



**Family centred care before and during life-sustaining treatment withdrawal in intensive care: a survey of information provided to families by Australasian critical care nurses**

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**TITLE:** Family centred care before and during life-sustaining treatment withdrawal in intensive care:  
A survey of information provided to families by Australasian critical care nurses

**RUNNING TITLE:** Information provided to families before and during life-sustaining treatment  
withdrawal

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**CONFLICT OF INTEREST STATEMENT:**

No conflict of interest.

## **Abstract**

*Background:* A core component of family-centred nursing care during the provision of end-of-life care in intensive care settings is information sharing with families. Yet little is known about information provided in these circumstances.

*Objective:* To identify information most frequently given by critical care nurses to families in preparation for and during withdrawal of life-sustaining treatment

*Design:* An online cross-sectional survey

*Methods:* During May 2015, critical care nurses in Australia and New Zealand were invited to complete the Preparing Families for Treatment Withdrawal questionnaire. Data analysis included descriptive statistics to identify areas of information most and least frequently shared with families. Cross tabulations with demographic data were used to explore any associations in the data.

*Results:* From the responses of 159 critical care nurses, information related to the emotional care and support of the family was most frequently provided to families in preparation for and during withdrawal of life-sustaining treatment. Variation was noted in the frequency of provision of information across body systems and their associated physical changes during the dying process. Significant associations ( $p < 0.05$ ) were identified between the variables gender, nursing experience and critical care experiences and some of the information items most and least frequently provided.

*Conclusions:* The provision of information during end-of-life care reflects a family-centred care approach by critical care nurses with information pertaining to emotional care and support of the family paramount. The findings of this study provide a useful framework for the development of interventions to improve practice and support nurses in communicating with families at this time.

## **Key words**

Communication; Critical care; End of life care; Family centred care; Intensive Care; Nurse; Survey; Withdrawal of treatment

1   **INTRODUCTION**

2   The majority of patient deaths in intensive care occur following a decision to withhold or withdraw  
3   life-sustaining treatment.<sup>1,2</sup> With 86% of patient deaths in intensive care expected the provision of  
4   end-of-life care can be planned and facilitated in these circumstances.<sup>2</sup> Family-centred care is a  
5   model of care where the family can contribute to and participate in the planning and delivery of care  
6   in partnership with health care providers. Family-centred care should be at the core of critical care  
7   nurses' practice during the provision of end-of-life care,<sup>3,4</sup> with research indicating nursing practice  
8   consistent with this approach.<sup>5,6</sup> The proximity and constancy of the critical care nurse at the  
9   bedside, resultant from the high nurse-patient ratios, places critical care nurses in a unique position  
10  to facilitate positive patient- and family-centred end-of-life care experiences.<sup>7,8</sup>

11

12  An important component of family-centred care is the provision of information to and  
13  communication with the family. Key to the provision of a quality end-of-life care experience, and  
14  indeed to improving outcomes for bereaved family members is helping families understand events  
15  occurring prior to, and during withdrawal of life-sustaining treatment.<sup>9,10</sup> Previous research has  
16  identified that provision of information to families is a core and frequently undertaken component  
17  of nursing work during end-of-life care.<sup>7</sup> The actual content of messages imparted by critical care  
18  nurses to families at this time has received limited attention except through acknowledgement of  
19  the role of critical care nurses in answering questions posed by families and explaining what was  
20  happening to the patient.<sup>6,11-12</sup>

21

22  One study that has undertaken a more detailed and nuanced exploration of the type of information  
23  nurses give to families at this time was undertaken by researchers in the United States and focused  
24  on preparing families for death of their relative following withdrawal of mechanical ventilation.<sup>13</sup>  
25  Content analysis of the responses of 31 critical care nurses identified 43 descriptors of different  
26  types of information conveyed to families. The majority of descriptors (67.5%, n=29) were related to

27 physical sensations and symptoms although study authors acknowledged that the format of the  
28 questionnaire may have contributed to this finding due to prompts specifically provided for the  
29 physical domain.<sup>13</sup>

30

31 Given the opportunity for nurses to positively impact end-of-life care practice and the importance of  
32 a family centred care approach for critically ill patients and their families at this time, further  
33 research is needed to identify the content of information communicated by critical care nurses to  
34 families prior to and during withdrawal of life-sustaining treatment. This research can inform the  
35 development of educational content and interventions to be implemented in practice to assist  
36 critical care nurses sharing information with families.

