Intensive & Critical Care Nursing 50 (2019) 3–4

Contents lists available at ScienceDirect

Intensive & Critical Care Nursing

journal homepage: www.elsevier.com/iccn

Editorial

The future of family-centred care in intensive care

In true keeping with the concept of family-centred care where families are partners in healing, this Editorial is provided to you by a unique author team: a nurse and Chair of an international guidelines taskforce (JED) and a wife of sepsis survivor in Critical Care (SAS). It is our philosophy that patients and families have a unique perspective from which to provide reflections on clinical practice. As such patients and families deserve equal footing as co-authors on our papers when we learn directly, in their voice, from their experiences. Just as patients and families grace rounds with engagement and not mere presence, and professional societies routinely stage patients and families within panel discussions at conferences, it is time to move patient/family wisdom past the 'text box of Case 1' and into the mainstream of our educational dialogue.

In 2007, the Society of Critical Care Medicine (SCCM) released its first set of guidelines on family-centred care. (Davidson et al., 2007) Since publication of this widely cited paper, there has been a surge of interest in this area of practice resulting in a proliferation of research: and yet our understanding of family-centred care is still very much in its infancy. Ten years on in 2017, the SCCM published updated guidelines developed by an international taskforce. These guidelines are now endorsed by nine professional organisations including the European Society of Critical and Intensive Care Medicine and the British Association of Critical Care Nurses. (Davidson et al., 2017) Despite drawing on a much larger pool of research, only weak recommendations could be made due to the lack of large, interventional studies. In sum, family-centred care warrants further research.

With this in mind, let's begin the discussion of future research in family-centred care. In this Editorial we will discuss only three of the possible hundreds of understudied topics in family-centred care: pet presence, family engagement on rounds and the family instinct to protect the patient from harm (safeguarding).

Some consider pets a part of the family with the ability to heal through their calming presence and, as such, need consideration within the concept of family-centred care. One little known fact about developing the 2017 SCCM guidelines is that one of us (JED) was asked by colleagues to avoid the topic of pet visitation when embarking on the systematic review. It was thought, because the experimental literature was quite sparse and the topic was so controversial, that sceptics might be turned away from reading the guidelines if it were suggested that, in the absence of evidence of harm, dogs and cats should be permitted in the Intensive Care Unit (ICU). Being a tad rebellious, yet with professional caution, I conducted my own private review of the subject and saved it for future use. I learned that there are theoretical harms of zoonotic transmission by animals, but the last reported infection caused by a pet visiting the hospital was published in 1994 and was brought in on the hands of an employee, not a patient visitor. (Duncan, 2000) To the contrary, there is also evidence suggesting that people share their microbiomes with their pets. (Song et al., 2013) This begs the question of whether or not the pets of patients would actually be less likely to cause a negative immune response or infection than a pet therapy dog whom is a stranger to their immune system. I truly hope that when the next set of guidelines are produced, there is enough evidence to support a more open approach to the subject of pet visitation. To do this we need to know: Is the human immune system attenuated by exposure to pet microbiomes, making it less likely for humans to become infected? What is the effect of the presence of the patient's own pet versus a pet therapy animal on patient outcomes such as pain, anxiety and agitation? And as we focus as a profession on workplace wellness, what effect does pet presence have on us as clinicians? Finally, does the potential benefit of pet therapy to the patient and the care team outweigh the potential risks from zoonotic transmission?

Family engagement on rounds has been advocated for over 10 years with the theoretical premise that family input will improve patient safety by providing unique information, for example, regarding previously failed or deleterious drugs or treatments. However, the actual beneficial effect of the family on rounds has not yet been studied. A simple protocol recording and sorting the type of useful information provided by families during rounds is needed. How many adverse reactions are avoided or viable treatments started? How often does the family provide a more accurate interpretation of response to treatment because they know the patient's non-verbal cues and character?

The area for final consideration in this Editorial, and one that has not yet been studied in any form, is the concept of safeguarding. Safeguarding in family-centred care is a term used informally to describe a family member's instinct to protect the patient from harm, often by sitting vigil. We have all seen it; the family cannot pull themselves away from the bedside, whilst clinicians encourage them to 'go home to rest'. There is published anecdotal evidence that this forced separation may cause harm (Burr, 1998; Davidson et al., 2013). Are there factors that might predict this safeguarding need? What outcomes occur if the instinct to safeguard is not honoured? Several studies have demonstrated that messages of hope, caring and non-abandonment in family meetings (patient care conferences) to improve family outcomes (McDonagh et al., 2004; Selph et al., 2008; Stapleton et al., 2006). Anecdotal unpublished reports from staff who write in ICU diaries

https://doi.org/10.1016/j.iccn.2018.03.003

suggest it is theoretically possible that staff-written messages of hope, caring and non-abandonment in the diaries may decrease the time to resolution of this strong safeguarding instinct. One family stated [paraphrased] "*I knew I could go home and he would be cared for because when I came back I could read the note and there was evidence in the journal that someone was with him, and they cared.*" Are there interventions that would speed up the family's transition from fear, mistrust and the instinct to protect the patient from harm to faith in our abilities to provide care? Does the timing, quality or quantity of information provided to the family on a daily basis decrease time in the safeguarding instinct? Or is the desire to sit vigil instead related to duties imposed by religious or cultural norms? Do electronic interfaces such as use of Caring Bridge (https://www.caringbridge.org) or Facebook (https://facebook.com) help keep families informed so that they feel comfortable going home to rest? We know that sleep affects ability to problem solve. With this, do families that choose to remain in the ICU get better sleep than those who go home? And what affect does cumulative time in the hospital have on cognition and problem-solving capacity? These are just a few of the seemingly endless unanswered questions.

