INTERDISCIPLINARY COLLABORATION BETWEEN HUMANITIES AND MEDICINE

KE LUNCH MEETING TALK
22 SEPTEMBER 2014

Dr. Olga Zayts
School of English &
Dr. Brian Chung
Department of Pediatrics and Adolescent Medicine
Contact: zayts@hkucc.hku.hk; bchung@hku.hk

Areas of collaboration

1. Research:

- Research projects, including securing internal and external funding for the projects:

  - "Language, Medicine, and Culture: Using English as a Lingua Franca in Prenatal Genetic Counselling in Hong Kong" (2009-2012), RGC-funded, with the Department of Obstetrics and Gynecology, Department of Prenatal Diagnosis and Counseling, Tsan Yuk and QMH
  - Dr. Olga Zayts; Dr. Tang Hoi-Yin, Mary; Dr. Lee CP; Ms. Chan Ho Yan, Vivian

  - "A Discourse Analytic Study of Telegenetic Counseling in Hong Kong" (2011-2013), RGC-funded, with the Genetic Counseling Services, Department of Health & Department of Pediatrics and Adolescent Medicine, QMH, HKU
  - Dr. Olga Zayts; Prof. Srikant Sarangi; Dr. Lam, Tak Sum Stephen; Dr. Lo Fai-Man, Ivan; Dr. Lam, Chuen Fat, Albert

  - "Risk Communication and Decision-making in Genetic Counseling for Sudden Arrhythmia Death Syndrome" (pilot, 2011--), RGC funding application under review, with the Department of Pediatrics and Adolescent Medicine, QMH, HKU
  - Dr. Olga Zayts; Dr. Brian Chung; Dr. Tak-Cheung Yung; Dr. Kai Tung Chau; Dr. Anthony Liu; Prof. Srikan Sarangi

Areas of collaboration

- Research (cont'd)
- Conference presentations and manuscript preparation for publication in international peer-reviewed journals, edited volumes.

Zayts et al. Genetic counseling in South East Asia JoGC2013.pdf - Adobe Reader

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Background: Communicative Practices
Communication-Oriented Research on
The Current Practices of Genetic
Who provides genetic
The Impact of Cultural and
Conclusi

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ORIGINAL RESEARCH

Genetic Counseling/Consultation in South-East Asia: A Report from the Workshop at the 10th Asia Pacific Conference on Human Genetics

Olga Zayts · Srikant Sarangi · Meow-Keong Thong · Brian Hon-yin Chung · Ivan Fao-man Lo · Anita Sik-yau Kan · Juliana Mei-Har Lee · Carmencita David Padilla · Eva Maria Cutiongco-de la Paz · Sultana M. H. Faradz · Pornswan Wasant

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Abstract This paper reports on the workshop 'Genetic Counseling/Consultations in South-East Asia' at the 10th Asia Pacific Conference on Human Genetics in Kuala Lumpur, Malaysia, in December 2012. The workshop brought together professionals and language/communication scholars from South-East Asia, and the UK. The workshop aimed at addressing culture- and context-specific genetic counseling/genetic counseling/consultation research in Hong Kong. As other countries in South-East Asia have not yet embarked on communication-oriented empirical research, we report on the current practices of genetic counseling/consultation in these countries in order to identify similarities and differences as well as key obstacles that could be addressed through future research. Three issues emerged as 'problematic': language

Areas of collaboration

2. Teaching and training activities:

- Co-supervision of postgraduate students (2 full-time PhD students at the moment)
- Co-teaching on the MMedSc in Genetic Counseling programme at HKU:
- http://www.obsgyn.hku.hk/whatsNew/MMSciGeneticCounselling/MMSci%20Genetic%20Counselling%20-1.htm

Areas of collaboration

3. Knowledge exchange activities:

- Organization of panels & colloquia at international conferences *for healthcare professionals* (the European Meeting on Psychosocial Aspects of Genetics; Asia-Pacific Conference for Human Genetics)
- Organization of workshops & seminars for *professionals* and *healthcare communication researchers* (e.g. the annual Winter School on Health Communication; now in its 4th year: http://winterschoolhku.blogspot.hk/)

