Children's Voices in Rare Diseases: the SAMPI Study

Somanadhan, S. (1), Buckle, N. (1), Sinnott, S. (2), McNulty, S. (3), O'Neill, A. (4), Sweeney, A. (2), Rogers, Y. (2), O'Toole, D. (2), Bracken, S., (2), Awan, A. (2) and Kroll, T. (1).

Introduction

A Rare Disease is defined as any disease affecting fewer than 5 people in 10,000 in the EU (1). This number might appear small individually, but it translates into approximately 30 million people currently living with a rare disease in Europe (1). The rare disease research community is fragmented in Ireland/EU due to the large heterogeneity of rare conditions.

The SAMPI project was conducted to "give a voice to the children and their families with Rare Diseases" through Sand Play, Art, Music, Photovoice and Interviews. This project aims to answer a simple research question - "what is it like for a child to live with a rare disease and how can children be best supported to express this?"

Objective

Aim: To explore children's and young people's and their families' experiences of living with rare diseases.

Objectives:

- To explore the factors which enhance, inhibit and impact on the lives of children and young people living with a rare condition.
- To explore children and young people understanding of a rare diseases.
- To explore day-to-day parenting of a child and young people with a rare disease
- To examine knowledge and understanding of rare diseases from the perspective of children and young people.

Methodology

A total of (n = 30) children participated across all the modalities, and there was some participant overlap between modalities. A survey for parents was also run via social media (n = 107).

- Art sessions (facilitated by an art therapist) (n = 7)
- Music sessions (facilitated by a music therapist) (n = 5)
- Sand play (facilitated by an experienced clinical psychologist) (n = 7)
- Interviews (n = 11).

Participants were asked to draw on their experience living with their rare disease and then explain via each modality they chose. A thematic analysis of the transcripts was conducted using an inductive approach. This ensured that the findings were data-driven (2) and not influenced by pre-existing results. The children were purposefully selected to ensure that there are broad representations from each age group (4-7 years) (8-11 years) (12-16 years) and various rare disease categories.

Participatory research approach utilising multiple methods

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Data collection comprised of quantitative and qualitative multiple methods - sand play, music therapy, art, photovoice and interviews with children, and a parent survey.

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A quantitative element in the form of a questionnaire to capture parents different perspectives was also included.

Research Modalities

SAND PLAY

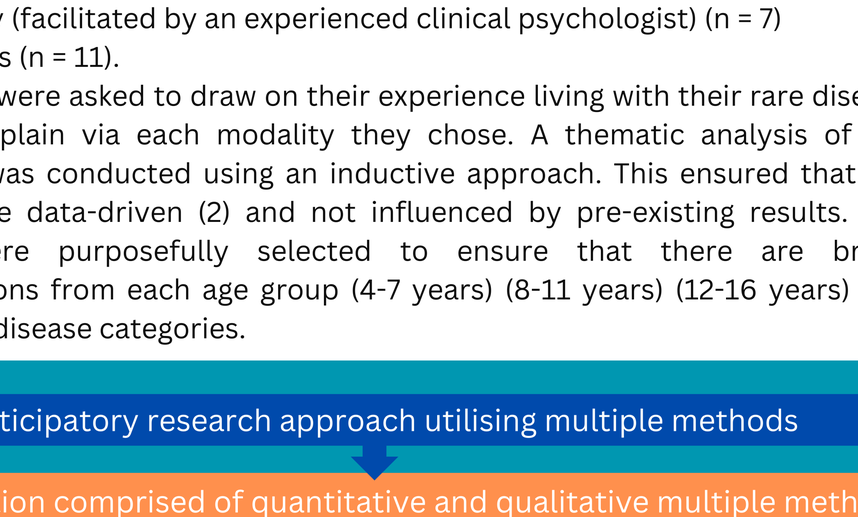


Figure 1: Participants' sand play trays, from the SAMPI Sand Play Modality

Themes:

- Danger or Threat
- Resistance
- The Self
- Burying Things
- Feeling Different
- The Role of Diet in Rare Disease Treatment

