

Emotional, Psychological, Religious and Spiritual Support Offered During Infants' End of Life (EOL) Care on the Neonatal Unit - Then and Now

Ganjigunta V, Rizvi H, Naik V, Patel V - Neonatal unit, Grange University Hospital

Introduction

Providing parents' information about the availability of emotional, psychological, religious and spiritual support is integral to an infant's end of life care. Its importance has been emphasized by national guidelines and professional bodies - **NICE, Together for Short Lives, RCPCH and BAPM.**

Background

In the **first audit** conducted from 2016 to 2018, information about emotional/psychological support was offered to a very small number of parents (<1/4th) and about religious/spiritual support to 2/3rd of them during their infants' EOL care. Several Quality Improvement measures were introduced following this.

Quality Improvement Measures

- EOL care and Bereavement team was formed with Medical (Consultant) and Nursing leads.
- The EOL care and Bereavement pathway was updated with prompts.
- Regular teaching and awareness sessions were conducted for medical and nursing teams.
- Resource folder, staff posters and information leaflets were produced.
- Ty Hafan Neonatal Palliative Care nurse joined the team in 2023.

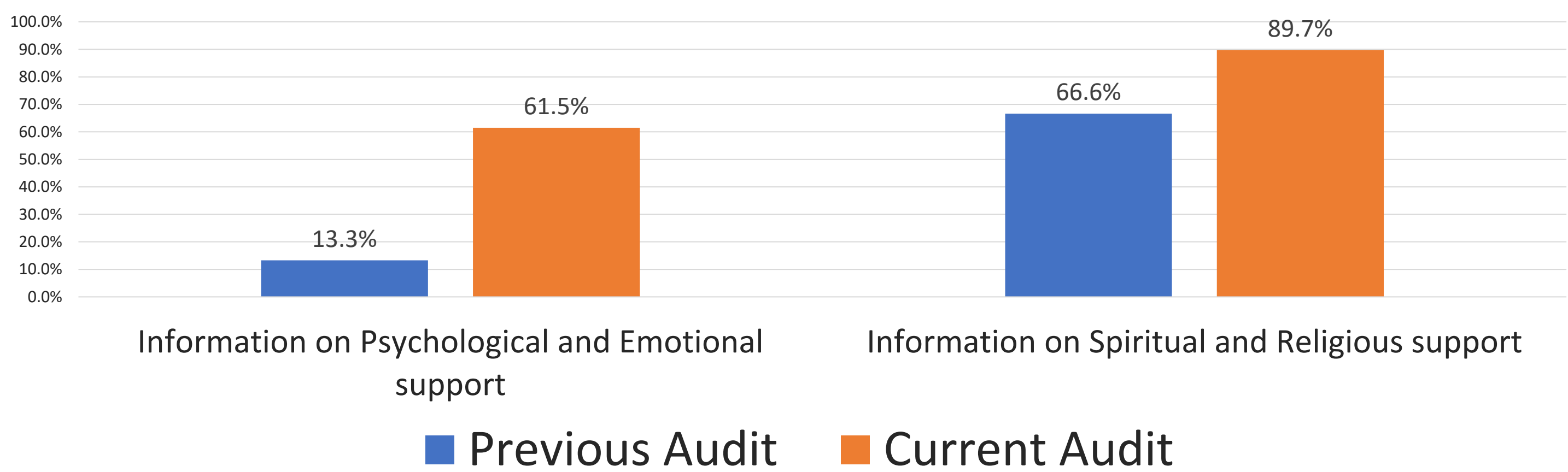
Method

- Retrospective review** of clinical records from **January 2019 to December 2023.**
- Conducted at the NICUs of the **Royal Gwent** and **Grange University Hospitals.**
- Inclusion criteria:** Infants with life-limiting and life-threatening conditions who died following withdrawal of intensive care.
- Families who were offered information about availability of emotional, psychological and religious, spiritual support during their infants' EOL care were identified through clinical notes, parent communication sheets, Badgernet death summaries and EOL Care Pathway.

Results

39 babies met the inclusion criteria.

- 24 families** were offered information about emotional, psychological support.
- 35 families** were offered information about religious, spiritual support.



Conclusion

The above Quality Improvement steps led to a significant increase in providing above information to the parents during their infants' EOL care.

Besides religious and spiritual support, chaplaincy service provides valuable emotional and pastoral support, which has now been highlighted in the EOL care pathway as an essential prompt.

Way Forward

Availability of a Clinical Psychologist would further improve the provision of emotional and psychological support. A business case has been submitted to address this gap.