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Research

Perspectives of Intensive Care Patients and Family Members on Competencies for Advanced Intensive Care Nurses in Europe

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ABSTRACT

Background

One output from the International Nursing Advanced Competency-based Training for Intensive Care (INACTIC) collaboration is a set of core competencies for advanced practice Intensive Care Unit (ICU) nurses across Europe. Some European countries, such as the UK, have identified such competencies; however, these advanced practice roles are rarely practised across the rest of Europe. The INACTIC competencies were developed with an expert panel of 184 ICU nurses from 20 countries. It is also important to examine what patients and relatives with experience in intensive care felt about these competencies.

Aim

To examine the views of recovered ICU patients and relatives regarding the INACTIC competencies.

Methods

Three patient and relative focus groups were conducted in England (n=5), Scotland (n=4) and Greece (n=4) to discuss a lay version of the INACTIC competencies. Discussions were open-ended, followed a topic guide, recorded and transcribed verbatim. Analysis followed a conventional thematic approach, with the findings discussed iteratively among the authors.

Results

The feedback from across the focus groups resulted in three themes: 1) the importance of nurses being empowered to advocate for the patient; 2) the centrality of communication; and 3) the impact of variability in ICU practices. There was a notable difference with the Greek focus group; because of restricted family visiting policies, relatives did not feel encouraged to participate in patient care.

Conclusions

The perspectives of patients and relatives largely align with the consensus of the INACTIC expert panel. Participants varied experiences regarding ICU contextual practices and professional roles underscore the need for targeted research and strategies within certain ICUs. This includes addressing appropriate leadership, training, and policy approaches to effectively incorporate the INACTIC competencies within local contexts.

Keywords: Competencies, focus group, intensive care, nurses, patients, relatives

INTRODUCTION

A review of existing competencies for advanced nurses in critical care found very few countries across Europe used advanced

nursing roles in ICU settings (Egerod et al., 2021). Previous studies showed that there are marked differences in how ICUs are organised across Europe, and that the amount of autonomy that critical care nurses have varies widely between countries (Benbenishty et al., 2005; Papathanassoglou et al., 2012).

Telephone interviews with ICU nurse leaders from 24 European countries revealed that 70% of countries had formal basic critical care nursing education programmes, whilst ICU nursing was recognised as a specialty in only 54% (Endacott et al., 2015). Where such educational programmes existed, eligibility requirements and the duration of the programmes varied considerably, anywhere from 240-hour long to 24 months. Career progression into advanced nursing roles is reliant on the legislated recognition of Critical Care Nursing as a specialty area across Europe. A Europe-wide critical care nursing specialist education programme has been suggested to ensure ICU nurses have the requisite knowledge and skills to ensure high-quality care (Fullbrock et al., 2012; Labeau et al., 2012; Endacott et al., 2015). Therefore, new strategies are needed such as the implementation of a comprehensive, educational framework that would establish sustainable advanced practice roles in ICU nursing across Europe (Endacott et al., 2015). Additionally, the identification of Europe-wide competencies would facilitate the development and the recognition of appropriate critical care nursing training courses across country borders, enabling workforce mobility and ensuring a consistent standard of care equitable for all patients.

While advanced practice nurse roles in critical care are common in the United Kingdom (UK), this career progression for ICU nurses is rare across Europe. Competencies have been established for such roles in the UK (The National Education and Competency Framework for Advanced Critical Care Nurses, 2008). In 2018-2019, the Nursing and Allied Health Professionals (NAHP) Committee of the European Society of Intensive Care Medicine (ESICM) ran a Delphi study to establish Europe-wide critical care competencies (International Nursing Advanced Competency-based Training for Intensive Care -INACTIC) (Endacott et al, 2022). The INACTIC competencies were developed with an expert panel of 184 ICU nurses from 20 European countries. The survey has been translated into seven languages (Croatian, French, German, Greek, Polish, Spanish, and Turkish) to maximise participation. Ninety-five competency statements were identified within four domains: knowledge, skills, and clinical performance; clinical leadership, teaching and supervision; personal effectiveness; safety and systems management, through three rounds. Overall agreement for the statements ranged from 85 to 97.5%.

