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'Something normal in a very, very abnormal environment' – Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia

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1 'Something normal in a very, very abnormal environment' – nursing work to honour the life of dying
2 infants and children in neonatal and paediatric ICU

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16

17 **Abstract**

18

19 The majority of deaths of children and infants occur in paediatric and neonatal intensive care

20 settings. For nurses, managing an infant/child's deterioration and death can be very challenging.

21 Nurses play a vital role in how the death occurs, how families are supported leading up to and after

22 the infant/child's death. This paper describes the nurses' endeavours to create normality amidst the

23 sadness and grief of the death of a child in paediatric and neonatal ICU. Focus groups and individual

24 interviews with registered nurses from NICU and PICU settings gathered data on how neonatal and

25 paediatric intensive care nurses care for families when a child dies and how they perceived their

26 ability and preparedness to provide family care. Four themes emerged from thematic analysis: (1)

27 respecting the child as a person; (2) creating opportunities for family involvement/connection; (3)

28 collecting mementos; and (4) planning for death. Many of the activities described in this study

29 empowered parents to participate in the care of their child as death approached. Further work is

30 required to ensure these principles are translated into practice.

31 **Keywords**

32 Neonatal intensive care unit (NICU)

33 Paediatric intensive care unit (PICU)

34 Paediatric nursing

35 End of life care

36 Death

37 Dying

38 Rituals

39

40 **Implications for Clinical Practice***

- 41 ● Pediatric and neonatal intensive care nurses need specialist skills to be able to
- 42 support families and honour the dying child.

- 43 ● Creating opportunities for families to interact with the dying child, and inform the
44 death are essential.
- 45 ● There is scope for neonatal and pediatric intensive care nurses to go beyond the
46 ‘routine’ collection of mementos as a way of supporting grieving families.

47 **Background**

48 The primary goal of therapy in intensive care units (ICUs) is to assist the recovery of seriously ill
49 patients through technologically sophisticated care (Copnell, 2005; Hamric & Blackhall, 2007).

50 Despite this goal, mortality is higher than most other health care settings (Yu & Chan, 2010); this is
51 no less for paediatric and neonatal intensive care (PICU and NICU), as the majority of in-hospital
52 deaths of children and infants take place in these settings (Chang et al., 2013; Stark et al., 2008;
53 Yorke, 2011).

54 For parents, the death of an infant or child is regarded as one of the most devastating events
55 endured (Davies, 2004). Not only is parental grief intense, but it can also be overwhelming because
56 they lose a part of themselves and the hopes and dreams they had for the child (Davies, 2001;
57 Davies, 2004). Given that the majority of children who die are hospitalised at the time of their death
58 (Chang, et al., 2013), the experience and grief of parents associated with the loss of their child is
59 influenced by interactions with, and actions of, various clinicians involved in their child’s care (Butler
60 et al., 2015; Meert et al., 2001).

61

62 Deterioration in a child’s condition and/or their death can also result in personal grief and a sense of
63 failure for nurses, especially if they are primary carer /nurse within the care team (Hamric &
64 Blackhall, 2007; Yam et al., 2001). Consequently, nurses often attempt to rationalise a death as a
65 way of coping. But rationalising the death of an infant or child is significantly harder than an adult

66 because society regards the death of a young person as an 'undeserved death' (O'Connor et al.,
67 2010).

68 When death occurs in NICU and PICU, nursing care of the family is equally as challenging as caring
69 for the dying infant or child in the time leading up to and after death. Nurses play a role in what
70 happens as death approaches, how the death occurs and how the family are engaged after death.
71 Nurses express concerns about knowing what to say to parents, how to prepare them for imminent
72 death and how to support parental grief (Ahern, 2013).