37

38

## 39 **METHOD**

### 40 **Study Aim**

41 To identify information most frequently given by critical care nurses to families in preparation for  
42 and during withdrawal of life sustaining treatment.

43

### 44 **Design**

45 An online cross-sectional survey was used in this study.

46

### 47 **Preparing Families for Treatment Withdrawal questionnaire**

48 The survey instrument used in this study was developed from previous research undertaken by  
49 Kirchhoff, Conradt and Anumandla (2003).<sup>13</sup> Kirchhoff et al. originally designed the questionnaire to  
50 explore the content of messages given to families by critical care nurses in preparation for  
51 withdrawal of life-sustaining treatment and expected death of the patient.<sup>13</sup> Self-regulation theory  
52 (SRT) is based on the premise that providing a person with information regarding a potentially

53 stressful event will assist them in coping with the experience.<sup>13</sup> The four concrete-objective domains  
54 of SRT (1. Physical sensations and symptoms, 2. Temporal characteristics, 3. Environmental features  
55 and 4. Causes of sensations, symptoms and experiences) provided a framework for the  
56 questionnaire, under which participants could record a narrative response of the information that  
57 they provided to families in preparation for treatment withdrawal.<sup>13</sup> Each SRT domain heading was  
58 accompanied by a definition to enhance clarity for the participant. In addition, eight sub-headings  
59 (respiratory, skin, neurologic, musculoskeletal, sense organs, gastrointestinal, genitourinary and  
60 others) were provided with the physical sensation and symptoms domain to capture all possible  
61 information provided to families within these categories. Kirchhoff et al. circulated their  
62 questionnaire to a sample of critical care nurses and from the 31 responses, content analysis  
63 identified 43 descriptors of information provided to families to prepare them for treatment  
64 withdrawal.<sup>13</sup>

65

66 Permission was given to use and re-develop the questionnaire (KT Kirchhoff, personal  
67 communication, 18 November 2014). For this study, the original headings comprising the SRT  
68 domains were retained and descriptors identified by Kirchhoff et al.<sup>13</sup> were placed on a 1-5 rating  
69 scale (Never, Rarely, Sometimes, Often, Always). The 'don't address' descriptors for the  
70 gastrointestinal and genitourinary physical domains from Kirchhoff et al. were not included in the  
71 revised survey instrument as they were deemed unnecessary as this information could be obtained  
72 from a 'never' response by a participant. The instrument was reviewed for face validity by a  
73 reference group, comprised of individuals meeting the inclusion criteria for participation. In  
74 response to the comments of this reference group, the descriptor 'eye closed' was removed from  
75 the revised instrument. The final revised instrument consisted of 40 descriptors of information  
76 potentially provided to families to prepare them for treatment withdrawal.

77

78 The online questionnaire also included a series of questions to obtain demographic information from  
79 the respondent including age, gender, years of nursing experience, years of critical care experience,  
80 highest qualification in nursing, current workplace and location (Australia or New Zealand).

81

## 82 **Setting and participants**

83 Australian and New Zealand critical care nurses who had provided end-of-life care in an intensive  
84 care unit within the last 12 months were the target population for this study. All members of the  
85 Australian College of Critical Care Nurses who had registered their willingness to be contacted for  
86 research purposes and critical care nurses working in two Intensive Care Units in New Zealand were  
87 the population sampled for this study.

88

89 An email invitation to participate in the study was circulated to potential participants in May 2015.  
90 The invitation contained a link to the questionnaire available online using the platform Survey  
91 Monkey (<http://www.surveymonkey.com>). A reminder email was circulated two weeks later as a  
92 method of encouraging participation. The survey remained available online for a period of five  
93 weeks.

94

## 95 **Data analysis**

96 Data analysis was undertaken using SPSS version 21. Descriptive statistics were calculated for each  
97 demographic variable to ascertain the potential representativeness of the sample to the broader  
98 critical care nurse population in Australia and New Zealand.

