

Insights on Sensitive Language Use in the Hong Kong Healthcare Setting: Perceptions of Parents and Caregivers of Patients Affected with Down Syndrome

YWY CHU, SPW CHU, WKY MOK, TY TAN, BHY CHUNG

Abstract

Appropriate use of language in healthcare settings is an increasingly studied area. However, most of the current literature is English based. This study aims to explore the characteristics of sensitive language used in the healthcare setting in Hong Kong. Through the Hong Kong Down Syndrome Association, 116 participants were recruited, consisting of parents and caregivers of patients with Down syndrome (DS). These participants were asked to rate 43 items of words in Cantonese as "offensive"/"not offensive", and were invited to give additional words that they have heard in healthcare setting which they considered to be offensive. We found that the use of "abnormal" (唔正常), the assumptions on abilities and behaviours of individual with DS and the use of allusions to blame parents are the characteristics of sensitive language. This study result provides insight for health professionals to be aware of their word choices in order to reduce the stigmatisation to parents and caregivers.

Key words Cantonese; Down syndrome; Language

Introduction

Each and every word used by a professional in a healthcare setting may have a lasting impression for the patient and their family, making it crucial to select words appropriately. Stereotypic or offensive words used to

describe individuals with physical or intellectual disabilities must be avoided in order to minimise stigmatisation. It is good practice to use milder expressions in exchange for ones considered to be too blunt. In linguistics, this is called 'euphemism', defined as "a word or phrase used as an alternative to a dispreferred expression".¹

Dysphemism, or an offensive expression, can be demonstrated by the words once used to describe Down syndrome. The syndrome was first described by Dr. John Langdon Down in the late 1800s. In one of his reports in describing features of Down syndrome,² the title was written as "*Observations on an Ethnic Classification of Idiots*". Other words that he chose to describe this group of patients in the same report included "*Mongols*" and "*feeble-minded*". These dysphemistic words are now considered taboo.

Since the twentieth century, considerable changes of language to reference individuals with special needs have been made. Lexical alternatives like "*mental deficiency*", which was later changed to "*mental retardation*", were used and were once considered as euphemism. However, the word "*retard(ed)*" is now considered as offensive and derogatory by advocacy community of intellectual and developmental disabilities.³ This course of lexical changes showed that former euphemism would become dysphemism later on.

Department of Paediatrics and Adolescent Medicine, Queen Mary Hospital, Li Ka Shing Faculty of Medicine, The University of Hong Kong, Hong Kong, China

YWY CHU (朱穎瑤) BAsc, MGenCoun

SPW CHU (朱沛樺)

WKY MOK (莫嘉欣) BSc, MMedSc

TY TAN (陳忠洋) MBBS, FRACP, PhD

BHY CHUNG (鍾侃言) MBBS, FHKAM(Paediatrics),

FCCMG(Clinical Genetics)

Victorian Clinical Genetics Service, Murdoch Children's Research Institute, Royal Children's Hospital, Department of Paediatrics, University of Melbourne, Melbourne, Australia

TY TAN (陳忠洋) MBBS, FRACP, PhD

Correspondence to: Dr BHY CHUNG

Received September 1, 2015

Other than the lexicon, syntax – structure of sentence – is also considered as an important component of euphemisms for referring individuals with disability or disease. The 'People-First' approach was proposed for promoting the notion that a diagnosis or disability is not a definition of personhood.^{1,4} For example, instead of stating "*a disabled person*", it should reference as "*a person with disability*". This proposed syntactic change recognises that the power of dysphemistic language can offend and stigmatise individuals with disease or disability and influence the societal perceptions on disabilities.⁵

The use of euphemisms that refer to individuals with disabilities in U.S. has been encouraged as the norm. A well-known example is the Rosa's Law, signed by President Obama in October 2010. This law explicitly stated that all federal policies on health, education and labour must replace "*mental retardation*" with "*intellectual disability*". Moreover, references of "*mentally retarded individual*" must be replaced with "*individual with intellectual disability*".⁶

Down syndrome (DS) is a well described disease in paediatrics. This syndrome is associated with developmental delay, characteristic facial features and various issues including congenital heart condition, gastrointestinal blockage. In Hong Kong, DS occurs in approximately 1 in 767 newborns.⁷ There are multiple health disciplines involved in the management of patients with DS, such as prenatal diagnosis and paediatric medicine. Health professionals need to be aware of the choice of language when communicating with the parents and caregivers of individuals with DS. This is why it is important to understand the perception of parents and caregivers on the choice of language.

