Postgraduate Certificate in Children's Palliative Care

# Research And Evidence Based Practice

Abstract
Summary, Synopsis
A concise, stand-alone paragraph that outlines the purpose, methods, key findings, and conclusions of a research study. In children's palliative care, an abstract allows clinicians to quickly assess the relevance of evidence to practice. Example: An abstract of a mixed-methods study on family coping strategies highlights the prevalence of grief-related anxiety and the effectiveness of a narrative therapy intervention. Challenges include ensuring brevity without omitting critical methodological details, and avoiding jargon that may obscure meaning for multidisciplinary readers.

Access to Care
Healthcare equity, Service availability
The degree to which children with life-limiting conditions and their families can obtain appropriate palliative services without undue barriers. Practical application: Mapping regional hospice resources to identify gaps in home-based support. Challenges involve geographic disparities, insurance limitations, and cultural factors that affect utilisation of services.

Advocacy
Policy influence, Family voice
Active efforts by professionals, families, or organisations to influence health policy, resource allocation, and public awareness for children's palliative care. Example: A research-informed briefing paper presented to a health ministry, citing evidence on reduced hospital admissions when early palliative care is introduced. Barriers include limited political will, competing priorities, and the need for robust data to support arguments.

Aims
Objectives, Research questions
Clear statements describing what a study intends to achieve. In a postgraduate certificate, aims may include "to evaluate the impact of a structured bereavement program on parental grief outcomes." Well-formulated aims guide methodology and analysis. Common pitfalls are overly broad aims that dilute focus, or aims that are not measurable.

Algorithm
Clinical pathway, Decision tree
A step-by-step visual or textual guide that assists clinicians in making evidence-based decisions. For instance, an analgesic algorithm that progresses from non-opioid to opioid medication based on pain intensity scores. Implementation challenges involve ensuring the algorithm aligns with local formulary constraints and that staff receive adequate training.

Analgesic Ladder

Pain management hierarchy, WHO ladder
A framework originally developed by the World Health Organization to guide escalating pain relief strategies—from non-opioids to weak opioids, then strong opioids. In children's palliative care, adaptations address age-specific dosing and routes of administration. Practical use requires regular pain assessment and monitoring for side effects. Limitations include potential under-treatment of breakthrough pain and the need for individualized dosing.

Antecedent
Preceding factor, Trigger
A variable or event that occurs before a measured outcome, potentially influencing it. In research, identifying antecedents helps clarify causal pathways. Example: Investigating whether lack of early psychosocial support (antecedent) predicts higher levels of parental depression during bereavement. Challenges include accurately timing data collection and controlling for confounding variables.

Appraisal
Critical evaluation, Quality assessment
The systematic examination of research evidence for methodological rigour, relevance, and bias. Tools such as the CASP checklist are used to appraise qualitative studies on family experiences. Effective appraisal informs evidence synthesis and guideline development. Common difficulties arise from limited expertise in appraisal techniques and time constraints in clinical settings.

Audit
Quality improvement, Clinical review
A systematic review of practice against established standards, often involving data collection, analysis, and feedback. In a palliative care unit, an audit might compare the proportion of children receiving advance care planning documentation against national benchmarks. Practical steps include defining measurable criteria, gathering reliable data, and implementing change cycles. Barriers include staff resistance, data accessibility, and resource limitations.

Bias
Systematic error, Confounding
Any factor that distorts the true relationship between exposure and outcome. Types include selection bias, information bias, and publication bias. Example: A retrospective chart review that only includes families who completed a satisfaction survey may overestimate service quality. Mitigation strategies involve careful study design, transparent reporting, and statistical adjustments. Recognising bias is essential for interpreting evidence accurately.

Case Study
In-depth analysis, Narrative inquiry
A qualitative or mixed-methods investigation focusing on a single individual, family, or service model to explore complex phenomena. In children's palliative care, a case study might document the multidisciplinary management of a child with a rare metabolic disorder, highlighting coordination challenges and successful interventions. Strengths include rich contextual detail; limitations involve limited generalisability and potential researcher bias.

