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Island Voices: Experiences of Living with Cleft Lip and or Palate.

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Comments

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Island Voices: Experiences of Living with Cleft Lip and/or Palate

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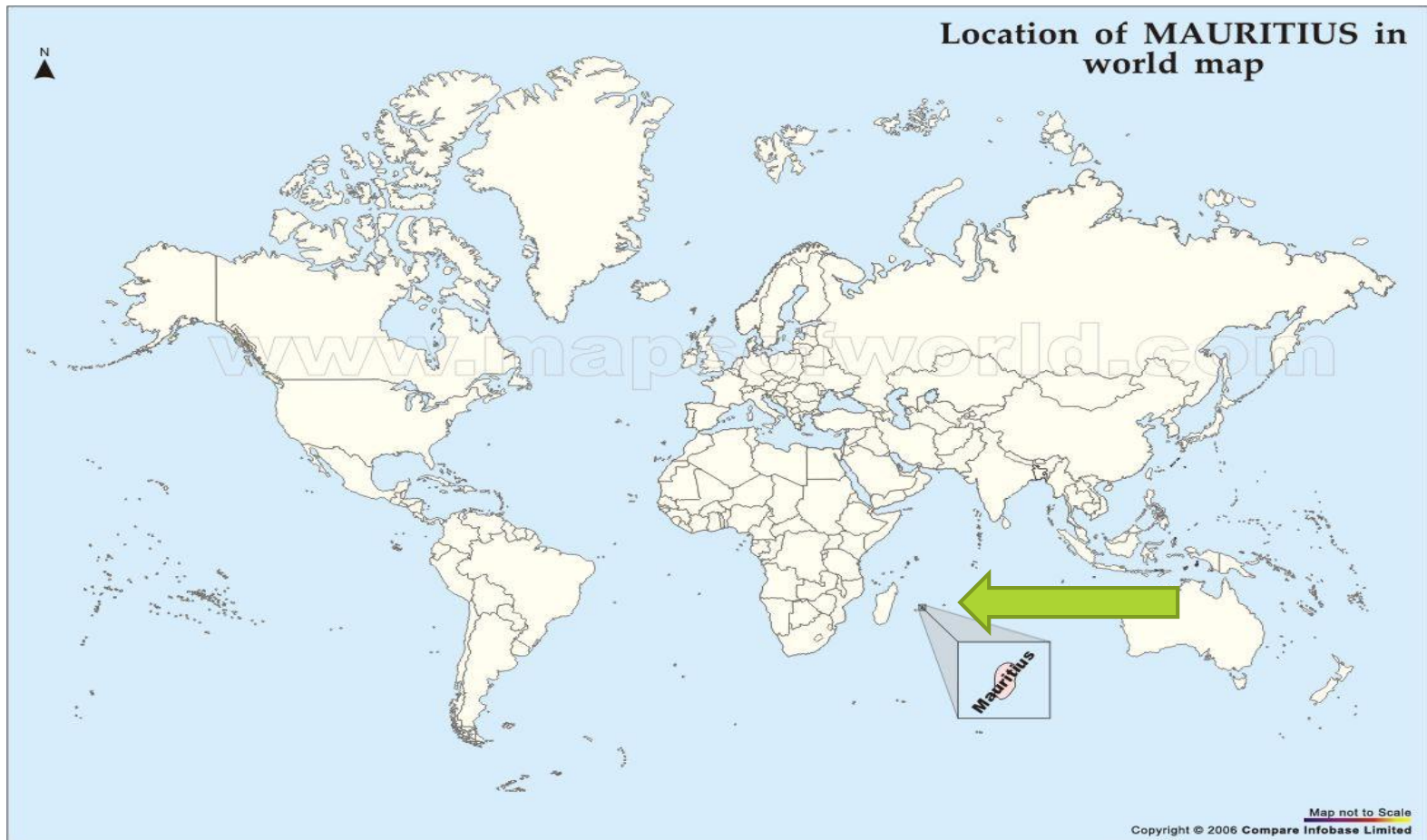
East Tennessee State University, USA

**13th International Congress on Cleft Lip and Palate &
Related Craniofacial Anomalies
Chennai, INDIA
8 – 11 February 2017**

Disclosure

- ▶ Dr. Gopal has no financial or non-financial disclosures; she is employed by the Ministry of Health and Quality of Life, Mauritius.
- ▶ Dr. Louw has no financial or non-financial disclosures; she is employed by East Tennessee State University, Johnson City, TN.

Experiences of Living with CL/P in Mauritius: Where is Mauritius?



Current approach to cleft care in Mauritius

CURRENT CARE PROVIDED

Age of identification of cleft

new-born

Surgical history

(median age)

- Primary lip repair
- Primary palate repair

5 months

12 months

Follow up in Plastic Surgery clinic and Speech Therapy until adolescence.