73

74 Numerous studies have identified other factors that impact upon the parental experience. Caring
75 actions, sensitive and caring staff and understandable explanations were cited in one study as being
76 most helpful to parents (Brooten et al., 2012). Similarly, other studies have stressed the importance
77 of communication between clinicians and parents (Darbyshire et al., 2013; Meert, et al., 2001; Yorke,
78 2011), with another paper stating that families relied more heavily of nursing professionals than
79 other family members (Beckstrand et al., 2009). Importantly however, when clinicians demonstrate
80 caring in other ways, which go above and beyond the professional role (Meyer et al., 2006), the
81 parental experience is also improved. A recent PICU study found that measures such as making the
82 PICU environment more comfortable and welcoming, minimising the imposing nature of the
83 technology, and facilitating parents' time at the bedside by giving them access to a telephone and
84 hospital meals were identified by bereaved parents as strategies to improve their experience (Yorke,
85 2011).

86 Parents also appreciate the rituals and practices designed to mark the death of an infant/child and
87 create memories (Butler, et al., in press). The making of memories is increasingly recognised as an
88 aid in parental coping and grieving (Schott et al., 2007). Often nurse initiated, they include keepsakes
89 such as a lock of hair, hand and foot prints, memory boxes and hospital ID bands (Abib El Halal et al.,
90 2013; Brooten, et al., 2013; Meert et al., 2009; Meyer, et al., 2006). These keepsakes, also referred
91 to in the literature as mementos, were described as helpful for parents in their grief (Brooten, et al.,

92 2013). Photographs of the infant/child before and after death are also common and are said to
93 provide both memory and meaning to the parents' experience of their child after the loss (Heartfelt,
94 n.d.; Michelson et al., 2013; Yorke, 2011).

95 Other studies report that rather than physical keepsakes, parents and families instead appreciated
96 other actions/gestures by clinicians that demonstrated that the infant/child was important and
97 special and respectful of the parent and family's needs (McGuinness et al., 2014; Meert, et al., 2009).

98 This included having time alone with the infant/child and being encouraged and supported to
99 provide care to the infant/child leading up to the death (Brooten, et al., 2013; Meert, et al., 2009;
100 Yorke, 2011).

101 Some studies of parental experiences indicated that activities which they valued were not universally
102 performed, for reasons which are unclear. Parents reported not being allowed to be with their child
103 either during or after death (Neidig & Dalgas-Pelish, 1991), a lack of privacy while their child was
104 dying (Abib El Halal, et al., 2013), and not receiving desired mementos, an outcome justified against
105 miscommunication between families and clinicians (Widger & Picot, 2008).

106 This paper reports on one aspect of a larger study that examined nurses' experiences of caring for
107 families when a child dies, and their preparedness to provide family centred end-of-life care. We
108 describe the nurses' endeavours to create memories for families and facilitating families'
109 interactions with the dying infant/child amidst the sadness and grief of the death of a child in
110 paediatric and neonatal ICU.

111 **Method**

112 Focus groups and individual interviews were utilised to gather data on how NICU and PICU nurses
113 care for families when a child dies and how they perceived their ability and preparedness to provide
114 family care. Thematic analysis provided a framework to elicit themes which highlighted the actions
115 taken by nurses to create a sense of normality around the death.

116 **Setting and Sample**

117 The study was conducted in two NICUs and two PICUs located in two Australian metropolitan
118 hospitals. Convenience sampling was used in this study. Details of the study were forwarded
119 to NICU and PICU nursing staff via email, following contact with Nurse Unit Managers. Potential
120 participants were asked to determine their own eligibility according to the inclusion criteria. Twenty-
121 one registered nurses from NICU (N=8) and PICU (N=13) settings participated. Participants were
122 eligible for inclusion if they were employed as a Registered Nurse (RN), had at least one year of
123 nursing experience in either NICU or PICU and had cared for at least one child who had died in the
124 NICU or PICU.

125

126 Interested nursing staff were asked to make contact with the researchers to register their interest
127 and interview times and locations were negotiated following dissemination of an Explanatory
128 Statement. At the time of meeting with the potential participants, the research and the Explanatory
129 Statement were discussed and all questions answered. Written consent was then gained prior to
130 commencement of individual and focus group interviews.

