Posters symposium

PS-050 QUALITY OF LIFE FOR PARENTS OF VERY-LOW BIRTH WEIGHT INFANTS ENROLLED IN A CLINICAL STUDY

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Background In this study we wanted to evaluate if parents of very-low birth weight (VLBW) infants enrolled in a clinical study developed a lower quality of life compared to parents from a control sample.

Methods We recruited parents of children attending the Norwegian multicenter study for premature nutrition (PreNu). The PreNu study was a randomised clinical nutritional trial, where 50 VLBW-children (<1500 g) were recruited within the first hours of their life. We also recruited parents of VLBW-children born immediately before and after the recruitment period of the PreNu study, to serve as a control group.

The parents (n = 63) were given a questionnaire with validated measures on quality of life (Quality of Life Scale), anxiety and depression (Hospital Anxiety and Depression Scale), fatigue (Lee Fatigue Scale), sleeping disturbance (General Sleep Disturbance Scale), pain (Brief Pain Inventory), comorbidity (Self-Administered Comorbidity Questionnaire) and hope (Herth Hope Index). The parents were asked to answer as they would have done at the time their children were at the NICU.

Results The response rate was 69%. T-tests showed no significant difference between the groups on all measures except for quality of life. The PreNu parents rated their quality of life significantly higher than the control group (p = 0.018).

Conclusion Our fear that the parents of the PreNu-children suffered an intolerable burden seems unfounded. The results suggest that being the parent of a VLBW-child attending a clinical study is not a burden, but may in fact be an enrichment.

PS-052 SETTING PRETERM BIRTH RESEARCH PRIORITIES WITH MULTIPLE PROFESSIONS AND SERVICE USERS IN THE UK

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Background Preterm birth is the most important determinant of adverse infant outcomes. Research agendas in this area have been determined primarily by researchers.

Objectives To identify and prioritise future research areas in preterm birth that are most important to service users and practitioners.

Methods A priority setting partnership was established with families with experience of preterm birth and organisations representing them, obstetricians, neonatologists, midwives and neonatal nurses. Research uncertainties were gathered from surveys and analysis of systematic reviews and clinical guidance. Prioritisation was through voting; final ranking occurred at a facilitated workshop, as advocated by the James Lind Alliance.

Results 593 uncertainties were submitted by 386 respondents (58% service users, 30% healthcare professionals and 12% from both roles); 52 were identified from literature