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This issue includes a selection of papers specifically around about patient or family experiences of critical illness. This important topic can often be forgotten amongst the technical nature of the intensive care unit, but we, as critical care nurses, have an important role to play in 'humanising' this highly foreign environment for patients and their families. The papers all focus on a different aspect of this subject.

The guest editorial [1] by the British Association of Critical Care Nurses (BACCN) Chair, Nicki Credland and BACCN Conference Director, Karin Gerber, encourages us to value ourselves and articulate the work that we do as critical care nurses, as our worth has never before become more apparent to society than during the COVID-19 pandemic. They also inform us of the upcoming (now virtual, online) annual BAACN conference on 14-15 September 2020 [2] https://www.baccn.org/conference/ and encourage all members and non-members to participate in this conference, with the theme of 'Critical Care Nursing: the next decade'.

The first paper, a critical commentary, by Lumley et al [3] is hopefully the first of many papers with a focus on the COVID-19 pandemic. This highly relevant critical commentary has systematically described the changes required for critical care nursing for patients with Covid-19 and proposed that the use of the Systems Engineering Initiative for Patient Safety (SEIPS) human factors model may facilitate organisational evaluation and surge preparedness during a pandemic. This highly practical commentary offers us expert opinion and practical solutions for planning future critical care delivery in pandemic situations.

With around 35,000 adult cardiac surgery procedures performed per year in the United Kingdom (UK) and Ireland [4] understanding these patients experience of critical care is as important as any general ICU patient. Eder and colleagues [5] explored the experiences of 100 thoracic and cardiovascular surgical adult patients who spent at least one night in intensive care in Turkey, using a mixed methods approach. They used the validated intensive care experiences scale alongside interviews [6]. They found in this group of patients (undergoing major surgery) that many patients had a partially positive experience of the ICU, when they realised they had come out of surgery alive. This finding may be unique to this group of patients, with many being consented for surgery with a high risk of death or morbidity. Thus, despite many having negative experiences of pain (large thoracic incisions are painful), fear and inability and frustration to communicate whilst intubated, many were glad to see they had survived the surgery. Patients who bled and required reoperation, children and those not wanting to talk about their experiences were excluded, risking some bias, but this nevertheless sheds some light on these patients' unique experiences.

In our efforts to mitigate post-intensive care syndrome (PICS) we need to understand what matters to patients in intensive care. Connelly and colleagues [7] undertook a quality improvement program to explore what really mattered to patients (in critical care units) and that could improve their experience in a UK ICU. On each morning ward round patients were asked 'what matters to you today' and this was included in the daily goals list. 196 adult patients made 592 statements which were analysed qualitatively. They found four themes: medical outcomes and information, the critical care environment, personal care and family and caregivers were the most important considerations. Interestingly, many patients asked for simple things which could be easily provided and improve their experience of being in the

ICU. This could easily be incorporated into any ICU's daily practice and make a real difference to patients.

The next paper focusses on visits to the ICU by patients' family members and friends, their potential impact on patients' physiological parameters and nurses' views about visiting rules. In Akbari et al.'s clinical trial [8], patients in four medical ICUs in Iran were randomly allocated to an intervention group, in which frequent and longer visits were allowed, or a control group with much more restricted visiting hours. In the intervention group, there was a significant decrease, within normal limits, in systolic and diastolic blood pressures and heart rate 10 and 30 minutes after the visits, suggesting a potential therapeutic effect of the presence of familiar persons on critically ill patients' haemodynamic stability. However, the results should be interpreted with caution due to the difficulties in completely excluding the impact of other factors (apart from visitation policy) on the observed changes. The finding that less than half the nurses were in favour of flexible visiting hours reinforces the importance of accompanying increased visiting time with improved nurse-to-patient ratios because attending to relatives' information and psychological needs has an impact on the time available for direct patient care. Cultural differences should also be taken into consideration.

Although implantable cardioverter defibrillators (ICDs) have become a common treatment modality in several countries, relatively few studies have examined the experience of living with an ICD from the patients' perspective. This led Palese and her colleagues [9] to explore Italian patients' experiences before, during and after receiving an electrical shock by an ICD. Participants were recruited from an academic hospital in north-eastern Italy and interviews were conducted with the fifty patients who met the inclusion criteria. The richness of the study is enhanced by a thematic presentation of the range of antecedents, phenomena and consequences of ICD shocks, each of which is vividly supplemented by the patients' own choice of words to describe their experiences. Perhaps the most striking overall finding is that the experiences are based on two polarities which is congruent with the ambivalent "love-hate" relationship between the patients and their ICD, as reported in a similar recent study conducted in Singapore [10]. The study is potentially limited by convenience sampling, recall bias, gender imbalance and the variable length (and, therefore, depth) of the interviews. Nonetheless, its finding should be invaluable in sensitising nurses and other health professionals working with such patients to the physical and emotional impact of living with an ICD. The worrying finding that approximately half the participants did not know why the ICD had been implanted should motivate cardiology personnel to improve the quantity and quality of patient education before the implantation procedure and at follow up services.

The last two papers in this issue take us to Scandinavia and explore the experiences of the closest family members of critically ill patients, namely their partners, and collectively contribute to the growing body of literature on family-centred critical care nursing. Vester et al.'s [11] study focuses on the experience of being a couple during an ICU admission. They conducted dyadic interview with a purposive sample of couples, in each of which one member had been admitted to the 44-bed ICU of a university hospital in Denmark. Using a hermeneutic-phenomenological approach aimed at enhancing both comprehension and explanation of the participants' experience, three themes were identified: for *better and for worse*; *meaningful proximity*; and *being a couple*. The study contributes to the body of literature about critical illness as an intrusion into the life of a couple but also indicates that each spouse's perspectives on the illness and attitude towards care may vary. Consequently, nurses should care for the couple both as individuals and as a unit, a balance which requires more research and education.

In a similar vein, Nelderup and Samuelson's [12] study focusses on the experiences of partners of intensive care partners 6 to 10 months after their partner had been discharged from an ICU. This is important because most of the previous research in this area mainly focussed on partners' needs during or shortly after the ICU stay. Participants were recruited from among those receiving follow up services in Sweden and selected by purposive sampling in an effort to include partners of patients with different age, gender reason for admission and length of stay. Data were collected through in-depth interviews and analysed by indictive content-analysis. The findings make it abundantly clear that recovery from an ICU admission is prolonged, not just for patients themselves but also for their close family members. The study, therefore, underscores nurses' role in mitigating the sense of chaos brought about by critical illness and the ICU environment. By shedding light on the partners' experiences several months after a patient's discharge from the ICU, the findings provide guidance to nurses working in intensive care units and to health professionals providing follow up services.

The studies reported in this collection of papers adopted different approaches and were conducted in a range of clinical settings and geographical regions. Yet, they are all motivated by a passionate and meticulous attempt at learning more about the experience of critical illness for patients and/or their close relatives. Their findings should reinforce critical care nurses' efforts at making a positive difference in their clients' experience of acute or critical illness, and thus improving their perceptions about the quality of the care provided.

References

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