99

100 The frequency of participant response to each item on the survey was calculated. Mean and  
101 standard deviation were also calculated to identify the most and least frequent information given to  
102 families based on mean score. Cross tabulations, using the Monte Carlo method (with default  
103 confidence level of 99% and number of samples 10000), were calculated to explore associations

104 within the data. Specifically, if each of the ten information items most and least frequently provided  
105 to families were associated with select demographic variables (country of practice, gender, nursing  
106 experience and critical care experience).

107

108 Cronbach's alpha was calculated to assess the internal consistency of the items for the whole  
109 instrument and for each of the four SRT domains of the instrument. Cronbach's alpha of greater than  
110 0.70 was considered satisfactory internal consistency.<sup>14</sup>

111

## 112 **Ethical Considerations**

113 Prior to the commencement of this study, ethical approval was obtained from the University Human  
114 Research Ethics Committee (Monash University Ethical Approval: CF15/569 - 2015000260; Victoria  
115 University of Wellington Ethical Approval: 21642). This study was conducted in accordance with the  
116 Declaration of Helsinki.<sup>15</sup> Potential participants were provided with an explanatory statement  
117 informing them of the purpose of the study, requirements of participation and potential benefits  
118 and risks. Consent to participate was implied by participants accessing and completing the  
119 questionnaire online.

120

## 121 **RESULTS**

### 122 **Respondent profile**

123 159 completed survey responses were received, with 62.9% of respondents from Australia (n=100)  
124 and 36.5% of respondents from New Zealand (n=59, response rate 28%). The mean age of  
125 respondents was 43.6 years (SD 10.2) and 88.4% were female. Respondents were experienced  
126 nurses with 93.7% having more than five years nursing experience and 84.8% having more than 5  
127 years' experience in a critical care setting. In addition, 98.7% had completed postgraduate  
128 qualifications in nursing (see Table 1).

129



130 The majority of respondents (80.9%) were currently working in a level 3 intensive care unit<sup>23</sup> and  
131 most (61%) were practising in adult ICUs. All participants had provided end-of-life care within the  
132 past 12 months, which for 61% had occurred in the last month. Thus, respondents were reflecting on  
133 recent clinical practice experience in the provision of end-of-life care in the critical care context.

134

### 135 **Preparing families for treatment withdrawal**

136 Preliminary evidence of the internal consistency of the 40 rating scale items in the Preparing Families  
137 for Treatment Withdrawal questionnaire was obtained with a Cronbach's alpha score of .933  
138 demonstrating high internal consistency and only 3 of the 40 scale items scored <0.3. Subset analysis  
139 of the 4 domains achieved alpha scores of .540 to .933 (see Table 2).

140

141 Mean scores for the individual items ranged from 2.60 (SD 1.10) to 4.87 (SD 0.41) with only 7 items  
142 scoring less than 3.0, indicating that most of the information items were provided by nurses at least  
143 'sometimes' (see Table 3). The ten information items most frequently provided by critical care  
144 nurses in this study when preparing families for and during treatment withdrawal demonstrate a  
145 concern for patient and family support by critical care nurses at this time (see Table 4). Table 5  
146 documents the ten information items least frequently provided. All ten information items least  
147 frequently provided came from the physical domain. Cross tabulations revealed no significant  
148 associations between the items most and least frequently provided by critical care nurse  
149 respondents from Australia and New Zealand. Significant associations were noted in the cross  
150 tabulations between gender and some of the information items most frequently provided by critical  
151 care nurses. Significant associations between some of the items most and least frequently provided  
152 and the variables nursing experience and critical care experience were also identified (see Table 6).

153

154

## 155 **DISCUSSION**

156 The provision of quality care at end-of-life in intensive care settings is the current focus of research  
157 efforts internationally.<sup>16</sup> Information provided to families before and during life-sustaining treatment  
158 withdrawal in intensive care by critical care nurses is integral to family-centred care at this time. The  
159 results of this study highlight that areas of information focusing on emotional care and support of  
160 the patient and family are a priority for nurses whilst less emphasis is placed on explanation of  
161 physical symptoms associated with the dying process. The variables gender, nursing experience and  
162 experience in critical care were associated with some of the information most and least frequently  
163 provided at this time.

