

## Appendix 1 Summary of findings

| Author, Year                         | Lead author profession | Country | Publication                      | Aim   | Population & Setting                                | Methods                  | Context                       | Key findings related to voice of nurse  |
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| <b>Baird <i>et al.</i> (2015)</b>    | Nurse                  | US      | Journal of Pediatric Nursing     | To explore the impact of hospital and unit-based rules upon patient and family-centred care in PICU | PICU Nurses (n=12) & Parents<br><br>Single PICU     | Interviews & observation | Families and patients in PICU | -Nurses described role as rule enforcer<br>-Not always consistent in enforcing rules<br>-Parents who deviate from expected behaviour labelled as 'difficult'  |
| <b>Baird <i>et al.</i> (2016)</b>    | Nurse                  | US      | Nursing Research                 | To explore nurses' views on continuity of care  | PICU Nurses (n=12) & Parents<br><br>Single PICU     | Interviews & observation | Families and patients in PICU | -Continuity of care valued by nurses for importance to families, allows nurses to get to know families<br>-Can impact skill maintenance as a result nurses have desire to care for a wide variety of patients<br>-Faces practical challenges including staffing |
| <b>Birchley <i>et al.</i> (2017)</b> | Nurse                  | UK      | Archives of Disease in Childhood | To explore participants' experiences of decision-making in PICU related to child's 'best interests. | PICU Nurses (n=8), parents & MDT<br><br>Single PICU | Interviews               | EoL in PICU                   | -Nurses introduce snippets of information to families to help parents<br>-Clinicians 'reframe' information to increase parental acceptance<br>-Shared decision-making described as important but no agreement for what it means                                 |

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| <b>Bloomer <i>et al.</i> (2015)</b> | Nurse | Australia | Australian Critical Care            | To explore how NICU/PICU nurses care for families before and after death  | NICU and PICU nurses (n=13)<br><br>Multiple PICU/NICU | Interviews & focus groups | EoL in PICU                        | -Nurses role to prepare families for death<br>-They feel that they know families best and use this rapport to support families<br>-Death part of job,<br>-Colleagues identified as a source of support to cope with death   |
| <b>Bloomer <i>et al.</i> (2016)</b> | Nurse | Australia | Intensive & Critical Care Nursing   | To explore nurses' experiences of caring for children at end of life  | NICU and PICU nurses (n=13)<br><br>Multiple PICU/NICU | Interviews & focus groups | EoL in PICU                        | -Role change to focus on families as death approaches<br>-Create opportunities to let family be with their child and create memories  |
| <b>Bower <i>et al.</i> (2018)</b>   | Nurse | UK        | Intensive and Critical Care Nursing | To explore nurses' views on interruption during medication administration                                       | PICU nurses (n=10)<br><br>Single PICU                 | Interviews & observation  | Healthcare delivery                | -Nurses felt a need to respond to interruptions<br>-Multi-tasking while doing meds including observing the patient<br>-Increased focus when medication was unfamiliar   |
| <b>Buckley <i>et al.</i> (2022)</b> | Nurse | Canada    | Frontiers in Pediatrics             | To explore paediatric nurses' perspectives on their work environment, work attitudes, and experience of burnout | NICU & PICU Nurses (n=9)<br><br>PICU/NICU             | Interviews                | Nurse as a healthcare professional | -Burnout is complex, difficult to self-identify but regularly occurs in nurses.<br>-Burnout also impacts ability to find meaning in work.<br>-Variety of work, acuity of care and team help reduce burnout<br>-Felt that their role differs to other nurses around hospital therefore need different support. |
| <b>Burton <i>et</i></b>             | Nurse | Ca        | Dimension                           | To better understand  | NICU & PICU   | Focus                     | Nurse as                           | -Nurses concerned with quality  |

