

"Anything you want to ask?": Assessing understanding of genetic information by children in genetic counselling

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Background Information

Global and Local emphases on child participation in healthcare

➤ The United Nations Convention on the Rights of the Child (1989)

Article 12 (1):

"Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child."

➤ Code Of Professional Conduct by Medical Council of Hong Kong

A Guidance for Registered Medical Practitioners

2.12.1: Consent given by a child under the age of 18 years is not valid, unless the child is capable of understanding the nature and implications of the proposed treatment. If the child is not capable of such understanding, consent has to be obtained from the child's parent or legal guardian.

2.12.2: The degree of maturity and intelligence required for a child to understand the nature and implications of the proposed treatment will depend upon the importance and complexity of the case. It is the doctor's duty to ensure that the child is truly capable of such understanding before acting in reliance on the child's consent.

Complexity of professional-parent-child interactions in medical encounters

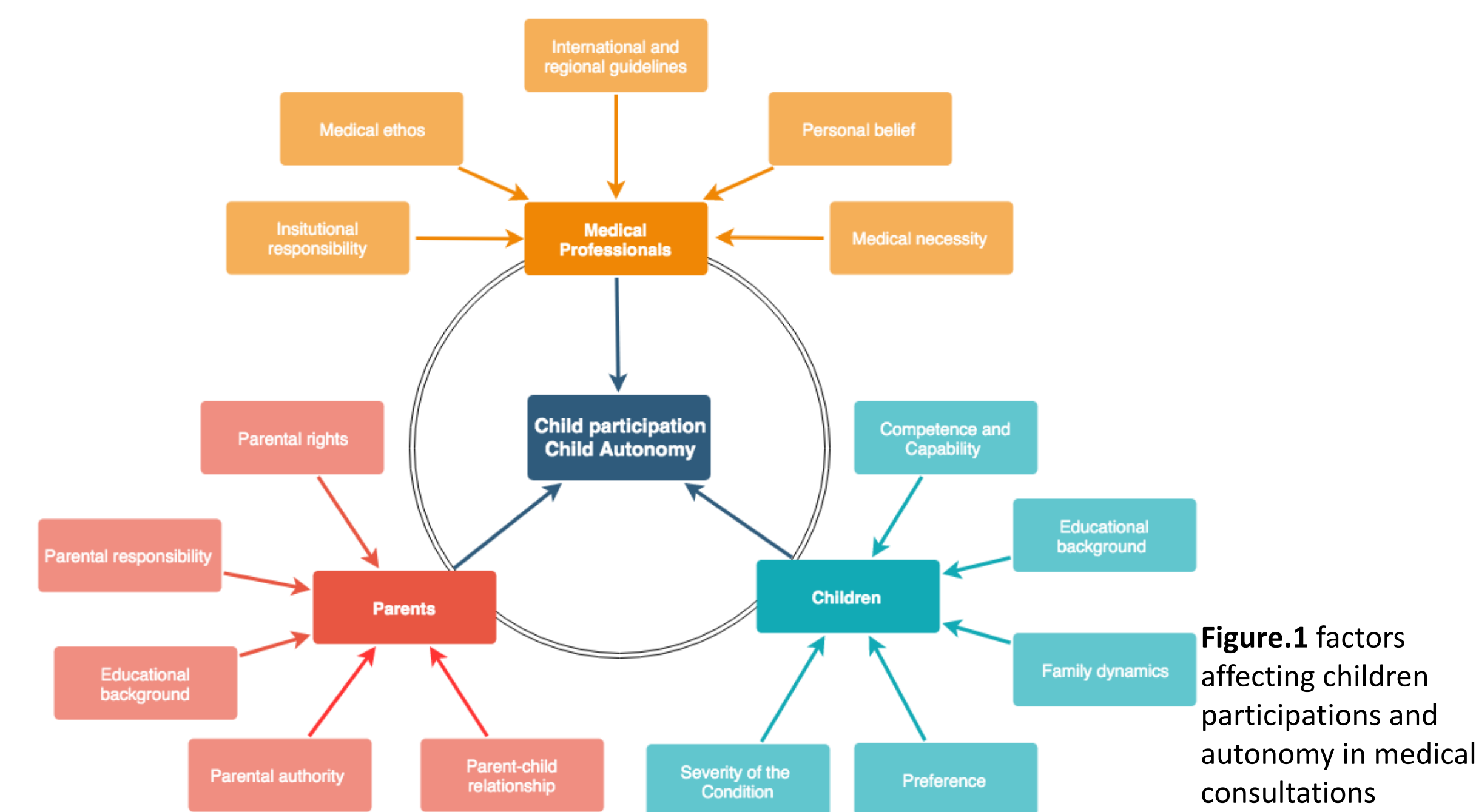
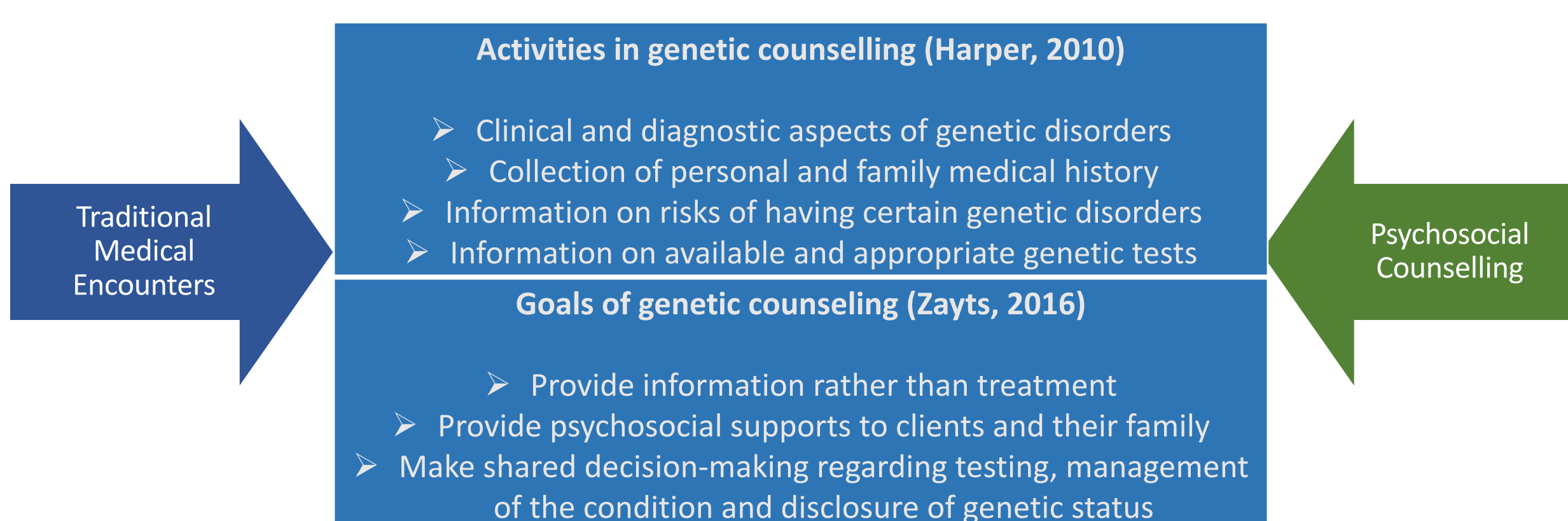