164

165 Encouraging the family to talk and touch the patient, reassuring the family and providing support  
166 were amongst the information items most frequently shared and are consistent with previous  
167 accounts of family-centred care during end-of-life in critical care settings.<sup>6, 11, 17</sup> These findings are in  
168 contrast to the original work by Kirchhoff et al. where emphasis was placed on explanation of  
169 physical symptoms.<sup>13</sup> This may be a reflection of contemporary critical care practice, where greater  
170 emphasis has been placed on family-centred care and family support in critical care settings over the  
171 past ten years.<sup>3, 4</sup>

172

173 The physical domain was the most comprehensively covered domain in the survey instrument, with  
174 23 out of the 40 information items pertaining to this area compared to three to four items in each of  
175 the other domains. The extensive number of items in the physical domain permits greater discretion  
176 by respondents and increases the likelihood that some of these items would be less frequently  
177 provided. Specifically, the items in the subdomains gastrointestinal, genitourinary, musculoskeletal  
178 and neurologic were the areas of information least frequently included by nurses in their  
179 communication with families in this study. Physical information provided was instead dominated by

180 descriptions pertaining to the sense organs (that the patient may be able to hear/feel) and changes  
181 to breathing patterns. Preparation of families for physical changes that occur during the dying  
182 process is recommended and changes to the skin and breathing patterns have been frequently  
183 mentioned by nurses in previous research.<sup>3, 13</sup>

184

185 The association identified between participant gender and the information items most frequently  
186 provided to families reflecting emotional support practices warrants further investigation. A  
187 previous study also identified a statistically significant association between gender and emotional  
188 support practices.<sup>18</sup> A future larger study with stratified sampling by gender is needed to investigate  
189 these associations.

190

191 Previous research suggests that nurses learn through participation in the provision of end-of-life  
192 care.<sup>6, 19</sup> Experiential learning whereby nurses engage in caring for the patient and family contributes  
193 to building knowledge for future practice. The findings of this study identified significant associations  
194 between the demographic variables of nursing experience and critical care experience and some of  
195 the most and least frequently reported information items, predominately from the physical  
196 symptom domain. Through experience in practice, nurses gain opportunity to communicate with  
197 family members, reflect on their interactions and revise the messages that they can provide in future  
198 encounters with families of patients at end-of-life.

199

200 Knowledge gained from this research can inform recommendations for practice, education and  
201 further research to support critical care nurses in the provision of family-centred end-of-life care in  
202 intensive care units. There has been much emphasis on providing information leaflets to families of  
203 patients admitted to the intensive care unit.<sup>10, 20-21</sup> Our findings may provide a useful framework for  
204 the development of an intervention such as a brochure or guideline to assist critical care nurses

205 sharing information with families. The findings also provide a framework for professional  
206 development activities focusing on communication with families at end-of-life. The information  
207 areas highlighted as being least attended to can inform the content for educational interventions to  
208 support nurses in this important aspect of critical care nursing. Future research should be  
209 undertaken to evaluate the effectiveness of interventions implemented to improve the quality of  
210 end-of-life care that is family-centred and delivered by critical care nurses supported in their  
211 practice. Future research from the perspective of the family would make an important contribution  
212 to understanding the information needs of families prior to and during withdrawal of life-sustaining  
213 treatment and if these needs are adequately met.

214

215 Further testing is needed to provide evidence of the psychometric properties of the questionnaire  
216 and areas for potential future development of the instrument. Specifically, further development of  
217 possible information items within the domains, other than physical domain, may be needed to  
218 ensure adequate coverage of all domains of interest. The involvement of consumers in future survey  
219 development is required to provide voice to the information needs of families at this time. In  
220 addition, the use of the questionnaire with a larger sample and exploratory factor analysis of the  
221 dataset obtained is needed to identify the latent constructs within the questionnaire. A minimum  
222 sample size of at least 5 participants per item is recommended for factor analysis,<sup>14</sup> thus at least 200  
223 participants are required with a 40-item instrument.