Despite core competencies for advanced nurses in critical care have been identified by ICU nurses, it is unclear what nursing competencies ICU patients and family members perceive as most important. ICU patients and their relatives

are extremely vulnerable and completely reliant on the care being provided to them for their survival and emotional well-being, and what is important for them may differ from what healthcare professionals view as core skills (Yang., 2016). Patient feedback within the healthcare setting is also important and it has been used recently to improve and redesign services, examine staff behaviours, and establish person-centred care (Maxwell., 2020). No previous research has explored the perceptions of ICU patients and family members about ICU nursing competencies. The current study aimed to examine what ICU patients and relatives think about critical care nurses' competencies as they were identified by the INACTIC collaboration.

Ethical approval

The Research Ethics and Integrity Committee, [name of institution, blinded for peer review], approved the study in the UK (study reference 18/19-1137). Research committees of two public hospitals approved the study in Greece, along with the medical directors of the respective ICUs.

METHODS

The study was framed by an exploratory qualitative design (Murphy et al., 1998), employing a focus group approach. Exploratory research is a methodological approach that can be used to investigate topics and research questions that have not previously been studied in depth. As there is no previous research exploring ICU patients and their relatives' perception of ICU nursing competencies it was decided to use focus groups. This is a common method to explore a topic area where little is known, and it has been used successfully in past research with recovered ICU patients and their family members (Bench et al., 2016). In addition, focus group research has been used to understand patient-family-nurse care interactions in ICU (Kydonaki et al., 2020). Focus groups capitalise on the advantages of group interaction during which hitherto unearthed topics can surface in conversation (Kreuger & Casey, 2014; Stewart & Shamdasani, 2014).

Participants, sampling, and recruitment

Patients and relatives with experience in ICU, able and willing to share their views, were eligible for participation; our participant sample was restricted to adults since paediatric nursing is commonly a sub-specialty in many countries. A non-probability, purposive sampling approach was used to recruit from this hard-to-reach population.

In the UK, recruitment took place through the peer support group charity ICUsteps, which supports ICU patients and their families during their recovery following critical illness. It has 22 peer support groups around the UK and Ireland. One of its aims is to support research that advances the care of patients and relatives both in ICU and during recovery post-ICU. Using this structure, an

advertisement, explaining the purpose of the research and introducing the facilitators, was sent to all the local ICUsteps support groups for volunteers to attend one of two UK focus groups; one organised in Milton Keynes, England, and one in Edinburgh, Scotland. In addition, the members of the European Society of Intensive Care Medicine (ESICM) Nursing and Allied Health Professional Committee were approached to organise two focus groups outside the UK. As a result, a focus group was conducted in Athens, Greece, where participants were recruited through email and telephone contact.

Attendees were provided with travelling expenses and light refreshments during the focus group, but no other incentives were used. Participants may or may not have received care from an advanced ICU nurse, as the deployment of advanced critical care nurses is inconsistent across ICUs in Europe, and the formal existence of this role varies, including in Greece. While the patients and relatives from Milton Keynes may have encountered an Advanced Nurse Practitioner, as there is one working in the ICU there, the ICU in Edinburgh site didn't have such a position at the time the focus group participants were in ICU.

Data collection

Three focus groups were conducted, one in Milton Keynes, England (3 ICU patients and 2 relatives) facilitated by CJ & MP (both female); one in Edinburgh, Scotland (4 ICU patients) facilitated by CJ & PR (both female); and one in Athens, Greece (2 ICU patients and 2 relatives) facilitated by KI (female), between September – December 2019. A further non-UK based focus group proved impossible to organise due to the difficulty in identifying ICU patients and relatives to recruit to the group.