Language/s spoken at home

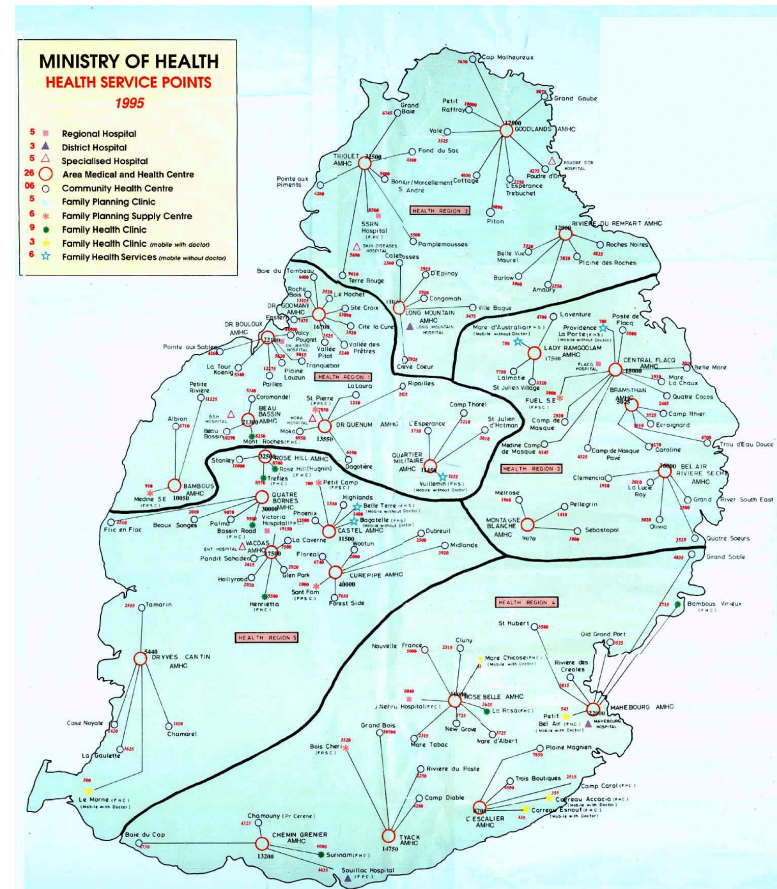
- Most commonly 'Creole'
- 2 languages (Creole and French)

91%

58%

Schooling (Primary and secondary)

English



The Aim of the Study

To date there is a lack of information on **HOW** young adults in Mauritius, a representation of the majority contexts, experience living with CLP.

The **aim of this study** is to give a voice to young Mauritian adults with CLP; in describing their treatment journey and satisfaction with cleft care.

Research Methodology

A **qualitative descriptive research** design was employed to generate collective views of the participants

Method:

- ▶ Questionnaire completed individually
- ▶ Focus group

Participants:

- ▶ 21 young adults (18-40 years old) participated in the study. Participants of both genders with a range of cleft types were all Mauritians and spoke, English, French, Mauritian Creole in addition to ethnic languages. 3 did not have the fluency for English therefore the final participants were 18 only.
- ▶ Main Researcher: An experienced speech-language therapist and audiologist
- ▶ Facilitator during the focus group discussion
- ▶ Assistant to make digital audio and video recording of the focus group discussion

Material:

- ▶ Questionnaire based on the CFEQ (Roberts & Shute, 2011); Focus group prompts/questions

Apparatus:

- ▶ Sony Digital video and audio recorder

Participants (n =21)

Characteristic	Characteristics	Number of Participants	Percentage (%)
Age Range	<u>16-21</u>	<u>12</u>	<u>57</u>
	21-27	4	19
	28-33	2	10
	34-40	3	14
Gender	<u>Female</u>	<u>12</u>	<u>57</u>
	Male	9	43
Education	Nil	1	5
	Primary	1	5
	<u>Secondary</u>	<u>14</u>	<u>66</u>
	Tertiary	4	19
	Pre-Voc	1	5
Occupation	<u>Student</u>	<u>11</u>	<u>52</u>
	Sales-related job	2	10
	Not employed	2	10
	Other (accountant, lab tech, RA, housewife, driver)	6	28
Marital Status	<u>Single</u>	<u>18</u>	<u>86</u>
	Married	2	9
	Divorced	1	5
Cleft Type	<u>BCLP</u>	<u>7</u>	<u>33</u>
	ICP	5	24
	UCL	2	10
	<u>UCLP</u>	<u>7</u>	<u>33</u>

Questionnaire based responses (modified CFEQ) (Roberts & Shute, 2011)

STRESSORS

- ▶ Response of others
- ▶ Disabilities and Impairments
- ▶ Treatment
- ▶ Self-Acceptance Stressors

POSITIVE ASPECTS

SCALE:

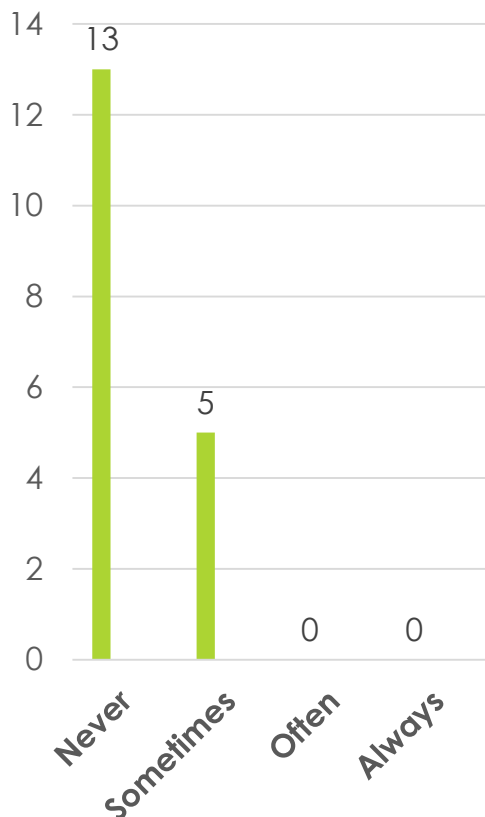
1 = Never

2 = Sometimes

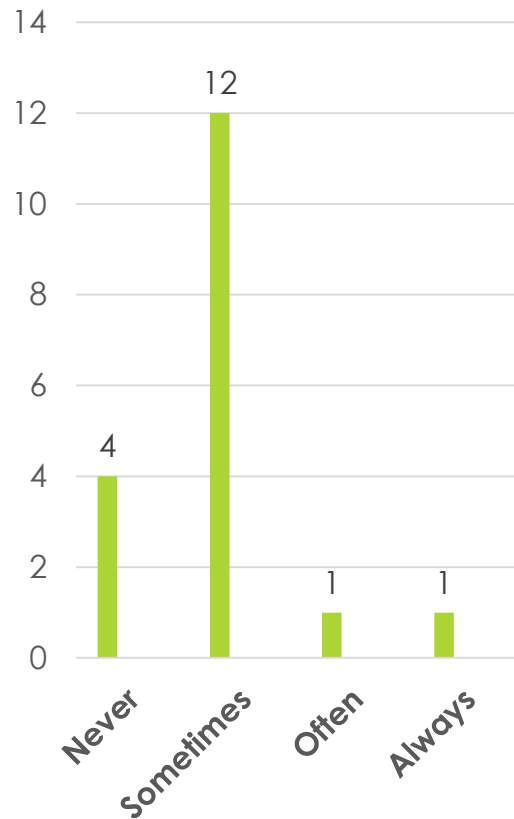
3 = Often

4 = Always

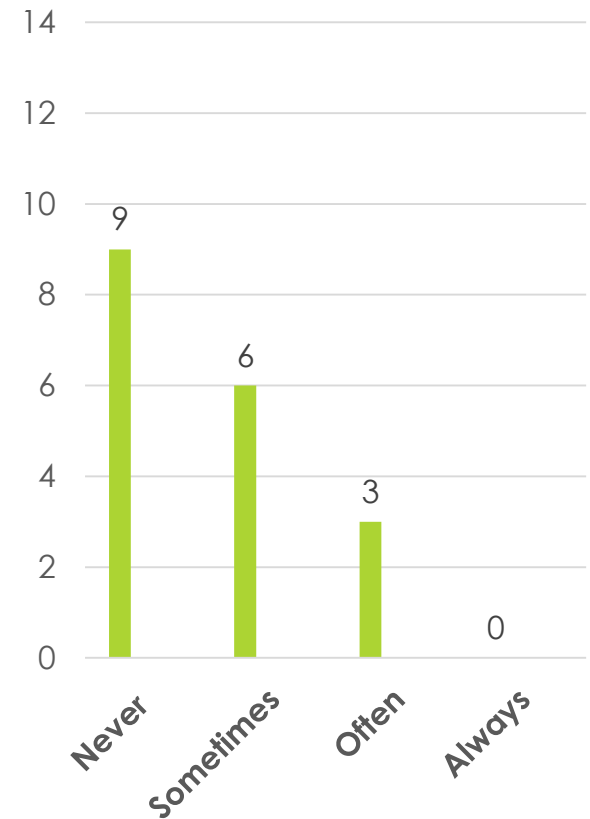
Responses of Others (n=18)



Having difficulty being accepted by others (n=18)