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| <b>al. (2020)</b>                         |       | na<br>da          | s of Critical<br>Care<br>Nursing      | PICU & NICU nurses<br>understanding and<br>experience of moral<br>distress                  | Nurses<br>(n=57)<br><br>Multiple<br>PICU/NICU                 | groups          | a<br>healthcar<br>e<br>profession<br>al | of life of patients and families<br>-Concerns that families don't<br>have adequate information due<br>to communication issues<br>-Nurses input not always<br>valued can lead to moral<br>distress<br>-More moral distress when<br>nurses do not agree with care<br>plans<br>-Some nurses had to leave due<br>to clinical care  |
| <b>Butler <i>et al.</i><br/>(2017)</b>    | Nurse | Au<br>stra<br>lia | Nursing in<br>Critical<br>Care        | To explore nurses'<br>perceptions of working<br>with families in the<br>PICU                | PICU nurses<br>(n=5)<br><br>Single PICU                       | Interview<br>s  | Families<br>and<br>patients in<br>PICU  | -Role as gatekeeper, not<br>necessarily negative as it<br>supports family's involvement<br>in care provision<br>-Difference caring for chronic<br>vs acute patients<br>-Controlled delivery of<br>information based on perceived<br>ability of families to cope<br>-Act as channel between<br>medical and families for<br>communication<br>-Continuity of care important<br>but variety valued more by<br>nurses |
| <b>Carnevale<br/><i>et al.</i> (2011)</b> | Nurse | Ital<br>y         | Journal of<br>Child<br>Health<br>Care | To understand<br>decision-making<br>around life sustaining<br>treatment in PICU in<br>Italy | PICU Nurses<br>(n=26),<br>parents &<br>MDT<br><br>Single PICU | Focus<br>groups | EoL in<br>PICU                          | -Nurses felt excluded from<br>treatment decision-making<br>-Nurses described the<br>important contributions that<br>they could make, given their<br>relationships with parents.<br>-Decisions and care provision<br>contribute to moral distress   |

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| <b>Carnevale et al. (2012)</b> | Nurse   | France & Canada | Journal of Child Health Care      | To understand decision-making around life sustaining treatment in PICU in France and Canada | PICU Nurses (n= 24) & Medical team<br><br>Multiple PICUs | Focus groups | EoL in PICU                   | -Nurses have in-between role when communicating<br>-Frequently absent from meetings and commonly silent even when present<br>-Often raise life-limiting therapy before medical team   |
| <b>Coats et al. (2018)</b>     | Nurse   | US              | American Journal of Critical Care | To explore nurses' perspectives on providing FCC in PICU                                    | NICU & PICU Nurses (n=10)<br><br>PICU/NICU               | Interviews   | Families and patients in PICU | -Family presence allows relationship building and nurses give parents jobs to be involved in care<br>-Challenging when parents distract from care provision<br>-Can be stressful having families present<br>-Single rooms better for families but can be isolating for nurses |
| <b>Craske et al. (2017)</b>    | Nurse   | UK              | Journal of Advanced Nursing       | To explore nurses' decision-making around sedation withdrawal                               | PICU Nurses (n=12)<br><br>Single PICU                    | Interviews   | Healthcare delivery           | -Caring for children on consecutive days enhances assessment<br>-Use parents to support assessment to help identify normal behaviour for that child<br>-Sedation weaning score does not support complex thinking involved in decision-making related to weaning               |
| <b>de Weerd et al. (2015)</b>  | Medical | Netherlands     | European Journal of Pediatrics    | To explore suffering in children while in PICU  | PICU nurses (n=29), parents & MDT<br><br>Single PICU     | Interviews   | Healthcare delivery           | -Nurses were focused on the signs that caused discomfort and on the treatment of this discomfort<br>-Focused on short-term perspective on suffering   |