Causality
Cause-effect relationship, Attribution
The inference that an exposure directly influences an outcome. Establishing causality requires criteria such as temporality, dose-response, and plausibility. Randomised controlled trials (RCTs) are the gold standard for demonstrating causality, yet in palliative care ethical considerations often preclude randomisation. Alternative designs (e.g., stepped-wedge trials) can provide stronger causal evidence while respecting patient preferences.

Clinical Trial
Interventional study, Experimental research
A research design that tests the efficacy and safety of interventions, typically involving random allocation to treatment or control groups. In children's palliative care, trials may evaluate novel symptom-relief medications or psychosocial programmes. Practical considerations include obtaining age-appropriate assent, ensuring minimal burden, and adhering to strict safety monitoring. Recruitment challenges are common due to small patient populations and parental concerns.

Cohort Study
Prospective observational, Longitudinal design
A study that follows a group of individuals sharing a defining characteristic (e.g., diagnosis of a life-limiting condition) over time to observe outcomes. Cohort studies can identify risk factors for frequent hospital admissions or explore the long-term impact of early palliative integration. Strengths include temporal clarity; weaknesses involve potential loss to follow-up and the need for large sample sizes.

Confounding Variable
Extraneous factor, Hidden influence
A variable that is associated with both the exposure and the outcome, potentially distorting the observed relationship. For example, socioeconomic status may confound the link between access to home palliative services and child quality of life. Strategies to address confounding include randomisation, stratification, multivariable regression, and propensity-score matching.

Consent
Informed agreement, Ethical permission
The process by which participants (or their legal guardians) voluntarily agree to partake in research after receiving comprehensive information about purpose, procedures, risks, and benefits. In pediatric palliative research, consent must be obtained from parents while also seeking assent from the child when developmentally appropriate. Challenges include navigating emotional distress, ensuring comprehension, and respecting cultural variations in decision-making.

Continuum of Care
Integrated service pathway, Seamless transition
A coordinated series of services that span diagnosis, treatment, hospice, and bereavement phases, ensuring that children and families receive appropriate support at each stage. Mapping the continuum helps identify service gaps and informs research on transition points (e.g., from curative to comfort-focused care). Implementation barriers often involve fragmented funding streams and differing professional cultures.

Data Triangulation
Methodological triangulation, Multi-source validation
The use of multiple data sources, methods, or investigators to corroborate findings and enhance credibility. A study might combine caregiver interviews, child self-report scales, and electronic health record data to examine symptom burden. Benefits include richer insight and reduced bias; challenges involve complex data integration, increased workload, and potential inconsistencies across sources.

Evidence Hierarchy
Level of evidence, Grading system
A ranking of research designs based on methodological strength, typically placing systematic reviews and meta-analyses at the top, followed by RCTs, cohort studies, case-control studies, and finally expert opinion. While useful for guideline development, strict hierarchy may undervalue qualitative insights crucial for understanding family experiences. A balanced approach recognises the complementary value of different evidence types.

Evidence Synthesis
Systematic review, Narrative overview
The process of collating, appraising, and integrating findings from multiple studies to produce a comprehensive summary. In children's palliative care, a systematic review of interventions for dyspnoea may inform clinical pathways. Effective synthesis requires transparent protocols, rigorous search strategies, and appropriate analytic techniques (e.g., meta-analysis for quantitative data, thematic synthesis for qualitative data). Common obstacles include heterogeneity of outcomes and limited availability of high-quality studies.

Ethics
Research morality, Institutional Review Board (IRB)
The principles and regulations governing the protection of participants, particularly vulnerable populations such as seriously ill children. Core ethical considerations include beneficence, non-maleficence, autonomy, and justice. Practical steps involve submitting detailed protocols to an IRB, establishing data safety monitoring boards, and ensuring ongoing consent. Ethical dilemmas often arise when balancing research rigour with the emotional burden on families.

Family-Centered Care
Holistic approach, Partnership model
A care philosophy that recognises the family as the primary unit of care, involving them in decision-making, planning, and service delivery. Research may assess family-centered outcomes like parental satisfaction, communication quality, and shared decision-making scores. Implementation requires interdisciplinary training, flexible visiting policies, and culturally sensitive communication. Barriers include time constraints and differing expectations among health professionals.

