



Application of Motivational Interviewing (MI) Strategies with the Extended Parallel Process Model (EPPM) to Improve Risk Communication for Parents of Children with Familial Hypercholesterolemia

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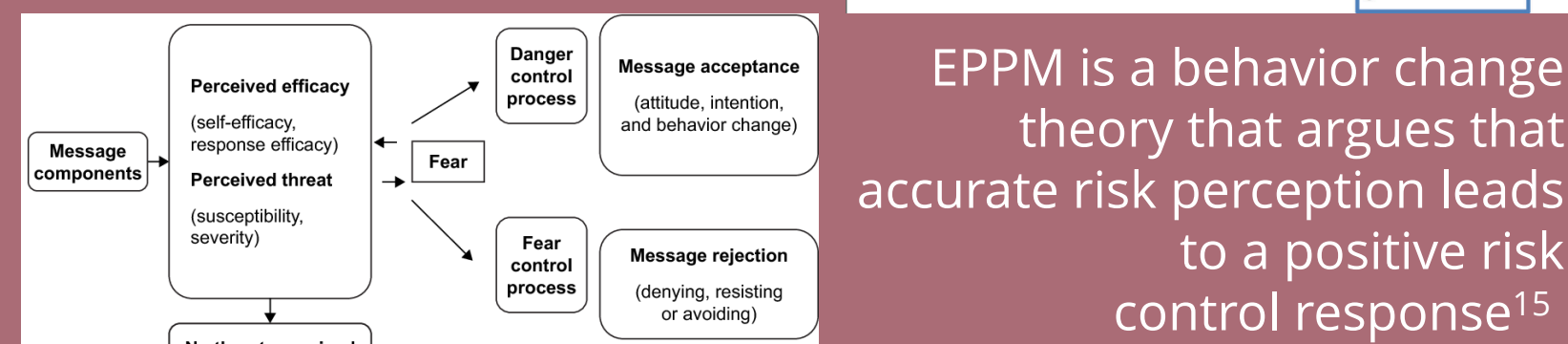
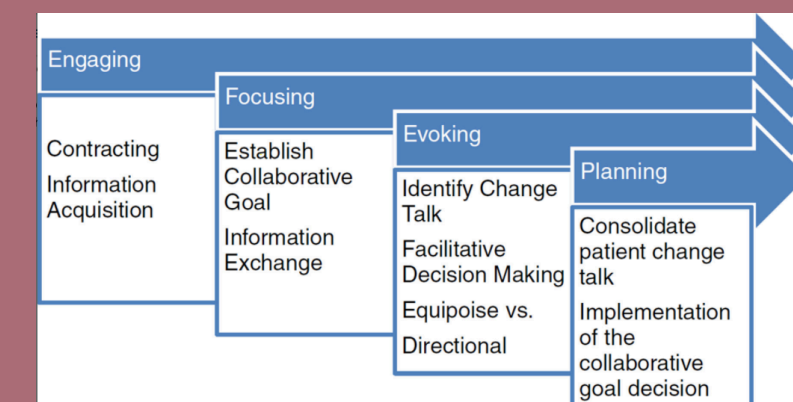
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Background

Positive health outcomes rely on family communication, especially for hereditary conditions¹⁻¹¹

- Several known common motivators and barriers to risk communication
- Facilitation of genetic information is described as both a benefit and outcome of genetic counseling, and yet, traditional non-directive counseling strategies do not increase risk communication

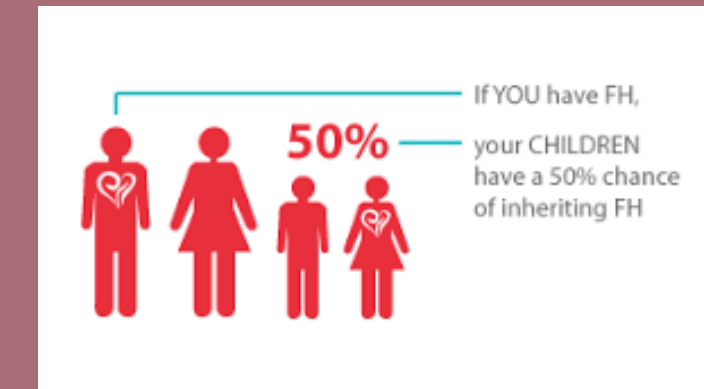
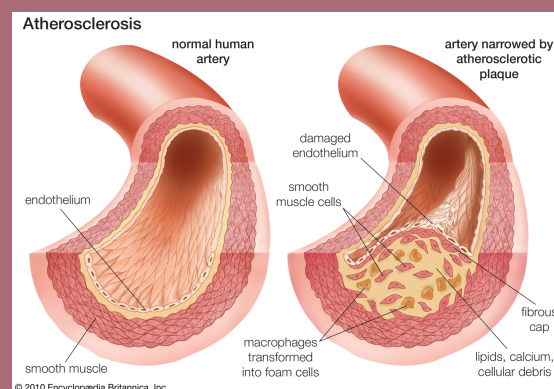
Motivational Interviewing (MI) is congruent with REM and evokes patients' own motivations for change and adherence to treatment¹²⁻¹⁴