The following study is the first study to explore linguistic variants in Cantonese used in the Hong Kong healthcare setting. In particular, there has not been a study on the characteristics of sensitive language. There have been past studies on lay individuals' perception of different word choices.^{5,8} However, these studies only explore word choices in English. This study explores acceptability of certain sensitive Cantonese words used in a clinical setting for patients with DS and families in Hong Kong.

Methods

Participants

The targeted study group chosen was the parents and

caregivers of paediatric and adult patients with Down syndrome. Participant recruitment was done through the Hong Kong Down Syndrome Association (HKDSA). The HKDSA is a well-established support group for over 800 individuals with DS and their families in Hong Kong. This study has received ethics approval from the Institutional Review Board of the University of Hong Kong / Hospital Authority Hong Kong West Cluster.

Data Collection

This study is part of the study of Medical and Social Concerns for Individuals with Down Syndrome. A questionnaire containing seven sections for the purpose of understanding the health service utilisation and the quality of life of patients with DS was used for data collection. One of seven sections of the questionnaire aimed to assess participants' perception on language being used to describe individuals with DS. The language perception section contained 43 items of words. Some words/phrases came from the study of Sensitive Language and the New Genetics (SLANG)⁵ and were translated into Cantonese. The research team added extra words/phrases that health professionals use to describe individuals with Down syndrome. The words/phrases were subsequently evaluated by the scientific committee of HKDSA. Participants were asked to rate each words/phrases as offensive/not offensive. The last question of the language perception section invited participants to give other words/phrases which they have heard in clinical settings and found offensive.

HKDSA organises and hosts special events, gatherings, and activity classes regularly in order to equip their members with skills to become socially integrated. Through these social activities, researchers distributed questionnaires to family or caregivers of individuals with DS. After questionnaires were completed, social workers in HKDSA helped to collect them back for the research team to collect.

Data Analysis

An online tool (<http://www.yueyv.cn/>) is used to generate the phonetic writings of all Cantonese words used in this study. Each of 43 items of Cantonese words was translated into two translations, literal and figurative. Literal translation involves translating Cantonese words with their literal meaning in English. On the other hand, figurative translation involves translating Cantonese words into English in the context of describing features related to DS.

Result

Demographic of Participants

A total of 116 participants returned the responded questionnaires (conservative estimated response rate of 14.5%). All of them use Cantonese as their primary language. The demographic details of participants and individuals with DS whom they care for are summarised in Table 1.

Analysis

All words were grouped according to the contexts in which they might be used, which is similar to the analysis used in the SLANG study.⁵ Words in the same group do not necessarily have the same meaning. Two researchers independently translated all words in Cantonese with their literal meanings in English, then into figurative translations/ in the context of DS.

The data analysis involved counting the number of responses given to particular words. Percentages of participants who found words offensive were calculated and summarised in Table 2. Participants also provided additional words that they found offensive (Table 3).

Discussion

After the exploratory study of SLANG⁵ was published, the awareness in language choices in describing medical conditions has risen among the genetic health professionals in Hong Kong. The SLANG study provides suggestions of better alternative words when communicating with patients. As mentioned in this study, the choice of language could influence different aspects of genetic counselling process: framing of genetic risks, client anxiety levels, autonomy and respect for persons. These aspects are important in the genetic counselling process because they can influence clients' decision making.

The Use of the Word 'Abnormal'

In each category of Table 1, most words that contain *ng4 zing3 soeng4* 唔正常 (literally: abnormal), *ng4 wui5* 唔會 (literally: no possibility/ability), *ng4 sik1* 唔識 (literally: do not have ability to know) and *mou4* 冇 (literally: no/do not have) were deemed offensive by a higher percentage (>60%) of participants.

Most participants perceive the use of *ng4 zing3 soeng4* 唔正常 (literally: abnormal) as offensive. The probable

reason for that may be because of being abnormal seems to disrespect the individual as a person. The responses documented in the SLANG study⁵ on using "not normal" suggest that this term detracts from the identity of a person. This suggestion also emphasizes the 'Person-First' approach, where the person is respected and disabilities thought of as human traits.⁴ Therefore, one should not see the individual with disabilities, including DS, as abnormal.

