

EMPOWERING YOUNG WOMEN WITH THE RARE GENETIC DISORDER 22Q11.2 DELETION SYNDROME TO SHARE THEIR LIVED EXPERIENCE OF MENTAL HEALTH

Lorna Kerin (Lorna@loveknowledge.ie). Kerin, L.¹, McNicholas, F.², Lawlor, A.³

¹ Love Knowledge Consultancy, ² UCD Child and Adolescent Psychiatry, ³ 22q Ireland.

1. Purpose

Although young people with the genetic disorder 22q11.2 Deletion Syndrome are at elevated risk of psychiatric disorders (Schneider, 2014), their lived experience and voice has not yet informed the development of programmes or services that are responsive to their mental health needs.

It is internationally acknowledged best practise (UNCRC, 1989) and national policy (DCYA 2015) to facilitate the participation of youth in research issues that concern them.

This research project therefore aimed to privilege young people's experience and voice through participatory action research with the goal of hearing and communicating their mental health needs to policy makers and clinical service providers.



2. Method

Research Process

- Six participants aged 18-35 years old were recruited onto an 'Irish Youth Expert by Experience Panel' through the national family support organisation.
- Four creative arts based groups were facilitated to support peer group cohesion and to identify emergent key themes
- Two video recorded focus groups were conducted on six identified mental health themes and these groups were additionally supported by a consultant Child and Adolescent Psychiatrist
- A digital story was created of participants' discussion of mental health themes in the focus groups
- Participants collaboratively presented this digital story and their experience of the research process at the national 22q11 Ireland conference
- A shared research dialogue was co-facilitated by the collaborating clinician, researcher, youth panel member and parent at the national Children's Research Network Ireland and Northern Ireland (CRNINI) conference

Participatory Action Research methods included:

- Somatic methods to decrease anxiety (body awareness, mindfulness, breathing techniques, progressive relaxation or yoga nidra)
- Narrative, arts based methods to increase group cohesion and creative expression (body mapping, lifeline, photo collage, creative writing)
- Photovoice methods to facilitate voice and resistance to invisibility & silencing
- Digital storytelling methods to disseminate key messages(MDT clinic targeted at clinicians & policy makers, mental resilience message targeted at parents)

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Contact: Lorna Kerin lorna@loveknowledge.ie ,
Fiona McNicholas Fiona.mcnicholas@ucd.ie Anne Lawlor alawlor4@gmail.com



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3. Research Project Design

Phase 1: Planning

Funding application to Irish Research Council, UCD ethics approval; Participant recruitment via 22q Ireland; Project logistics



Phase 2: Action

Preparatory groupwork, data collection through creative artwork, photovoice, journaling and focus groups



Phase 3: Reflection and Dissemination

Collaborative review and editing of video footage to produce a digital story; Presentation by YEEP members at the national 22q Ireland conference presentation; Research dialogue presentation with collaborators at national Children's Research Network conference.



4. Key findings: The young women identified six key themes related to mental health that they wanted to discuss. These were: (1) Acceptance (2) Anxiety (3) Communication (4) Friendship and Relationship (5) Mental Resilience (5) Telling Other People.

When asked to reflect after the focus group discussion on the value of participating in this narrative, creative research, the following themes emerged:

1. Participation increased protective factor of mental health awareness and literacy:

'Being in a group helped me talk about how I feel. For example we talked about thoughts and feelings and mental health which usually we don't talk about every day. We need to talk about mental health more.' (Ai)

'We all experience anxiety and feeling stress and down from time to time.' (E)



2. Participation decreased risk factors of social isolation & stigma and increased protective factors of belonging and confidence

'Growing up I always thought I was the only one who had this syndrome, I thought wrong. I used to feel lonely and afraid. But then I met these lovely ladies who now I call friends for life' (Ai)

'It has made me feel more confident with having 22q as I didn't really like to talk about it with anyone else. But when your in a group with people that have it, it makes it so much easier and it takes the stress off you because they know how you understand and feel about it.' (A)

'I learned that we are the only ones that understand about us like nobody else.' (E)

'I feel a bit more confident since being part of the group because I am surrounded by people who are going through the same things as me and it helps that I have someone to turn to.'

'It was a nice feeling being in the same room as other people who have the same condition as you, and not being under pressure to have to fit in.' (Ai)



Finding 3: Participation increased acceptance of having 22q11.2DS and the uniqueness of having this rare condition

'I found the group very worthwhile, it helped me accept my condition more.' (E)

'Just tell everyone about 22q, it just makes life easier. You get so much help and support once you trust friends' (S)

Finding 4: A multidisciplinary care center staffed by a care coordinator and experienced clinicians would best support the complex medical, psychiatric and mental health needs of children, young people and adults with 22q11

'I think there should be doctors in the clinic to talk about anxiety as it is common for everyone with 22q and the doctors should know how to help me to cope with anxiety and big groups. Sometimes I hear sounds and voices like ghosts and I think doctors should be able to help.' (K)

'It's important that doctors understand about 22q because it's really annoying when they don't understand. I think we should have lots of different doctors in one clinic because we need to see bone doctors or our spine, back and hips and a dentist that doesn't make us stress and a blood doctor cos our immune systems are so low. We also need a foot doctor and a heart doctor and a lymphedema doctor. And doctors should understand learning difficulties and mental health and nutrition and there should be genetic counsellors and counsellors that help with anxiety - anything that helps!' (S)

'I think the clinic should have a care coordinator to help and be there at appointments. I want the doctors to read the files before we come in so we don't have to explain

ourselves and they should educate the new doctors who come in. Doctors should talk to the 22q patient first and then to the parent or carer or partner.' (Ai)

'I think the clinic should be colourful and friendly and the doctors should listen to us and explain stuff in a way that we can understand.' (N)



Finding 5: The young women encouraged and inspired parents at the 22q Ireland by sharing their lived experiences and advice to younger children and parents

'We would like a lot more interaction with the YEEP group!' (Parent)

'The YEEP group were fab!' (Parent)

'We would like the 22q children and young adults to get to know each other and possibly form friendships!' (Parent)

'Would like to see construction of the YEEP group for the next generation of young adults or a similar group!' (Parent)

'Perhaps the most important thing that I personally have observed are the benefits that the YEEP group themselves have reaped. I have watched them grow in confidence and strength. They have formed a bond with one another, a unique sharing with one another of what life is like being a young adult with 22q11.2 DS and this in turn has empowered them to share their experiences with the rest of us. They are teaching us!!!' (Volunteer with 22q Ireland)

'We received a lot of informal feedback from (conference) attendees. Many expressed how emotional they found the YEEP group's presentation and how inspiring they were especially to those who have young children. The group gave them great hope for their children and for what they could achieve!' (Volunteer with 22q Ireland)