During the focus groups, participants were encouraged to talk to and ask questions of each other, and comment on others' experiences and opinions (Jamieson & Williams, 2003). To ensure that the participants could engage fully in the focus groups, locations with good transport links and parking were chosen, the target group size was 4 – 8 (patients and relatives), the time of the meeting was early afternoon to avoid rush hour, and the moderators were all experienced ICU nurses used to translate medical terms into everyday language (Tausch & Menold, 2016). In addition, the moderators, who all had previous experience running focus groups, ensured that no interruption would occur during the meeting; two recorders were used for each focus group, which lasted between 60 and 90 minutes. A lay summary version of the competencies was developed and verified with the members of the Expert Panel, to ensure the original meaning of each statement was retained.

Participants were provided with the lay summary competencies (Table 1) and asked to consider these before the meeting. A semi-structured interview schedule (Table 2) was used to ensure the focus groups covered all the lay

summary competencies, but this was used flexibly to guide the discussions allowing participants to share their views at their own pace and words. Participants were informed that no mention would be made of their own illness and would be free to leave the focus group at any point without giving a reason. The focus groups lasted between 60 – 90 minutes each.

Table 1.

Lay Summary of Competencies for Advanced Intensive Care Nurses

Theme	Advanced intensive care nurses should ….
Intensive care knowledge and skills	• Have up-to-date knowledge about how best to manage the patient's illness, treatment and recovery • Interpret information provided by patient monitoring systems and act as necessary • Carry out practical procedures skilfully • Do everything possible to control symptoms such as pain and confusion • Encourage families to participate in their loved one's care
Leadership skills	• Work well as part of a team, taking leadership of the team when necessary • Remains calm under pressure • Inspire colleagues to always provide the best possible care for the patient and family • Recognise when other members of the team need support • Provide leadership to the team in emergency situations • Speak up on behalf of the patient and family when appropriate • Ensure the right number and skill level of nursing staff is available
Communication with patients	• Communicate with patients in ways they can understand • Keep patients informed about plans for their care • Give opportunities for patients to communicate their wishes, fears and anxieties • Give opportunities for patients to ask questions • Involve patients and families in decisions about care
Communication with families	• Communicate with patients in ways they can understand • Give family members the opportunity to ask questions • Ensure family members understand current and future plans for their loved one's care • Ensure transition to end of life care is fully discussed and options clarified

Table 2.

Questions in Semi-structured Focus Study Interview on Perspectives of Intensive Care Patients and Family Members on Competencies for Advanced Intensive Care Nurses in Europe

1. Would you say that the competencies you have had the opportunity to read through cover the role of an expert intensive care nurse using your experience of nurses in ICU?
2. Do the competencies identified have enough emphasis on patient and family needs?
3. Are there things you are dissatisfied with? If so, what are they? Why is that? How should they change?"
4. Are there other recommendations that you have, or suggestions you would like to make?
5. Are there other things you would like to say before we finish?"

Data analysis

The recordings were transcribed verbatim shortly after the meetings. A qualitative data management software (NVivo 12, QSR International Ltd) was used to facilitate data analysis. The transcripts were analysed using qualitative content analysis, which involved the researchers reading through the transcripts noting text segments of conceptual interest to which they applied thematic labels, before grouping these under broader categories (Bertschy et al., 2015). The analysis focussed on participants' views relating to ICU nurses' competencies, based on their experience in the ICU.

The Milton Keynes and Edinburgh transcripts were analysed by two researchers, both experienced in qualitative research (CJ, PR). Analysis of the Athens transcript was initially undertaken by a researcher with Greek as a first language (KI); then, a translated transcript in English was shared with a bilingual researcher (AX, male) to check contextual relevance of the translation and of the thematic labels. Transcripts, coding categories, data extracts and themes were crosschecked by both researchers (AX, KI) throughout the coding process and discussions held until consensus was reached. The final set of themes was discussed among the researchers who analysed the focus groups (CJ, PR, KI, AX) and agreed. among them. Table 3 presents an example of first level coding and higher-level categories from the Greek focus groups. The COREQ checklist has been used to report the findings of the study.

Table 3.