Areas of collaboration

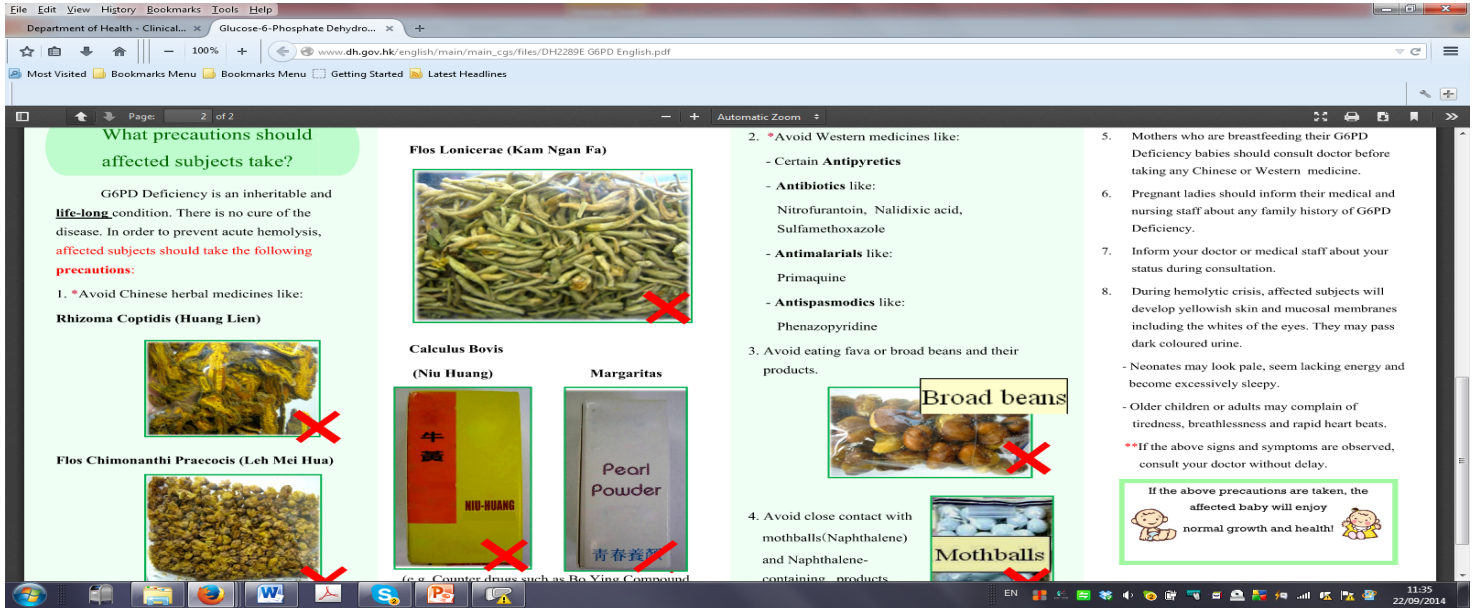
- Knowledge exchange activities (cont'd):
- 13th Communication, Medicine and Ethics (COMET) conference

Areas of collaboration

- Knowledge exchange (cont'd):
- Language in Healthcare (LiH) initiative: http://hkulih.hku.hk/
- "… An inter-disciplinary academic initiative seeking to research, facilitate, and enhance healthcare communication. A team of linguists, medical professionals, and organizations have come together to create projects that move healthcare communication research away from a strictly academic setting and toward a reciprocal relationship that contributes to the medical profession and public awareness…"

Areas of collaboration

- Knowledge exchange (cont'd):
- Mentoring KE projects by postgraduate students, development of patient information resources: G6PD deficiency: http://www.dh.gov.hk/english/main/main_cgs/files/DH2289E%20G6PD%20English.pdf



