space, which could be further  
156 exacerbated by the need to facilitate staff breaks and lengthy patient transfers out of ICU. A busy  
157 workload was a barrier to the delivery of the bundle. Caring for a critically unstable patient could  
158 negatively influence the care of other patients under their supervision and interventions like  
159 sedation interruptions or extubation might be delayed. Staff reported that assessments were  
160 completed but not formally documented due to lack of time. Staff felt that there was a role for  
161 support staff such as nursing auxiliaries and volunteers to sit with patients when they are agitated to  
162 reduce staff workload. Damaged or missing seating and equipment blocking corridors were  
163 additional barriers to early mobilisation.



164 2. Lack of in-service education about the effects of sedation and the negative impact of delirium was  
165 cited as a barrier. Interviewed staff reported having a poor knowledge of delirium management  
166 policies and a general perception among staff that sedated patients lacked awareness of noise and  
167 care activities. The majority of staff interviewed were not aware of recommendations for non-verbal  
168 pain scores and daily screening for delirium and compliance with delirium screening was poor across  
169 all of the ICUs included in this study.

170 *‘Does it matter, if someone is heavily sedated and they come to do that, are they aware to a*  
171 *certain level?’ [FG12, Physiotherapist, M]. [speaking about washing patient in the middle of*  
172 *the night].*

173 *‘There is a tendency for staff to leave radios on in sedated patients’ rooms.’ [FG11, Nurse, F].*

174 3. Anxious relatives often created a barrier to the delivery of interventions in two ways; they asked  
175 excessive questions that increased staff workload and created a chaotic environment for patients.  
176 Staff felt that this was due to fear and lack of control and they discussed how flexible visiting (can  
177 visit at any time but advised to avoid busy times or night-time) rather than open visiting (open 24  
178 hours) could be beneficial to patients and families as they needed permission to go home and often  
179 felt guilty for leaving.

180 4. Patient safety concerns especially during busy times was felt to be a barrier to the delivery of the  
181 bundle. Staff reported using higher doses of sedation to maintain patient safety especially when  
182 covering for staff breaks, transfers or patient care. Additionally, they reported that weaning patients  
183 off sedation was often delayed as it was easier to get patient care activities, administration of  
184 medications and documentation completed when looking after a sedated patient.

185 5. A further barrier cited was a difference in cultural perceptions. Staff discussed how families in  
186 other countries provided food and personal care for patients and they felt this culture shift had not  
187 occurred in the UK. Historically, deep sedation was required for the management of an intubated,

188 ventilated patient in the ICU and as a result, a culture of deep sedation emerged which often meant  
189 there was a reluctance to mobilise these patients for fear of dislodging their ET tubes.

190 *'I think if they've got the mask or they have got a [tracheostomy], you slightly do push them*  
191 *further than you would if they had an ET tube.'*[FG3, ICU nurse, F].

192 In relation to barriers regarding specific components, staff felt the whiteboard might raise concerns  
193 about confidentiality by displaying patients' information; especially in small ICUs where this  
194 information was more readily seen. Regarding early mobilisation, physiotherapists felt they might be  
195 restricted by competing priorities: chest physiotherapy was often seen as a priority over early  
196 mobilisation, which might restrict their time to deliver this intervention.

#### 197 **ICU survivors and their families' perceptions of the multicomponent bundle**

198 There were two generic factors that survivors and their relatives perceived would facilitate their use  
199 of this bundle:

200 1. Re-establishing normality was seen as a facilitator to the delivery of a multicomponent  
201 intervention. Survivors reported that they felt being able to mobilise out of bed, listen to music and  
202 get their hair washed gave them a sense of normality and improvement and this helped them  
203 engage with the interventions as they perceived them as beneficial.

204 *"But I think just as importantly, getting out of bed, you're actually thinking, great, I'm out of*  
205 *ICU in the next couple of days"* [FG10, ICU survivor, M].

206 2. Flexible visiting for relatives was a facilitator to communication, family participation, orientation  
207 and early mobilisation. Relatives reported that a flexible visiting policy could allow them to assist  
208 with care, orientation, mobilising, choosing music for loved ones and bringing in communication  
209 materials. Flexible visiting also allowed relatives to manage visiting more effectively so everyone  
210 was not arriving at the same time and tiring the patient.