Figure.1 factors affecting children participations and autonomy in medical consultations

Genetic counselling: a 'hybrid' activity of traditional medical encounters and psychosocial counselling



Research Objectives

To investigate:

How much?

- The extent of children's participation in genetic counselling consultations

Where?

- The stages of genetic counselling where children participate most

How?

- The specific discourse/rhetorical strategies used by genetic professionals, parents and children?

Materials and Methods

Data

23 genetic counselling consultations for Sudden Arrhythmic Death Syndromes (SADS)	
Method of data collection	Audio- and video-recordings
Length of consultation	15 to 50 minutes each
Language	Cantonese (no. 21) English (no. 2)
Age Range	3 - 17 years old
Sex	13 males, 10 females
Participants	Clinical geneticist, Genetic Counsellor, Cardiologist, Parent (s), Child

Analytic method: Quantitative and Qualitative Approaches

➤ Theme-oriented discourse analysis (Roberts & Sarangi, 2005; Sarangi, 2010)

➤ Structural, interactional, and thematic mapping

➤ Linking analytical themes (discourse & rhetorical strategies) to the focal themes (child participation in genetic counselling; child autonomy, etc.)

Results

Verbal contributions of each participant in each genetic counselling consultation in relation to child age

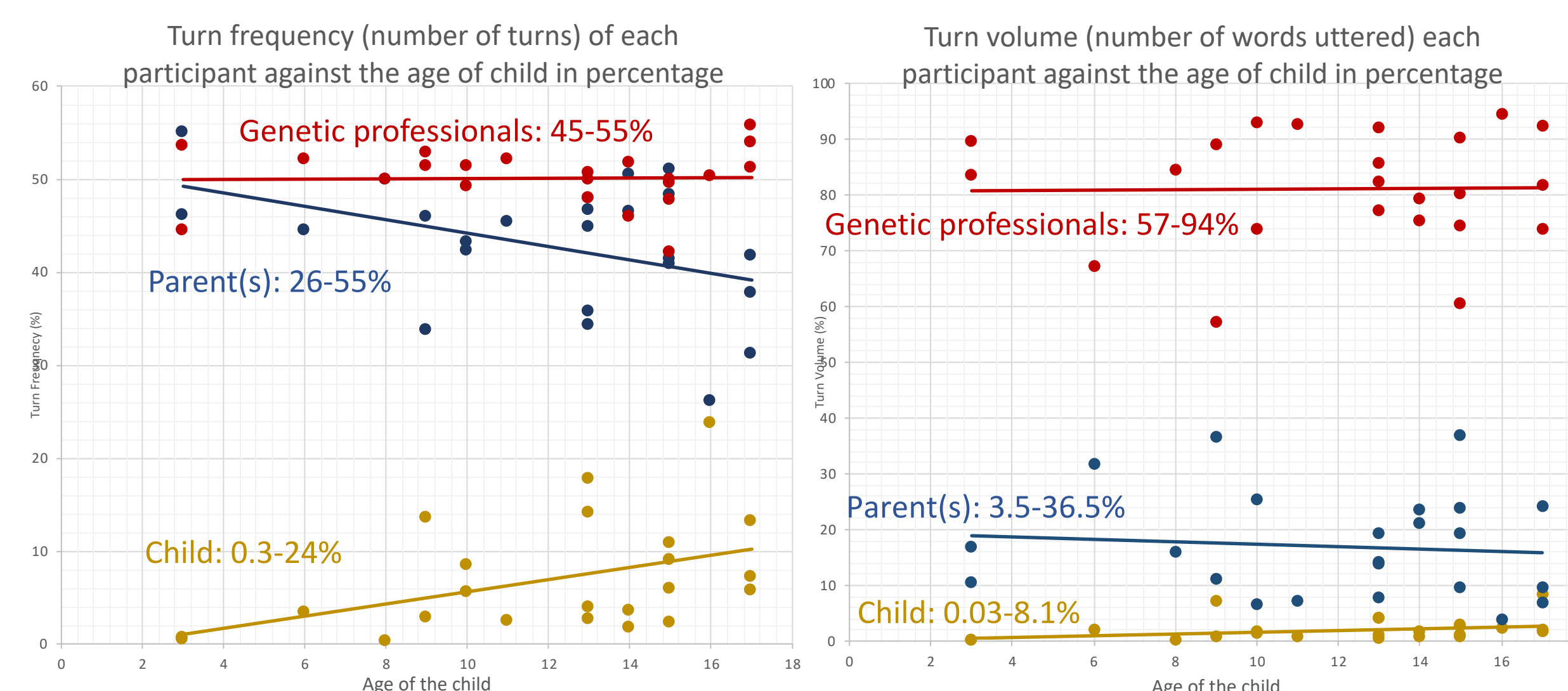


Figure.2a Correlation between number of turns (in percentage) of each participant and the child's age

- Genetic professionals' participation is consistent
- As the age of a child increases, parents' participation decreases and a child's participation increases

Figure.2b Correlation between number of words uttered (in percentage) of each participant and the child age

- Genetic professionals contribute most to the interaction.
- Parents' contribution exceeds a child's contribution.
- The correlation between turn volume of each participant and the age of a child is not immediately obvious, as is the case of turn frequency

Stages where children participate more often

Family history taking

Explanation of genetic result of the proband

Description of the genetic disorder in question

Relational talks

Management of the condition

Assessing understanding

Relational talks

