

Exploring the Impact of Creative Arts Programming on the Psychosocial Well-being of Families with Children with Serious Illness

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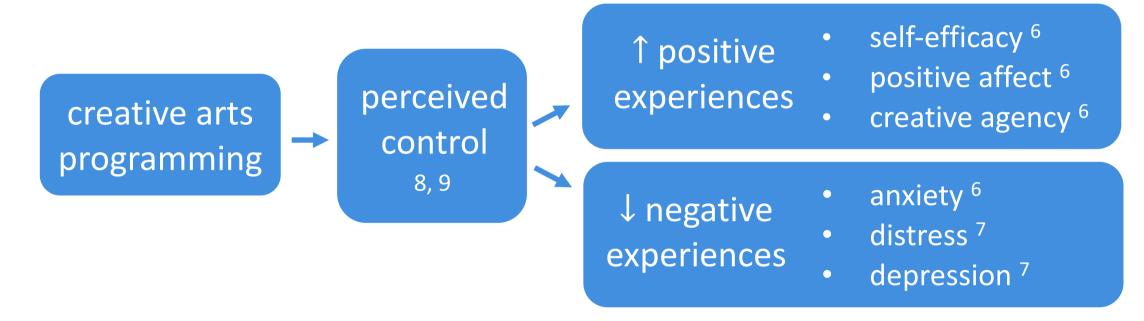
Background

Context & Gap:

- Our Space, Inc. is a non-profit that brings art programming to families with children with serious illness in the Boston area
- Focuses on healing powers of art and human connection
- Current gap: Our Space lacks the impact data that makes grant applications competitive

<u>Literature review:</u>

- diagnosis of pediatric illness is a low-control situation ¹ that challenges one's sense of personal control ²
 - all family members experience this loss of control
 - resulting impact on psychosocial well-being includes high levels of stress and anxiety ^{3, 4, 5}
- creative arts programming has been found to positively impact the psychosocial well-being of adult patients ^{6, 7}



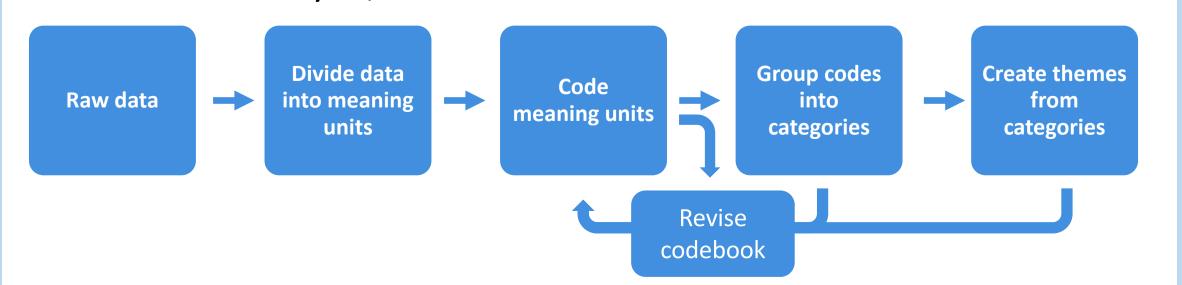
yet there is limited research on the impact of creative arts
 programming for pediatric patients or their families

Purpose & Aims

- 1. employ interviews to qualitatively explore the impact of creative arts programming on the psychosocial well-being of families with children with serious illness
- 2. produce data illustrating impact of Our Space programming

Methods

- helped run in-person and virtual Our Space events
- semi-structured interviews conducted over Zoom with 6 previous
 Our Space participants (5 parents, 1 child)
- participant demographics collected via survey
 - 3 female: 3 male | ages: 16-59 | all identify as White
- Zoom transcripts edited for accuracy against recording
- interview contents coded in iterative process of qualitative content analysis, with use of Nvivo ^{10, 11}



Results

Research question #1 ("Context"):

How does diagnosis and treatment of serious illness impact the psychosocial well-being of families with children with serious illness?

"It was what we had to do though, you know and, but we all understood that. My son, my husband, [daughter] and I we both, we all understand that we had to. If we had a chance, if we were going to get to have a chance at her living, we would have to do whatever we had to do" (2)

context

impact

"it's just fun to see their the you know

the kids wheels turning and and see

them get excited
about having control
over their little
project, you know
when there's so much
they can't control you

they can't control you
they can decorate this,
however they want"

facilitating
connection

context

"it's a little bit of a lonely journey when you're far away from home" (4)

impact

providing a

sense of

control

"It matters a lot to have some experience. So when Gail was able to talk with [child] and, I imagine this is the same with a lot of the kids, about her experience being bald, about her experience getting shots and being in the hospital and taking chemo, that's a real point of connection. And it makes kids feel like 'oh yeah, we we both know what that's like'" (1)

Research question #2 ("Impact"):

How does Our Space impact the psychosocial well-being of families with children with serious illness?

"24 hours a day, seven days a week, all the time you think about it. It's you know you're constantly thinking about what we can do, what we need to do, where we need to go" (2)

impact

context

an escape from the bad

supporting siblings

been hard and we.

And just knowing
that I was in
treatment, and it
was like she was
separate from us,
but she also felt the
exact same pain that
we did" (6)

"it was like just

kind of an escape

in a way to take

your mind off the

other stuff going

on and an avenue

to focus your

attention" (3)

"That must have

impact

context

"she loved it especially being with
[her brother] and then because she
saw [him] in a very difficult
situations. For teenagers, you know
16 years old, giving her the
opportunity to see her brother also
laughing and having fun, even
though going through this" (5)

Strengths & Limitations

- Strengths: coded data twice and cross-checked, annotated audit trail of analysis, kept data organized
- Limitations: small sample size, convenience sample where many participants have long-lasting relationships with Our Space, only 1 coder (triangulation not possible)

Conclusion

- Our Space impacts well-being in a way that begins to address common experiences that negatively affect well-being of families
 - connection in time of isolation, choice during loss of control, opportunity to escape stressors, and supporting siblings when the attention is focused on child with serious illness
- results suggest arts programming can address unmet psychosocial needs of children with serious illness, as well as their family
- project produced critical Impact data for Our Space
 - results shared via infographic and written report
 - data will strengthen future grant applications
 - grant funding would provide the stability critical to sustaining and expanding programming (number of visits, different locations)



Infographic

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