131

132 **Data Collection**

133 Focus groups (defined in this study as an interview of two or more participants) and individual
134 interviews both utilised a semi-structured conversational approach, facilitated by the researcher to
135 encourage communication and interaction amongst participants (Liamputtong, 2009). For those
136 unavailable for a focus group, individual interviews were conducted using the same semi-structured
137 conversational approach used in the focus groups.

138

139 From the four participating units, six focus group interviews were conducted, with between two and
140 four participants in each focus group, and four nurses were interviewed individually, totalling 21
141 participants. The type of interview was determined mostly by the availability of willing participants.

142 Where possible, participants were grouped together to enable a focus group interview, but where
143 scheduling did not allow this, participants were instead offered individual interviews. All interviews
144 (focus group and individual) were conducted between November 2012 and January 2013 in a private,
145 quiet space located in the hospitals. Interviews lasted between 17 and 50 minutes. They were audio-
146 taped and transcribed verbatim for analysis. No field notes were made during the interviews.

147

148 **Data Analysis**

149 Inductive content analysis was used to analyse the data because it is well-suited to analysing
150 multifaceted and sensitive phenomena that are characteristic in nursing (Elo & Kyngas, 2008;
151 Moretti et al., 2011). Inductive content analysis, in which coding categories are derived directly and
152 inductively from the raw data, is an approach to qualitative analysis that attempts to limit, as much
153 as possible the researchers' subjective interpretations (Moretti, et al., 2011). The process involved
154 two researchers independently reading and re-reading the interview manuscripts to gain a sense of
155 the whole and highlighting phrases that appear to capture the essence of the interviews; taking
156 notes of the content; 112 grouping content together into categories; revising the categories and
157 organising and/or linking the categories and subcategories until the themes were determined (Elo &
158 Kyngas, 2008; Moretti, et al., 2011).

159

160 This process of analysis was made more robust by the development of a study protocol, in which all
161 procedures were described in detail and established prior to data analysis, assuring consistency and
162 transparency and that the themes developed out of the raw data rather than any pre-conceived
163 themes (Moretti, et al., 2011). Once both researchers had determined the final themes, the findings
164 were shared amongst the team and the analysis further refined until the final themes were settled.

165

166 **Ethical Considerations**

167 Whilst this study gained ethical approval as 'low risk', given the highly emotive nature of the work of
168 neonatal and paediatric intensive care nurses in providing end of life care, the authors considered it
169 important to safeguard the welfare of nurse participants. An employee counselling service was
170 available to support any participants who became distressed as a result of their participation in this
171 study, however this was not necessary. No patient or family data was collected as part of this
172 research. Furthermore, In order to protect the anonymity of participants, once eligibility of
173 individuals was determined, no other demographic data was collected. The intent was to explore the
174 experience and emotion as reflected by the participants at that time, irrespective of these other
175 factors.

176

177 **Results**

178 Six focus groups and four individual interviews were conducted across the four units (NICU x2 and
179 PICU x 2). For the purposes of reporting participant voices, quotes have been anonymised and
180 instead are labelled according to the type of interview (individual or focus group), interview
181 number/transcript page number and whether the interview involved PICU or NICU staff.

182

183 Participants expressed that their role and responsibilities change as death neared. When it was
184 evident that death was likely, participants said that the focus of their role shifted to place more
185 emphasis on the family: *'It's still caring for the patient, but maybe a little – yes, a little bit more
186 split between for the family and the patient'* (FG Int 5/10, PICU).

187 Inductive analysis identified four key themes that demonstrated how participants worked to ensure
188 families were left with heart-warming memories of their child following their death. The key themes
189 derived from the analysis were: (1) respecting the child as a person; (2) creating opportunities for
190 family involvement/connection; (3) collecting mementos; and (4) planning for death.

