

Identification of Key Themes Related to Quality of Life in Cleft Lip and Palate Patients

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Plastic Surgery The Meeting 2014

Disclosures

Nothing to disclose

Introduction

- Most outcome measures in CLP are objective assessments
- Limited subjective indicators of QoL in CLP¹


Goal: Identify major themes implicated in the satisfaction of CLP patients and parents




Generate: Comprehensive, valid subjective questionnaire

Staged Development

**Stage 1: Themes → Preliminary Questionnaire
+ Pilot Testing**



**Stage 2: Field Testing → Revision and
Finalization of Questionnaire**

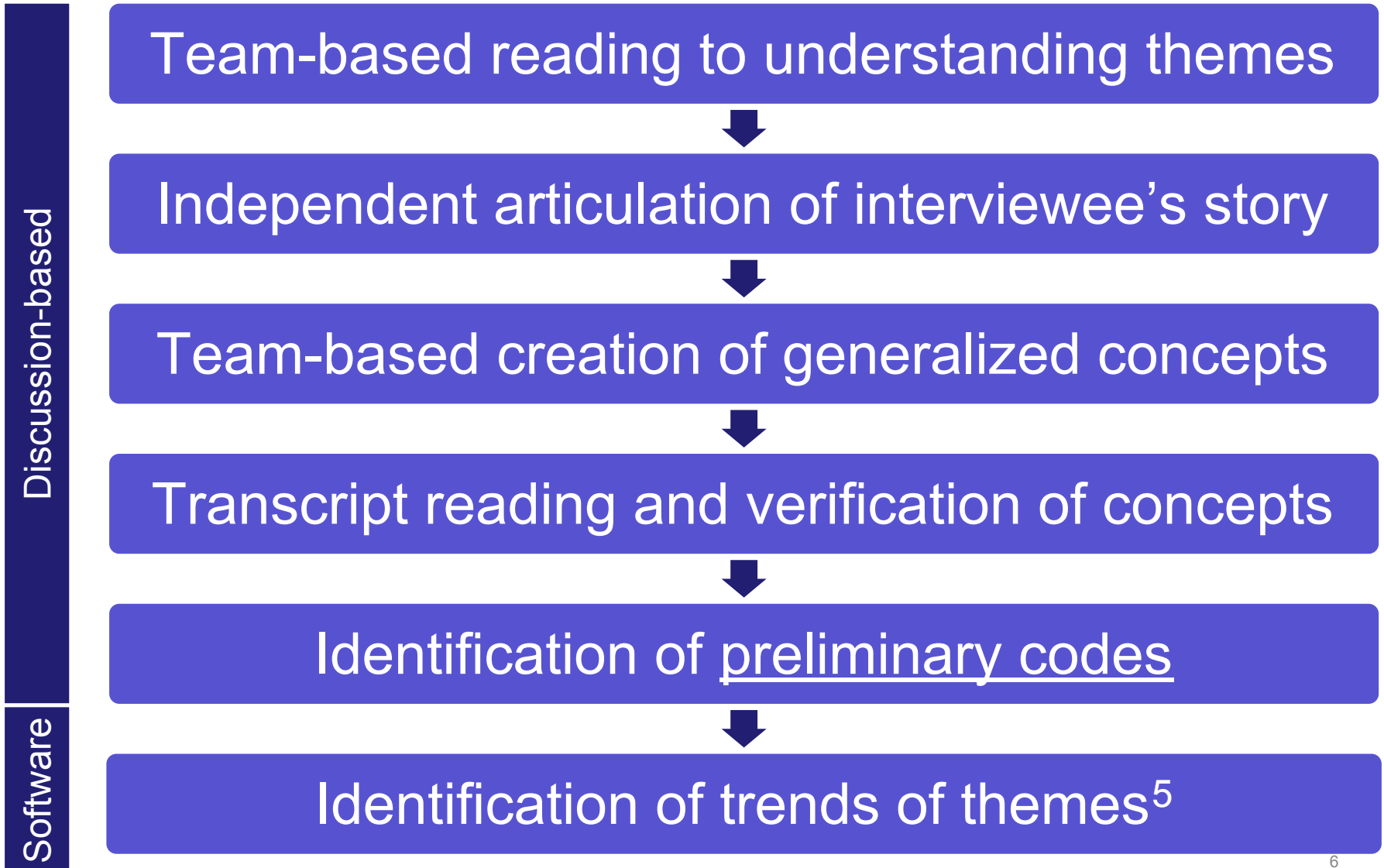


Stage 3: Evaluation for Validity and Strength

Methods: conducting focus groups

- Patients and their parents with cleft lip and/or palate invited to discuss satisfaction/QoL
- Moderator-conducted focus groups
 - 60 minutes
 - Audio-recorded
 - Partially-structured
- Audio recordings transcribed verbatim and de-identified

Methods: data analysis^{2,3,4}



Results

Five focus groups were conducted

- 2 patient groups
- 2 parent groups
- 1 provider group

Six major themes (codes)

1. Communication & Navigation of Care
2. Cosmesis
3. Financial Burden of Medical Care
4. Functionality
5. Self-Esteem
6. Support Systems & Social Adjustment