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| <b>Deja <i>et al.</i> (2021)</b>           | Researcher | UK     | Pilot and Feasibility Studies     | To explore parent and practitioner views on the acceptability of the proposed GASTRIC trial                                  | PICU nurses (n=31), parents & MDT<br><br>Single PICU | Interviews & focus groups | Healthcare delivery                | -Nurses concerned over potential change in practice even though limited evidence to support it<br>-Focus in PICU on doing things<br>-Different views from some junior nurses related to trial acceptability |
| <b>Denis-Larocque <i>et al.</i> (2017)</b> | Nurse      | Canada | Intensive & Critical Care Nursing | To explore nurses' perceptions of caring for parents of children with chronic medical complexity in the PICU                 | PICU nurses (n=10)<br><br>Single PICU                | Interviews                | Families and patients in PICU      | -Challenges due to parent as expert<br>-Need to negotiate care with parents<br>-Takes time to establish relationships   |
| <b>Dopson &amp; Long-Sutehall. (2019)</b>  | Nurse      | UK     | Intensive & Critical Care Nursing | To explore PICU nurses' knowledge, attitudes, and feelings when donation after circulatory death is an option at end of life | PICU Nurses (n=8)<br><br>Single PICU                 | Interviews & focus groups | EoL in PICU                        | -Limited education provided on donation<br>-Nurses may be best placed to have these conversations as they know the patients best but reluctant to do so   |
| <b>Felipin <i>et al.</i> (2018)</b>        | Nurse      | Brazil | Ciencia, Cuidado e Saude          | To explore the meaning of family Centered Care   | PICU and NICU nurses (n=19)<br><br>PICU/NICU         | Interviews                | Families and patients in PICU      | -Family extension of patient, aim to involve them in patient care<br>-Believe parents help children recover<br>-Parents gradually learn to provide care to their child in PICU                              |
| <b>Foglia <i>et al.</i> (2010)</b>         | Nurse      | US     | Critical Care Nursing Quarterly   | To explore factors that influence PICU nurses to leave their jobs  | PICU Nurses (n=10)<br><br>Single PICU                | Interviews                | Nurse as a healthcare professional | -Nurses describe the challenges of caring for sick children as a positive<br>-Insufficient resources and support are stressors<br>-Unrelieved stress as major reason leave job                              |

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| <b>Frechette et al. (2020a)</b>  | Nurse    | Canada | Nursing in Critical Care      | To examine PICU nurses' lived experience of caring for families following a major hospital transformation project. | PICU Nurses (n=15)<br>Single PICU   | Interviews & observation | Families and patients in PICU      | -Gatekeeping occurs when nurse enforce rules and dictate parental role in care<br>-Value an environment that offers personalised care<br>-Often focused on the child rather than the family  |
| <b>Frechette et al. (2020b)</b>  | Nurse    | Canada | Journal of Nursing Management | To explore nurses' professional identity following a redesign  | PICU Nurses (n=15)<br>Single PICU   | Interviews & observation | Nurse as a healthcare professional | -Reluctance to care for chronic long-term patients due to moral distress and pull from acute patients<br>-Can be challenging to adjust to different care needs for chronic patients eg. Less monitoring<br>-Can result in increased patient load when less acute which is challenging in single rooms  |
| <b>Gagnon &amp; Kunyk (2022)</b> | Nurse    | Canada | Nursing Inquiry               | To explore the moral distress experiences of PICU nurses caring for child patients who are dying                   | PICU Nurses (n=7)<br>Multiple PICUs | Interviews               | EoL in PICU                        | -Desire to give children dignified death that was peaceful<br>-Burden of knowledge as an insider but not able to share with families can cause moral distress<br>-Limited ability to be heard in decision-making<br>-Use of language to communicate nurses' perspective<br>-Nurse can experience moral distress when dignity not prioritised |
| <b>Geoghegan</b>                 | Research | UK     | Pediatric                     | To explore the   | NICU & PICU                         | Interview                | Families                           | -Significant impact of caring for  |