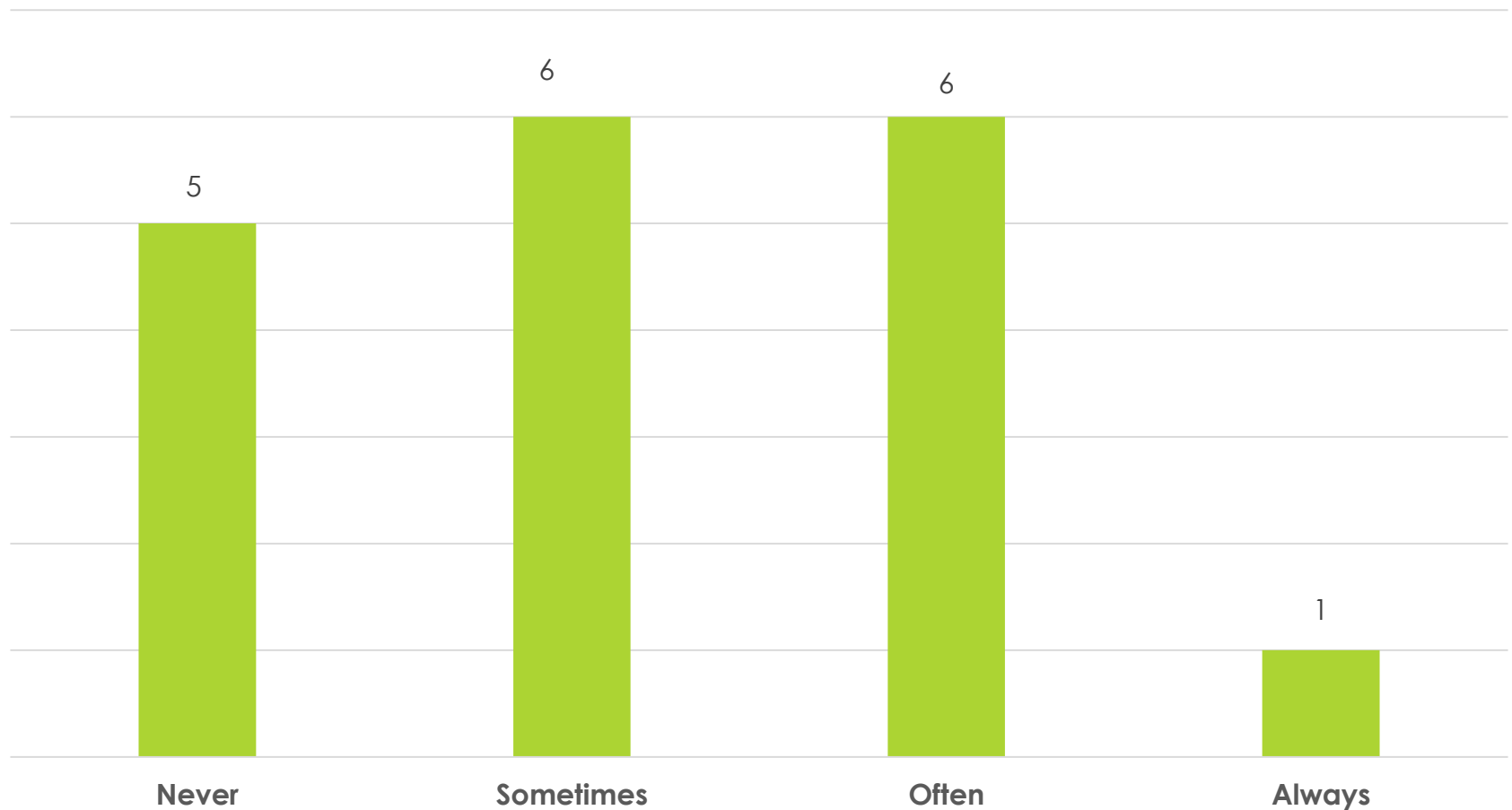
Being asked questions about my craniofacial condition (n=18)



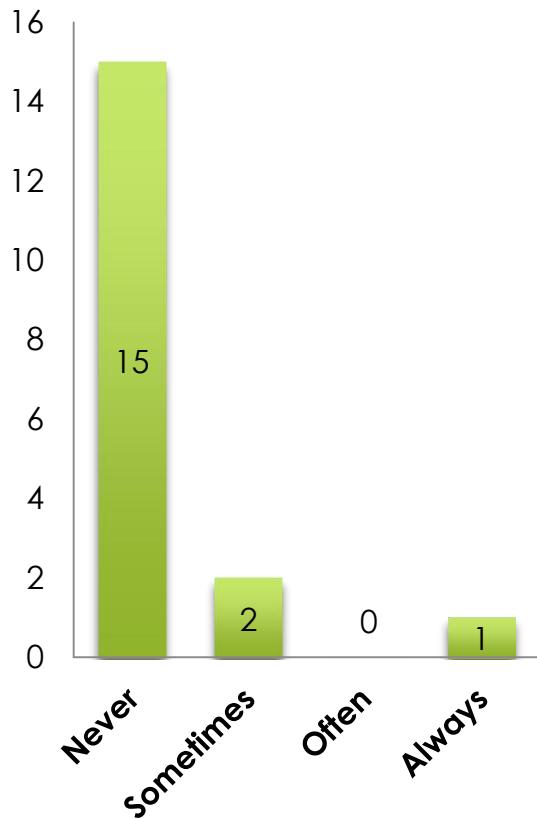
People make comments about my craniofacial condition (n=18)

