

**Perspectives of Non-Speaking ICU Patients and their Families
on Goals-of-Care and End-of-Life Discussions**

References

- Andreassen, P., Neergaard, M. A., Brogaard, T., Skorstengaard, M. H., & Jensen, A. B. (2017). The diverse impact of advance care planning: a long-term follow-up study on patients' and relatives' experiences. *British Medical Journal Supportive & Palliative Care*, 7(3), 335-340.
- Balandin, S., Hemsley, B., Sigafoos, J. & Green, V. (2007). Communicating with nurses: the experiences of ten adults with cerebral palsy and complex communication needs. *Applied Nursing Research*, 20, 56-62.
- Bartlett, G., Blais, T., Tamblyn, R., Clermont, R. & MacGibbon, B. (2008). Impact of patient communication problems on the risk of preventable adverse events in the acute care settings. *Canadian Medical Association Journal*, 178, 1555-62.
- Berlin, A. (2017). Goals of Care and End of Life in the ICU. *Surgical Clinics*, 97(6), 1275-90
- Bomhof-Roordink, H., Gärtner, F. R., Stiggelbout, A. M., & Pieterse, A. H. (2019). Key components of shared decision-making models: a systematic review. *British Medical Journal Open*, 9(12).
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Canadian Institute for Health Information. *Care in Canadian ICUs*. Ottawa, ON: CIHI; 2016

- Carling-Rowland, A., Black, S., McDonald, L., & Kagan, A. (2014). Increasing access to fair capacity evaluation for discharge decision-making for people with aphasia: a randomised controlled trial. *Aphasiology*, *28*(6), 750-765.
- Carruthers, H., Astin, F., & Munro, W. (2017). Which alternative communication methods are effective for voiceless patients in Intensive Care Units? A systematic review. *Intensive and Critical Care Nursing*, *42*, 88-96.
- Chidwick, P., Sibbald, R., & Hawryluck, L. (2013). Best interests at end of life: an updated review of decisions made by the Consent and Capacity Board of Ontario. *Journal of Critical Care*, *28*(1), 22-27.
- Cheng, C., Schommer, L., Tarver, M., LaValley, M., Lemieux, N., Mery, M., & Koul, R. (2024). Exploring Communication Needs and Challenges in the Intensive Care Unit: A Survey Study from Providers' and Patients' Perspectives. *American Journal of Speech-Language Pathology*, *33*(5), 2311-2326.
- Costello, J. M., Patak, L., & Pritchard, J. (2010). Communication vulnerable patients in the pediatric ICU: Enhancing care through augmentative and alternative communication. *Journal of pediatric rehabilitation medicine*, *3*(4), 289-301.
- Dedoose web application for managing, analyzing, and presenting qualitative and mixed method research data. (2015). Los Angeles, CA: Sociocultural Research Consultants, LLC.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., ... & Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of General Internal Medicine*, *27*, 1361-1367.

- Etchels, M. C., MacAulay, F., Judson, A., Ashraf, S., Ricketts, I. W., Waller, A., ... & Shearer, A. J. (2003). ICU-Talk: the development of a computerised communication aid for patients in ICU. *Care of the Critically Ill*, 19(1), 4-9.
- Gibbert, M., Ruigrok, W., & Wicki, B. (2008). What passes as a rigorous case study? *Strategic Management Journal*, 29(13), 1465-1474.
- Grignoli, N., Di Bernardo, V., & Malacrida, R. (2018). New perspectives on substituted relational autonomy for shared decision-making in critical care. *Critical Care*, 22(1), 260.
- Happ, M. B., Swigart, V. A., Tate, J. A., Hoffman, L. A., & Arnold, R. M. (2007). Patient involvement in health-related decisions during prolonged critical illness. *Research in Nursing & Health*, 30(4), 361-372.
- Happ, M. B., Garrett, K. L., Tate, J. A., DiVirgilio, D., Houze, M. P., Demirci, J. R., ... & Sereika, S. M. (2014). Effect of a multi-level intervention on nurse–patient communication in the intensive care unit: Results of the SPEACS trial. *Heart & Lung: The Journal of Acute and Critical Care*, 43(2), 89-98.
- Healthcare Consent Act, S.O. 1996, c. 2, Sched. A.
- Inouye, S. K., van Dyck, C. H., Alessi, C. A., Balkin, S., Siegal, A. P., Horwitz, R. I. (1990). Clarifying confusion: the confusion assessment method. A new method for detection of delirium. *Annals of Internal Medicine*. 1990;113(12): 941–948.
- Karlsen, M. M. W., Ølnes, M. A., & Heyn, L. G. (2019). Communication with patients in intensive care units: a scoping review. *Nursing in critical care*, 24(3), 115-131.
- Karlsson, V., Bergbom, I., & Forsberg, A. (2012). The lived experiences of adult intensive care patients who were conscious during mechanical ventilation: a

