

The CoBaTrICE Collaboration

The views of patients and relatives of what makes a good intensivist: a European survey

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Abstract *Objective:* This study examined the views of adult patients and relatives about desirable characteristics of specialists in intensive care medicine (ICM) to incorporate these into an international competency-based training programme, CoBaTrICE. *Design:* Convenience sample of patients and relatives administered after discharge from 70 participating ICUs in eight European countries (1,398 evaluable responses). The structured questionnaire included 21 characteristics of medical competence categorised as ‘medical knowledge and skills’, ‘communication with patients’, and ‘communication with relatives’. It was available in the national languages of the countries involved. Questions were rated by respondents for importance using a four-point Likert scale. Responses to open questions were also invited. *Results:* Most characteristics were highly rated, with priority given to medical knowledge and skills. Women were more likely to emphasise communication skills.

There were no consistent regional differences. Free-text responses welcomed the opportunity to participate. *Conclusions:* Patients and relatives with experience of intensive care in different European countries share similar views on the importance of knowledge, skills, decision making and communication in the training of intensive care specialists. These generic patient-centred components of training have been incorporated into the international competency-based ICM training programme, CoBaTrICE.

Keywords Intensive care · Critical care · Professional competence · Training · Physician-patient relations · Professional-family relations

Introduction

An international partnership of training organisations has developed a competency-based training programme in intensive care medicine for Europe (CoBaTrICE, <http://www.cobatrice.org>) and other world regions [1]. This project used consensus techniques to involve critical care professionals, trainers and trainees, pa-

tients and relatives in identifying and prioritising core competencies (outcomes of training) for specialists in intensive care medicine (ICM). As part of this initiative we conducted a detailed European survey of patients and relatives with experience of intensive care to obtain their views of the knowledge, skills and attitudes that they expect of ICM specialists and to integrate these responses in the CoBaTrICE competencies.

This work has previously been presented in abstract form [2, 3].

Experiences of critical illness and intensive care are particularly challenging for patients and relatives [4–11], and supporting them makes special demands on staff. Studies of ICU survivors identify the need for clear and timely information and for compassionate and personalised care [6–8]. Relatives value receiving information comprehensibly, fully and in an unhurried way by physicians [6, 12, 13], and improved communication can reduce the burden of bereavement amongst relatives [14]. A literature review of studies on the relationship between relatives and ICU nursing staff [15] identified the key role of staff in giving information, support and hope. Both patients and relatives describe a need for patients to be made to feel secure [11]; vulnerability is increased by impersonal care if patients feel ignored, or if staff talk about them as if they were not there [6, 16]. Professional competence and skill, being ‘in good hands’, is seen by patients and relatives as part of a positive ICU experience [17], including effective analgesia and perceptions of good team working [10]. From the consumer perspective, competence has been variably described as ‘a range of caring behaviours and related skills’ [18], and includes being kept well-informed, learning about what is happening and being present to watch the care being administered [19]. These aspects are of particular importance when training staff in end-of-life care [14, 20–25].

In these special circumstances of critical illness what intensive care patients and relatives want of their physicians may differ quantitatively or qualitatively from those receiving elective care in hospital wards or in their own homes (the subject of previous studies [12]). Patients and relatives in ICU have a unique perspective on the desirable characteristics and competencies of ICM specialists through their experience of the ICU environment, and by direct and frequent observation of the ‘outcomes’ of training, that is, the specialists themselves. We wished to ensure that we had incorporated these insights in the CoBaTrICE programme by conducting a consumer survey, specifically exploring the attributes that patients and relatives expect of an ICM specialist, across representative regions of Europe. The main aim of this study therefore was to develop a general view of what patients and relatives consider to be desirable characteristics of ICM specialists.

Methods

A survey by self-completion questionnaire in the national language was selected as the most effective means to explore the views of patients and relatives across different countries within the time and fiscal constraints of the project.

Questionnaire development

We examined qualitative research published during the 15 years before 2004 when this survey started, to identify themes previously reported by patients and their relatives. We also conducted four qualitative interviews in the United Kingdom with persons who had experience of the ICU as a patient or relative. Although there was an absence of research specifically targeting patients’ or relatives’ views of ICM specialists, studies of patient and relative experiences of the ICU in general provided some insight into the qualities that may be valued in ICM specialists (see Electronic Supplementary Material, ESM, Table 1). This material formed the basis for the content of the questionnaire.

Questionnaire content

We used the same survey tool for both patients and relatives to simplify distribution. The survey employed short sentences to aid concentration, non-medical terminology, a tick-box format, a limited number of questions and a large type face.