Disabilities & Impairments (n=18)

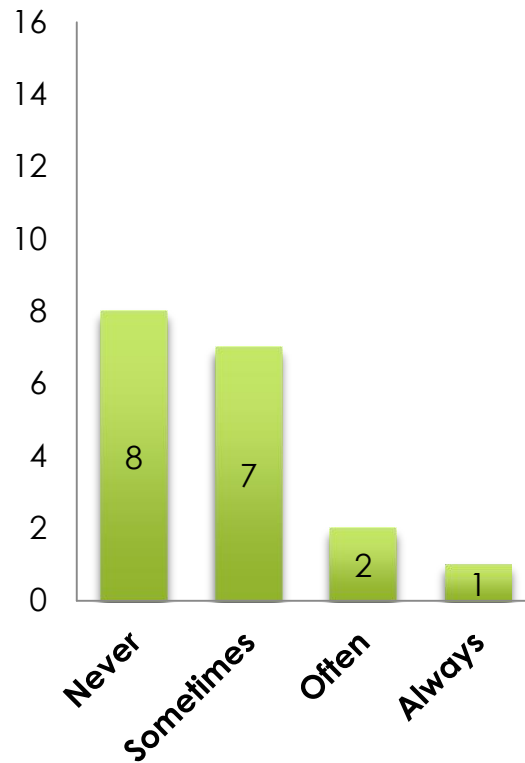
People having trouble understanding participants' speech



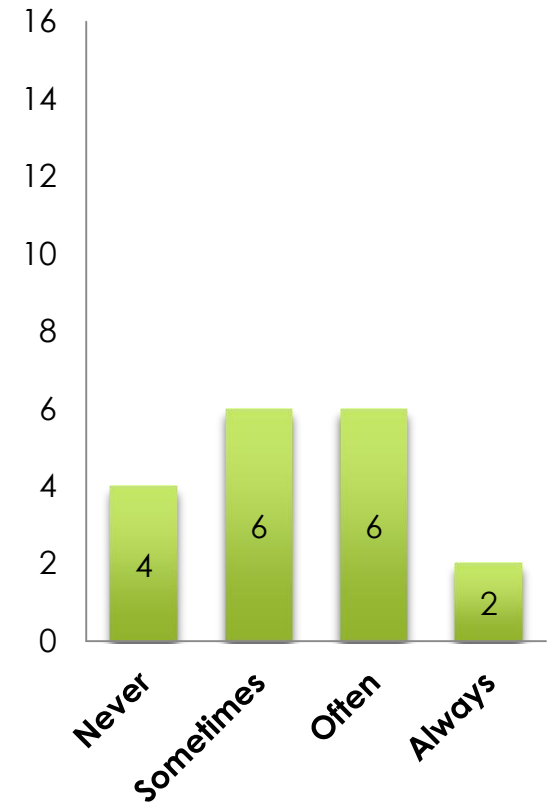
Treatment (n=18)