Framework
Conceptual model, Structural guide
An organized set of concepts that provides a systematic way to understand, design, or evaluate a phenomenon. The "Palliative Care Quality Framework" outlines domains such as symptom management, psychosocial support, and care coordination. Researchers use frameworks to develop measurement tools,

align interventions, and compare findings across settings. Selecting an appropriate framework demands alignment with study objectives and population characteristics.

Generalizability
External validity, Transferability
The extent to which study findings can be applied to broader populations or settings beyond the sample. A trial conducted in a tertiary children's hospital may have limited generalisability to rural hospice settings. Enhancing transferability involves describing contextual factors, using diverse samples, and conducting replication studies. Over-generalisation can lead to inappropriate policy or practice recommendations.

Guideline
Clinical recommendation, Practice standard
A systematically developed statement that assists clinicians and families in making informed decisions about appropriate health care for specific circumstances. For example, a guideline on pediatric pain assessment recommends using age-appropriate scales such as the FLACC or Wong-Baker faces. Development requires rigorous evidence synthesis, stakeholder consultation, and clear grading of recommendation strength. Updating guidelines regularly is essential to incorporate emerging evidence.

Implementation Science
Knowledge translation, Practice uptake
The study of methods to promote the systematic uptake of research findings into routine practice, thereby improving health outcomes. In children's palliative care, implementation science may evaluate strategies (e.g., audit-feedback, educational workshops) to increase adherence to a new bereavement protocol. Key concepts include fidelity, sustainability, and context adaptation. Challenges include limited resources, staff turnover, and complex organisational structures.

Informed Consent
Voluntary agreement, Participant autonomy
A process ensuring that participants understand the nature of the research, its risks, benefits, and alternatives before agreeing to take part. In pediatric settings, the consent hierarchy typically involves parental permission plus child assent where feasible. Effective communication strategies—plain language, visual aids, and repeated discussions—aid comprehension. Situations of acute illness may necessitate deferred consent, which must be ethically justified.

Intervention
Therapeutic action, Program component
Any structured activity, treatment, or programme designed to produce a measurable change in health outcomes. Examples include a music-therapy session for pain relief, a family support group, or a medication protocol for nausea. Intervention development follows a logical sequence: needs assessment, pilot testing, evaluation, and refinement. Common challenges are ensuring cultural relevance, maintaining fidelity, and measuring outcomes that capture both clinical and psychosocial dimensions.

Literature Review
Background synthesis, Knowledge mapping

A comprehensive, critical, and contextualised summary of existing research on a particular topic. In the postgraduate certificate, students may conduct a literature review on “Barriers to early palliative referral in neonates.” Effective reviews identify gaps, inform research questions, and avoid duplication. Pitfalls include limited search strategy, selection bias, and failure to appraise study quality.

Meta-analysis
Statistical synthesis, Quantitative pooling
A statistical technique that combines results from multiple studies to produce an overall effect estimate. When conducting a meta-analysis of interventions for pediatric dyspnoea, researchers calculate pooled mean differences or risk ratios, assess heterogeneity, and explore sub-group effects. Strengths include increased power and precision; limitations involve publication bias, heterogeneity, and the quality of included studies.

Mixed Methods
Combined design, Integration approach
Research that integrates quantitative and qualitative components within a single study to address complementary aspects of a phenomenon. A mixed-methods project might quantify symptom prevalence while also exploring parental coping narratives. Integration can occur at design, data collection, analysis, or interpretation stages. Benefits include richer insight and triangulation; challenges involve methodological expertise, increased time, and complex data integration.

Outcome Measure
Indicator, Endpoint
A variable used to assess the effect of an intervention or the status of a health condition. In children’s palliative care, common outcome measures include pain intensity scales, quality-of-life questionnaires (e.g., PedsQL), and caregiver burden inventories. Selecting valid, reliable, and age-appropriate instruments is essential. Issues arise when measures lack sensitivity to change or are not culturally adapted.