191

192 **1. Respecting the child as a person**

193 Participants expressed the need to acknowledge the child as a person and demonstrate respect for
194 their personhood. This was achieved largely by consideration of their physical appearance.
195 Participants expressed that rather than just using their technical expertise and skill, it was important
196 to consider how the child was presented to the parents and family:

197 *'We are very pedantic sometimes in the way you sort of – well, not just care for them,*
198 *but their physical appearance as well...we had braided her hair and things like*
199 *that...and they're so excited that somebody has taken some time and some care'* (FG
200 Int 155 3/5, PICU).

201

202 Participants saw this as a way of keeping 156 the parental and family focus on the child, rather than
203 the technological interventions surrounding them:

204 *'...to actually have, to look at how their child is presented and not just the physical*
205 *[interventions] that we're doing, but you know, their outward appearance. So it's not*
206 *just the machines...'* (FG Int 3/6, PICU)

207 *'lots of them [parents] have never held them without tubes, never seen their faces*
208 *without stuff stuck on them...'* (FG Int 2/8, NICU).

209 Another participant explained their role not just in preparing the baby, but also in presenting a
210 respectful environment:

211 *'...we can get the baby into some sort of fit state of presentation....Because*
212 *sometimes the babies really do look like they've been in a war zone by the time*
213 *they're dying, and so it's pretty important to make sure the baby is clean and that the*
214 *environment is clean, and all the extraneous clutter is no longer there....and*
215 *redressing the baby in clothing that they may choose...'* (FG Int 3/10, PICU).

216

217 In circumstances where changing and grooming the child was not possible due to the fragile nature
218 of the child's critical illness, participants worked hard to emphasise the positives in the infant/child
219 in communication with their parents and family:

220

221 *'I talk about the positive features of the nice look of the baby. I find whatever features*
222 *are looking sort of attractive...whether it's his skin or hair – sometimes they have a*
223 *nice head of hair, or whatever it is. I sort of like to talk about what's positive about the*
224 *baby...it's an honouring of their life, it's more of a recognition. Like this was a human*
225 *being that was – you know, had lots of perfection about it too'* (FG Int 10/4, NICU).

226

227 **2. Creating Opportunities**

228 A second theme arising from the interview data was the imperative to create opportunities for
229 parents and families to be with and spend time with their child leading up to and after their death, in
230 ways that that they previously may not have been able :

231

232 *'...I want to make this experience the best it can be, so you can have the nice*
233 *memories and that side of things...because it's their baby and their child and their*
234 *dreams for the future'* (FG Int 2/5, NICU).

235 *'[One parent said] "I've never had a chance to lay down with my baby until it died". You*
236 *can put a baby on a bed and you can put a mother or father on that bed. It doesn't*
237 *matter, but let them be – so something normal in a very, very abnormal environment'*
238 (FG Int 3/10, PICU).

239 Despite the fragility of the critically ill infant/child, the importance of needing to make opportunities
240 for parents to have time with them was not forgotten, and often required significant commitment by
241 the staff:

242 *'I like to make sure that the parents have a lot of time holding their baby – so even if*
243 *the child has been really critically ill and not moved much, I may call colleagues in to*

244 *help me, make sure I can safely move that baby off its bed ... and into the parents'*
245 *arms, and that can just take hours'* (FG Int 10/2, NICU).

246

247 Another participant spoke of how she listened to families and the needs they express, through
248 including extended family such as siblings and grandparents into the experiences she facilitated:

249

250 *'A lot of the families, you sort of ... 199 get led by them. If they want their children to*
251 *be involved, then you obviously deal with that and sort of, you know, try and make it*
252 *as normal - I know it's not a normal situation, but try and make it as normal for them*
253 *as possible; still sort of refer to the baby as their brother or sister, or you know, try*
254 *and get them involved if we're giving the baby a wash and things like that'* (Individual
255 Int 9/13, NICU).