phenomenological-hermeneutic study. *Intensive and Critical Care Nursing*, 28(1), 6-15.

Kettunen, T., Poskiparta, M., & Karhila, P. (2003). Speech practices that facilitate patient participation in health counselling - A way to empowerment? *Health Education Journal*, 62(4), 326-340. <https://doi.org/10.1177/001789690306200405>

Khalaila, R., Zbidat, W., Anwar, K., Bayya, A., Linton, D. M., & Sviri, S. (2011). Communication difficulties and psychoemotional distress in patients receiving mechanical ventilation. *American Journal of Critical Care*, 20(6), 470-479.

Kozalinski, R. S., Tappen, R. M., & Viggiano, D. (2015). Evaluation of Speak for Myself with patients who are voiceless. *Rehabilitation Nursing Journal*, 40(4), 235-242.

LaValley, M., Chavers-Edgar, T., Wu, M., Schlosser, R., & Koul, R. (2024). Augmentative and Alternative Communication Interventions in Critical and Acute Care with Mechanically Ventilated and Tracheostomy Patients: A Scoping Review. *American Journal of Speech-Language Pathology*, 33(5), 2667-2686.

Laerkner, E., Egerod, I., & Hansen, H. P. (2015). Nurses' experiences of caring for critically ill, non-sedated, mechanically ventilated patients in the intensive care unit: A qualitative study. *Intensive and Critical Care Nursing*, 31(4), 196-204.

Light, J., McNaughton, D., Beukelman, D., Fager, S. K., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019). Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication*, 35(1), 1-12.

- Lindberg, C., Sivberg, B., Willman, A., & Fagerström, C. (2015). A trajectory towards partnership in care—patient experiences of autonomy in intensive care: a qualitative study. *Intensive and Critical Care Nursing*, 31(5), 294-302.
- Mobasheri, M. H., King, D., Judge, S., Arshad, F., Larsen, M., Safarfashandi, Z., ... & Darzi, A. (2016). Communication aid requirements of intensive care unit patients with transient speech loss. *Augmentative and Alternative Communication*, 32(4), 261-271.
- Nabozny, M. J., Barnato, A. E., Rathouz, P. J., Havlena, J. A., Kind, A. J., Ehlenbach, W. J., ... & Schwarze, M. L. (2016). Trajectories and prognosis of older patients who have prolonged mechanical ventilation after high-risk surgery. *Critical care medicine*, 44(6), 1091-1097.
- Premack, D., & Woodruff, G. (1978). Does the chimpanzee have a theory of mind? *Behavioral and Brain Sciences*, 1(4), 515-526
- Richards, K. A. R., & Hemphill, M. A. (2018). A practical guide to collaborative qualitative data analysis. *Journal of Teaching in Physical Education*, 37(2), 225-231. [Statistics Canada. Table 13-10-0715-01 Deaths, by place of death \(hospital or non-hospital\)](#)
- Rodriguez, C. S., Spring, H. J., & Rowe, M. (2015). Nurses' experiences of communicating with hospitalized, suddenly speechless patients. *Qualitative health research*, 25(2), 168-178.
- Rodriguez, C. S., Rowe, M., Thomas, L., Shuster, J., Koepfel, B., & Cairns, P. (2016). Enhancing the communication of suddenly speechless critical care patients. *American Journal of Critical Care*, 25(3), e40-e47.