Results: frequency of themes

	Communication/ Navi gation	Cosmesis	Financial Burden	Functionality	Self-Esteem	Support Syst./ Social Adjust.	Totals
Patient FG 1	10	5		3	7	13	41
Patient FG 2	6	8		1	3	4	22
Parent FG 1	6			3		2	11
Parent FG 2	10	8	3	8	5	6	44
Totals	32	21	3	15	15	25	

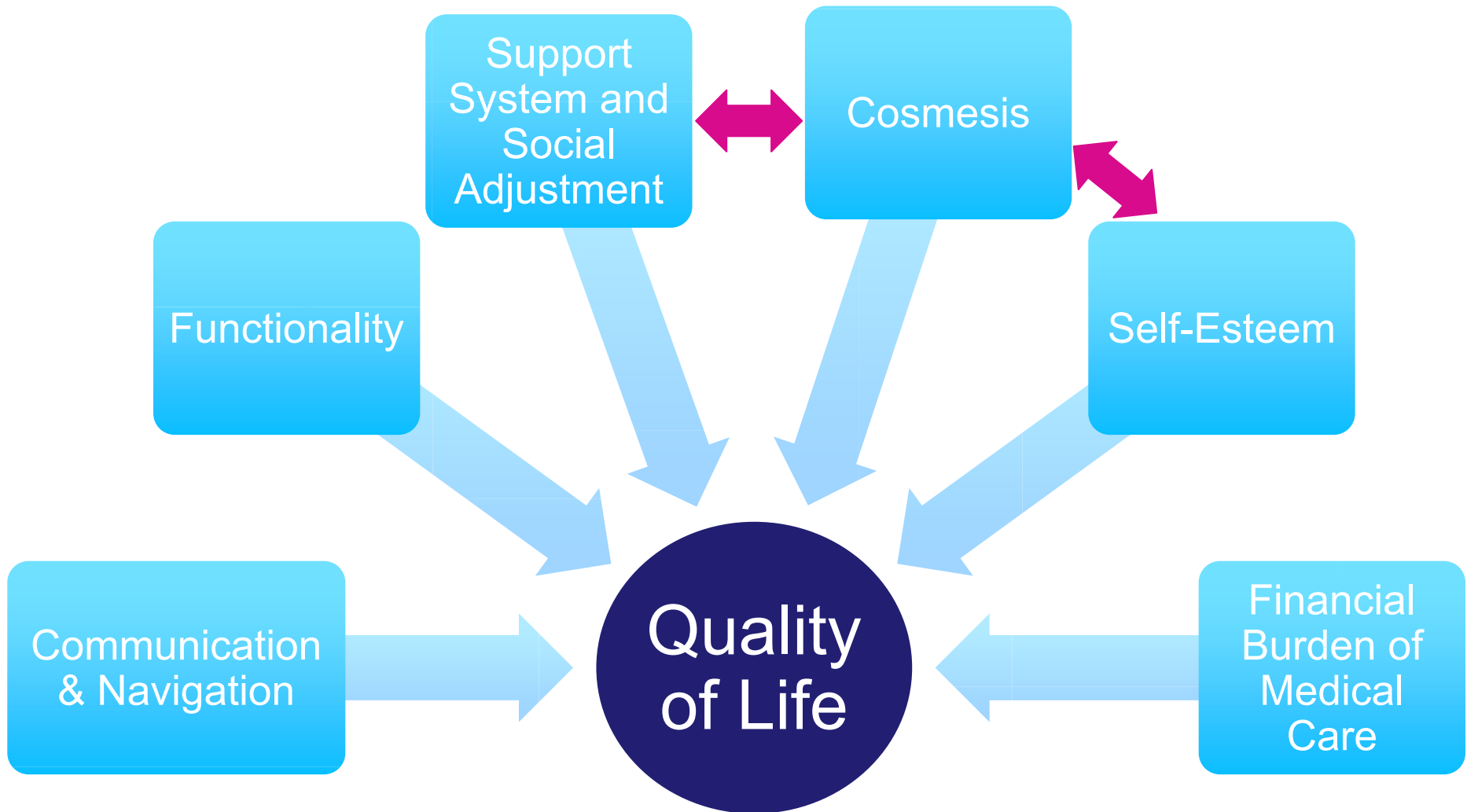
Results: co-occurrence within text

	"What's Most Important"	Communication/Navigation	Cosmesis	Financial Burden	Functionality	Self-Esteem Support	Syst./Social Adjust.	Totals
"What's Most Important"			4	3		3	4	14
Communication/Navigation			1		1	1	1	4
Cosmesis	4	1				7	6	18
Financial Burden	3					1		4
Functionality		1					2	3
Self-Esteem	3	1	7	1			3	15
Support Syst./Social Adjust.	4	1	6		2	3		16
Totals	14	4	18	4	3	15	16	



I was five, and these little kids were saying they didn't want to play with me because I had this big red line on my face. And I was like 'I can't help it!' They really didn't understand, and they kept on calling me ugly and just really bad names.

Discussion



Future Directions

- Creation of a preliminary **questionnaire** based on themes identified
- Additional recruitment of **patients** and **parents** for more focus groups
- Focus groups with **providers** for possible areas of discordance
- Focus groups with **non-native English speakers**

References

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