Palliative Care
Comfort-focused care, End-of-life support
A multidisciplinary approach that aims to improve quality of life for children with life-limiting illnesses and their families, addressing physical, emotional, social, and spiritual needs. Core components include symptom management, advance care planning, psychosocial support, and bereavement services. Research in this field explores effectiveness of interventions, service models, and family experiences. Barriers to optimal palliative care include limited workforce expertise, funding constraints, and societal misconceptions about palliative services.

Qualitative Research
Exploratory study, Narrative analysis
Methodologies that collect non-numeric data (e.g., interviews, focus groups, observations) to understand meanings, experiences, and social processes. In children’s palliative care, qualitative studies illuminate parental decision-making, cultural attitudes toward death, and staff coping mechanisms. Rigorous qualitative work employs strategies such as member checking, reflexivity, and transparent coding. Challenges include ensuring participant comfort, managing emotional content, and achieving credible

analytic depth.

Randomised Controlled Trial (RCT)
Experimental design, Gold-standard study
A study in which participants are randomly allocated to intervention or control groups, minimizing selection bias and allowing causal inference. Conducting an RCT on a new analgesic in children with cancer requires careful dose selection, safety monitoring, and ethical justification. Advantages include high internal validity; disadvantages involve high cost, complex logistics, and potential difficulties recruiting vulnerable populations.

Risk Assessment
Hazard evaluation, Safety analysis
The systematic process of identifying, analysing, and prioritising potential risks associated with an intervention or service delivery. For a home-based palliative program, risk assessment may examine medication errors, equipment failures, and caregiver fatigue. Findings inform mitigation strategies such as training, checklists, and emergency protocols. Limitations include unpredictable events and the need for ongoing reassessment.

Sample Size
Power calculation, Participant number
The number of participants required to detect a statistically significant effect, based on anticipated effect size, variability, significance level, and desired power. Under-powered studies risk type II errors, while over-sized studies may waste resources. In rare pediatric conditions, achieving adequate sample size often necessitates multi-site collaboration or adaptive designs.

Stakeholder
Interested party, Partner
Individuals or groups with a vested interest in the research outcomes, such as families, clinicians, policy makers, and advocacy organisations. Engaging stakeholders throughout the research cycle enhances relevance, feasibility, and uptake of findings. Practical techniques include advisory panels, co-design workshops, and dissemination events. Barriers include conflicting priorities, power imbalances, and logistical constraints.

Systematic Review
Comprehensive synthesis, Evidence map
A methodologically rigorous review that follows a predefined protocol to identify, appraise, and summarise all relevant studies on a specific question. Systematic reviews in children's palliative care may focus on "Effectiveness of virtual support groups for bereaved siblings." Key steps involve exhaustive literature searches, dual screening, risk-of-bias assessment, and transparent reporting (e.g., PRISMA). Limitations are often related to heterogeneity and paucity of high-quality primary studies.

Validity
Accuracy, Truthfulness
The degree to which an instrument measures what it intends to measure. Types include content validity

(adequacy of item coverage), construct validity (relationship to theoretical concepts), and criterion validity (correlation with gold-standard measures). For example, validating a new child-reported distress scale requires factor analysis and comparison with established measures. Threats to validity include poorly defined constructs, translation errors, and respondent fatigue.

Validity
Accuracy, Truthfulness
(Repeated entry removed – ensure each term is unique.)

Variable
Measured factor, Data point
Any characteristic, trait, or condition that can take on different values among participants. Variables are classified as independent (exposure), dependent (outcome), or confounding. In a study of symptom control, medication dose is an independent variable, while pain score is the dependent variable. Precise definition and consistent measurement are essential for reliable analysis.

Yield
Result, Output
The amount or quality of information generated by a research activity. For example, the yield of a screening audit may be the proportion of children identified as having unmet spiritual needs. High yield indicates efficient data collection processes, whereas low yield may suggest redundant measures or poor instrument sensitivity.

Ethical Review Board (ERB)
Institutional Review Board, Research ethics committee
A formal group that evaluates research proposals to ensure protection of participants, especially vulnerable children. The ERB reviews consent procedures, risk-benefit ratios, data confidentiality plans, and investigator qualifications. Obtaining ERB approval is a prerequisite for funding and publication. Common hurdles include lengthy review timelines and the need for revisions to meet ethical standards.