First-Level Coding and Higher-Level Categories Example from Greek Focus Group

Excerpts from participants in Greek language (former ICU patient)	Translated quote to English verified by two researchers	First level code	Higher level category
Ούτε καν οι φίλοι επιτρέπεται να έρχονται και επομένως δεν είχε τη δυνατότητα να έχει μία πρόσβαση τουλάχιστον σε μένα η νοσηλεύτρια. Από εκεί και πέρα στη μία ώρα αυστηρά φεύγανε κλοτσηδόν οι συγγενείς και από εκεί και πέρα για τι να ενθαρρύνει για την ευρύτερη οικογενεια..μόνο όταν φεύγεις από την εντατική έχεις τη δυνατότητα.. τότε να ενθαρρύνουν την ευρύτερη οικογένειά να συμμετέχει κτλπ	P1: Not even friends were allowed to visit me; therefore, the nurse could not access me. From then on, strictly within an hour, the relatives were " kicked out" of the ICU, and then how would nurses encourage the extended family? Only when you leave the intensive care unit she/he [the nurse] may be able to encourage the extended family to participate, etc.	Family's participation is restricted by the short visitation time	Communication with family

RESULTS

The analysis resulted in three themes: (1) the importance of nurses being empowered to advocate for the patient, (2) the centrality of communication, and (3) the impact of significant variability in ICU practices. Next, these three themes are discussed and illustrated using representative quotes from patients and

relatives.

Importance of nurses being empowered to advocate for the patient

The feedback from across the three focus groups confirmed the inclusion of statements about empowerment of nurses, such as speaking out on behalf of patients and not deferring to the opinions of medical colleagues. In the experience of one relative who described himself as 'spending a substantial amount of time on intensive care', this deference was frustrating and impaired communication about the patient*:*

I had a striking memory as a relative who spent a substantial amount of time on intensive care, I really wanted the nurses to speak more. So if I said, well any question nearly always the response was we'll get the doctor to speak to you. I wanted to say to them [the ICU nurses] "no, this is up to you because you're with the patient 24/7, on this long shift" (Milton Keynes (MK)/Relative (R)1).

When my sister, who was estranged at the time, when she saw me she wanted more information the nurse said you need to see the doctor (MK/Patient (P)2).

The importance of nurses' role as patient advocate was also set in the context of ICU nurses having '*a better foundation of knowledge about the patients*' (MK/R2) than doctors, likely stemming from nurses' familiarity with patients' fluctuating physical, mental and social needs, and developed through sustained interaction and presence at the bedside (Xyrichis et al. 2017). This was also described as fundamental to the ICU nurse's advanced role:

It's about really being receptive to communicating clearly with relatives and not just saying automatically deferring to the doctor. And really that's the essence of the Advanced role that you have the confidence to be able to have your own opinion about somebody's care and also somebody's condition (MK/R1).

Examples of advocacy were also provided, for example:

I was abused by one of the night nurses in hospital … I still had a trachy and couldn't speak. It was dealt with, the head nurse came in and wrote everything down as I indicated. And that person was never allowed to be on the ward again …. So that nurse acted as my advocate, to protect me. I couldn't tell my children. So that advocacy role is really important (MK P3).

And empowered to represent the patient's interests as well. I could've done with senior

nurses in intensive care to have fought my corner when faced with a DNR, which was completely wrong. But the consultant was so convinced that it was the right course of action. Although the nurses were positive about representing me, they didn't feel empowered to actually challenge the decision with the consultant. And if they had been it would have made life easier, not so much for me but for my wife. They almost have, in some respects, a better foundation of knowledge about the patient than the doctors do, because they are with them all the time (MK P2).

The inclusion of leadership competencies was seen as a key part of the advanced ICU nurse's role:

I did notice who were the leaders and that was important to me (Edinburgh (E)/P2).

it is important for patients and relatives to know that there is somebody with leadership skills taking, for example, charge when there is an emergency (E/P1).

Thinking about the family meetings and we regularly had them. The meeting was always chaired by a consultant and quite often the consultant would ask the nurse, "have you got anything to add?'. And almost always they said "no". I was dismayed as they had so much to offer (MK/R2).