In conclusion, many aspects of family-centred care require closer scrutiny. We recommend research on different models of family-centred care considering more diverse outcomes such as quantifiable changes in the patient's treatment plan made as a result of family input, better patient and quality of life outcomes, and reductions in family, patient and caregiver stress disorders and hospital costs. Some possibilities worth future exploration have been described here including potential roles for pet therapy, diaries in the ICU, use of social media and smart phone apps. In developing and defining the family-centred care research agendas for the future we have one final suggestion. As recommended by the National Institute for Health Research (Hayes et al., 2012) inclusion of family members within research teams help prioritise and develop research protocols focused on items of importance for patients and families (Gill et al., 2016; Potestio et al. 2015). Working in partnership with family members will yield research of greater significance than research undertaken by those who have not walked a day in the shoes of the family in ICU.

Acknowledgements

With appreciation to the ICU patients and family members who teach us through their experiences.

References

Burr, G., 1998. Contextualizing critical care family needs through triangulation: an Australian study. Intensive Crit. Care Nurs. 14 (4), 161–169.

Davidson, J.E., Powers, K., Hedayat, K.M., Tieszen, M., Kon, A.A., Shepard, E., Armstrong, D., 2007. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. Crit. Care Med. 35 (2), 605–622.

Davidson, J.E., Harvey, M., Schuller, J., Black, G., 2013. Post-intensive care syndrome: what it is and how to help prevent it. Am. Nurse Today 8 (5), 32–37.

Davidson, J.E., Aslakson, R.A., Long, A.C., Puntillo, K.A., Kross, E.K., Hart, J., Curtis, J.R., 2017. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and adult ICU. Crit. Care Med. 45 (1), 103–128. https://doi.org/10.1097/ccm.0000000000002169.

Duncan, S.L., 2000. APIC state-of-the-art report: the implications of service animals in health care settings. Am. J. Infect. Control 28 (2), 170–180.

Gill, M., Bagshaw, S.M., McKenzie, E., Oxland, P., Oswell, D., Boulton, D., Stelfox, H.T., 2016. Patient and family member-led research in the intensive care unit: a novel approach to patient-centered research. PLoS ONE 11 (8), e0160947. https://doi.org/10.1371/journal.pone.0160947.

Hayes, H., Buckland, S., Tarpey, M., 2012. Briefing notes for researchers: public involvement in NHS, public health and social care research. INVOLVE Eastleigh, <http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf> (accessed 20.02.18).

McDonagh, J.R., Elliott, T.B., Engelberg, R.A., Treece, P.D., Shannon, S.E., Rubenfeld, G. D., Curtis, J.R., 2004. Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. Crit. Care Med. 32 (7), 1484–1488. doi:00003246-200407000-00005 [pii].

Potestio, M.L., Boyd, J.M., Bagshaw, S.M., Heyland, D., Oxland, P., Doig, C.J., Stelfox, H. T., 2015. Engaging the public to identify opportunities to improve critical care: a qualitative analysis of an open community forum. PLoS ONE 10 (11), e0143088. https://doi.org/10.1371/journal.pone.0143088.

Selph, R.B., Shiang, J., Engelberg, R., Curtis, J.R., White, D.B., 2008. Empathy and life support decisions in intensive care units. J. Gen. Intern. Med. 23 (9), 1311–1317. https://doi.org/10.1007/s11606-008-0643-8.

Song, S.J., Lauber, C., Costello, E.K., Lozupone, C.A., Humphrey, G., Berg-Lyons, D., Knight, R., 2013. Cohabiting family members share microbiota with one another and with their dogs. Elife 2, e00458. https://doi.org/10.7554/eLife. 00458.

Stapleton, R.D., Engelberg, R.A., Wenrich, M.D., Goss, C.H., Curtis, J.R., 2006. Clinician statements and family satisfaction with family conferences in the intensive care unit. Crit. Care Med. 34 (6), 1679–1685. https://doi.org/10.1097/01.CCM.0000218409.58256.AA.

Judy E. Davidson
UC San Diego Health, 200W. Arbor Drive, San Diego, CA 92103, United States
E-mail address: jdavidson@ucsd.edu

Steffanie A. Strathdee
UC San Diego Department of Medicine, 9500 Gilman Drive, Mailstop 0507, La Jolla 92093, United States