224

## 225 **Limitations**

226 This study is limited by the small response rate and non-randomised sampling methods used to  
227 recruit participants. The respondents may not be representative of the wider critical care nursing  
228 population in Australia who are not members of the professional association. Of particular note was

229 the high level of postgraduate nursing qualification (89.7%) amongst respondents, which is  
230 consistent with a previous study involving a sample drawn from the same population (Ranse et  
231 al.2016)<sup>7</sup> but much greater than that reported in the latest critical care nursing workforce statistics  
232 (53.9%).<sup>22</sup> Respondents higher levels of experience as a critical care nurse (*M* 15.4; *SD* 8.7) and a  
233 registered nurse in general (*M* 21.1; *SD* 10.6) may have also introduced a recruitment bias.

234

235 The New Zealand sample was limited to two large tertiary intensive care units and it is  
236 acknowledged that the experience in small intensive care units and/or regional centres may be  
237 different. However, the content of information provided by nurses could be the same given that  
238 university education and in-service training post qualification for nurses may be similar regardless of  
239 the location of their intensive care unit.

240

241

242

## 243 **Conclusion**

244 Family-centred care is key to the delivery of quality care at end-of-life. A core component of family-  
245 centred care is the provision of information to and communication with the family. Critical care  
246 nurses most frequently provide information directed at the emotional care and support of the  
247 family. The findings of this study indicate variation in the frequency that physical symptoms  
248 attributed to different body systems are shared with families. Physical changes in the neurological,  
249 musculoskeletal, gastrointestinal and genitourinary are amongst the least frequently provided  
250 information. Significant associations were identified between the demographic variables gender,  
251 nursing experience and critical care experience and some of the information items most and least  
252 frequently provided to families. Knowledge gained from this research can inform recommendations  
253 for practice, education and further research to support critical care nurses in the provision of family-  
254 centred end-of-life care in intensive care units.

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348 **Table 1: Participants' experience, education, current workplace and participation in end-of-life**  
 349 **care**

Characteristic	%	M (SD)
<b>Nursing Experience (years) (n = 158)</b>		21.1 (10.6)
0–5	6.3	
6–10	14.6	
11–15	15.2	
16–20	11.4	
20+	52.5	
<b>Critical Care Experience (years) (n = 158)</b>		15.4 (8.7)
0–5	15.2	
6–10	22.2	
11–15	14.5	
16–20	19.6	
20+	28.5	
<b>Highest Qualification in Nursing (n = 156)</b>		
Hospital certificate/Diploma/Undergraduate Degree	10.3	
Postgraduate Certificate	32.1	
Postgraduate Diploma	28.2	
Masters	25.6	
PhD	1.3	
Other	2.5	
<b>Current workplace (n = 159)</b>		
Adult ICU	61.0	
Paediatric ICU	9.4	
High Dependency	1.9	
Mix of the above	27.1	
Other	0.6	
<b>What level of care does your Unit provide? (n = 157)*</b>		
Level 3	80.9	
Level 2	15.9	
Level 1	3.2	
<b>Time since provision of end-of-life care (n = 159)</b>		
Within the last week	22.6	
Within the last month	38.4	
Within the last 6 months	32.7	
In the last 12 months	6.3	

350 *Note.* ICU = intensive care unit. \*Level of care according to the *Minimum Standards for Intensive*  
 351 *Care Units*<sup>23</sup>

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355 **Table 2: Internal consistency of the scales in the *Preparing families for treatment withdrawal***  
356 **survey instrument (n = 159)**

<b>Scale</b>	<b>No of items</b>	<b><math>\alpha</math></b>
Physical Sensations/Observations	23	0.933
Temporal characteristics	3	0.711
Environmental features	4	0.669
Causes of sensations, experiences	3	0.540

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**Table 3: Participant responses as a percentage of the sample, means and standard deviations for each item in the *Preparing families for treatment withdrawal* survey instrument (n = 159)**