EPPM is a behavior change theory that argues that accurate risk perception leads to a positive risk control response¹⁵

Familial Hypercholesterolemia (FH)¹⁶⁻¹⁹

- AD condition that affects 1/250 individuals, with only 1-10% of individuals diagnosed in the US
- American Heart Association (AHA) and the American College of Cardiology (ACC) and the CDC prioritized FH as one of three top tier 1 genetic conditions with a great need for implementation of cascade screening



The primary aim of this study is to investigate the efficacy of genetic counselor motivational interviewing strategy integrated with the extended parallel process model, and its association with self-motivating statements (change talk) and risk communication

Methodology

1. Intervention Guide

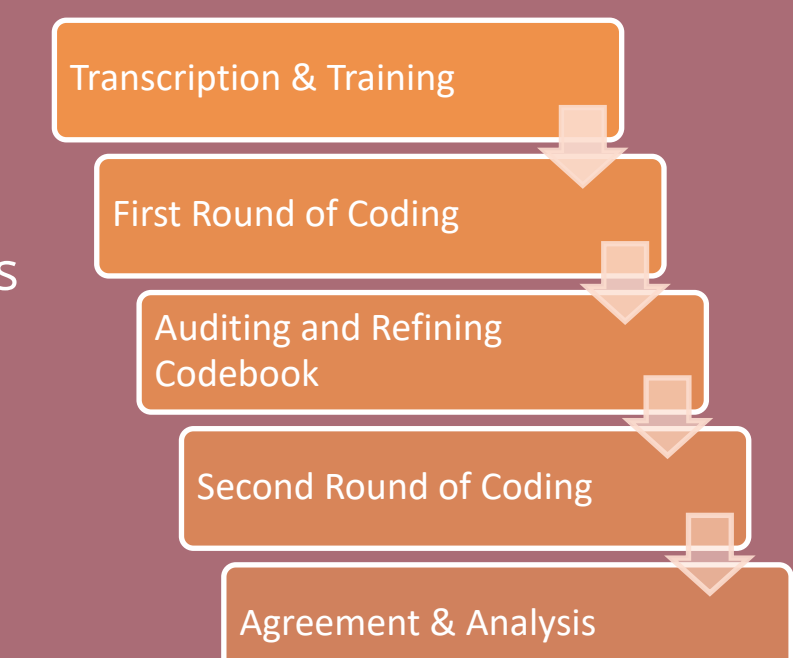
GC-MI Intervention guide²⁰ including: pre-survey, phone call intervention (mean duration of 54 minutes), 2 post surveys (1 & 6 months)

2. Recruitment

2 phase recruitment through UMN Lipidology clinic & FH Foundation via in-clinic, letter, and newsletter

3. Directed content analysis

Via the Motivational Interviewing Skill Code version 2.1 (MISC 2.1) framework and QSR International's NVivo 12 qualitative data analysis software. Assessed agreement via Kappa (κ; range -1 to 1).



κ = 0.98 for all codes
κ = 0.93 for positive/neutral codes

4. Inductive Thematic Analysis

Audio files and transcripts were analyzed for emergent themes that address the complex environment surrounding familial communication and cascade screening. Relevant quotes were selected to illustrate identified themes.

