The Child's Experience of Single Room Isolation

DONNA AUSTIN

UNIVERSITY HOSPITAL SOUTHAMPTON

Aims of the session

- To explore the background to the study concept
- Review the literature
- Understand the underpinning methodology, methods and recruitment strategy
- Present and discuss the findings and themes in context of current practice
- Provide conclusions to the study

Study concept

- Clinical academic pathway
- Research question derived from rotational practice within remit of infection prevention
- Child at centre of question and way to answer clinical question
- Observed that children in isolation have a different experience

Literature Review

- Limited adult literature – coping, emotional response, social isolation, physical environment, PERSONAL Protective Equipment (PPE)

Paediatric literature review:

- **1970s** (5 studies) delayed social development, separation for older children, anxiety (Drotar et al, 1976; Freedman et al, 1976; Kutsanellou-Meyer & Christ, 1978; Simons et al, 1973)
- **1980s** (4 studies) normal motor development, inconsistencies in terms of development in one study of 4 children, misinterpretation of PPE, separation (Broeder, 1985; Dalton, 1981; Lazar et al, 1983; Tamaroff et al, 1986)
- **1990s** (1 study) Isolation deemed a stressor (Kronenberger et al, 1998)
- **2000-2017** (6 studies) separation, parental burden, PPE impairing relationships, desire to cheat on isolation rules (Chan et al, 2007; Koller et al, 2006; McKeever et al, 2002; Rotegard & Sykepleievitenskap, 2007; Russo et al, 2006; Wu et al, 2005)

Study question

What is the child's experience of single room isolation whilst in hospital?

Methodology

- Child centred methodology
- Social construction (Guba & Lincoln, 2005)
- Narrative inquiry (Engel, 1999; Kohler-Riessman, 1993, Labov, 1972)

Setting

- Regional hospital with 10 paediatric wards
- Regional specialist centre for a number of specialities

Sampling

Purposive sampling:

- Children aged 6-17 years
- Parents of children who were isolated
- Clinical practitioners working with children in isolation

Data Collection Methods

- Video diary methods (2 participants)
- Retrospective interviews (semi-structured)

Recruitment

Prospective and retrospective

- Children n=8
- Parents n=12
- Staff n=21

All participants were asked to provide insight into the CHILD'S experience

Sample

Name	Age	Diagnosis	Type of Isolation	Length of Isolation	Previous Isolation Experience	Who participated?
Lara	12	Pulmonary Ciliary Dyskinesia	Protective/Source	2 weeks	Hospitalised once before: 1 week in isolation	Lara (in video diary and no follow up interview)
Simon	16	Spinal Tuberculosis	Initially in source isolation with suspected respiratory tuberculosis	2 weeks	No experience of hospitalisation or isolation	Simon (in video diary and follow up interview)
Harriet	6	Haemolytic Uraemic Syndrome, presumed Ecoli	Source	7 days	No experience of hospitalisation or isolation	Harriet and Mum
Eloise	17	Infective diarrhoea (Crohns' Disease)	Protective	2 days	Hospitalised once before: nursed in a bay for 2 days	Eloise and Mum
Imogen	9	Acute Myeloid Leukaemia	Source and protective at different times in three different hospitals	Multiple admissions to isolation, longest 6 weeks	Hospitalised intermittently since diagnosis 9 months ago: protective isolation during bone marrow transplant, source isolation for RSV, protective isolation when on shared care ward and on main bay on oncology ward.	Imogen and Mum
John	6	Cystic Fibrosis	Source and protective	10 days	One previous admission at 6 months of age to protective isolation	Mum
Erica	8 months	Mitochondrial Disorder, haemorrhagic hydrocephalus with VP shunt, hypertrophic cardiomyopathy, hypothyroidism, obstructive sleep apnoea and gastroesophageal reflux. RSV	Source	First 5 months of life in hospital in main bays between three different hospitals. Subsequently has been admitted 5 times to 4 different wards, for up to 3 weeks; of these 3 times were in isolation up to 2 weeks at a time.	Experience of main ward in 3 hospitals and experience of isolation on different wards	Mum
James	7	Cystic Fibrosis and pseudomonas	Source and protective	7 days	4 previous episodes of hospitalisation; all in isolation	James and Mum
Jessica	14 months	Bronchiolitis RSV	Source	4 days	3 previous episodes of hospitalisation – in isolation and main bay when cohorted with other children with RSV.	Mum
Rachel	2	EBV Encephalitis	Source	5 days	One previous experience of hospitalisation in isolation for 8 days	Mum
Freddie	2	Hand, foot and mouth – Enterovirus	Source	8 days	No previous experience of hospitalisation or isolation	Mum and Dad
Nicholas	12	C Difficile Crohns	Source	2 days	1 previous experience of hospitalisation on main ward	Nicholas and Mum
Sophie	14	Cellulitis, Impetigo – Staphylococcus Aureus	Source	5 days	No previous hospitalisation or isolation experience	Sophie and Mum

Data Analysis Methods

Narrative analysis approach (Kohler-Riessman, 1993):

- Attending to the story
- Telling the story
- Transcribing the story
- Analysing the story

Codes from each participant/family, categorised to themes

Themes

- Coping
- Control
- Community/separation

Coping

- Children – distraction, explanation of isolation, parental presence
- Parents – distraction, familiarity, guilt on leaving/burden of staying
- Staff – preparation, lack of stimulation made the situation more challenging, familiarisation with hospital/ward made it easier for families

Control

- Children – Need for time out of isolation, resignation to fate of being in isolation
- Parents – Resignation to isolation precautions, parental/nursing blur role, familiarity with the ward altered how in control the family felt,
- Staff – Parents can continue “normal life”, staff concerns about safety, reliance on parents, guilt, inconsistent isolation “rules”