Alternatives such as "chromosome variation", instead of "abnormality", are recommended for minimising the effects of labelling and stigmatisation.⁹ Our result supports this recommendation, as our result shows that more participants perceived *Geil jan1 ng4 zing3 soeng4* 基因唔正常 (literally: gene not normal) as more offensive than *jim5 sik1 ban6 ji6 soeng4* 染色體異常 (literally: chromosome variant). It is recommended that health professionals should emphasize more on other positive aspects that value patients' potential abilities.⁹ This recommendation reflects that the use of "abnormality" is not only potentially stigmatising, but also disvalues and overlooks patients' potentials in other positive aspects. Our data further support the notion that individuals with genetic conditions should not be defined by their intellectual or physical disabilities nor should their personalities and future potential be limited.

Table 1 Demographic details of individuals with Down syndrome (DS) and the survey participants

	n	%
Individuals with DS		
Age (in years)		
0-12	14	12%
13-18	19	16%
19-30	66	57%
31-53	17	15%
Gender		
Male	63	54%
Female	53	45%
Participants' relationship to individuals with DS		
Mother	97	90%
Father	6	6%
Sibling	4	4%
Relative	1	1%

Table 2 Percentage of participants who find words offensive

	Words in the questionnaire (Cantonese)	Literal translation	Figurative translation in the context of Down syndrome (DS)	Percentage of participants who find words offensive
Aetiology of DS				
	Ji6 bin3 異變	Abnormal change	Mutant, a change that is not of normal occurrence	52
	Gei1 jan1 ng4 zing3 soeng4 基因唔正常	Gene not normal	Genetic abnormality	52
	Wai6 zyun6 bing6 遺傳病	Inheritable disease	A general term describing the disease/condition is due to inheritance	44
	Gei1 jan1 kyut3 ham6 基因缺陷	Gene defect	A defect in the genetic makeup of an individual	43
	Gei1 jan1 dat6 bin3 基因突變	Gene sudden change	An unexpected change in the genetic makeup of an individual, implying that the gene change is not inherited from either parents	41
	Gei1 jan1 goi2 bin3 基因改變	Gene change	A change in the genetic makeup of an individual	40
	Jim5 sik1 ban6 ji6 soeng4 染色體異常	Chromosome variant	The chromosomal makeup is different from normal individuals	35
Features of DS				
Congenital difference	Ng4 zing3 soeng4 唔正常	Not normal	Appearance, behaviour and intellectually functioning abnormally	76
	Keoi5 ng4 Normal 佢唔 Normal	He/she is not normal	He/she is not normal	61
	Sin3 tin1 sing3 ji6 soeng4 先天性異常	Congenital difference	Born to be different	49
	Tin1 sang1 kyut3 ham6 天生缺陷	Congenital defect	Describe one who was born with defect	47
Appearance	Dak6 bit6 cau2 joeng6 特別醜樣	Especially ugly	The appearance of individuals with DS is differ from most people, and they do not look pleasant	71
	Dak6 bit6 gwaai3 特別怪	Especially weird	The appearance of individuals with DS differs from most people. They look weird	70
	Sang1 dak1 ng4 zing3 soeng4 生得唔正常	Born abnormally	It is a more colloquial term in describing a person was born to be abnormal	69
	Tin1 sang1 kei1 jing4 天生畸形	Congenital deformity	As the appearance of individuals with DS look different from most people, this term is used to describe the different appearance	68
	Jat1 ngaan5 tai2 dak1 ceot1 一眼睇得出	One eye recognise	Recognisable right away; implying the features of the patient are immediately apparent	58
Growth	But6 juk6 ng4 zing3 soeng4 發育唔正常	Growth abnormal	Abnormal development, referring to the physical aspects of development	57
	But6 juk6 fau2 cyun4 發育不全	Development not complete	Incomplete development physically	44
	But6 juk6 zi6 wun6 發育遲緩	Growth delay	The physical development of the individual is slower than expected	35
Development	Joek6 zi3 弱智	Weak intellect	Mentally retarded, also sometimes used as an insulting phrase when applied to people without intellectual disability	49
	Zi3 zoeng3 智障	Intelligent obstacle	Retard, intellectually disabled	44
	But6 zin2 dak1 maan6 發展得慢	Developing slow	The development of the individual is slower than expected	41

(continued on page 30)

Table 2 Percentage of participants who find words offensive (cont'd)