The questionnaire comprised 21 statements related to three general themes: (a) medical knowledge and skills, (b) communication with patients and (c) communication with relatives (see Table 1). Respondents were asked to rate the importance of these statements using a four-point Likert scale (4 = essential, 3 = very important, 2 = not too important, and 1 = does not matter). The questionnaire deliberately did not ask about patients’ and relatives’ own experience of intensive care, but only about the qualities they believed to be the most important for an ICM specialist. They were not asked to rank these qualities, but we did include two questions asking them to compare the importance of two competing positive qualities: whether it is more important that physicians in intensive care are good at communicating with patients and relatives than that they are expert at providing treatment, and whether experience on the job is more important in making a good intensive care physician than keeping up to date with the latest research and new developments. Towards the end of the questionnaire respondents were asked whether there was any other important quality that a physician in intensive care should have, and they were offered an opportunity to expand on answers given to the tick-box questions. The questionnaire concluded with questions about gender, year of birth, level of higher education achieved, status (patient or relative) and length of stay at the time of questionnaire completion (to indicate period of experience of ICU). The English language version of the questionnaire can be found in the Electronic Supplementary Material (ESM, Fig. 1).

Table 1 Questionnaire statements grouped by theme and indication of the CoBaTrICE competencies in which these statements were finally represented

Theme	Doctors in intensive care should ...	CoBaTrICE competency statement reference ^a
Medical knowledge and skills	Be decisive when action is needed	1.1
	Carry out practical procedures skilfully	5.1–5.24
	Do everything possible to control pain	5.19, 7.2
	Have up-to-date knowledge about illness and treatment	3.1, 12.13
	Handle crises calmly	1.2, 2.2
Communication with patients	Work well as member of a team	12.2, 12.7–12.10
	Inform patients about future care	12.1
	Give patients an opportunity to ask questions	12.1
	Give patients full information even when upsetting	12.1
	Discuss fears and anxieties with patients	12.1
	Explain in ways patients can understand	12.1
	Not talk as if patients are not there	12.1
	Involve patients in decisions about care and treatment	12.4
	Treat patients as individuals	12.6, 12.12
	Listen to patients	12.1
	Give bad news in a caring way ^b	12.1
	Be courteous and polite ^b	12.5, 12.6
	Do not give information that is upsetting ^b	12.1
Communication with relatives	Give relatives an opportunity to ask questions	12.1
	Involve relatives in decisions about care and treatment	12.4
	Find out what relatives think and feel	12.1, 12.4
	Give bad news in a caring way ^b	12.1
	Be courteous and polite ^b	12.5, 12.6
	Do not give information that is upsetting ^b	12.1

^a Number refer to pertinent competence statements, as presented in Table 3 of reference [1]

^b Statements assigned both to ‘communication with patients’ and to ‘communication with relatives’

Distribution and data collection

A convenience sample in eight European countries was chosen representing eastern, western, central and southern regions and social and cultural characteristics (broadly defined by per capita gross domestic product and population density) and the four dominant models of ICM training [26], and ICUs in these countries were invited to participate. The questionnaire was professionally translated (including reverse translation) into national languages and distributed through the CoBaTrICE project network; this included two senior clinicians in each country (CoBaTrICE National Coordinators) who recruited between eight and ten different ICUs (via the ICU director), and an ICU representative within each unit (physician or nurse). The ICU representative was responsible for local distribution of questionnaires; they were sent detailed instructions and a predetermined number of questionnaires (based on the number of ICU beds). The survey was approved by national and local research ethics committees as applicable.

Recruitment took place during 2004–2005 over a 3-month period in each ICU. The questionnaire, a prepaid response envelope and an information sheet was offered to a convenience sample of patients who were being discharged from the ICU (ICU survivors), and to one close relative of each ICU in-patient (relatives of potential

survivors and non-survivors whose eventual ICU outcome is unknown, but who were all receiving intensive therapy at time of questionnaire completion). The questionnaire was not distributed to anyone under 15 years of age, experiencing serious psychological distress, with a cognitive and/or psychiatric illness, or who could not read or write in the national language. Questionnaires were offered only to relatives who were the patient’s spouse, parent, sibling or adult child. Responses were anonymous and were returned directly by post for central analysis.

This method facilitated simultaneous distribution in all eight countries, and preserved patient confidentiality. We intentionally did not require local representatives to record the number of questionnaires distributed or to follow-up non-responders, and a response rate was therefore not determined. Six hundred questionnaires were sent to each country, with an anticipated return of approx. 100 questionnaires per country.