Centrality of communication

Relatives' need for up-to-date, daily information about their loved one's unexpected problems was raised in the Athens focus group. However, relatives also pointed out that ICU nurses should be cautious about the information conveyed to family members, given that patients' conditions can be unstable in ICU; thus, information changes.

Information on the patient's care plan should be carefully communicated to the family by the nurses, since their condition continuously changes (Athens (A)/P2).

With one of the family meetings, I had questions which I felt weren't answered, and I knew that they hadn't answered my questions and it left me feeling very confused. Even though I had asked the questions they had counteracted and said they know what they're doing, and I left feeling very confused. It was a treatment that I had found out about and researched, and I feel they should have explained their reasoning for not using it. They should have been able to hear someone else's opinion and not be instantly defensive. It was a rare illness. It's about being open to new things (MK/R2).

The impact of significant variability in ICU practices

There was notable variability in intradisciplinary roles and public perceptions of the nursing profession in ICU with the Athens focus group. Because of restricted family visiting policy, patients felt that encouraging their relative's participation in patient care was not possible.

Relatives are kicked out of the ICU strictly in an hour … so why would the nurse encourage the family … nurses can only encourage the family to participate when the patient goes to the ward (A/P1).

In addition, the perception of the Athens focus group was that the current professional training of ICU nurses does not prepare them to advocate for patients, as illustrated below:

The physician should have the role to communicate about the patient's end-of-life decisions with the family … this can't be a nurse's role .. they [nurses] are not accountable… nor do they have the knowledge compared to physicians (A/P1).

Traditional gender roles appear to somehow exist in Greek social structures, as the head relative of the family, according to the following statement, receives and conveys any information about the patient's progress.

Only the most senior nurse should talk on behalf of the family when this is necessary. In big families … there may be a patriarchal figure .. then the family might say…how come she [the nurse] will be talking on our behalf (A/P2)?

DISCUSSION

This is the first study to examine the views of patients and relatives about ICU nurses' advanced competencies with samples from North-Western and South-Eastern Europe.–The present study aimed to discuss the INACTIC nursing competencies identified by an expert panel of European ICU nurses with patients and relatives with experience in ICU and to understand which INACTIC competencies were important to them. Findings from the focus groups show the importance of ICU nurses' autonomy, communication and advocacy to patients and relatives, whilst the expert panel of ICU nurses in the INACTIC collaboration placed greater emphasis on leadership skills, a competency that was not articulated by the focus group participants.

Our finding on centrality of communication contrasts with the patient and family consultation undertaken as part of the Competency Based Training for Intensive Care Education (CoBaTrICE) study (The CoBaTrICE collaboration, 2007). Therein, the authors found that ICU patients and relatives gave priority to

medical knowledge and skills as desirable characteristics of ICU medical specialists, with women more likely to emphasise communication skills. Unlike the results of the current study, no contextual differences were observed in the CoBaTrICE study. This may be due to the study method (i.e., using a questionnaire rather than focus groups). But it may also reflect the way the training, public expectations and role of ICU nurses vary considerably across Europe (Endacott et al., 2015). The need for accurate and detailed information and support has been previously identified as very important amongst relatives of ICU patients (Al-Mutair et al., 2013a,b). Provision of clear information is important to service users irrespective of context given that face-to-face interviews with fifteen Greek relatives of hospitalised ICU patients revealed that relatives also wanted comprehensible and honest information from healthcare personnel (Koukouli et al., 2018).

In our study, the autonomy of nurses to advocate for the patient in relation to their medical colleagues was a key point of difference between Milton-Keynes, Edinburgh and the Athens focus group. Indeed, in a previously conducted cross-sectional survey in Greece (N=431) Greek ICU nurses reported only moderate autonomy in their clinical practice (Iliopoulou and While., 2010). This was also reflected in a study conducted in 65 European paediatric ICUs, across 19 countries, examining interprofessional team involvement in decision-making, nurse staffing and perceived nursing autonomy and influence over decisions. Here, the authors found greater nurse engagement in the Northern European countries compared to the Central and Southern countries (Tume et al., 2017). Lack of medical leadership that promotes family involvement and lack of skills amongst nurses were two of the barriers to implementing family-centred care identified in the World Federation of Societies of Intensive and Critical Care Medicine (WFSICCM) survey (Kleinpell et al., 2018). It is important, therefore, that improving relative partnership with healthcare staff is seen as a key component of the ICU nurse's advanced role.

