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

AUTHOR(S):

Dr Kristen Ranse, PhD[1]

Dr Melissa Bloomer, PhD[2]

Prof Maureen Coombs, PhD[3]

Prof Ruth Endacott, PhD[4, 5]

AFFILIATION(S):

1. Disciplines of Nursing & Midwifery, Faculty of Health, University of Canberra, ACT 2601, Australia

2. Centre for Quality and Patient Safety Research, School of Nursing and Midwifery, Deakin University, Geelong, VIC 3220, Australia

3. Graduate School of Nursing, Midwifery and Health, Victoria University Wellington, New Zealand and Capital and Coast District Health Board, Wellington Regional Hospital, Wellington, New Zealand

4. School of Nursing & Midwifery, Monash University, Peninsula Campus, PO Box 527, Frankston, VIC 3199, Australia

5. School of Nursing & Midwifery, Plymouth University, Drake Circus, Plymouth, PL4 8AA, UK

CONTACT AUTHOR:
e-mail: Kristen.Ranse@canberra.edu.au

AUTHOR CONTRIBUTIONS
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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

INTRODUCTION

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

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

One study that has undertaken a more detailed and nuanced exploration of the type of information nurses give to families at this time was a study undertaken in the United States and focused on preparing families for death of their relative following withdrawal of mechanical ventilation.[13] Content analysis of the responses of 31 critical care nurses identified 43 descriptors of different types of information conveyed to families. The majority of descriptors (67.5%, n=29) were related to physical sensations and symptoms although study authors acknowledged that the format of the

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questionnaire may have contributed to this finding due to prompts specifically provided for the physical domain.[13]

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

METHOD

Study Aim

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 was used in this study.

Preparing Families for Treatment Withdrawal questionnaire

The survey instrument used in this study was developed from previous research undertaken by Kirchhoff, Conradt and Anumandla (2003).[13] Kirchhoff et al. originally designed the questionnaire to explore the content of messages given to families by critical care nurses in preparation for withdrawal of life-sustaining treatment and expected death of the patient.[13] Self-regulation theory (SRT) was used to underpin the study and the four concrete-objective domains (1. Physical sensations and symptoms, 2. Temporal characteristics, 3. Environmental features and 4. Causes of

sensations, symptoms and experiences) were provided as headings, under which participants could record a narrative response of the information that they provided to families in this situation.[13] Each SRT domain heading was accompanied by a definition to enhance clarity for the participant. In addition, eight sub-headings (respiratory, skin, neurologic, musculoskeletal, sense organs, gastrointestinal, genitourinary and others) were provided with the physical sensation and symptoms domain to capture all possible information provided to families. Kirchhoff et al. circulated their questionnaire to a sample of critical care nurses and from the 31 responses, content analysis identified 43 descriptors of information provided to families to prepare them for treatment withdrawal.[13]

Permission was given to use and re-develop the questionnaire (KT Kirchhoff, personal communication, 18 November 2014). For this study, the original headings comprising the SRT domains were retained and 40 descriptors identified by Kirchhoff et al.[13] were placed on a 1-5 rating scale (Never, Rarely, Sometimes, Often, Always). The instrument was then reviewed for face validity by a reference group, comprised of individuals meeting the inclusion criteria for participation.

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

Setting and participants

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

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

Data analysis

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

The frequency of participant response to each item on the survey was calculated. Mean and standard deviation were also calculated to identify the most and least frequent information given to families based on mean score. Cross tabulations, using the Monte Carlo method (with default confidence level of 99% and number of samples 10000), were calculated to explore associations within the data. Specifically, if each of the ten information items most and least frequently provided to families were associated with select demographic variables (country of practice, gender, nursing experience and critical care experience).

