

Formative research as a tool to address ethical concerns during a family-based home-based counselling and testing (FBCT) intervention development process in KwaZulu-Natal

N. Ngcobo¹, Z. Essack¹, N. Gillespie¹, L. Knight², T. Rochat¹ and H. van Rooyen¹

¹Human Sciences Research Council, South Africa, ²School of Public Health, University of the Western Cape, South Africa
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Introduction

Home-based counseling and testing (HBCT) is a highly acceptable, scalable, and cost-effective method to increase HIV testing and linkage to care in sub-Saharan Africa(1). The HSRC team has developed and evaluated a HBCT model that achieved >90% coverage of HIV testing of adults in households, identified HIV-infected persons early and linked 90% of the participants to care by 6 months. A family-based home-based counseling and testing (FBCT) model was developed with the aim of testing hard to reach groups (children, adolescents, couples and men), increasing linkage to care, facilitating disclosure and addressing family level stigma.

Formative research involves collecting data useful for the development and implementation of intervention programs. It can be used to make intervention programs both culturally and geographically appropriate (2). Formative research was undertaken to explore the familial, sociocultural and community factors that could impact the effective delivery of a FBCT model. Following formative research we identified that many of the concerns raised by respondents were ethical issues.

This poster aims to present the ethical concerns raised key informants (KI) and community stakeholders (CS) using a popular ethical framework for research in developing countries by Emanuel et al.(3).

Methods

Study Design	Qualitative study
Sample	20 x Key Informants 20 x Community Stakeholders
Data Collection	In-depth interviews
Discussion topics related to the FBCT model	<ul style="list-style-type: none"> FBCT Model Ethical considerations Potential social harms Implementation challenges Barriers to uptake Facilitators to uptake Considerations related to different members of the family unit
Data analysis	Thematic analysis
Software	Nvivo 10

