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A QUALITATIVE ANALYSIS ABOUT FAMILY CENTRED CARE (FCC) EXPERIENCED IN A CHILDREN'S HOSPITAL

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Background: families have an important role for the health and well being of patients of all ages, particularly in paediatrics. Family centred care is a model adopted world wide to plan, perform and evaluate care in many paediatric hospitals, such as Bambino Gesù Children's Hospital (OPBG).

Aims: to evaluate the experience of FCC at OPBG in its different levels of practice: from the absence of involvement in care to involvement, participation, collaboration and partnership.

Methods: for this research question was chosen a qualitative approach. Subjects included in the study were health professionals of OPBG (nurses, doctors, allied health professionals), parents of children admitted for more 24 hours at OPBG.

Data collection: data was collected through n.10 focus groups (FG). Two first pilot FG were performed to refine the interview questions and the facilitator's role. All FG have been conducted with parents and professionals from different care settings (intensive care, chronic care and acute care).

Data analysis: was performed with the method of the long table analysis and NVivo 8 software to define the conceptual categories and themes descriptive of the phenomenon.

Ethic: the study was approved by the Ethical Committee of OPBG. Participants subscribed the information consent.

Results: the main themes that have emerged relate to parent's presence at the child's bedside, parent's desired involvement in care, nursing perceptions of it and desired parent participation in care, partnership and parent's information and educational needs.

Conclusions: the study addresses important issues to implement FCC in the hospital

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CARE CLOSER TO HOME FOR CHILDREN AND YOUNG PEOPLE WHO ARE ILL: HOW FAR CAN WE GO?

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Background and aims: Delivering care closer to home (CCTH) for children and young people who are ill is a policy aim in many countries. The evidence base about the costs and effectiveness of CCTH is underdeveloped, as is understanding about best practice in service delivery and organisation.

This study aimed to:

- review international evidence on costs and effectiveness
- survey CCTH models provided across England
- explore families', children's and services' experiences of receiving, providing and commissioning CCTH
- explore the health economics of CCTH.

Methods:

1. A systematic review of international evidence on the effectiveness and costs of CCTH, updating an earlier systematic review of paediatric home care.
2. A survey of all health providers in England to establish CCTH coverage and its delivery and organisational features.
3. Organisational case studies in four areas, involving documentary and policy analysis, and in-depth interviews with commissioners and providers of different CCTH models and the families and children who use them.

4. Health economic modelling of the costs and effectiveness of CCTH models.

Results: The international evidence base on costs and effectiveness of CCTH remains weak. Three main models of CCTH are evident, with different organisational and delivery features and costs.

Conclusions: Children with complex, long-term care needs, as well as children with acute conditions that will resolve can be and are cared for safely closer to home. However, barriers and facilitators to further development of CCTH need to be addressed before we can understand 'how far we can go'.

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ASSESSING PSYCHOLOGICAL WELL-BEING IN MOTHERS OF CHILDREN WITH DISABILITY: PREDICTING DEPRESSIVE SYMPTOMS, PARENTING STRESS, RESILIENCY, AND FAMILY FUNCTIONING

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Background/aims: In family-centred children's services, it is critical to understand how mothers are responding to the challenges that childhood disability brings to the family. Some mothers will meet these challenges with resiliency and adequate coping; others will need more support and assistance from professionals to care for their child. Currently, there are no brief, psychometrically-sound measures of psychological well-being for use during intake to childhood disability services. The aim of this study was to evaluate two new measures designed to assess the need for psychological support in mothers of children with disability.

Methods: Canadian mothers ($N = 195$) of children with serious health and developmental disabilities completed the Parenting Morale Index (PMI) and Family Impact of Childhood Disability (FICD) scale, and validation measures via computer-assisted telephone-interview. Of these, 154 completed additional validation measures 1 year later.

Results: Confirmatory factor analysis supported the factor structure of the PMI and FICD. The PMI and FICD demonstrated strong internal consistency and temporal stability, as well as convergent and discriminant validity. After 1 year, the PMI and FICD jointly predicted maternal depressive symptoms, parenting stress, family resiliency, and family

adjustment, with adjusted R^2 s of .30, .36, .29, and .22, respectively.

Conclusion: Together, these brief measures appear to capture unique, but important aspects of maternal psychological well-being, and adaptive coping in the care of their child with disability. Within the Process Model of Stress and Coping, the PMI and FICD can be recommended to complement clinical interviews at intake to childhood disability services.

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PARENTAL SATISFACTION CONCERNING THEIR CHILD'S HOSPITAL CARE: A QUESTIONNAIRE SURVEY

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Background: Nowadays, healthcare needs to be more evidence-based, patient-oriented and families' perspectives must be taken into account in the appraisal of health services.

Aim: The aim of this study was to rate parental satisfaction concerning their child care during hospitalization and the factors that determine it.

Methods: Parents of 206 children, randomly selected, hospitalized in two pediatric and two surgical units. Data collection was based on interviews using a 68 item questionnaire, the Swedish Pyramid Questionnaire. Stepwise multiple regression was used to explore the characteristics which may have affected the parents' answers.

Results: Parents showed greater satisfaction with staff attitudes and medical treatment, whereas they were less satisfied with the information concerning routines and the staff work environment. They were pleased by the nursing care ($N=180$, 87.37%), nurses' concern ($N=179$, 86.89%) and from the respect to their needs ($N=181$, 87.86%) or their child's needs ($N=186$, 90.29%). Fathers gave statistically significant higher ratings for information