ART

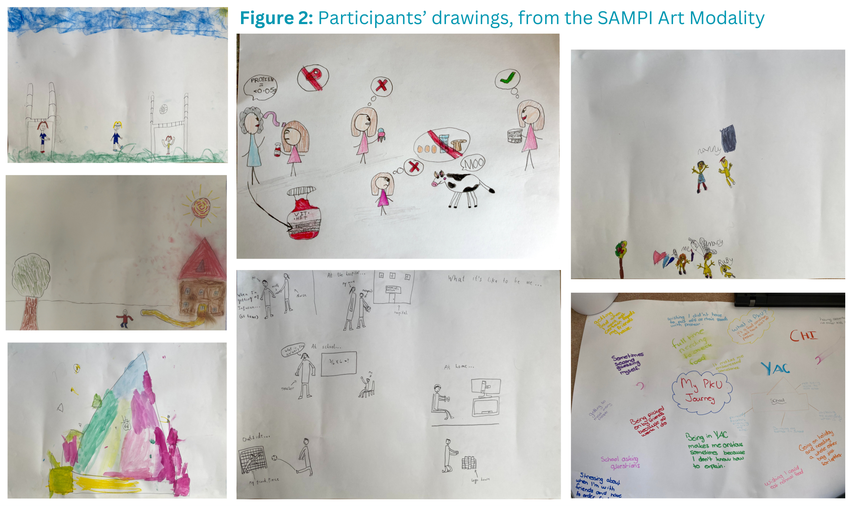
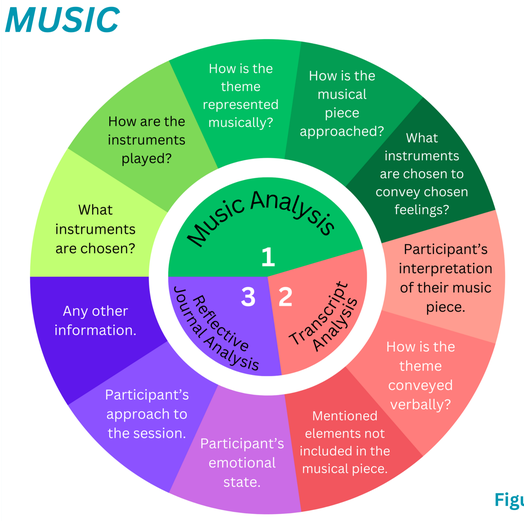


Figure 2: Participants' drawings, from the SAMPI Art Modality

- Knowledge and Understanding of Rare Diseases
- Fitting In vs. Feeling Different

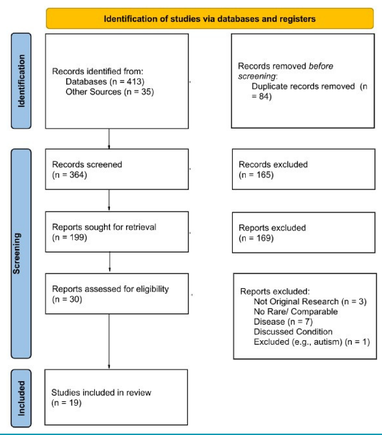
MUSIC



- Positive Experiences
- Negative Experiences
- Finding the Child's Voice
- Rare Disease as a Journey

Figure 3: Data Analysis Framework, adapted from Buckle et al. (3)

MUSIC SCOPING REVIEW



- Physiological & Clinical Support
- Psychological Wellbeing

Figure 4. Prisma Flow Diagram of Scoping Review Study Selection Process

PARENT'S SUPPORTIVE CARE NEEDS (PNS-RD)

Themes:

- Understanding the Rare Disease
- Working with Healthcare Professionals
- Emotional Challenges
- Financial Needs

Results and Conclusion

Results: Frameworks were developed to analyse each modality thematically. The common themes that emerged across all the modalities were 'Normal vs Different', 'Family: Present vs Hidden', and 'Friends'. These themes highlight the contradictory experience of living with a rare disease and the role of family and friends in influencing the participants' experiences. For parents, the emotional and psychological impacts of having a child with a rare disease were identified as a significant burden.

Conclusions: Developing a data analysis framework (3) benefitted the thematic analysis of each modality. This study concludes that sand play, music, art and interviews can aid health and social care professionals in understanding children's experiences living with rare diseases and their unmet psychosocial care needs.

Affiliations:

1. UCD School of Nursing, Midwifery and Health Systems, University College Dublin, Belfield, Dublin 4, D04 C1P1, Ireland.
2. Childvision Dublin, Grace Park Road, Drumcondra, Dublin 9, D09 WKOH, Ireland.
3. Children's Health Ireland at Temple Street, Temple St, Dublin 1 D01 XD99, Ireland.
4. School of Psychology, Trinity College Dublin, the University of Dublin College Green, Dublin 2 D02 PN40, Ireland.

References:

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For more information, please contact the Principal Investigator of the SAMPI Project: Dr Suja Somanadhan (suja.somanadhan@ucd.ie).