Item	Never	Rarely	Sometimes	Often	Always	M (SD)
<b>Physical Sensations/Observations: Respiratory</b>						
Irregular breathing pattern/Cheyne stokes	1.3	1.3	16.4	42.1	39.0	4.16 (0.83)
Noisy/gurgling breathing	1.9	1.9	13.2	31.4	51.6	4.29 (0.90)
Laboured/gasping agonal breathing	2.5	5.0	17.6	34.0	40.9	4.06 (1.01)
<b>Physical Sensations/Observations: Skin</b>						
Colour changes (mottling/dusky)	4.4	11.9	27.7	28.9	27.0	3.62 (1.13)
Temperature changes/cool	4.4	13.8	29.6	27.0	25.2	3.55 (1.14)
Skin moist/clammy	10.1	23.3	32.1	18.9	15.7	3.07 (1.21)
Skin dry	13.2	32.7	30.2	11.9	11.9	2.77 (1.19)
Pale	5.7	16.4	28.3	30.2	19.5	3.42 (1.14)
<b>Physical Sensations/Observations: Neurologic</b>						
Varying level of consciousness	2.5	5.7	15.2	30.4	46.2	4.12 (1.03)
Change in pupil response	21.4	27.7	25.2	17.6	8.2	2.64 (1.23)
Spastic movements/seizure activity	7.5	13.8	40.9	23.3	14.5	3.23 (1.10)
<b>Physical Sensations/Observations: Musculoskeletal</b>						
Flaccid (n=158)	14.6	24.1	30.4	23.4	7.6	2.85 (1.16)
Rigid/stiffness	11.3	25.2	34.0	22.0	7.5	2.89 (1.11)
Decreasing movements	8.2	18.2	21.4	34.6	17.6	3.35 (1.20)
Twitching, involuntary movements	5.0	10.1	37.7	30.2	17.0	3.44 (1.05)
<b>Physical Sensations/Observations: Sense organs</b>						
May be able to hear/encourage talking to patient	1.3	1.9	3.1	20.8	73.0	4.62 (0.75)
May be able to feel/encourage touch	1.3	2.5	3.8	19.5	73.0	4.60 (0.79)
Eyes open	1.9	9.4	32.7	30.8	25.2	3.68 (1.10)
Dry mouth/tongue	2.5	9.4	28.3	35.2	24.5	3.70 (1.02)
<b>Physical Sensations/Observations: Gastrointestinal</b>						
Loss of bowel control/incontinent	9.4	28.3	32.1	21.4	8.8	2.92 (1.11)
<b>Physical Sensations/Observations: Genitourinary</b>						
Foley in place	5.7	13.2	25.2	27.7	28.3	3.60 (1.19)
Decreasing urine output	10.7	27.0	28.9	23.3	10.1	2.95 (1.16)
Incontinent of urine	15.1	36.5	28.3	13.8	6.3	2.60 (1.10)
<b>Others</b>						
Offer religious support	0	0.6	6.3	18.9	74.2	4.67 (0.62)
Explain monitor changes	1.3	4.4	9.4	22.6	62.3	4.40 (0.92)
Emotional support	0	0.6	3.1	7.5	88.7	4.84 (0.48)
<b>Temporal characteristics</b>						

Item	Never	Rarely	Sometimes	Often	Always	M (SD)
Variable time frame for death	0.6	2.5	3.8	15.7	77.4	4.67 (0.73)
Pain medications/sedation provided	0.6	0.6	1.9	11.3	85.5	4.81 (0.56)
Breathing/heart rhythm changes	0	3.1	6.9	27.7	62.3	4.49 (0.76)
<b>Environmental features</b>						
Less restricted visitation	8.2	3.1	1.3	6.9	80.5	4.48 (1.21)
Possibility of transfer	1.9	20.8	30.8	25.2	21.4	3.43 (1.10)
Unnecessary equipment/monitors removed	0.6	1.3	6.3	26.4	65.4	4.55 (0.73)
Family offered options in post withdrawal care	1.9	3.8	11.9	26.4	56.0	4.31 (0.95)
<b>Causes of sensations, experiences</b>						
Decreasing oxygen supplied to body/organs	1.3	14.5	33.3	37.1	13.8	3.48 (0.95)
Answer family questions – don't address directly	5.0	8.8	21.4	33.3	31.4	3.77 (1.14)
Airway impaired	1.3	11.9	32.7	35.2	18.9	3.58 (0.97)
<b>Other information</b>						
Emotional support – re: decision to withdraw	0	1.3	2.5	22.6	73.6	4.69 (0.59)
Offer spiritual care	0.6	1.9	6.3	20.1	71.1	4.59 (0.75)
Be available for support as family needs	0	0.6	1.9	9.4	88.1	4.85 (0.45)
Reassurance to family of patient comfort	0	0.6	0.6	10.1	88.7	4.87 (0.41)

Note. M = mean; SD = standard deviation.