Data analysis

Answers were dichotomised into the categories of ‘essential’ (importance score 1) and ‘not so essential’ (importance scores 2–4). Rankings were derived from the ratings of importance by dividing the number of ‘essential’ ratings

by the number of responses. For further analysis questionnaire statements were aggregated into three main themes (knowledge and skills, communication with patients, communication with relatives; Table 1).

Responses from Denmark, The Netherlands and Switzerland were grouped as Central Europe, the United Kingdom represented Western Europe, the South consisted of Italy and Spain, and the Eastern region comprised the Czech Republic and Poland.

Summary data are presented as mean ± SD and median (25th–75th percentile) where appropriate. To test for differences in ranking between questions the χ^2 test was used. Friedman statistics and Wilcoxon signed ranks test were used to check for significance of differences, and Spearman’s rank-order correlation was used to test associations between themes. Univariate analysis was performed using the aggregated levels of importance as dependent variables, and age, sex, educational level, length of stay in ICU and geographical region as explanatory variables. The Kruskal–Wallis test was used to check for differences between groups. Differences with a *p*-value less than 0.05 were considered statistically significant. Statistical analysis used SYSTAT 11 (Systat Software, Erkrath, Germany).

Sample characteristics

Seventy ICUs participated in the survey. A total of 1,398 questionnaires were suitable for analysis; higher proportions were received from southern and eastern regions (Table 2). Female respondents were more numerous in Italy and Poland; relatives outnumbered patients by 2 to 1. The mean age of respondents was 51 ± 16 years (56 years for patients, 49 years for relatives); 288 respondents (21%) were over 65 years of age. Over one-third of respondents had more than 10 days experience of an ICU. Further details are given in ESM Table 2.

Results

Ratings of importance

Although there was a significant difference (*p* < 0.001) between the highest and lowest rated questions, the majority of the 21 statements were rated either as ‘essential’ or ‘very important’ (ESM Table 3). When ranked by the number of ‘essential’ ratings, the five top ranks all belonged to the theme ‘medical knowledge and skills’ whereas the five lowest prioritised were in the themes ‘communication with patients’ or ‘communication with relatives’ (see also ESM Table 4). High importance was given to clarity of explanation (‘explain medical matters in ways patients can understand’, ranked 6), and less to aspects of autonomy (‘involve patients in decisions about care and treatment’, ranked 18). Rankings by country are given in Table 3. Generally the responses are consistent; there were no evident geographical differences.

There was also considerable uniformity of responses between patients and relatives when statements were grouped by theme. Mean rating for ‘medical knowledge and skills’ was 1.39 ± 0.32 for patients and 1.37 ± 0.32 for relatives (*p* = 0.125, Kruskal–Wallis); the respective data for ‘communication with patients’ were 1.76 ± 0.40 and 1.73 ± 0.37 (*p* = 0.173), and for ‘communication with relatives’ 1.98 ± 0.49 and 1.86 ± 0.46 (*p* < 0.001). When single statements were examined, patients gave higher importance than relatives to physicians involving patients in decisions, and giving them full information whereas relatives saw the qualities of giving bad news in a caring way and treating patients as individuals as more important than did patients. There was a tendency for women to give greater priority than men to communication with patients and relatives (*p* < 0.001). Educational attainment had no consistent effect.

Table 2 Characteristics of total returns. Due to missing data the sum for gender and status is less than 1,398. For definitions of models of ICM training see [26]

Country	Region	Model of ICM training [26]	Total returns	Gender		Status	
				Male	Female	Patient	Relative
Czech Republic	East	Sub-specialty	137 (10%)	59	75	59	78
Denmark	Central	Sub-specialty	96 (7%)	44	49	28	68
Italy	South	Sub-specialty	249 (18%)	102	142	29	213
The Netherlands	Central	Supra-specialty	88 (6%)	44	41	27	58
Poland	East	Sub-specialty	222 (16%)	85	123	88	120
Spain	South	Primary specialty	285 (20%)	133	147	78	200
Switzerland	Central	Primary, supra-specialty	197 (14%)	103	93	99	93
United Kingdom	West	Supra-specialty	124 (9%)	58	63	54	67
All	–	–	1,398 (100%)	628 (46%)	733 (54%)	462 (34%)	897 (66%)

Table 3 Ranking of statements for importance by country. For each country the rank for each item is given as number (1 = highest rank, 21 = lowest rank). The items are shown in this table in sequence, as defined by rank of the total sample (*SP* Spain, *IT* Italy, *CR* Czech Republic, *PL* Poland, *SW* Switzerland, *NL* The Netherlands, *DK* Denmark, *UK* United Kingdom)