5. Statistical Analysis

- Multivariate analysis of variance (MANOVA) to assess for effect size
- Analysis of variance (ANOVA) was conducted to assess the impact on each EPPM construct on participant change talk

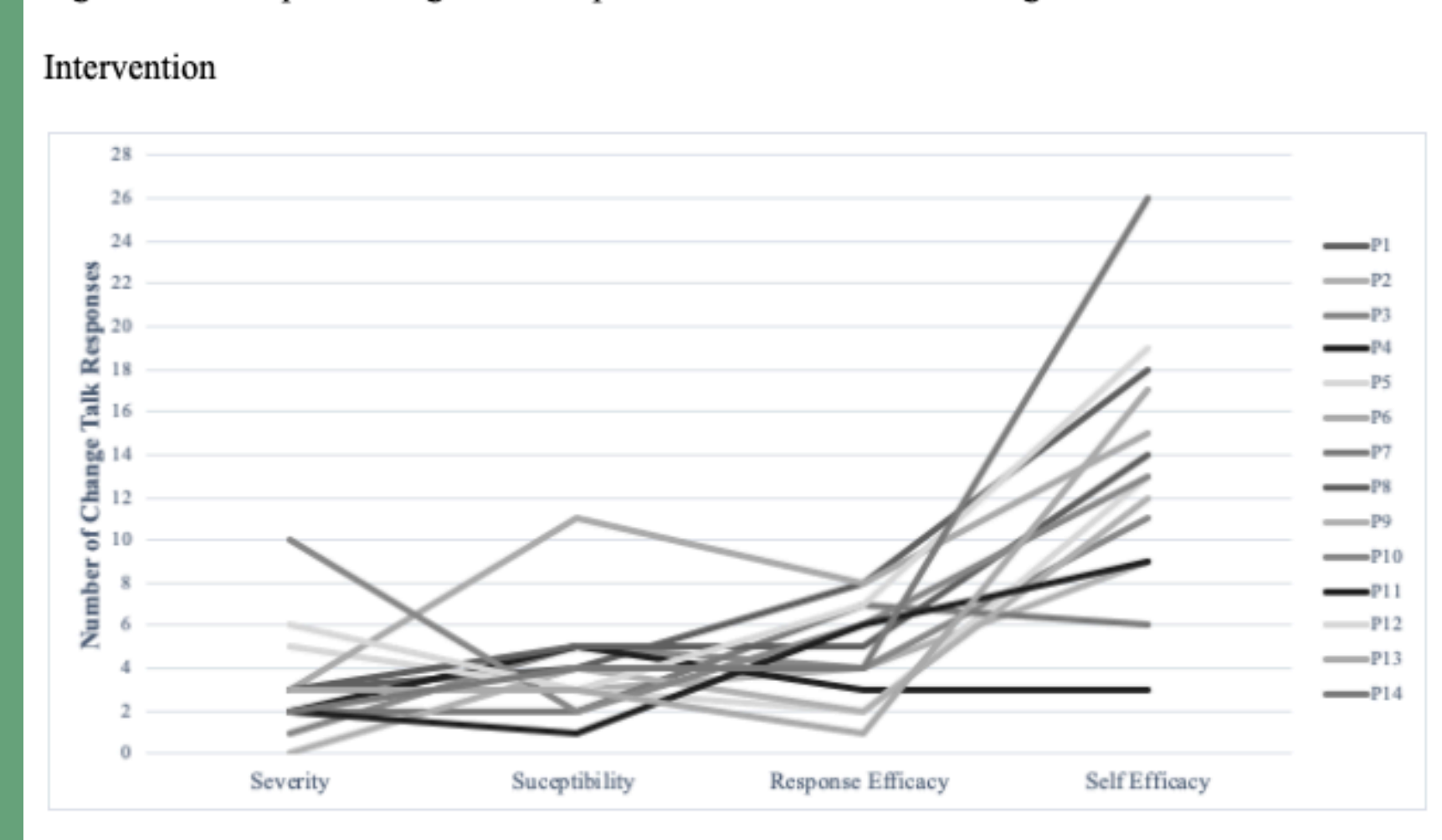
Results & Discussion

- 4 out of 12 available (33%) participants communicated to additional relatives during our intervention
- There was a very large effect size ($\eta_p^2=0.43$), which was driven by the difference in change talk when discussing perceived susceptibility of family members ($\eta_p^2=0.41$)

Table 1. Demographics	n (%)
Total Participants	14
FH status	
Participant has FH	6 (42.8%)
Other biological parent has FH	6 (42.8%)
Unknown	2 (14.3%)
Race	
White, not Latin	13 (92.8%)
White, Latin	1 (7.1%)
Gender Identity	
Woman	12 (85.7%)
Man	2 (14.3%)
Marital status	
Married	12 (85.7%)
Divorced	1 (7.1%)
Unmarried couple	1 (7.1%)
Highest level of education	
High school graduate or GED	1 (7.1%)
Vocational/technical school graduate/certificate	1 (7.1%)
Some college, but no degree	4 (28.6%)
College graduate (BA, BS)	6 (42.8%)
Postgraduate/professional degree (MA, MS, PhD, MD, etc.)	2 (14.3%)
Total Household Income	
less than \$15,000	1 (7.1%)
\$15,000 or more	11 (78.6%)
would rather not report	2 (14.3%)

Separated by the 4 phases of the EPPM, we saw an increase of change talk responses throughout our GC-MI intervention (Figure 1.)