Having trouble finding a doctor/dentist

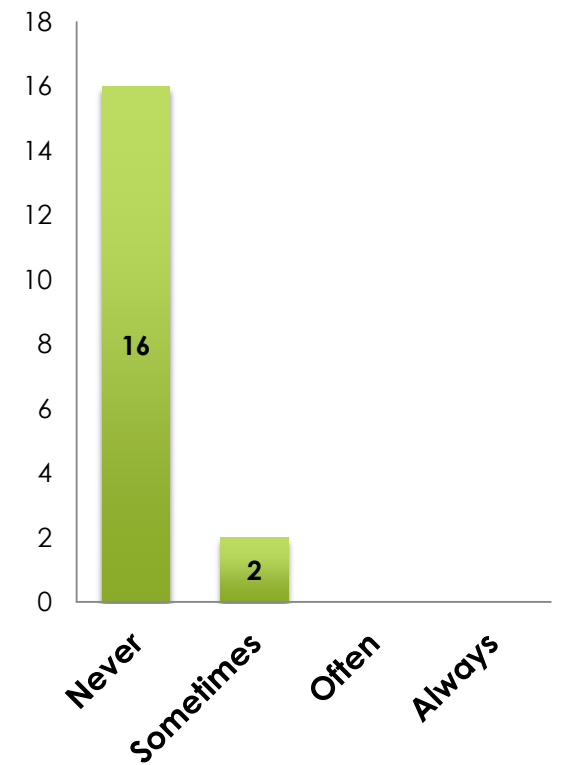
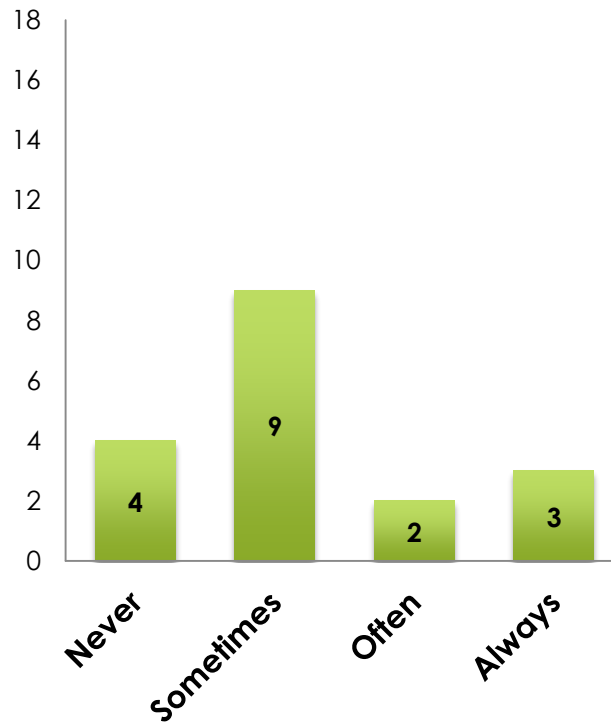
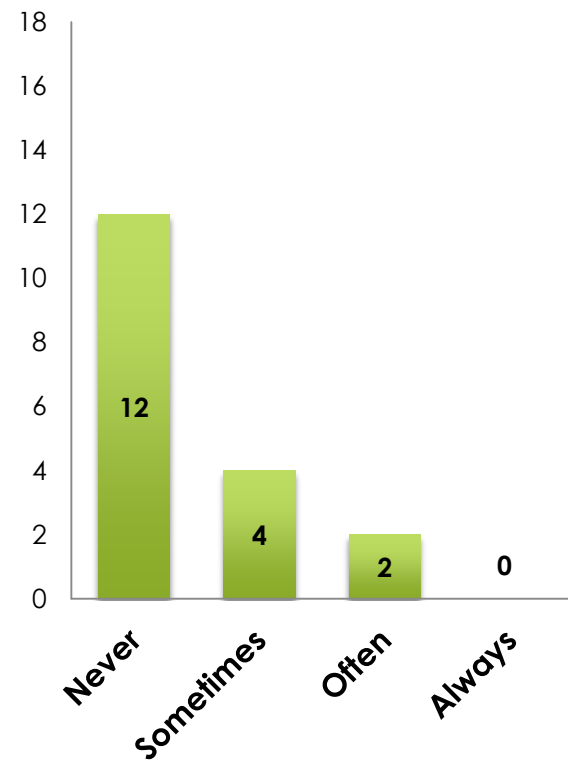


Missing out on work



Stressed about operation

Self-Acceptance (n=18)



Participants not liking their appearance (n=18)

Participants thinking about their cleft palate (n=18)