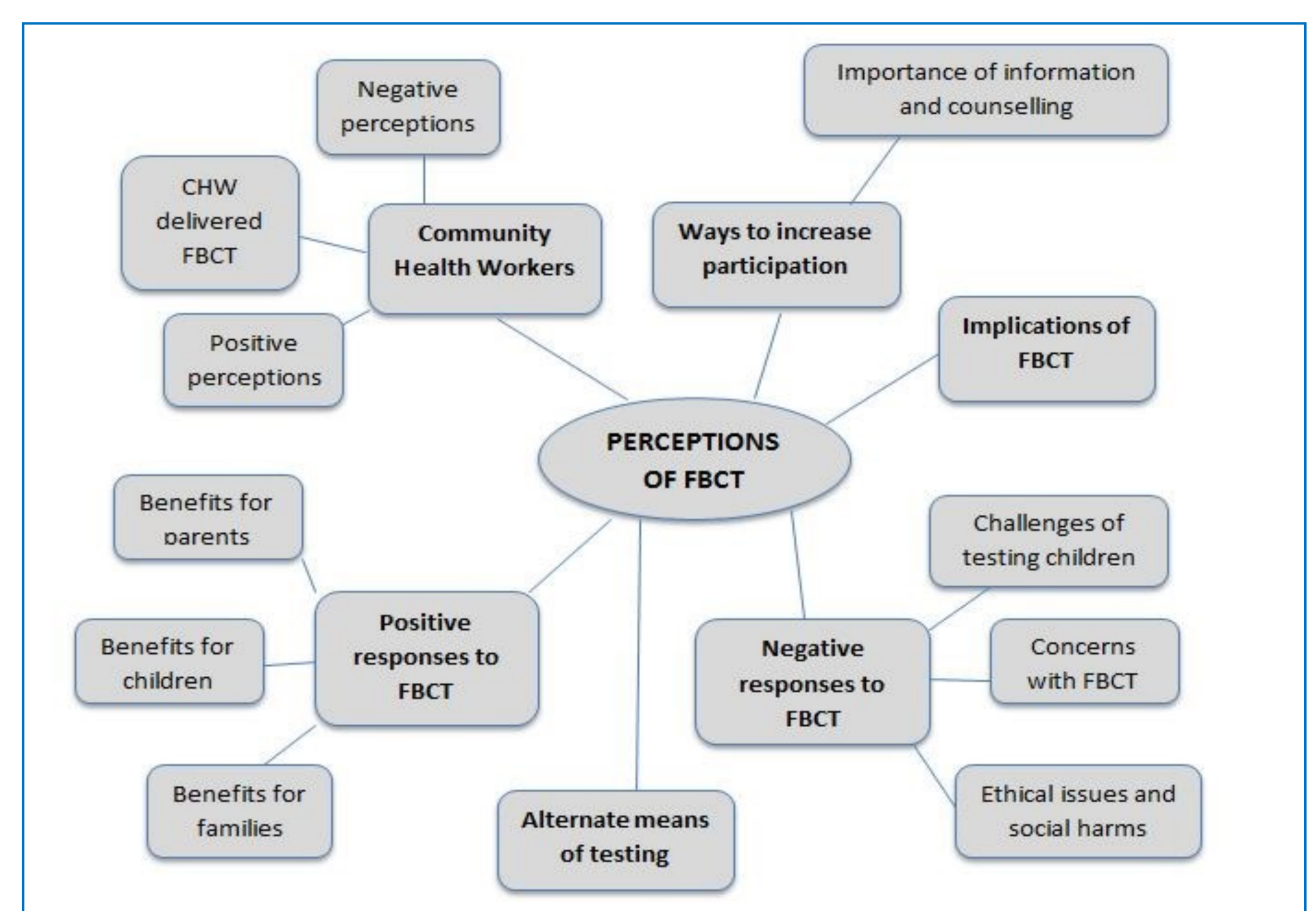


Figure 1: Thematic analysis of perceptions of the FBCT model

Results

Formative research identified areas of support and concern regarding the FBCT intervention. Following Emanuel and colleagues these can be clustered according to eight key ethical benchmarks: collaborative partnerships, social value, scientific validity, favourable risk/benefit ratio, informed consent, independent review, fair selection of participants, and on-going respect for participants. Some of these concerns are identified below.

Respondents reported potential positive outcomes of the intervention including enabling families to access a service at home rather than a clinic (**risk-benefit ratio**) and improved opportunities for disclosure (**social value**) which could lead to support within the family.

"Because when I go to the clinic, I go alone. Get tested alone. Leave the kids at home. But if I do it in front of the kids, they will realise it is the right thing to do". CS, female, 31

"so it helps because it makes them feel free because they are at their homes and they know everybody... because I think by the time the health care gives encourage disclosure between themselves as a family they will support each other; unlike when a family member go for testing at the clinic or the store". KI, male, 24

Concerns that adolescents will be coerced to test for HIV relates to **informed consent**, and fears of disclosing to family members and the broader community relate to **risk-benefit considerations**.

"Another challenge the families on their own have, maybe you will find that aunt is talkative, and would gossip because the family is big, maybe family members do not get along well so this aunt will take the news from one to another and you will find them insulting each other in the streets live". KI, male, 24

"The challenges that you might face along the way because you will find that a person used to go for virginity testing and now she doesn't but she's now being tested for HIV...she will be scared to test because she knows that she's now sexually active. And for a parent, it won't be a problem to say test my child". KI, male, 35

Respondents raised concerns about confidentiality of their HIV results which relates to the principle of **on-going respect for participants**.

"Maybe the negative thing that I could highlight with using Community Health Workers is that they know the family and then the issue of trust and confidentiality. You see. Then maybe I think the negative thing about them is that it would be someone from the community who will also work within that community. I don't think that would be a good idea even those people in that family, they will not trust him or her. They will not be able to be open and disclose to them". KI, female, 36

This data was used to refine the intervention and address stakeholders' concerns by engaging the community, training intervention staff on ethics, and incorporating independent consent mechanisms for adolescents that recognizes their legal right to independent testing but allows opportunities for family-based testing and disclosure.

Conclusion

Formative data from the interviews with key informants and community stakeholders assisted the research team to address concerns about confidentiality and disclosure prior to piloting the FBCT model. The data also assisted in addressing family, socio-cultural and community factors that may impact the effective delivery of a FBCT intervention.

References

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