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368 **Table 4: The mean and standard deviation for the 10 information items in the *Preparing families***  
 369 ***for treatment withdrawal* survey instrument most frequently provided to families in preparation**  
 370 **for and during withdrawal of treatment based on their mean score (n = 159)**

Item	M (SD)
Reassurance to family of patient comfort	4.87 (0.41)
Be available for support as family needs	4.85 (0.45)
Emotional support	4.84 (0.48)
Pain medications/sedation provided	4.81 (0.56)
Emotional support – re: decision to withdraw	4.69 (0.59)
Variable time frame for death	4.67 (0.73)
Offer religious support	4.67 (0.62)
May be able to hear/encourage talking to patient	4.62 (0.75)
May be able to feel/encourage touch	4.60 (0.79)
Offer spiritual care	4.59 (0.75)

371 *Note.* M = mean; SD = standard deviation

**Table 5: The mean and standard deviation for the 10 information items in the *Preparing families for treatment withdrawal* survey instrument least frequently provided to families in preparation for and during withdrawal of treatment based on their mean score (n = 159)**

Item	M (SD)
Incontinent of urine	2.60 (1.10)
Change in pupil response	2.64 (1.23)
Skin dry	2.77 (1.19)
Flaccid	2.85 (1.16)
Rigid/stiffness	2.89 (1.11)
Loss of bowel control/incontinent	2.92 (1.11)
Decreasing urine output	2.95 (1.16)
Skin moist/clammy	3.07 (1.21)
Spastic movements/seizure activity	3.23 (1.10)
Decreasing movements	3.35 (1.20)

*Note.* M = mean; SD = standard deviation

**Table 6: Cross tabulations (Exact tests Monte Carlo option) between select demographic variables and some of the items most and least frequently provided by critical care nurses.**

<b>Demographic Variable</b>	<b>MOST frequently provided information</b>	<b>Fisher's exact test</b>	<b>Sig. (2-sided)</b>	<b>CI</b>	<b>Linear by linear association</b>	<b>Sig. (2-sided)</b>	<b>CI</b>
Gender	Reassurance to family of patient comfort	20.191	.003	.002-.005			
	Be available for support as family needs	14.077	.035	.031-.040			
	Emotional support	14.043	.031	.026-.035			
	Variable time frame for death	18.299	.019	.015-.022			
	May be able to hear/encourage talking to patient	18.286	.016	.013-.019			
	May be able to feel/encourage touch	15.933	.037	.032-.042			
	Offer spiritual care	18.623	.015	.012-.018			
Nursing experience	Variable time frame for death	23.411	.036	.031-.041	.858	.380	.367-.392
	Offer religious support	24.211	.006	.004-.008	11.126	.000	.000-.001
Critical care experience	Emotional support	12.621	.270	.259-.282	4.131	.041	.036-.046
	Variable time frame for death	24.530	.010	.008-.013	1.949	.163	.154-.173
	Offer religious support	17.130	.076	.069-.083	12.171	.000	.000-.001
<b>Demographic Variable</b>	<b>LEAST frequently provided information</b>	<b>Fisher's exact test</b>	<b>Sig. (2-sided)</b>	<b>CI</b>	<b>Linear by linear association</b>	<b>Sig. (2-sided)</b>	<b>CI</b>
Nursing experience	Flaccid	13.709	.590	.577-.602	5.074	.026	.022-.031
	Decreasing urine output	22.187	.091	.083-.098	7.573	.005	0.003-.007
	Decreasing movements	14.143	.553	.540-.566	5.076	.023	.019-.027
Critical care experience	Incontinent of urine	18.348	.266	.255-.278	4.890	.028	.023-.032
	Flaccid	18.628	.264	.252-.275	6.331	.012	.009-.015
	Rigid/stiffness	10.713	.835	.826-.845	4.325	.038	.033-.043
	Decreasing urine output	15.338	.485	.472-.498	6.972	.009	.006-.011
	Decreasing movements	24.740	.042	.037-.048	5.490	.019	.015-.022