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| <b>et al. (2016)</b>                            | cher    |          | Critical Care Medicine           | challenges of caring for long-stay patients in the PICU  | Nurses (n=7) & MDT<br>Single PICU               | s            | and patients in PICU          | long-stay patients (LSP)- moral distress and low morale<br>-Desire for variety of patients, particularly acute patients<br>-Patients with no long-term plan most challenging                       |
| <b>Gonzalez-Gil et al. (2021)</b>               | Nurse   | Spain    | Enfermeria Intensiva             | To explore nurses' experience related to promoting the visits of siblings to PICU                        | PICU nurses (n=12)<br>Single PICU               | Interviews   | Families and patients in PICU | -Emerging demand for sibling visits but no policy<br>-Decisions not documented making consistency difficult<br>-Overall nurses support visits but need to prepare environment to minimise distress |
| <b>Greenway et al. (2019)</b>                   | Medical | US       | Pediatric critical care medicine | To explore barriers to communication in PICU   | PICU nurses (n=3), parents & MDT<br>Single PICU | Interviews   | Families and patients in PICU | -Breakdown in communication when deviation from plan<br>-Difference in findings from families, limited presentation of voice of nurse.   |
| <b>Henao-Castano &amp; Quinonez-Mora (2019)</b> | Nurse   | Colombia | Enferm Intensiva                 | To explore nurses' coping with death in PICU   | PICU nurses (n=10)<br>Single PICU               | Interviews   | EoL in PICU                   | -Value of good communication<br>-Focus on care provision at end of life and meaning from work  |
| <b>Ji et al. (2022)</b>                         | Nurse   | China    | Journal of Nursing Management.   | To explore ward and PICU nurses experiences of transferring patients out of PICU                         | Ward and PICU nurses (n= 14)<br>Single PICU     | Focus groups | Healthcare delivery           | -Different priorities between ward and PICU nurses<br>-Request for written handover to improve communication   |
| <b>Kahveci et al. (2014)</b>                    | Medical | Turkey   | Indian journal of pediatrics     | To understand how decisions are made in PICU settings where critically ill children require life-support | PICU nurses (n=9), parents & MDT                | Interviews   | EoL in PICU                   | - Should be physician's responsibility to make the decisions in medically critical situations.<br>- Nurses seemed to have more   |

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|                               |              |          |                                     | decision   | Single PICU   |                                      |                                    | understanding of the parents' feelings, compared to the doctors.<br>-Decision-making gets easier with more experience in PICU   |
| <b>LaFond et al. (2015)</b>   | Nurse        | US       | Journal of Pediatric Nursing        | To explore factors nurses, consider when assessing pain and selecting interventions in PICU  | PICU nurses (n=40)<br><br>Single PICU               | Interviews & vignette questionnaires | Healthcare delivery                | -PICU nurses used their own assessment over patient reported pain scores  |
| <b>LaFond et al. (2016)</b>   | Nurse        | US       | Journal of Pediatric Nursing        | To describe PICU nurses' beliefs regarding the assessment and management of children's pain. | PICU nurses (n=40)<br><br>Single PICU               | Interviews & vignette questionnaire  | Healthcare delivery                | -Nurses use behaviour to describe pain over pain scores<br>-Each patient unique making self-report difficult to rely on<br>-Use experience to guide assessment  |
| <b>Lima et al. (2018)</b>     | Psychologist | Portugal | Nursing in critical care            | To describe PICU nurses experiences with the sudden death of children/adolescents            | NICU & PICU (n=36) Nurses<br><br>Multiple PICU/NICU | Interviews & questionnaire           | EoL in PICU                        | -Sudden death of patients resulted in significant impact on nurses<br>-Experience helped with coping<br>-Limited training and local support for this situation  |
| <b>Mahon (2014)</b>           | Nurse        | Canada   | Intensive and Critical Care Nursing | To explore PICU nurses job satisfaction through an ethnographic view of PICU                 | PICU Nurses (n=31)<br><br>Single PICU               | Interviews & observation             | Nurse as a healthcare professional | -Change in way nurses spoke and communicate with experience<br>-Value on experience and education<br>-Lack of respect and power imbalance contributes to staff leaving<br>-Value in provision of 'good death' doesn't contribute to intent to leave |
| <b>Mattsson et al. (2011)</b> | Nurse        | Sweden   | Journal of Child                    | To explore nurses' clinical experiences of   | PICU Nurses (n=17)                                  | Interviews                           | Healthcare delivery                | -Assessment on patient presentation   |



