Abstract

Supporting Caregivers in Pediatric Palliative Care Through Narrative Medicine: The "Ali di Carta" Pilot and a Multicenter Nursing Study

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Citation: Sebastiani A, Salata M, Magnera A, Tiozzo E, Gawronski O. "Supporting Caregivers in Pediatric Palliative Care Through Narrative Medicine: The "Ali di Carta" Pilot and a Multicenter Nursing Study" (2026) *International Journal of Health Supplements* 1(Suppl. 1):91. Supp. DOI: https://doi.org/10.82051/ijhs-2026-1

Introduction. Caregivers of children with complex chronic conditions face high emotional and psychological burden. In pediatric palliative care, nurse-led Narrative Medicine (NM) interventions may support coping and resilience by promoting reflection, meaning-making, and shared experiences.

Methods. In 2024, the pilot project Ali di Carta was conducted at an Italian Pediatric Palliative Care Center. Twelve mothers participated in five online NM sessions (90 minutes each), facilitated by certified trainers and supported by a narrative diary. The Parenting Stress Index (PSI) was administered before and after the intervention, followed by semi-structured interviews. Based on these findings, a multicenter observational study (2025–2026) has been designed across ten Italian regions, involving 150 caregivers (15 per region) with mixed quantitative (PSI at baseline, post-intervention and 3-month follow-up) and qualitative evaluation (focus groups and narrative thematic analysis).

Results. Preliminary findings showed a reduction in total and parental distress PSI scores in 50–66% of participants. Qualitative analysis highlighted increased emotional awareness, empowerment, and stronger peer support. Participants described NM sessions as a safe and supportive space for sharing experiences.

Discussion. NM appears feasible and valuable in supporting caregivers in pediatric palliative care. The forthcoming multicenter study will further evaluate its impact and contribute to evidence-based nursing interventions supporting families in complex care settings.

Keywords: Burden, Caregivers, Narrative Medicine, Pediatric Palliative Care, Complex or Serious Illnesses

Funding: This research received no external funding. **Conflict of Interest:** The authors declare no conflict of interest.