How we work together

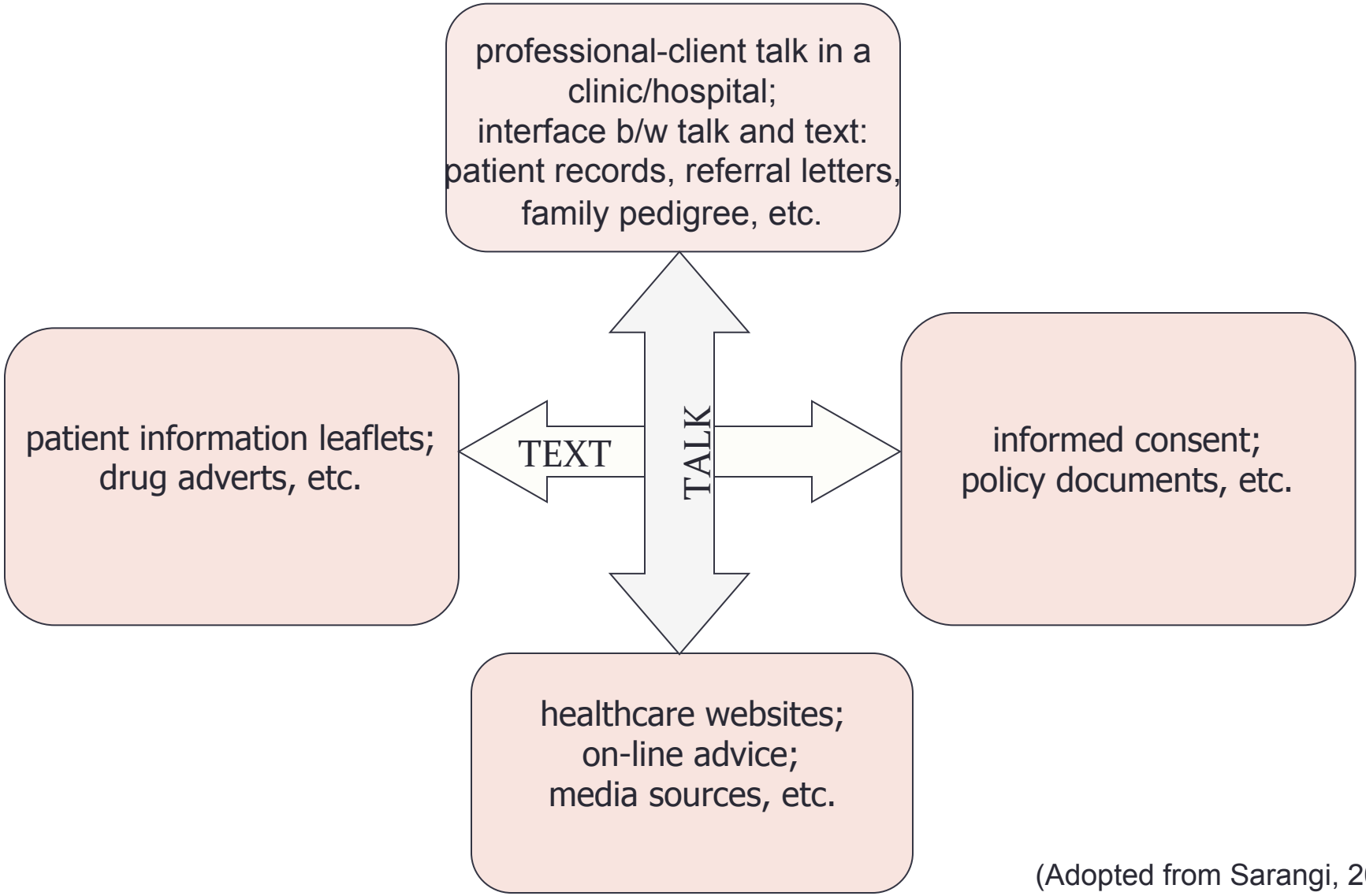
1. Points of first contact: establishing trust and demonstrating credibility of interdisciplinary collaborations

'I have always though that linguistics is art, but after your presentation I understand that it is science' (a senior cardiologist)

1. Data collection: ensuring authenticity and representativeness of sources
2. Data transcription
3. Data mapping and categorizing
4. Data analysis: *'thick description' (Geerz, 1973) through 'thick participation' (Sarangi, 2007)*
5. 'Experimental' expert appraisals: *validating the analysis*
6. Dissemination: *reflexivity and relevance of research*

Data collection in healthcare sites

(synchronic; diachronic; across cultures; across conditions)



(Adopted from Sarangi, 2011)

Transcription: Chinese-English (SADS)