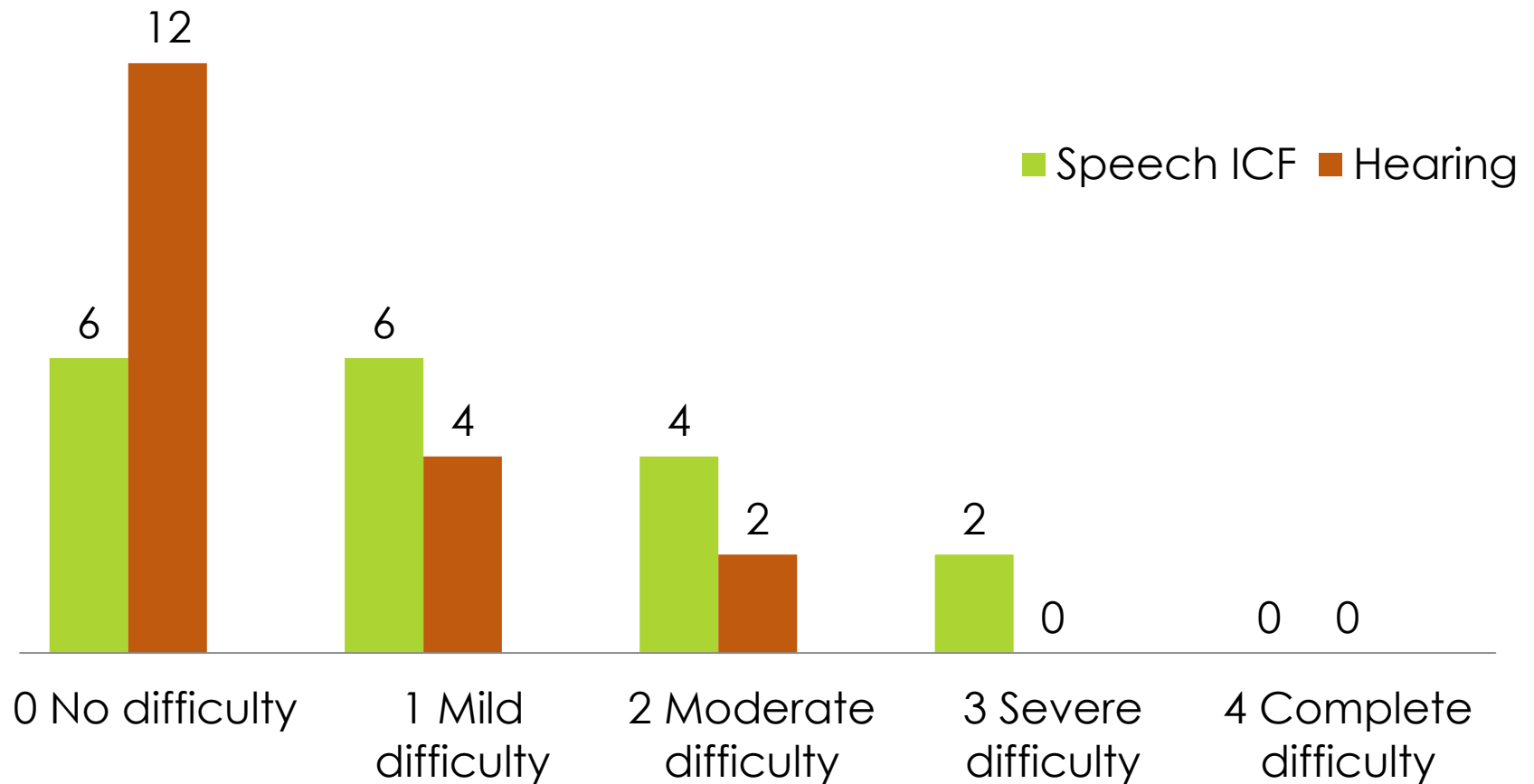
Participants hiding their cleft lip/palate (n=18)

Positive Aspects

Among the 15 attributes listed the following were identified by 50% as significant:

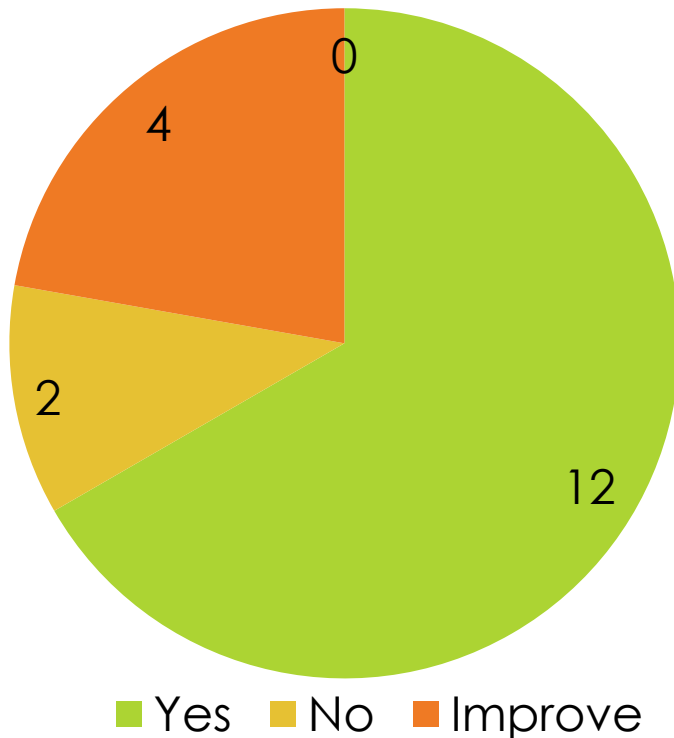
- ▶ Being kinder to other people
- ▶ Being understanding of other people with disabilities and being nicer to people who are different in some way
- ▶ Getting support from the doctors and other people in the hospital

ICF Speech and Hearing (n=18)