211 Specifically focusing on individual components of the bundle, providing an escape from the loud,  
212 hostile environment by using earplugs, music and headphones were perceived as helping to facilitate  
213 sleep and relaxation for survivors. Importantly, survivors and their relatives felt it was essential to  
214 give patients the choice of using these devices as they may not suit everybody. Additionally, relatives  
215 welcomed the communication bundle and made useful suggestions such as having a dedicated box  
216 with communication materials that was easily accessible to staff and relatives.

217 There were three generic factors that survivors and their relatives perceived as barriers to the  
218 delivery of this bundle:

219 1. Relatives felt that low staff numbers could be a barrier to the delivery of the bundle as staff may  
220 not have the time required to deliver the interventions on top of a busy workload.

221 2. ICU survivors perceived that staff lacked awareness and understanding about patients  
222 experiences under sedation and were not aware that patients were often privy to their personal  
223 conversations. Survivors also felt staff did not understand their difficulties retaining information and  
224 as a result, their need for constant reorientation. Relatives suspected this lack of awareness might  
225 contribute to staff not engaging with the bundle.

226 *“They would come next to your bed and speak to one another but they wouldn’t engage the*  
227 *patient” [FG 10, ICU survivors, F].*

228 3. Intubation and upper limb weakness can restrict a patients’ ability to communicate in ICU.  
229 Difficulty communicating was perceived as a barrier to participation in many components of the  
230 bundle as survivors felt physically unable to participate or quickly became frustrated if staff could  
231 not understand them. One participant reported that there was ‘no way to communicate because  
232 [he] couldn’t even move a finger and even if [he] could there wasn’t a fingerboard” [FG10, ICU  
233 survivor, M]. Survivors and relatives considered whiteboards helpful for communication and  
234 orientation and when questioned they had no confidentiality concerns.

235 In relation to barriers concerning specific components, fear was a barrier to family participation as  
236 relatives were cautious that they might cause harm or damage to the patient. Regarding early  
237 mobilisation, survivors felt that limb weakness often limited their ability to participate. Survivors  
238 reported significant muscle wastage during their ICU stay and many were shocked at the speed at  
239 which muscle strength deteriorated. They felt they needed to rely heavily on staff to support them  
240 and help them back into bed.

## 241 **DISCUSSION**

242 This study found that a multicomponent delirium bundle was acceptable to survivors and families  
243 and feasible to deliver in the ICU by staff with the exception of pharmacy involvement on the ward  
244 round and early mobilisation of patients with endotracheal tubes. The most important facilitators  
245 perceived by staff for delivering the intervention were the provision of additional supportive staff,  
246 increased family engagement and presence and more in-service education about sedation and its  
247 effects. Indeed, all participant groups recognised family presence as a facilitator and lack of  
248 education and awareness, lack of staff and communication as barriers.

249 Studies have reported high levels of anxiety, depression and Post Traumatic Stress Disorder (PTSD) in  
250 family members of ICU patients <sup>(28, 29)</sup>. Family members' anxiety can be reduced by providing the  
251 knowledge and tools for them to participate in care giving <sup>(30)</sup>. A survey by Garrouset-Orgeas (2010)  
252 found that 96% of families' favoured participation in care and educating family members to assist in  
253 delivery of interventions would help relieve some of the burden for staff <sup>(31)</sup>. In our study, groups  
254 suggested ways in which families could participate such as assisting with orientation, communication  
255 and aspects of personal care.

256 To ensure effective implementation of the bundle in practice, additional organisational resources  
257 would be required. There is a need to address staff support in the ICU to deliver early mobility to all  
258 patients and during delivery of sedation interruption (SI) especially for agitated patients.

259 Surprisingly, staff reported that sedated patients were often treated differently to awake patients

260 and staff believed there was a lack of knowledge about levels of awareness amongst sedated  
261 patients. Gesin et al (2012) found that an education programme on delirium improved nurses'  
262 knowledge of delirium and their understanding about why it is important to recognise delirium so a  
263 similar delirium education programme for staff would address knowledge deficits that exist and help  
264 change the culture of excessive noise and deep sedation <sup>(32)</sup>. A consensus meeting in 2014 outlined  
265 safety considerations that should be reviewed prior to mobilisation of adult, mechanically ventilated  
266 patients and these should be incorporated into a protocol with a non-verbal pain tool and a daily  
267 care plan with an area for the evening ward round to plan sedation breaks for the next day <sup>(27, 33, 34)</sup>.  
268 Improving communication was a major priority for all participant groups and therefore training is  
269 required and provision of appropriate tools shown to improve communication between nurses and  
270 patients in ICU will need to be considered in the bundle <sup>(35)</sup>. These are simple, patient-centred  
271 realistic facilitators that could enhance delirium management in the ICU with no additional  
272 organisational cost.