Figure 1: Participant Change Talk Responses across the EPPM throughout the GC-MI Intervention



Inductive Thematic Analysis Quotes

How to Approach Information Delivery

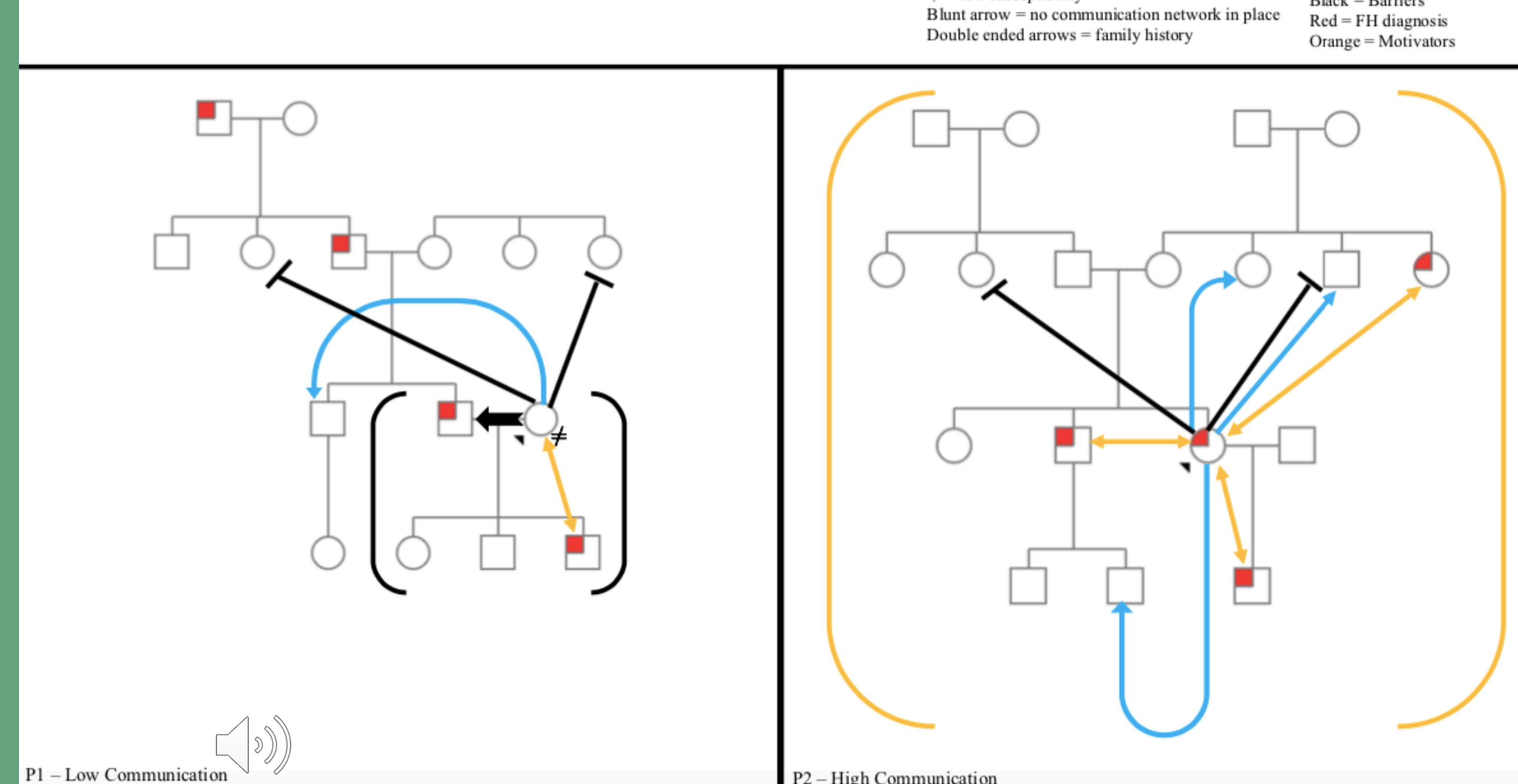
P1, FH+: "...so my youngest as I've mentioned has type 1 diabetes, so her risk profile is more hour by hour with insulin so we really don't have that much to communicate about this, given that she's taking Statin once a night, that's sort of an easy thing for her...[Reason +]
GC1: Right, right. For her the diabetes, I mean Statin once a night versus the daily you know the hourly checks, the Statin once a night must feel pretty minimal [Reflect]"