256

257 **3. Collecting mementos**

258 Participants discussed at length, the importance of collecting mementos for families prior to and
259 after a death. 'Memory boxes' were used as a way of enabling the collection of mementos and
260 trinkets that may be appreciated by the family after death:- *'every time I find something that I*
261 *think they might like, I just put it all in a book for them'* (FG Int 10/16, NICU).

262

263 Collecting handprints and taking photos seemed a common way to connect family members to their
264 infant. Participants suggested that these were ways to prepare families for impending death:

265 *'...because they're helping families and the siblings put the handprints together, and*
266 *put all the fingerprints together...I was really sort of helping and getting the family a*
267 *little bit more prepared for what was going to happen...'* (Individual Int 4/5, PICU)

268

269 *'Photographs, like it's important to try and get [photographs]. I try and get [volunteer*

270 photography service] *in if we've got time and preparation*' (FG Int 10/16, NICU).

271

272 **4. Providing an appropriate environment for the death**

273

274 As well as creating opportunities for families to spend time with their critically ill infant or child when
275 death was approaching, participants recounted stories of the lengths taken to give the parents an
276 opportunity to have an input into planning for an eventual death. Participants stressed that any
277 infant/child death is a life cut too short, and thus any way in which they could accommodate the
278 wishes of the family were prioritised. For some, this involved creating an environment that was less
279 clinical and technical than a standard ICU environment:

280 *'We have a room...there's a bed in there...they took the baby in with them, and*
281 *everybody stayed in there overnight for quite a few hours...then in the next day there*
282 *was some back and forwards with bringing the baby back up from the mortuary so*
283 *anyone else who need to come to say goodbye did so...'* (FG Int 10/2, NICU).

284

285 In other cases, in fulfilling the parents' wishes, death occurred outside of the hospital, facilitated and
286 supported by ICU staff:

287 *'We did have a baby years ago who died travelling down the river on a boat cruise*
288 *with her twin, and it was expected she would die, so that was where she died, and*
289 *her parents were really happy with that...'* (Individual Int 9/9, NICU).

290

291 Another participant described another out of hospital death, as requested by the family and
292 facilitated by ICU staff:

293 *'we recently had a death at the [animal park]. Our consultant went out of the way to*
294 *provide what the parents wanted, and they were very focussed on animals and, yes,*
295 *they took him to see them'* (FG Int 10/21, NICU).

296

297 This same child's death was also brought up by another participant, who recalled the significance of
298 the experience, not just for the family, but also the staff:

299 *'Withdrawal of care happened in a quiet place in the [animal park]...we were*
300 *absolutely amazed that it was possible to do that. I think the [animal park] was*
301 *something important to them. It was something that meant a lot to them, and*
302 *therefore, they wanted their child to see the animals, to go to the [animal park] with*
303 *them, and he did'* (Individual Int 9/9, NICU).

304

305 Data analysis demonstrated the lengths to which NICU and PICU nurses will go, to facilitate family
306 care as their child approached the end of their life, which goes beyond what might be evident or
307 feasible in other ICU environments.

308

309 **Discussion**

310 In this study, it became clear that the focus group interviews provided much richer data than the
311 individual interviews. This is thought to be attributed to the synergistic nature of focus groups, in
312 which a stronger social context is created (Finch & Lewis, 2003), resulting in nurse participants
313 engaging more deeply with each other, most likely because of their shared experiences. When this
314 occurs, they are less influenced by the external researcher.

315

316 Several studies have detailed the needs of parents and families inside the ICU including consistent
317 staff presence and expressions of sympathy and caring (Latour, 2008; Meert, et al., 2001). Through
318 respecting the child as a person and emphasising the child as an individual, the nurses in our study
319 were demonstrating the child's importance to the family. Other studies also highlight the need for
320 adequate information and coordinated care (Meert, et al., 2001; Meyer, et al., 2006) and
321 preservation of the preservation of the parent-child relationship leading up to death (Meyer, et al.,

322 2006). Similarly this study reveals the lengths to which NICU and PICU nurses went to to create
323 opportunities for parental and extended family involvement in care.