[GC=Genetic Counselor, C=Client]

57. GC: 噉 成日 話 改變 改變 **.hh** 講 返**:** **<**少 少**>** 遺傳科
gam sengjat waa goibin goibin gong faan siu siu waicyunfo
so always say change change tell back little little genetics

啲 資料 俾 你 聽 先**:** **.hh** 噉>我 有 啲< 圖片
di ziliu bei nei teng sin gam ngo jau di toupin

解 俾 你 聽
gaai bei nei teng
explain to you listen

'So we always talk about mutation and mutation. Let me tell you some information about genetics first. So I have some diagrams to explain to you'

58. C. Mm.

Transcription: interactional details

[MP = Medical Provider; P = Patient]

1	MP:	Or, can you decide today? Or you want- you prefer to talk to your husband first?
2	P:	It's ok, which is the best for me? [I(h) (h)don't k(h)now. ((bubbling through))
3	MP:	[Naa, see (.) Naa, see, now whether you want to have the, the first thing, is (.) you decide you want to have test, or no test, ok? And the second thing is whether you want to have direct test, or indirect test. Whether you want to have an accurate test, or whether you want to have a safe test. If you want to have a safe test, then you need to undergo the screening test. But if you think that I want to have an accurate test, then you need to undergo the, the::, the::, the other test.
		(10)
4	P:	((patient looks at the papers in front of her))°huh huh huh .hhh° ((chuckles))
5	MP:	((smiles)) is that too much information for you today? Or we will have an ultrasound first, and then you dis- you discuss with your husband, and you call me back, what test you want? Or if you have any problem I can explain to you again. Is there any part you don't- you are not very sure?
6	P:	°Twelve weeks, (.) seventeen weeks°, (.)
7	MP:	Yeah.

Mapping of the data

- Structural mapping
- Interactional mapping
- These two types of mapping outline *broad thematic content* and *the division of participation/ involvement* within a given encounter

Cf. Structural mapping: Two pediatric clinics

Clinic A

Turns	**Phase**
1-4	Opening
5-9	Symptoms
10-14	Treatment
14-16	Symptoms
16-20	Examination
20	**Diagnosis**
20-28	Treatment
28-31	Symptoms
32-36	Treatment
37-39	Closing

Clinic B

Turns	**Phase**
1-4	Opening
2-26	Symptoms
27-31	Treatment
31-40	Symptoms
41-43	examination
44-51	Symptoms
52	Treatment
53-54	Examination
55	Casual explanations
56-58	Symptoms
59-63	Examination
64-65	Non-medical
66-72	Symptoms
73-83	Causal explanation
83-85	Treatment …
116-121	Closing