Our study identified that differences in ICU interdisciplinary roles and policies between UK and Greece exist suggesting that little has changed in the public perception of nursing since the study of Greek ICU and Emergency care nurses in 2011 (Karanikola et al., 2011). There was a greater emphasis on the doctor's curing illness and less on those, like nurses, actually providing care. These perceived differences in the empowerment of nurses across different countries can also be seen in their ability to take a lead in research studies (Malloy et al., 2009). In the RACHEL diary study (Jones et al., 2010) there were three Southern European study centres in Italy and Portugal. In the Italian ICU taking part it was the doctors who led the study, despite diaries being seen as a nursing intervention. In the two Portuguese ICUs taking part in the study, the physicians

led the research team, although the nurses were involved. In the Northern European study centres, in the UK, Sweden, Denmark and Norway, the research team were either entirely nurse-led or nursing with medical support (Jones., 2010). This could not be attributed to the fact that nursing is a predominantly female occupation as the Italian and Portuguese doctors leading the study were all female (CJ principle investigator for this study).

Another difference in ICU policies identified in our study was family visitation. Family visiting policies vary considerably across countries as identified by a survey undertaken by the WFSICCM, with 345 respondents from 40 countries. Fully open visiting in adult ICUs was reported by 39.6% (n=136) (Kleinpell et al., 2018). Similar to the findings from the Athens focus group in our study, a survey of 143 ICU nurses from six public hospitals in Greece identified that nurses were resistant to family visiting; most (94.4%) did not want an open visitation policy in their unit, even though they perceived open visiting policies as supportive for patients and relatives (Athanasiou et al., 2014). Hence it is not surprising that this emerged as a difference between the UK and Greek focus groups. While family-centred care has been shown to have positive effects on patient and family outcomes, such as ICU length of stay and mental health outcomes (Goldfarb et al., 2017), it appears that deliberate strategies to promote family-centred care, such as implementing flexible visiting policies, are still necessary.

Our study adds to the existing literature by engaging patients and relatives to research. There has been a shift from recruiting patients simply as research participants to engaging them as full research partners (Fiest et al., 2020), for example in designing a weaning-off ventilation support trial (Burns et al., 2016) and developing a peer support model for ICU recovery (Haines et al., 2019). In the UK and Australia, this is embedded at the policy level (NHMRC, 2016; NIHR, 2019). This approach has been less developed across other countries in Europe. Given the aforementioned diversity in family engagement and in patient management across different countries, this is not surprising. However, the design and conduct of research does provide an opportunity to acknowledge the value of patient and their relatives' experiences in the ICU and so provide a voice to openness and transparency.

Limitations

The self-selection of participants, while broadly representative of our target population, suggests that the transferability of our findings may require empirical validation in more countries. The UK participants were all individuals who already attended ICUsteps peer support groups and as such may have felt they had to represent the views of their support group rather than their individual feelings.

One of the major limitations of the study was that it proved impossible to organise more than one focus group outside of the U.K. because of the lack of follow-up or support groups for ICU patients across Europe. The differences between the UK focus groups and the one undertaken in Athens may have been more or less pronounced if a focus group in another non-UK country could have been organised. These differences are an important finding of the current study, and a point to be addressed in future research with the involvement of more countries.

CONCLUSIONS

The perspectives of patients and relatives are largely aligned with the professional consensus of the expert panel, in particular, related to Advanced ICU nursing skills and nurses' personal attributes. Contextual differences in patients' and families' ICU experience highlight that some ICUs would need to make structural changes in their policies, leadership and training of their staff in order for the advanced critical care competencies to be embedded in practice. However, those changes must be tested before their implementation, as strategic tailoring to the local context is required.

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