273 Interestingly, ICU staff and survivors had divergent views on the confidentiality of whiteboards with  
274 information displayed about the patient to enhance communication. Staff felt that this could be a  
275 confidentiality issue while in contrast, survivors had no concerns about the information being  
276 displayed and felt it would be very useful. Therefore, the whiteboard component would need to be  
277 considered for individual ICUs and staff may need to contemplate local adaptations to ensure  
278 privacy of this information.

279 The available literature on barriers and facilitators to non-pharmacological bundles is limited. A  
280 study of implementation of the awakening and breathing coordination, delirium monitoring and  
281 early mobility bundle (ABCDE) reported similar findings to our study with education identified as an  
282 important facilitator and knowledge deficits, workload concerns and lack of communication  
283 reported as common barriers <sup>(36)</sup>. In contrast to our study, this study identified the strength and  
284 quality of the evidence base for the bundle as a facilitator and this was not highlighted in our

285 interviews<sup>(36)</sup>. In addition, the importance of family presence as a facilitator was agreed in all  
286 participant groups and has been emphasised previously in other studies<sup>(37, 38)</sup>.

### 287 **Strengths and limitations of the study**

288 A strength of this study was that we recruited ICU survivors and their families from different  
289 geographical locations in the UK and represented a range of admission types with good experience  
290 of the interventions discussed. Tape-recording the interviews, multiple coding during analysis and  
291 co-author checks also enhanced the rigour of this study.

292 A limitation of this study was that high levels of sedation, disorientation and confusion during the  
293 survivors' ICU stay might have diminished patients' memories and views of pain, agitation and  
294 delirium management. Participants self-selected for this study and this may have resulted in a  
295 biased sample, as participants with particularly strong opinions may be more likely to have  
296 volunteered. There were inherent difficulties in recruiting ICU survivors and in particular, their family  
297 members to participate in this study likely due to the burden of supporting the recovery and  
298 cognitive and functional impairments that present as part of the typical illness trajectory post ICU.  
299 This is not unusual in ICU research and has previously been reported as very challenging<sup>(39)</sup>.

### 300 **CONCLUSION**

301 This bundle of non-pharmacological interventions may present a useful and relatively inexpensive  
302 approach to delirium management in critically ill patients. The four components are deemed feasible  
303 and acceptable to staff, ICU survivors and their families. However, like any complex intervention  
304 there will need to be adaptations made depending on the resources available to the particular ICU,  
305 especially regarding pharmacy involvement on the ward round and early mobilisation of patients  
306 with endotracheal tubes. This approach is paramount to defining an intervention and has helped  
307 shape this bundle, which is now being taken forward to test in a feasibility study.

### 308 **Additional files**

309 Additional file 1: Table 1: Characteristics of staff participants

310 Additional file 2: Table 2: Characteristics of ICU survivors and relative participants

311 Additional file 3: Standards for Reporting Qualitative Research (SRQR) checklist

312 Additional file 4: Appendix 1: Focus group interview topic guide.

### 313 **Keywords**

314 Delirium, Focus groups, Non-pharmacological, Perceptions.

### 315 **Abbreviations**

316 Intensive Care Unit (ICU). British Association of Critical Care Nurses (BACCN). Richmond Agitation

317 Sedation Score (RASS). Sedation interruption (SI). Critical Care Pain Observation Tool (CPOT).

318 Awakening, Breathing Coordination, Delirium management and Early mobilisation (ABCDE).

### 319 **Conflicts of interest**

320 LB has attended study days sponsored by Orion pharmaceuticals.

### 321 **Authors' contributions**

322 LB collected data, analysed the data, interpreted the data and wrote the manuscript. JM analysed

323 and interpreted 15% of the transcripts. BB, DM and MC advised on data analysis and BB and JM

324 provided critical input into the manuscript writing and completion. All authors approved the final

325 version of the paper and are entitled to authorship as listed authors.

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