Micro-analysis of professional-parent-child interactions in assessing understanding

Case.1 10 year-old male (CG: Clinical Geneticist; GC: Genetic Counsellor; M: Mother; C: Child)

- CG: ((停止打字)) 小朋友，我同媽媽傾偲講啲嘢你明唔明呀？
((Stop typing)) little kid, do you understand the things mother and I have talked about?
- C: 唔：明（點頭）。
Um: understand (nod).
- CG: 明啲，唔明啲。
understand some, and some don't.
- M: 明啲，唔明啲。
understand some, and some don't.
- CG: 你有冇嘢要問醫生？我頭先唔記得問，我淨係問咗媽咪有冇嘢要問我，你有冇野問我呀
Do you have anything you wanna ask doctor? Just now I forgot to ask, and I have only asked if mother has anything to ask me. Do you have anything you wanna ask me?
- C: ((搖頭))
((Shake head))
- CG: 冇，冇咩嘢擔心或者乜嘢呀？
No, are there certain worries or anything?
- C: 冇乜嘢。
Not much.
- CG: 冇乜嘢呀，GOOD。
Not much, good.
- GC: ((向母親)) 咁呢就係簽名同埋寫返你個聯絡電話。
((To mother)) Then, sign your name and write down your contact phone number
- M: 佢可能而家仲係未夠嗰個年紀，唔識點樣—
Perhaps he hasn't reached the age now, doesn't know how to-
- CG: 唔知發生啲咩事。
Doesn't know what has happened.
- M: 係呀，係呀，懵懵懂懂咁樣。
Right, right. Like being muddleheaded (dull and ignorant) .

The clinical geneticist frequently asks yes/no interrogative questions which favor a "yes" and unelaborated response (Heritage, 2010). These questions are also non-specific, which doesn't really indicate what should be understood or worried.

The child then responded minimally and sometimes non-verbally.

Although not requested, the mother provides an explanation for her son's passive role as "he hasn't reach the age".

Conclusion

- Participation can be defined in terms of the volume of verbal and non-verbal contributions.
- Children's participation is dependent on adult's participation.
- The ethos of including children in medical decisions may be challenging to attain in the actual medical practice, globally (Coyne & Gallagher, 2011; Stivers, 2012), and locally in Hong Kong
- Children are ratified participants of the analyzed consultations but efforts should be directed at making their participation more information and decision-oriented – **agentive participation**.
- Communication-oriented research could contribute to developing communication strategies aimed at enhancing and sustaining children's participation at different stages of genetic counselling consultations.