	South SP	IT	East CR	PL	Central SW	NL	DK	West UK	All
Be decisive when action is needed	4	4	1	1	1	1	1	1	1
Up-to-date knowledge about illness and treatment	1	2	3	3	4	2	4	2	2
Handle crises calmly	5	3	2	5	6	3	2	5	3
Carry out practical procedures skilfully	11	7	5	4	5	4	7	4	4
Do everything possible to control pain	7	11	7	2	7	5	12	3	5
Explain in ways patients can understand	3	5	10	9	3	8	6	7	6
Treat patients as individuals	6	1	8	11	2	9	10	6	7
Work well as member of a team	2	6	4	14	11	6	3	10	8
Give bad news in a caring way	10	9	9	12	12	14	8	8	9
Do not talk as if patients were not there	15	10	11	8	10	7	5	13	10
Listen to patients	8	12	12	16	9	11	11	9	11
Inform patients about future care	12	14	15	6	8	10	14	11	12
Be courteous and polite	9	8	6	7	17	17	15	16	13
Discuss fears and anxieties with patients	13	13	13	10	13	12	16	12	14
Give the relatives an opportunity to ask questions	14	15	14	13	15	15	9	14	15
Give patients the opportunity to ask questions	16	16	16	15	14	13	13	15	16
Involve relatives in decisions about care and treatment	18	17	21	18	18	19	17	17	17
Involve patients in decisions about care and treatment	19	21	17	21	19	16	19	19	18
Give patients full information even when this is upsetting	21	18	19	19	16	18	18	18	19
Find out what relatives think and feel	17	19	20	20	20	21	20	20	20
Do not give information that is upsetting	20	20	18	17	21	20	21	21	21

Cell color: green, rank 1–5; white, rank 6–16; red, rank 17–21

Free-text comments

Free-text commentary was included by 450 (32%) respondents; most reinforced the themes already represented in the questionnaire. Moral qualities which underpin some of the statements such as integrity, kindness, truthfulness and compassion were made explicit. ‘Humanity’ was a quality desired by both patients and relatives, who frequently referred to the need for patience, approachability, a smile and a sense of humour. Some respondents added comments about their own experiences which were in most cases good. Reflecting on personal experiences, relatives cited continuity of care seeing the same physician, or ensuring effective communication between physicians as an aspect which could be improved. Many respondents expressed gratitude for the treatment they had received at the hands of dedicated intensive care staff and for being offered an opportunity to feed back their views (see Appendix).

Discussion

This is the first study to seek the views of patients and relatives on desirable characteristics of ICM specialists. The survey shows that patients and relatives prioritise medical knowledge and skills as most important, followed by com-

munication with patients and then with relatives. Not unexpectedly, however, all 21 statements in this questionnaire were seen as either ‘essential’ or ‘very important’ by the majority of respondents. With the exception of ‘not giving information that is upsetting’, all the statements were positive qualities derived from previously identified views of patients and relatives.

The most obvious result is the consistency between countries and regions, which contrasts with other studies demonstrating regional differences, for example, in ethical issues [27]. This lends support to the view that training programmes can be harmonised across national borders. Although differences were found in patients’ and relatives’ ratings of certain single statements, when the statements were grouped into general themes, these differences disappeared; this suggests that patients and relatives identify similar types of characteristics but differ somewhat on how these qualities are manifested perhaps because of variations in their experiences of the ICU environment and specialists within it. Communication with relatives was significantly more important for relatives than for patients, as one would expect. Overall, quality of communication was rated more important than involvement in the process of decision making.

When challenged to discriminate between two competing positive qualities, the majority of respondents were either unsure whether one was more important than the other

or ascribed equal importance to the two qualities in each question. These findings emphasise the difficulty in choosing between elements of professional competency, when all are considered desirable qualities. Patients and relatives can legitimately expect their physician to be experienced, up to date, good at talking to patients and expert at providing treatment. This perhaps highlights the essence of professionalism, the whole being greater than the sum of the parts.

Surveys of this type appear deceptively simple, but suffer from a number of limitations. Our method of distribution worked well, and the sample included responses from 70 ICUs. However, limited resources made it necessary to distribute the survey in a non-randomised manner through a dedicated network of local representatives whose involvement and activity will have influenced response rates. Participation by the United Kingdom was delayed as a result of an initially adverse ethics committee decision which was overturned on appeal. We did not attempt to compare specialists in ICM with other medical specialties or other professions working in the ICU. The three main questionnaire themes were identified from the materials and not by factor analysis. We restricted our literature review to publications pre-2004 and a small number of qualitative interviews carried out in the United Kingdom, which may have introduced an English language bias. However, free-text responses gave no indication that the selection was inappropriate or inadequate in any of the eight countries in which the survey was carried out. This suggests that what users of intensive care regard as important qualities for an ICM specialist is relatively universal, and although elements of professional competency may be given different emphasis in different cultural and social contexts there is nonetheless widespread consensus on what those elements are.

