Building a Health and Wellness Clinic with Patients and Families: The Application of Experience-based Codesign to Paediatric Weight Management

> Jennifer Green, RD, MSc October 25th, 2016

DISCLOSURE OF CONFLICT OF INTEREST

I do **not** have an affiliation (financial or otherwise) with a pharmaceutical, medical device or communications organization.



Learning Objectives

By the end of this presentation you will:

- Have a basic understanding of how patients and families can be engaged in the creation a paediatric weight management clinic
- Be familiar with how to use patient and family feedback to change program components



Outline

- Background
- Methods
 - Initial Focus Groups
 - Pilot Programming Focus Group
- Results
- Discussion
- Next Steps



Background

- The KidFit Health and Wellness Clinic started in September 2015 (in one year have received over 350 referrals and completed over 110 new assessments)
- Trillium Health Partners (Mississauga, Ontario)
- Referral Criteria:
 - Ages 2-17
 - BMI > 95th percentile

Team:

- Paediatric Endocrinologist
- Registered Nurse
- Child Psychologist
- Social Worker
- Registered Dietitian
- Activity Therapist
- Senior Project Manager
- Clinic Manager





Background

- Attrition rates from paediatric weight management programs ranges from 27-73%¹
- One of the primary causes cited is the disconnect between patients' and families' expectations of the program, and actual program focus and components^{2,3}

Skelton, J. A., & Beech, B. M. (2011). Attrition in paediatric weight management: A review of the literature and new directions. *Obesity Reviews, 12,* e273-e281.
 Barlow, S. E., & Ohlemeyer, C. L. (2006). Parent reasons for nonreturn to a pediatric weight management program. *Clinical Pediatrics, 45,* 355-360.
 Giannini, C., Irby, M. B., & Skelton, J. A. (2015). Caregiver expectations of family-based pediatric obesity treatment. *American Journal of Health Behaviour, 39*(4), 451-460.

Health Partners

Better Together

Background

- One way to address this gap is to engage patients and families in the development of the program
- Informed by *experience-based co-design*
 - An approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership. ⁴

4. Donetto, S., Tsianakas, V. & Robert, G. (2014). Using Experience-based Codesign to improve the quality of healthcare: mapping where we are now and establishing future directions. London: King's College London. Health Partners

Better Together





Creation of the Patient Engagement Strategy

- Staff created together

3 main questions:

- 1. Why do we want to engage patients?
- 2. What do we hope to achieve from this strategy?
- 3. What are the underlying principles?

Underlying Principles

- 1. Truly value and utilize patients' and families' input
- 2. View patients and families as experts
- 3. Patient engagement should be an ongoing and sustainable process







Methods

First Focus Group

- Participants were parents of children awaiting initial assessment (recruited via phone calls from patient relations)
- 90 minute focus group facilitated by KidFit staff
- Informed consent obtained and session was audio recorded
- Recordings were professionally transcribed
- Data analyzed using principles of thematic analysis



First focus group



- 7 parents participated in the focus group

3 areas explored:

- 1. Language (name of the clinic)
- 2. Previous experience with weight management
- 3. What would be important to include in the KidFit program
- Received ++ feedback regarding language and stigma (e.g. terms such as "weight" or "body")



Results

Importance of Language



John (KidFit Parent):

"As soon as she says the word **'am I obese?'** and it's like mmmmmm....it's like it's all negative all of the sudden and it goes from being positive to negative"

Sarah (KidFit Parent):

"I didn't like 'minds' in that one, I liked 'healthy bodies', but I had a problem with minds, because it had a sort of connotation that you're unwell, that it's your fault, it's in your head"



Results



Importance of Language

Impact:

- KidFit Paediatric Weight Management Clinic
 → KidFit Health and Wellness Clinic
- Creation of the clinic vision statement:
 Small steps, Lasting change, Lifelong wellness







Methods

Focus Groups Post-Pilot Program

- Participants were parents and youths that took part in the pilot programming (recruited via phone calls from patient relations)
- Two 90 minutes focus groups(one group with parents, one with kids/teens)
- Informed consent obtained and session was audio recorded, and student note takers present
- Recordings were professionally transcribed
- Data analyzed using principles of thematic analysis



Methods

- Total of 10 participants (6 parents and 4 youths)
- Facilitated by staff from the Institute for Better Health (Research Institute) at Trillium Health Partners

3 areas explored:

- 1. Experience in the pilot group program
- 2. Format and content of the 12-week intensive program
- 3. Experiential hands-on learning vs. traditional didactic approach (Moving vs. sitting)



Results



Importance of building in physical activity

Robert (KidFit Parent):

"She's been at school all day and then she's coming here and then to be sitting down first thing again, I think - you know, **you can make it really interesting when you bring it into an activity**."

Impact:

- 7 out of the 12 sessions included activity
- On days where activity was not included, open
 - gym was offered before or after group





Discussion

Lessons learned:

- Parents were accepting of the method and appeared to enjoy the experience
- Kid/teens showed fatigue with the format of engagement
- Best if facilitators do not provide direct patient care, but are also familiar with the program



Next Steps

- Repeat program with embedded focus groups for next cohort in 12-week intensive phase
- Alter the kid/teen engagement method to be more hands-on
- Formalized method of staff engagement
- Explore as a team options for truly codesigning with families and patients



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Thank You!

Comments? Questions?

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