324

325 Existing research literature has highlighted the potential of early recognition of a life-limiting illness
326 and advance care planning as a way of improving the care of paediatric and neonatal patients and
327 their families (Mitchell & Dale, 2015). 266 Other research has demonstrated that, where available,
328 specialist paediatric palliative care services can allow for end of life care to be provided at home,
329 rather than in hospital (Chang, et al., 2013). Transferring the child home however is not always an
330 option, but what is important is privacy leading up to a child's death (Latour, 2008).

331

332 The themes that emerged from this study highlight the steps taken by NICU and PICU nurses to work
333 with parents to honour the life of the dying child. Activities described within all the themes have
334 been identified by parents as being helpful to them if performed well (Butler, et al., 2015). But to our
335 knowledge, no other studies have detailed instances where families and clinicians have worked
336 together to create special memories through the place of death. This study highlighted one example
337 where families and clinicians were able to facilitate a death at a specially chosen place outside of the
338 ICU and greater hospital, in this case an animal park; a venue chosen by the family for its special
339 significance in relation to the dying infant.

340 The nurses in our study did not detail the conversations behind facilitating a death outside of the ICU;
341 that is, it was not clear whether such requests were always initiated by parents, on the suggestion of
342 clinicians, or as a collaborative idea that evolved between parents and staff. They also did not
343 indicate whether parental requests were ever refused. Going to such lengths to facilitate a child's
344 death at a specific location, with the express purpose of creating memories for the families,
345 significantly contribute to the complexity of end of life care in PICU and NICU. What it also
346 demonstrated, similar to the work of Meert et al (2001), was the desire to preserve the parent-child
347 relationship by allowing parents to make at least some of the decisions in their child's last moments.

348

349 Despite the positive impact of such actions as demonstrated 288 in this study, there are scant other
350 examples in the research literature. We recommend that actions like this designed to facilitate
351 family coping and create memories be included in future studies, particularly prospective studies of
352 management of dying infants and children, which have hitherto taken a mechanistic approach to the
353 topic (Copnell, 2005).

354

355 Many of the activities described in this study empowered parents to participate in the care of their
356 child as death approached. These findings resonate with the body of work undertaken by Latour and
357 colleagues in the Netherlands (Latour, 2008; Latour et al., 2012; Latour, 2011).

358

359 The empowerment of parents has developed over time in NICU (Davis et al., 2003; Latour, et al.,
360 2012) and PICU (Sturdivant & Warren, 2009). However, whilst family-centred care in NICU has been
361 reported to have benefits for parental stress, comfort and confidence (Cooper et al., 2007), the
362 principles are not always translated into practice (Petersen et al., 2004). Similarly, studies in PICU
363 indicate deficits in the provision of family centred care (Butler, et al., 2015).

364

365 **Limitations**

366 This study was undertaken in two hospitals in one city in Australia. The findings cannot be assumed
367 to be generalizable to all PICU and NICU settings. Demographic data, such as age, sex, qualification
368 and experience of participants might have provided further insights in this study; however, the four
369 themes were evident across all interviews (paediatric and neonatal), indicating that the demography
370 of the participants may have had little effect.

371

372 **Conclusion**

373 This paper has described nursing work to create memories f 310 or families amidst the sadness and
374 grief of the death of a child in PICU and NICU. The themes illustrated nurses' concerns for family
375 members in preparing for the death, how to present the child to their parents in the best way, and
376 the enabling of opportunities for family involvement including the creation of mementos. Many
377 activities derived from the literature and described in this study were seen to empower parents'
378 participation in caring for their child both at the end of their life and after the death. Further work is
379 required to ensure these principles are translated into practice.

380

381

382

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385

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