Relationship to CoBaTrICE competencies

This survey was designed before the start of a simultaneous iterative online survey (modified Delphi) to collect suggestions of competencies from health care professionals. Content analysis from the Delphi (reported previously [1]) indicated that the majority of the characteristics identified by the survey of patients and relatives as being essential or very important (i.e. all 21 statements) were also frequently identified by health care professionals. Only two consumer items, 'treating patients as individuals' and 'informing patients about the care they will need in the future', were not represented in the Delphi material and were added as discrete items for rating by a Nominal Group; themes from the survey of patients and relatives could be linked to 76 of the 164 competence stems that were rated during this process [1]. In the final competence set the themes from the consumer

survey are evident across every domain ('domain' means competencies grouped by a common theme) where features of competent performance include the application of medical knowledge and skills, decisive decision making, and communication skills [1]. Reference to patients or relatives is made in almost one-third of the CoBaTrICE competencies. The non-technical characteristics of medical competence, and additional qualities highlighted in free text responses from this survey have been largely incorporated into a single domain, 'Professionalism', which is divided into communication skills, professional relationships with patients, professional relationships with relatives and self-governance [1]. Material from this survey is therefore evident in the individual competence statements within this domain and in the descriptions of competent performance and the syllabus which underpin them [1].

Conclusion

This survey is the first to acquire data about patients' and relatives' views of desirable characteristics of ICM specialists to inform the development of ICM competencies. Medical knowledge and skills were given the highest priority, followed by communication with patients and with relatives. There was consistency in responses between 'consumers' in different countries, despite different traditions and methods of training. This supports the principle of the CoBaTrICE programme, creating a trans-national, harmonised, competency-based, and patient-centred approach to specialist training in intensive care medicine.

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Appendix: Examples of free text comments

On the theme of medical knowledge and skills, respondents said such things as:

- They (doctors) should have both knowledge and experience of modern diseases. They should make a right diagnosis fast and be confident and self-controlled in the way they handle themselves in front of patients and relatives—but without talking down to them! (Relative, Poland).
- Although it is important to involve patients and relatives in the decision-making process, decisions should be based on the presenting evidence and should be informed by experience and expertise. It may thus be appropriate that relatives and patients are informed of decisions rather than fully involved. (Relative, United Kingdom)
- (Doctors should have) capacity to take responsibility. (Patient, Switzerland)

On communication with relatives:

- He (the doctor) has to be clear in the way he informs relatives and all doctors should give the same information. (Relative, Italy)

- Doctors should remember that contact with relatives is very important. They could find out a lot about the patient and his or her previous illness. . . . (Relative, Poland)
- Empathy. A doctor who can empathise with relatives or who encourages his team to be equally caring no matter how busy they are gives so much comfort in these times of distress. (Relative, United Kingdom)
- Don't always focus on the worst scenario; point out the positive signs too. (Relative, United Kingdom)

On communication with patients:

- (Doctors should be) kind, patient and open to working with patients. (Relative, Czech Republic)
- Never forget I am a human being. (Patient, Italy)
- (Doctors need to) speak a language that patients can understand. Terms used are often too medical. (Patient, The Netherlands)
- It is important that they (doctors) give themselves time to talk to patients and relatives. (Patient, Denmark)
- Listen properly to the patient and let them finish talking. (Patient, The Netherlands)

On moral qualities underpinning competencies:

- (Doctors should) keep smiling and be sensitive. It doesn't cost anything but helps a lot. (Relative, Czech Republic)
- It is important to see the patient as a *whole* human being not just a symptoms and illness. (Relative, Denmark)
- (Doctors should have) patience, compassion, sense of humour. (Patient, Spain)
- Nobody is perfect. Just like anyone else a physician is human. . . he/she can also make mistakes. If this happens it is important to acknowledge these and discuss them. (Relative, The Netherlands)
- Ability to treat patient with dignity (Relative, Poland)

On personal experiences:

- Saw so many different doctors did not have a clue who they were most of the time . . . but I stress the care was outstanding. (Relative, UK)
- Explaining what is going on with the patient has been done well! (Patient, Switzerland)
- I have noticed an excellent relationship between doctors/staff and family. Availability and humanity are 'little' things but in this moment of your life they make the difference. Thank you. (Relative, Italy)
- Thanks for giving me this chance to express myself. (Relative, Italy)

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