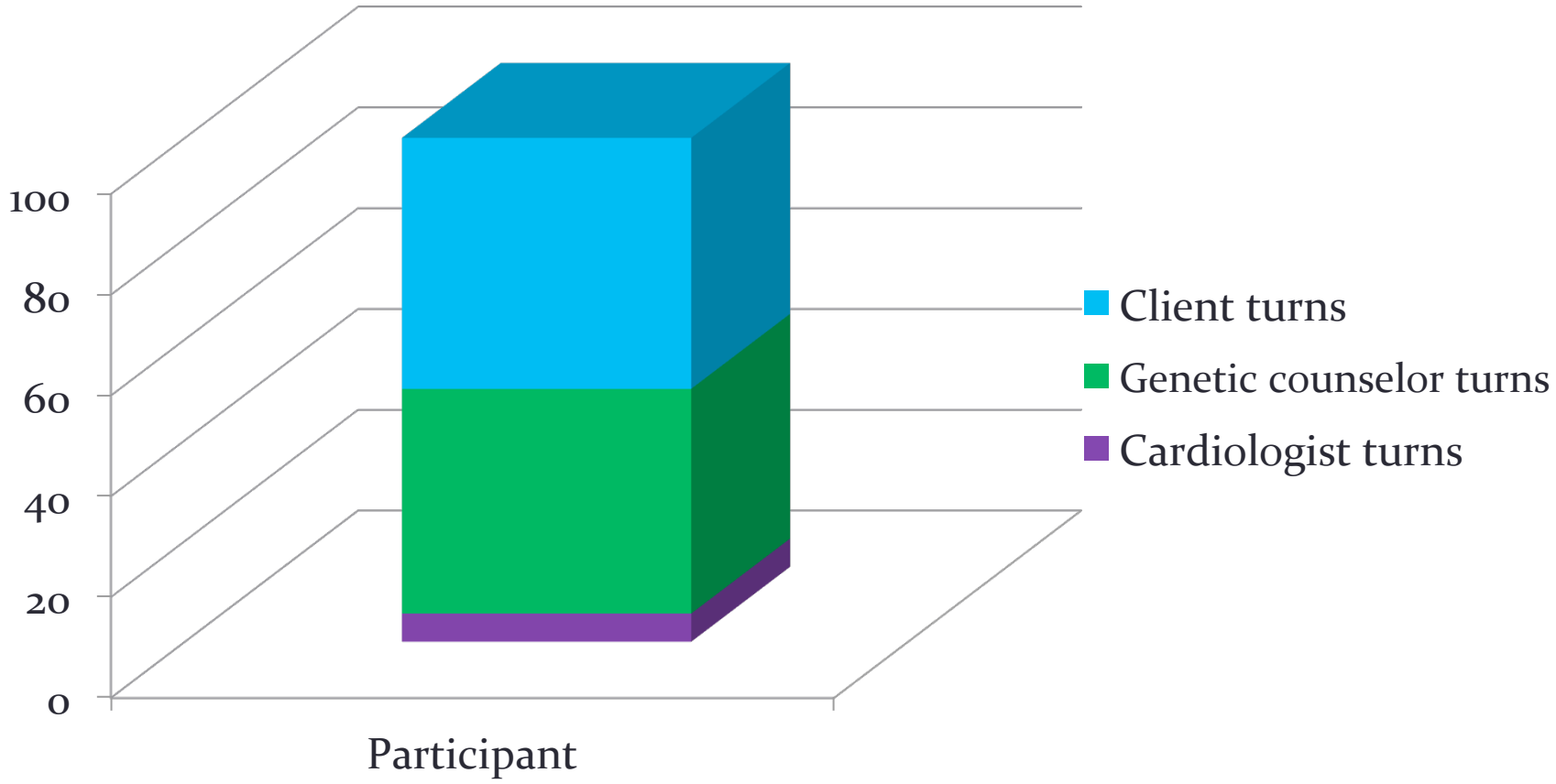
(Sarangi, 2010)

Structural mapping (symptomatic patient; SADS counseling)

- Opening (including purpose of the visit and agenda setting)
- Checking personal details
- Diagnosis delivery
- Explanation of diagnosis (including inheritance patterns, future risks, uncertainty, disclaiming expertise)
- Decisions about testing, disclosure of testing process and test results
- Outlining future procedures and making a clinic appointment
- Strategies of risk management
- Closing