	Words in the questionnaire (Cantonese)	Literal translation	Figurative translation in the context of Down syndrome (DS)	Percentage of participants who find words offensive
Implications of having DS to the individuals				
Medical implications	Mou4 dak1 ji1 無得醫	Do not have cure	DS is a condition that cannot be cure or treated completely	75
	Jau6 bing6 有病	Being sick	Can simply mean a person has an illness; when used as an insult, it describe someone who has done/said something ridiculous	58
	Caan4 zat6 殘疾	Handicap	Handicap/disability	43
	Ng4 gin6 cyun4 唔健全	Not physically complete	Describing someone who is physically inadequate e.g. missing a body part	40
Learning implications	Me1 dou1 ng4 sik1 咩都唔識	Doesn't know anything	Since individuals with DS have moderate to severe intellectual disability, therefore they do not know anything in learning new skills	70
	Ceon2 dik1 蠢啲	A bit stupid	The perceived developmental delay of individuals with DS make them more stupid	68
	Ng4 wui5 jau6 zeon3 bou6 唔會有進步	No ability to progress	The perceived developmental delay of individuals restricts them to make any progress in learning new skills	63
	Me1 dou1 hok6 ng4 dou3 咩都學唔到	No ability to learn anything	Unable to learn anything	63
	Ng4 sik1 ziu3 gu3 zi6 gei2 唔識照顧自己	He/she doesn't know about taking care of him/herself	Incapable of taking care of oneself, including basic needs	55
	IQ dai1 IQ 低	IQ low	Low IQ	51
	Hok6 zaap6 zi6 wun6 學習遲緩	Learning slow	Learning disability	42
	Hok6 zaap6 zoeng3 ngoi6 學習障礙	Learning barrier	Individuals' learning ability is challenging than others	39
	Hok6 je5 maan6 di1 學嘢慢啲	Learning slower	Describing someone learning things slower than others	38
	Implications of having individuals DS to the family			
	Sing4 wai6 fu6 daam3 成為負擔	Become a burden	Social, psychological, financial burden to the family	82
	Mou4 hei1 mong6 無希望	Hopeless	Perceived as "there is no hope to treat the individuals with DS" or "it is hopeless for these individuals to get well"	77
	Jiu3 ziu3 gu3 keoi5 sing4 sai3 要照顧佢成世	Need to take care him/her for whole life	Family members need to take care of individuals with DS for life	63
Social labels of individuals with DS				
	Mou4 jung6 無用	Useless	Perceived as "individuals with DS will be useless to the society"	77
	Caan4 zeong3 jan4 si6 殘障人士	Handicapped person	A socially used phrase to describe people with disability	41
	Dak6 syu4 jan4 si6 特殊人士	Special people	People who have special needs or require special care	36
	Seong1 caan4 jan4 si6 傷殘人士	Handicapped person	A socially used phrase to describe people with disability	34

Table 3 Additional offensive words provided by participants

Additional words (Cantonese)	Literary translation	Figurative translation in the context for Down syndrome (DS)
Describing the appearance of individuals with DS		
Ci5 gwaai3 mat6 似怪物	Like monster	The appearance of individuals with DS is like a monster, implying that they look scary
Hung2 bou3 恐怖	Horrible	The appearance of individuals with DS is horrible
Juk6 syun1 肉酸	Flesh sour	Figurative speech of expressing dislike of a particular thing; implying that the appearance is ugly and it is not pleasant to look
Mung4 gu2 zi2 蒙古仔	Mongol	A way to describe individuals with DS, like in the first description by John Langdon Down
Describing mental ability of individuals with DS		
Dai1 dai1 deng6 低低地	Low intellect	Describing the individual's intellect level is low; figurative and simplified speech of intellectual disability
So4 zi2/jyn5 傻仔 / 女	Idiot boy/girl	Describing a person is an idiot
Baak2 ci1 白痴	Clear stupid	Describing stupidity of a person
Ci1 sin3 痴線	Crazy route	"Route" implies the route of the nervous system, overall meaning the person is crazy and does not have normal mental ability
Keoi5 gong2 ng4 dou3 je5 佢講唔到野	S/he cannot talk	The speech ability of the individual is limited, which can be affected by development delay in DS
Relating to the fault of someone		
Fu6 mou5 zou6 co3 父母做錯	Father mother do wrong	Parents have done something wrong and cause their child having DS
Cin4 sai3 zou6 co3 前世做錯	Past life do wrong	The individuals (usually implying parents) have done something wrong in their past life and cause the individual has DS
Keoi5 hai6 lei4 lo2 zaai3 佢係嚟擺債	S/he here take debt	Implying that parents have done something wrong and are in "debt". Having a child with DS is to return the debt of their wrong doings in their past
Nei5 sang1 ge3 zi2 jau6 man6 tai4 你生嘅仔有問題	Your born child has problem	The child was born with problems (e.g. health); implying the mother is guilty of giving birth to the child with DS or other severe health problems
Describing behaviours of individuals with DS		
Wui5 soeng1 hot6 jan4 會傷害人	Able hurt people	Describing the ability to hurt others, usually in a physical way
Sing3 gaak3 bei3 gok3 gu3 zap1 性格比較固執	Personality comparatively stubborn	Describing individual's personality as relatively more stubborn than others
Sik6 co3 joek6 aa1? 食錯藥呀?	Take wrong medication?	Taking wrong medication could affect individuals' health, thoughts and behaviours; usually used to imply individuals' behaviours are abnormal or intolerable