Cronbach's alpha was calculated to assess the internal consistency of the items for the whole instrument and for each of the four SRT domains of the instrument. Cronbach's alpha of greater than 0.70 was considered satisfactory internal consistency.[14]

Ethical Considerations

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

RESULTS

Respondent profile

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

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

Preparing families for treatment withdrawal

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

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

DISCUSSION

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

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

The physical domain was the most comprehensively covered domain in the survey instrument, with 23 out of the 40 information items pertaining to this area compared to three to four items in each of the other domains. The extensive number of items in the physical domain permits greater discretion by respondents and increases the likelihood that some of these items would be less frequently provided. Specifically, the items in the subdomains gastrointestinal, genitourinary, musculoskeletal and neurologic were the areas of information least frequently included by nurses in their communication with families in this study. Physical information provided was instead dominated by descriptions pertaining to the sense organs (that the patient may be able to hear/feel) and changes to breathing patterns. Preparation of families for physical changes that occur during the dying process is recommended and changes to the skin and breathing patterns have been frequently mentioned by nurses in previous research.[3, 13]

The association identified between participant gender and the information items most frequently provided to families reflecting emotional support practices warrants further investigation. A previous study also identified a statistically significant association between gender and emotional

support practices.[18] A future larger study with stratified sampling by gender is needed to investigate these associations.

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

Knowledge gained from this research can inform recommendations for practice, education and further research to support critical care nurses in the provision of family-centred end-of-life care in intensive care units. There has been much emphasis on providing information leaflets to families of patients admitted to the intensive care unit.[10, 20-21] Our findings may provide a useful framework for the development of an intervention such as a brochure or guideline to assist critical care nurses sharing information with families. The findings also provide a framework for professional development activities focusing on communication with families at end-of-life. The information areas highlighted as being least attended to can inform the content for educational interventions to support nurses in this important aspect of critical care nursing. Future research should be undertaken to evaluate the effectiveness of interventions implemented to improve the quality of end-of-life care that is family-centred and delivered by critical care nurses supported in their practice. Future research from the perspective of the family would also make an important contribution to understanding the information needs of families prior to and during withdrawal of life-sustaining treatment and if these needs are adequately met.

Further testing is needed to provide evidence of the psychometric properties of the questionnaire and areas for potential future development of the instrument. Specifically, further development of possible information items within the domains, other than physical domain, may be needed to ensure adequate coverage of all domains of interest. In addition, the use of the questionnaire with a larger sample and exploratory factor analysis of the dataset obtained is needed to identify the latent constructs within the questionnaire. A minimum sample size of at least 5 participants per item is recommended for factor analysis,[14] thus at least 200 participants are required with a 40-item instrument.

Limitations

This study is limited by the small response rate and non-randomised sampling methods used to recruit participants. The respondents may not be representative of the wider critical care nursing population in Australia who are not members of the professional association. Of particular note was the high level of postgraduate nursing qualification (89.7%) amongst respondents, which is consistent with a previous study involving a sample drawn from the same population (Ranse et al. in press) but much greater than that reported in the latest critical care nursing workforce statistics (53.9%).[22] This may have introduced a recruitment bias.

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

Conclusion

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

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

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

Note. ICU = intensive care unit. *Level of care according to the *Minimum Standards for Intensive Care Units*[23]

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

Scale	No of items	α
Physical Sensations/Observations	23	0.933
Temporal characteristics	3	0.711
Environmental features	4	0.669
Causes of sensations, experiences	3	0.540

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)
Physical Sensations/Observations: Respiratory						
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)
Physical Sensations/Observations: Skin						
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)
Physical Sensations/Observations: Neurologic						
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)
Physical Sensations/Observations: Musculoskeletal						
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)
Physical Sensations/Observations: Sense organs						
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)
Physical Sensations/Observations: Gastrointestinal						
Loss of bowel control/incontinent	9.4	28.3	32.1	21.4	8.8	2.92 (1.11)
Physical Sensations/Observations: Genitourinary						
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)
Others						
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)
Temporal characteristics						

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)
Environmental features						
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)
Causes of sensations, experiences						
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)
Other information						
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.

Table 4: The mean and standard deviation for the 10 information items in the *Preparing families for treatment withdrawal* survey instrument most frequently provided to families in preparation 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)

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.

Demographic Variable	MOST frequently provided information	Fisher's exact test	Sig. (2-sided)	CI	Linear by linear association	Sig. (2-sided)	CI
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
Demographic Variable	LEAST frequently provided information	Fisher's exact test	Sig. (2-sided)	CI	Linear by linear association	Sig. (2-sided)	CI
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