

"It's Just Always Eating": The Experiences of Young People Growing up Medium Chain Acyl-CoA Dehydrogenase Deficiency (Mcadd) [abstract only]

NUTTING, Charlotte, PIERCY, Hilary <<http://orcid.org/0000-0002-7663-8858>> and YAP, Sufin

Available from Sheffield Hallam University Research Archive (SHURA) at:

<https://shura.shu.ac.uk/29582/>

This document is the Published Version [VoR]

Citation:

NUTTING, Charlotte, PIERCY, Hilary and YAP, Sufin (2021). "It's Just Always Eating": The Experiences of Young People Growing up Medium Chain Acyl-CoA Dehydrogenase Deficiency (Mcadd) [abstract only]. *International Journal of Qualitative Methods*, 20, p. 96. [Article]

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

Dr. Karen Matvienko-Sikarm, *University College Cork, Cork, Ireland*

UKI-CC-A1 - Women's Health, July 6, 2021, 1:00 AM - 2:00 AM

Introduction: The perinatal period, is a transition that can result in anxiety and stress for some women. Understanding women's lived experiences of perinatal anxiety and stress is essential to better support women. The aim of this qualitative evidence synthesis was to examine women's experiences and perceptions of, and barriers and facilitators to coping with, perinatal anxiety and stress. **Research question:** What are women's experiences and perceptions of anxiety and stress during the perinatal period? **Design:** Databases CINAHL, EMBASE, MEDLINE, PsycINFO and Maternity and Infant Care were searched from inception to June 2020. **Sample:** Of 20,318 identified articles, 13 studies met inclusion criteria and were included in this review. **Data collection and analysis:** Data was extracted using a standardised data collection form. Thematic synthesis was chosen to allow for a transparent and inductive synthesis of primary studies. Data analysis was managed using QSR NVIVO. **Results:** Our findings show that social support, women's experiences of healthcare, social norms and baby's health act as barriers and facilitators to coping with perinatal anxiety and stress. Our review also identified factors that impact on their ability to cope.

UKI-CC-B1.2 - Evaluation of Video Reflexive Ethnography as a Tool for Improvement in Multi-Disciplinary Maternity Teams

Dr. Siobhan Mchugh, *Yorkshire Quality and Safety Group, Bradford Institute for Health Research, Bradford, United Kingdom*

Professor Rebecca Lawton

Professor Jane O'Hara

Dr Laura Sheard

UKI-CC-B1 - Methodology 1, July 6, 2021, 1:00 AM - 2:00 AM

Introduction: In light of recent high-profile events in UK maternity services, recommendations suggest improvement in communication is essential in improving quality and safety of care. This is especially true of acute maternity services, where staff teams are increasingly multi-disciplinary. Video-reflexive ethnography (VRE) is identified as a novel tool for prompting improvement in non-technical skills in other acute healthcare environments. However, VRE had not been used in acute maternity services, and there was no formal evaluation of the use of VRE with acute healthcare teams. **Research Question:** a) is VRE feasible and acceptable for use in multi-disciplinary maternity teams? b) is VRE a successful in prompting

improvement of non-technical skills? **Design:** Mixed methods design. **Sample:** Our project ran on one acute maternity unit in an NHS Trust, and involved a total of 80 maternity staff. **Data collection and analysis:** Data was collected through ethnographic observation, semi-structured interviews and a short survey. Field notes and survey data was analysed using framework analysis, and survey data using t-tests. **Results:** Results identified VRE as a feasible, acceptable and successful improvement tool in prompting staff-led improvement to non-technical skills; also in giving staff the time, space and autonomy to collectively articulate and navigate their working practice.

UKI-CC-C1.3 - "It's Just Always Eating": The Experiences of Young People Growing up Medium Chain Acyl-CoA Dehydrogenase Deficiency (Mcadd).

Ms. Charlotte Nutting, *Sheffield Hallam University, Sheffield, United Kingdom*

Dr Hilary Piercy, *Sheffield Hallam University, Sheffield, United Kingdom*

Professor Sufin Yap, *Sheffield Hallam University, Sheffield, United Kingdom*

UKI-CC-C1 - Adolescence Experience; Gender Studies, July 6, 2021, 1:00 AM - 2:00 AM

Introduction: Medium chain acyl-CoA dehydrogenase deficiency (MCADD) is a rare metabolic disorder, and part of newborn screening programmes in many countries. Those diagnosed at birth are now progressing from childhood to adulthood. This study provides the first insights into the reality of having MCADD from the perspective of young people. **Research question:** The study aimed to explore young people's perceptions of having MCADD and their experiences of managing their condition. **Design:** A descriptive qualitative study design aligned to social constructionism. **Sample:** Participants aged 10-15 years were recruited from one regional paediatric metabolic disorder service in England. Recruitment materials were developed in consultation with a research advisory group composed of young people. **Data collection and analysis:** 12 participants from a cohort of 14 were recruited. Data collection involved single semi-structured interviews. Interviews were digitally recorded and transcribed verbatim. Data were analysed using a thematic approach and supported by QUIRKOS. **Results:** Two major themes were identified. 'Eating for energy' explored anxieties about maintaining adequate energy to stay safe. 'Growing into a self-management role' explored how self-monitoring and self-management skills had been nurtured from an early age. Ongoing healthcare support is important during childhood, and as young people transition into adulthood.