Community

- Children – “missing out”
- Parents – separation from family, lack of peer/staff support, stigma
- Staff – families miss out on community, separation from ward activities, stigma associated with being in isolation

Discussion

- Different perspectives produce different findings and cross over of findings
- Sample size and heterogeneity
- Length of time for data collection
- Clinical academic role
- Need for child at centre of the study
- Child centred methods – recruitment and benefit
- Clinical question and impact on practice

Conclusions

- Psychosocial care in isolation for the child and family must be considered/prioritised in care
- Care ratio numbers must be considered for children in isolation
- Need for consistency in terms of isolation precautions
- Need for candour when in isolation
- Further research is essential
- Use of the child's perspective is essential in paediatric specific research and child-specific research methods

References

BROEDER, J. L. (1985) 'School-Age Children's Perceptions of Isolation after Hospital Discharge', *MCN American Journal of Maternal and Child Nursing*, 14 (3), pp 153-174.

CHAN, S. S. C., LEUNG, D., CHUI, H., TIWARI, A. F. Y., WONG, E. M. Y., WONG, D. C. N., BARNSTEINER, J. H. & LAU, Y. L. (2007) 'Parental response to child's isolation during the SARS outbreak', *Ambulatory Pediatrics,* 7 (5), pp 401-404.

DALTON, R. (1981) 'The assessment and enhancement of development of a child being raised in reverse isolation', *Journal of the American Academy of Child Psychiatry*, 20 (3), pp 611-622.

DROTAR, D. D., STERN, R. C. & POLMAR, S. H. (1976) 'Intellectual and social development following prolonged isolation', *The Journal of Pediatrics*, 89 (4), pp 675-678.

ENGEL, S. (1999) *The stories children tell.* USA: W.H. Freeman and Company.

GUBA, E. G. & LINCOLN, Y. S. (2005) 'Paradigmatic Controversies, Contradictions, and Emerging Confluences', In DENZIN, N. K. & LINCOLN, Y. S. (Editors) *The Sage Handbook of Qualitative Research.* Third Edition. California: Sage Publications, pp 191-216.

FREEDMAN, D. A., MONTGOMERY, J. R., WILSON, R., BEALMEAR, P. M. & SOUTH, A. M. (1976) 'Further Observation on the Effect of Reverse Isolation from Birth on Cognitive and Affective Development', *Journal of the American Academy of Child Psychiatry,* 15 (4), pp 593-603.

KOHLER RIESSMAN, C. (1993) Narrative Analysis. London: Sage Publications.

KOLLER, D. F., NICHOLAS, D. B., GOLDIE, R. S., GEARING, R. & SELKIRK, E. K. (2006) 'When family-centered care is challenged by infectious disease: pediatric health care delivery during the SARS outbreaks', *Qualitative Health Research,* 16 (1), pp 47-60.

References

KRONENBERGER, W., CARTER, B. D., EDWARDS, J., MORROW, C., STUART, J. & SENDER, L. (1998) 'Psychological adjustment of mothers of children undergoing bone marrow transplantation: The role of stress, coping, and family factors', *Children s Health Care*, 27 (2), pp 77-95.

KUTSANELLOU-MEYER, M. & CHRIST, G. (1978) 'Factors affecting coping of adolescents and infants on a reverse isolation unit', *Social work in health care,* 4 (2), pp 125-137.

McKEEVER, P., O'NEILL, S. & MILLER, K. (2002) 'Managing space and marking time: Mothering severely ill infants in hospital isolation', *Qualitative Health Research*, 12 (8), pp 1020-1032.

ROTEGARD, A. K. & SYKEPLEIVITENSKAP, K. (2007) 'Children in an isolation unit - parents' informational needs', *Nordic Journal of Nursing Research & Clinical Studies*, 27 (4), pp 32-37.

RUSSO, K., DONNELLY, M. & REID, A. J. M. (2006) 'Segregation - the perspectives of young patients and their parents', *Journal of Cystic Fibrosis*, 5 (2), pp 93-99.

SIMONS, C., KOHLE, K., GENSCHER, U. & DIETRICH, M. (1973) 'The Impact of Reverse Isolation on Early Childhood Development', *Psychotherapy and Psychometrics*, 22 (2-6), pp 300-309.

LAZAR, R. M., TAMAROFF, M., NIR, Y., FREUND, B., O'REILLY, R., KIRKPATRICK, D. & KAPOOR, N. (1983) 'Language recovery following isolation for severe combined immunodeficiency disease', *Nature*, 306 (3), pp 54-55.

TAMAROFF, M., NIR, Y. & STRAKER, N. (1986) 'Children reared in a reverse isolation environment: effects on cognitive and emotional development', *Journal of Autism and Developmental Disorders*, 16 (4), pp 415-424.

WU, J., MU, P. F., TSAY, S. L. & CHIOU, T. J. (2005) 'Parental experience of family stess during hematopoietic stem cell transplantation of pediatric patients in germ-free isolation in Taiwan', *Cancer Nursing*, 28 (5), pp 363-371.

FLORENCE NIGHTINGALE FOUNDATION RESEARCH SCHOLARSHIP 2012-2013

HELEN RUSHFORTH AND JACQUI PRIETO- EDUACATIONAL SUPERVISORS, UNIVERISTY OF SOUTHAMPTON

UNIVERSITY OF SOUTHAMPTON CLINICAL ACADEMIC CAREER PATHWAY

ALL THE PARTICIPANTS WITHOUT WHOM THIS STUDY WOULD NOT HAVE BEEN POSSIBLE

Acknowledgements

Any questions?

THANK YOU FOR LISTENING