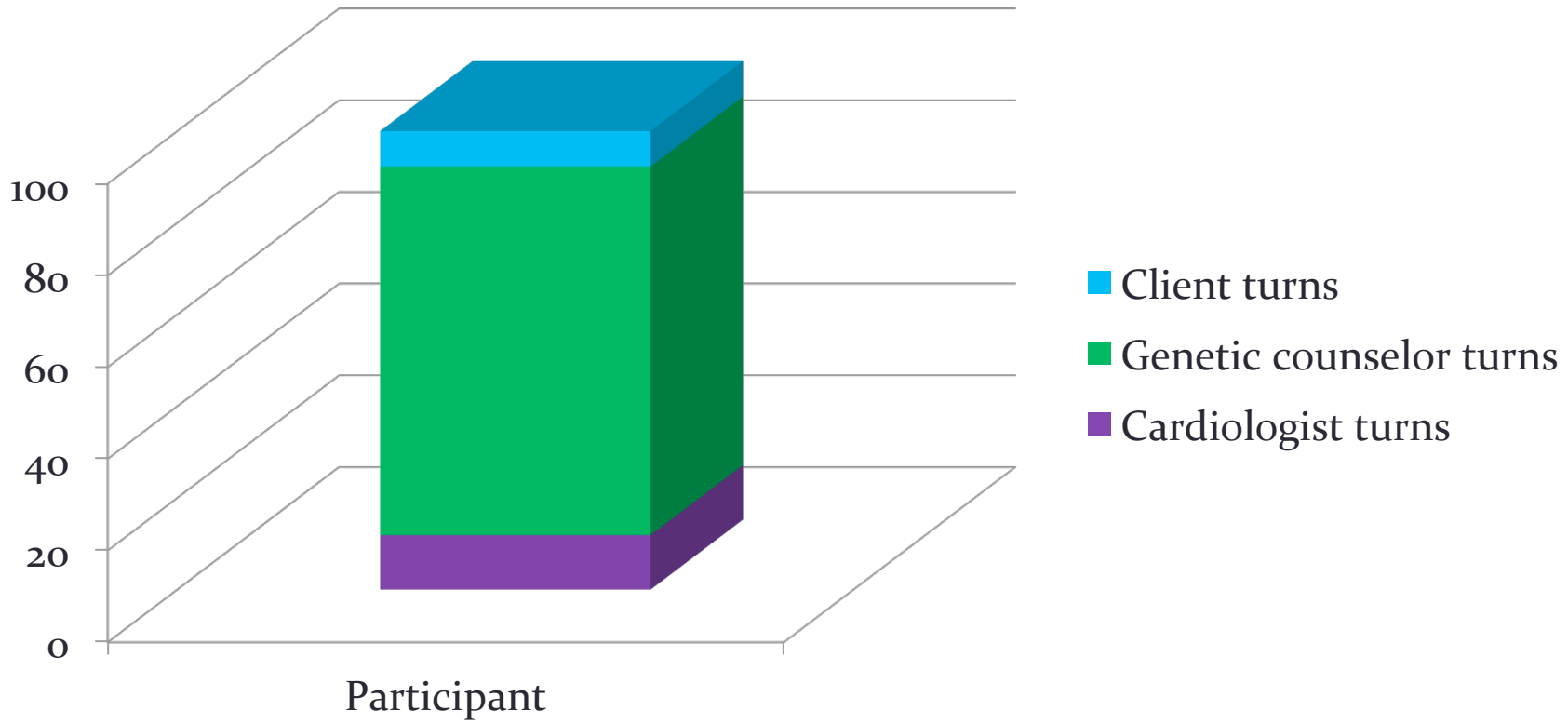
Interactional mapping (SADS)

Figure 1. Distributions of turns by frequency



Interactional mapping (SADS)

Figure 2. Distributions of turns by volume



Thematic mapping:

- Focal themes & analytic themes (theme-oriented DA)
- Focal themes connect to wider issues of professional practice: *'joint problematization'*
- Focal themes of genetic counseling:
  - non-directiveness/neutrality
  - advice-giving
  - risk explanation and perception
  - reassurance
  - uncertainty about diagnosis and prognosis
  - normalcy/deviance
  - ethical issues (e.g. autonomy; informed consent)
  - decision-making, etc.

Example of reassurance

45. GC: ...for this particular mutation of yours (.) .h actually, **in the past, in those patients with Long QT**,
46. C: Mm.
47. GC: **there was the same mutation.**
48. C: Yes.
49. GC: .h **so you are not the first case in the world.**
50. C: Mm mm.
51. GC: .h **there're already reported patients.**
52. C: Mm.
53. GC: **they <u>also</u> have the <u>same</u> mutation, which also occurs in this gene.**
54. C: Yes.

Analytic themes

- Analytical concepts which provide the theoretical background for the construction of meaning in a particular encounters:
  - discoursal and rhetorical devices (contrast; constructed dialogues; metaphor, hypothetical scenarios)
  - contextualization cues and inferences
  - face and face-work
  - social identity, etc.

Important aspects of interdisciplinary collaborations

- Mutual interests and relevance.
- ‘A friend of a friend’ approach to establish the initial contact.
- Introducing the key components of the methodology (Mullany 2008) to avoid participants’ unrealistic expectations.
- Your time budget and “hot” feedback (Sarangi 2002).
- Forms of feedback: Chinese participants’ preference for indirect feedback.
- Doing things not only *with* participants but also *for* participants: triangulation of feedback.

Feedback