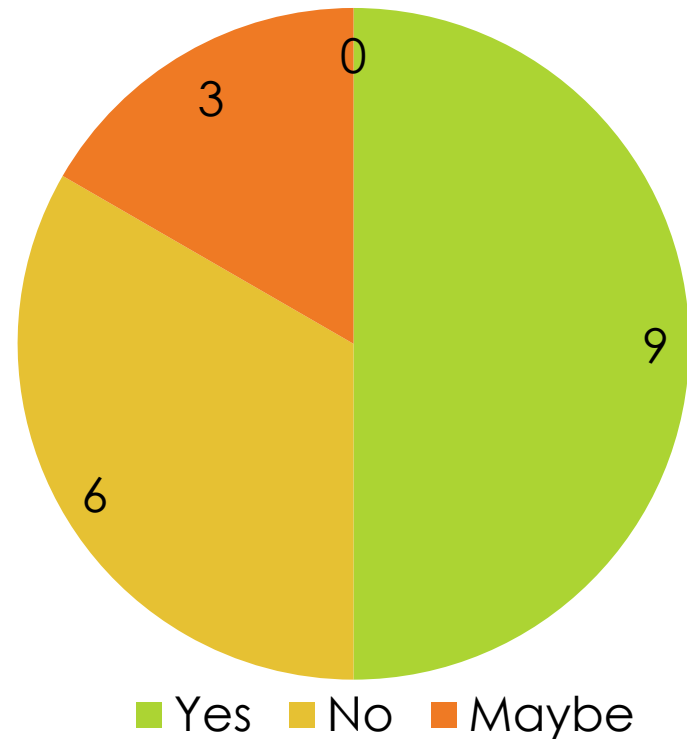


Satisfaction with appearance and further surgery (n=18)

Satisfaction with Appearance



Further Surgery



Interested in further surgery ($n=12$)

Aspect to improve	Number of participants
Speech	3
Hearing	1
Appearance	4
Appearance and Speech	2
Appearance, Speech and Hearing	2

Focus Group Logistics

Focus Group Participants

- ▶ Total number invited = 18
- ▶ Total number attended = 10
- ▶ Ideal number for FGD = 8-10

Gender

- ▶ Male = 3
- ▶ Female = 7

Type of Cleft

- ▶ BCLP = 5
- ▶ UCLP = 3
- ▶ UCL = 2

Venue

- ▶ ENT Hospital, Vacoas (conference room)

Language

- ▶ Creole (by group consensus)

Date Analysis

- ▶ Video and audio recording / Transcripts and note taker observations (by 4 independent listeners)



THANK YOU FOR YOUR PARTICIPATION!

Focus Group Discussion (n=10)

Theme The Treatment Journey: Living with CL/P

Memories of surgery	<ul style="list-style-type: none">-Several surgeries as many as 10-Poor memory as a young child-Memories of a frightful experience as bone grafting was done from the ribs.
Living with CL/P	<ul style="list-style-type: none">-I was teased and underestimated by most people-I am grateful and so should other patients with CLP be; for being healthy, fit and able to work.
Satisfaction with treatment received	<ul style="list-style-type: none">- Went through a lot of inconveniences during my treatment; I had to travel to different hospitals-many different places- Despite many surgeries in Mauritius I had to travel to China for further treatment-There are no separate wards for us ('we are normal') and we were admitted with burns cases and this was a traumatic experience. In addition the ward was dirty and I was afraid of infections- I was mentally well prepared for the surgery as the doctor had explained everything beforehand to me therefore I was not shocked with the end result.

Focus Group Discussion (n=10)

Satisfaction with appearance, speech and hearing

APPEARANCE

-I would like to improve my nose and lip

-I have been accepted by my girl-friend as I am

SPEECH

-I am quite but not very satisfied with my speech

-Patients need a lot of moral support from the therapists and doctors and the speech therapy is crucial!

-I am grateful to (my doctor) for being able to speak!

HEARING

*Questionnaire probed perception of hearing impairment

-Interestingly none of them made any comment about their hearing during the focus group discussion

*-*From the questionnaire 50% had the perception that they do not hear very well*

Focus Group Discussion (n=10)

Suggestions to improve cleft care

Overall the patients were satisfied with cleft care; to improve cleft care they suggested:

- ▶ There should be more than one Plastic Surgeon in the public sector (Waiting List will be shorter and patient's will have a choice)
- ▶ Orthodontic treatment should be available in the public sector. Psychologist's support should also be available from childhood to adulthood
- ▶ A separate hospital ward for cleft palate patients
- ▶ Treatment to improve speech and appearance should continue

Conclusion & Implications

- ▶ Health professionals should listen to the voices of the young adults with CLP and provide :
 - Patient-centered care
 - the required support.
- ▶ The participants had both negative and positive experiences during their life journeys. The negative experiences highlight the need for continual psychosocial support and the positive experiences indicate strengths that need to be capitalized in planning of cleft care planning.
- ▶ Research with young adults with CLP within the ICF (WHO, 2001) framework need to guide ongoing improvements in cleft care in majority contexts.

Acknowledgements

- ▶ Young adults with CL/P for their time, interest and participation.
- ▶ Anushka for facilitating the focus group discussion and Rudramun for the digital audio and video recordings
- ▶ Swadeka and Ramjan for arranging the appointments
- ▶ Mauritius Ministry of Health and Quality of Life for the ethical clearance and appreciation of the final report

Thank you for your attention



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