- Rose, L., Sutt, A. L., Amaral, A. C., Fergusson, D. A., Smith, O. M., & Dale, C. M. (2021). Interventions to enable communication for adult patients requiring an artificial airway with or without mechanical ventilator support. *Cochrane Database of Systematic Reviews*, (10).
- McLeod, C., & Sherwin, S. (2000). Relational autonomy, self-trust, and health care for patients who are oppressed. IN *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*, ed. Catriona Mackenzie and Natalie Stoljar, 259–79. Oxford, UK: Oxford University Press.
- Slatore, C. G., Hansen, L., Ganzini, L., Press, N., Osborne, M. L., Chesnutt, M. S., & Mularski, R. A. (2012). Communication by nurses in the intensive care unit: qualitative analysis of domains of patient-centered care. *American Journal of Critical Care*, 21(6), 410-418.
- Stake, R. (1995). *Case study research*. thousand oaks, CA: Sage.
- Statistics Canada. [Table 13-10-0715-01 Deaths, by place of death \(hospital or non-hospital\)](#)
- DOI:** <https://doi.org/10.25318/1310071501-eng>
- Szymkowicz, E., Bodet-Contentin, L., Marechal, Y., & Ehrmann, S. (2024). Comparison of communication interfaces for mechanically ventilated patients in intensive care. *Intensive and Critical Care Nursing*, 80, 103562.
<https://doi.org/10.1016/j.iccn.2023.103562>
- Tembo, A. C., Higgins, I., & Parker, V. (2015). The experience of communication difficulties in critically ill patients in and beyond intensive care: Findings from a

larger phenomenological study. *Intensive and Critical Care Nursing*, 31(3), 171-178.

Ten Hoorn, S., Elbers, P. W., Girbes, A. R., & Tuinman, P. R. (2016). Communicating with conscious and mechanically ventilated critically ill patients: a systematic review. *Critical Care*, 20, 1-14.

Thirsk, L. M., Panchuk, J. T., Stahlke, S., & Hagtvedt, R. (2022). Cognitive and implicit biases in nurses' judgment and decision-making: a scoping review. *International Journal of Nursing Studies*, 133, 104284.

Tolotti, A., Cadorin, L., Bonetti, L., Valcarenghi, D., & Pagnucci, N. (2023). Communication experiences of tracheostomy patients with nurses in the ICU: A scoping review. *Journal of Clinical Nursing*, 32(11-12), 2361-2370.

You, J. J., Fowler, R. A., & Heyland, D. K. (2014)a. Just ask: discussing goals of care with patients in hospital with serious illness. *Canadian Medical Association Journal*, 186(6), 425-432.

You, J. J., Dodek, P., Lamontagne, F., Downar, J., Sinuff, T., Jiang, X., ... & Heyland, D. K. (2014)b. What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families. *Canadian Medical Association Journal*, 186(18), E679-E687.

You, J. J., Downar, J., Fowler, R. A., Lamontagne, F., Ma, I. W., Jayaraman, D., ... & Neary, J. (2015). Barriers to goals of care discussions with seriously ill hospitalized patients and their families: a multicenter survey of clinicians. *Journal of the American Medical Association Internal Medicine*, 175(4), 549-556

Wunsch, H., Wagner, J., Herlim, M., Chong, D. H., Kramer, A. A., & Halpern, S. D.

(2013). ICU occupancy and mechanical ventilator use in the United States. *Critical Care Medicine*, 41(12), 2712-2719.

Zaga, C. J., Berney, S., & Vogel, A. P. (2019). The Feasibility, Utility, and Safety of

Communication Interventions With Mechanically Ventilated Intensive Care Unit Patients: A Systematic Review. *American Journal of Speech-Language*

Pathology, 28(3), 1335-1355. https://doi.org/doi:10.1044/2019_AJSLP-19-0001

Zaga, C. J., Freeman-Sanderson, A., Happ, M. B., Hoit, J. D., McGrath, B. A., Pandian,

V., ... & Vogel, A. P. (2023). Defining effective communication for critically ill patients with an artificial airway: An international multi-professional

consensus. *Intensive and Critical Care Nursing*, 76, 103393.