Lack of Outward Differences Can Be Deceiving

P12, OBP: "you look at my 11-year-old who weighs like 65 pounds and is like 5'2 you would never think in a million years that she has high cholesterol. You know I would have never thought that. [Reason +]"

P8,OBP: "Makes me feel like I need to be more proactive...what we've talked about in our family is the tricky thing about cholesterol is not something you can see and feel and so it's really easy to forget and kind of make choices and decisions not based on what's actually going on inside of your body when it's not affecting the way you feel now and...the long term and how hard it is to undo anything that's already there so...shocking. [Reason +]"

Figure 2: Impact of Family Dynamics on FH Risk Communication. Pedigrees have been modified to maintain anonymity of the participants.



Two participants who communicated to additional relatives throughout our GC-MI intervention, each family faced unique environmental circumstances outside of the intervention. We hypothesize the difference in levels of communication between P1 and P2 may be due to these factors (Figure 2).

Underestimation of Risk Severity

P11, OBP: "...for some reason during that period of time they said: 'oh they're just, they're too young it's no big deal' [Other -]"

P6, FH+: "I mean people take it lightly 'oh you have high cholesterol you're on statins' but nobody looks...at the impact it has on your quality of life or your functioning of life, you know. You just learn to push through. [Reason +]"

Motivators to Communication

P8, OBP: "Well, I wonder if his sister has had her kids screened and I think that would probably I would encourage him to have a conversation with her about it...they're not really very proactive typically so I just wonder if, if she's ever had her kids screened. [Taking Steps+]"

GC1: Yeah yeah so there's a different level of healthcare maybe involvement [Reflect]

P8, OBP: Just kind of knowledge...I didn't realize with that 50% I would say my husband needs to call his sister. [Reason +]"

Barriers to Communication

P13, unknown: "Yeah, it's just, we're in a different age now and my stepmom is the primary driver of that poo-pooing and she's a nurse...but it always seems to come back to well 'people live long lives and they probably had all this stuff and we didn't know about it'... It's what I battle. [Reason +]"

P12, OBP: "A lot of them [other children] haven't even been suggested that they screen their kids for cholesterol and that's actually a little bit scary to me..."

Conclusions & Limitations

- The first GC-MI intervention developed for FH
- There are significant communication and environmental context barriers to overcome for index patients
- Our study had a comparable increase in communication to other interventions, such as letters and videos, that attempt to increase risk communication about genetic conditions²¹⁻²⁶
- Perceived susceptibility may be a motivating factor to increase communication²⁷. Further research is needed.

Limitations

- Small sample with no randomization of control group to evaluate efficacy completely
- Motivated participants - already have increased severity/susceptibility?
- Variability in interventions (semi-structured)
- Variability in time since diagnosis
- Potential discrepancies between neutral and change talk (tonal differences of participants)

Practice Implications

- Alternative approaches are needed to increase risk communication and cascade screening for FH²⁸
- May suggest the need for increased MI education and training in GC programs

References

1) d'Agincourt-Canning, 2001; 2) Forrest et al., 2003; 3) Gaff et al., 2007; 4) Kenen et al., 2004; 5) Koehly et al., 2003; 6) Marteau & Richards, 1999; 7) Metcalfe et al., 2008; 8) Young et al., 2017; 9) Wiseman et al., 2010; 10) Wurtmann et al., 2019; 11) van den Nieuwenhoff et al., 2007; 12) de Geus et al., 2016; 13) Rollnick et al., 2008; 14) Ash, 2017; 15) Witte, 1992; 16) Najam & Ray, 2015; 17) Akiyamen et al., 2017; 18) Nordestgaard et al., 2013; 19) Grundy et al., 2018; 20) Kruger et al., 2019; 21) Miller et al., 2008; 22) Dheensa et al., 2018; 23) Forrest et al., 2008; 24) Harris et al., 2019; 25) Sermijn et al., 2016; 26) Suthers et al., 2006; 27) Birmingham et al., 2015; 28) Gidding et al., 2020

Acknowledgements

This study was completed as part of the larger Cholesterol Evaluation to Explore Risk Screening (CHEERS) project with the overarching goals to:

- to improve the identification of individuals with high cholesterol through talking with parents of a child with high cholesterol
- to increase communication of information about high cholesterol to their other family members.