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|                               |       | en       | Health Care   | pain in non-verbal children in the PICU   | Single PICU   |                           |                     | -Use of experience to measure pain<br>-Need to know patient baseline  |
| <b>Mattsson et al. (2022)</b> | Nurse | Sweden   | SAGE Open Nursing                                     | To explore nurses' challenges caring for children with substance withdrawal in the PICU                     | PICU nurses (n=5)<br><br>Single PICU                          | Interviews                | Healthcare delivery | -Focus on weaning to child's need not to desire to discharge from PICU<br>-Need for correct language to communicate assessment based on experience  |
| <b>Medeiros et al. (2022)</b> | Nurse | Brazil   | Revista Brasileira de Enfermagem                      | To explore staff perceptions of their relationship with families of children during palliative care in PICU | NICU & PICU nurses and nurse technicians* (n=17)<br>PICU/NICU | Interviews                | EoL in PICU         | -Staff impacted by family acceptance of death<br>-Influenced by communication of medical prognosis and false hope<br>-Focus on care needs of child including keeping them pain free and family needs  |
| <b>Mesukko et al. (2020)</b>  | Nurse | Thailand | Pacific Rim International Journal of Nursing Research | To explore perspective of palliative care in PICU   | PICU nurses (n=41) & medical team<br><br>Multiple PICU/NICU   | Interviews & focus groups | EoL in PICU         | -Communication essential for good palliative care<br>-Nurses should be at all planning meetings<br>-Need for continuity of care at EoL<br>-Nurses led symptom management related to EoL   |
| <b>Meyer (2014)</b>           | Nurse | US       | Journal of Pediatric Nursing                          | To explore nurses' experiences caring for dying children  | PICU Nurses (n=10)<br><br>Single PICU                         | Interviews                | EoL in PICU         | -Difference in caring for children who are expected to die versus those who die unexpectedly in the same shift<br>-When nurses realise approach of death, anxiety occurs until family updated<br>-Step back emotionally from situation<br>-Nurses provide care physically |

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|   |         |        |                                  |  |  |                           |             | and medically and focus on creating order in the chaos   |
| <b>Meyer <i>et al.</i> (2012)</b>               | Nurse   | US     | Pediatric Critical Care Medicine | To explore practitioners' response to parents asking, 'what would you do if this is your child?' during simulation in PICU | PICU nurses (n=13) & MDT<br><br>Single PICU          | Simulation & interviews   | EoL in PICU | -Focus on providing clinical information<br>-Varied responses from practitioners including sharing personal information<br>-Nurses focus on offering support   |
| <b>Michelson <i>et al.</i> (2011)</b>           | Medical | US     | Pediatric Critical Care Medicine | To explore the processes used in EoL decision-making and the roles in family conferences (FC)                              | PICU nurses (n=23), parents & MDT<br><br>Single PICU | Interviews & focus groups | EoL in PICU | -FC used to coordinate care and for communication<br>-Nurses act as advocates<br>-Nurses often asked questions after meeting even when not there<br>-Nurses often absent due to competing demands                                |
| <b>Michelson and Patel <i>et al.</i> (2013)</b> | Medical | US     | Pediatric Critical Care Medicine | To explore roles at end-of-life care   | PICU nurses (n=23), parents & MDT<br><br>Single PICU | Interviews & focus groups | EoL in PICU | -Nurses often act as family supporter and advocate<br>-Information mainly given by medical team<br>-Nurses often play role of secondary decision maker by censoring information given to families                                |
| <b>Mitchell &amp; Dale (2015)</b>               | Medical | UK     | Palliative Medicine              | To explore views regarding advance care planning (ACP) in pall care in PICU  | PICU nurses (n=6) & medical team<br><br>Single PICU  | Interviews                | EoL in PICU | -Failure to recognise approach of death stops ACP in practice<br>-Nurses often recognise approach of EoL first<br>-Considered good idea but needs MDT involvement<br>-Moral distress when not acting in best interest of patient |
| <b>Nilson <i>et al.</i> (2022)</b>              | Nurse   | Brazil | Inquiry                          | To explore nurses' experience of the   | PICU Nurses (n=25)                                   | Interviews                | EoL in PICU | -Research allowed nurses an opportunity to discuss this  |

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|                                     |       |           |   | decision-making process related to therapeutic support limitation in PICU | Multiple PICUs   |                          |                               | issue where they normally don't have voice<br>-Predominantly mediator in decision-making<br>-Feelings of frustration from exclusion  |
| <b>Park &amp; Oh (2022)</b>         | Nurse | Korea     | Child Health Nursing Research                         | To explore nurses and mothers' perceptions of partnership in PICU         | PICU nurses (n=12) & Parents<br><br>Single PICU              | Interviews               | Families and patients in PICU | -Differing views on partnership, nurses believe unequal due to knowledge imbalance<br>-Focus on clinical care, reluctance to deliver information   |
| <b>Poompan et al. (2020)</b>        | Nurse | Thailand  | Pacific Rim International Journal of Nursing Research | To explore experiences of EoL care in a Thai PICU                         | PICU nurses (n=24) & Parents<br><br>Single PICU              | Interviews & observation | EoL in PICU                   | -Nurses had to wait for medical team to redirect care before providing EoL care<br>-Once change to comfort nurses lead care and support parents to make decisions and provide care<br>-Nurses coordinate communication |
| <b>Soares et al. (2020)</b>         | Nurse | Brazil    | Revista Brasileira de Enfermagem                      | To explore nurses' perceptions of comfort in PICU                         | PICU nurses (n=40) and nurse technicians*<br><br>Single PICU | Interviews               | Healthcare delivery           | -Nurses aim to promote comfort<br>-Includes environmental for example noise and care specific including pain interventions   |
| <b>Schults et al. (2019)</b>        | Nurse | Australia | Australian Critical Care                              | To explore nursing practice of suctioning in PICU                         | PICU nurses (n=12)<br><br>Single PICU                        | Interviews               | Healthcare delivery           | -Nurses use experience to decide suctioning practice<br>-Aware of lack of research- they rely on own practice  |
| <b>Stayer &amp; Lockhart (2020)</b> | Nurse | US        | American Journal of Critical                          | To explore PICU nurses' ability to cope with death                        | PICU nurses (n=12)   | Interviews               | EoL in PICU                   | -Death part of the job but its emotionally demanding<br>-Focus on providing peaceful   |

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|  |         |             | Care                                   |   | Single PICU   |                                     |                                    | end of children<br>-Very hard when hope taken away but harder when reluctance to talk about death by medical team   |
| <b>van den Bos-Boon <i>et al.</i> (2021)</b> | Nurse   | Netherlands | Journal of Pediatric Nursing           | To explore the effectiveness of sim training in resus skills              | PICU nurses (n=19)<br><br>Single PICU                           | Interviews & simulation observation | Nurse as a healthcare professional | -Sim training increased nurses' confidence in resus skills<br>-Nurses had limited recognition of improvement of leadership communication during sim (traditionally medical led)   |
| <b>Vance <i>et al.</i> (2020)</b>            | Nurse   | US          | Advances in Neonatal Care              | To explore perspectives in facilitating FCC                               | NICU & PICU Nurses (n=10) & Medical<br><br>PICU/NICU            | Interviews                          | Families and patients in PICU      | -FCC nurse dependent<br>-To promote FCC, they focused on communication to get everyone on same page<br>-Decision-making happens ongoing not at a point in time<br>-Unit design impacts FCC  |
| <b>Walter <i>et al.</i> (2019)</b>           | Medical | US          | Journal of Pain and Symptom Management | To assess teamwork and communication with parents during family meetings. | PICU nurses (n=11) & medical<br><br>Single PICU                 | Observation & Survey                | Families and patients in PICU      | -Nurses' contribution focused on providing medical information related to care at the bedside<br>-They offered support and clarified elements for families  |
| <b>Watson &amp; October (2016)</b>           | Nurse   | US          | American Journal of Critical Care      | To explore clinical nurse participation in family meetings                | PICU nurses (47 survey & nurses in meetings)<br><br>Single PICU | Observation & survey                | Families and patients in PICU      | -A clinical nurse attended 20 (50%) of the family conferences that were audio-recorded but only made contribution in 25% of them.<br>-Unable to attend due to clinical demands<br>-Being present allows them to be present to hear news firsthand<br>-nurses who did not speak said |

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|                            |            |        |                                  |   |  |            |                                    | they had wanted to speak, and some of the reasons provided were that they were “uncomfortable speaking,” “were not asked” |
| Wei <i>et al.</i> (2020)   | Nurse      | US     | Critical Care Nurse              | To explore self-care to prevent burnout for staff in PICU               | PICU nurses (n=13) & Medical<br><br>Single PICU      | Interviews | Nurse as a healthcare professional | -Finding meaning in work kept staff motivated<br>-Support from colleagues important                                       |
| Zheng <i>et al.</i> (2018) | Researcher | Canada | Pediatric Critical Care Medicine | To explore impressions of early mobilization of critically ill children | PICU nurses (n=10), parents & MDT<br><br>Single PICU | Interviews | Healthcare delivery                | -Early mobility important but not a priority<br>-Felt like they had responsibility, but it increased workload             |