The Assumptions on Abilities and Behaviours of Individuals with DS

This study's participants felt that assumptions about the abilities and behaviours of individuals with DS are offensive. Words that contain *ng4 wui5* 唔會, *ng4 sik1* 唔識 and *mou4* 無 convey the overall meaning that individuals with DS do not have any hopes or abilities to learn and achieve goals. Participants also provided several additional offensive words that underestimate the abilities and behaviours of individuals with DS. For example, there are some assumptions that individuals with DS cannot talk, would hurt people and are more stubborn (see Table 2). According to the study of parents' experience of having children with DS,¹⁰ the majority of them feel that their children are capable of having happy lives, having a good relationship with family and making friends. This reflects that words like *me1 dou1 ng4 sik1* 咩都唔識 (literally: does not know anything), *ng4 wui5 jau6 zeon3 bou6* 唔會有進步 (literally: no ability to progress) underestimate and even wrongly describe the abilities and potential of individuals with DS.

The Use of Allusions to Blame Parents

Another major finding of our study is that some participants feel that the use of allusions to blame parents is offensive. There are several words that demonstrate the use of allusions, for example *fu6 mou5 zou6 co3* 父母做錯 (literally: father mother do wrong), *keoi5 hai6 lei4 lo2 zai3* 佢係嚟擺債 (literally: she/he here take debt) (see Table 2).

The use of allusions is related to the concept of *karma*, which is a "cosmic law that all crimes are suitably punished and all good deeds suitably rewarded, in the long run".¹¹ In Chinese culture, the birth of a child with a genetic condition is regarded as punishment to the family. In the study of cancer genetic counselling with Chinese-Australians,¹² senior family members from affected families believe that hereditary cancer is more likely the result of bad luck or fate, or some evil deed committed by an ancestor. Cancer is considered the price to pay by the younger generations.

It is unclear why participants regarded the use of allusions as offensive. One possibility is that the use of allusion compounds the shame and guilt experienced by the parents of a child with DS. Furthermore, the use of allusion in the healthcare setting is unscientific and unprofessional. The cause of DS is unrelated to any parental past behaviour and any blame based on mythical beliefs is unacceptable in the healthcare setting.

Implications for Language Used in Paediatrics Practice

The results of this study provide some preliminary insights into the characteristics of language of Hong Kong Chinese parents and caregivers of individuals with DS. We hope to raise awareness of this issue with health professionals in paediatrics in Hong Kong who have contact with patients with DS, and, more broadly, other genetic conditions. As emphasized in other literature,^{5,8} poor choice of words can be stigmatising and discriminatory. In healthcare practice, language use can affect perception of the severity of a condition and future impact on health, development, potential abilities and other aspects of lived experience.

Limitations

The majority (72%) of individuals with DS in this study were over 19 years old. This means that the parents and caregivers of these individuals have at least 19 years of experience of interactions with health professionals. Our survey did not ask participants to specify the time that they experienced offensive language. Recall bias may have led to over-ascertainment of language used in the past, and may not reflect current medical practice in Hong Kong.

Although this study provides data on the perception of parents and caregivers on language used in healthcare setting, it does not include the perception of health professionals. The perceptions of health professionals and parents and caregivers on word choices may have discrepancies, as shown in the study of the preferences of clinicians and patients on naming cancer-related mutation.¹³

Even though there may be perception discrepancies between health professionals and parents and caregivers, it is necessary for health professionals to explain carefully the terms that they used in order to reduce negative feelings from parents and caregivers.^{5,14}

Moreover, the design of the questionnaire used in this study did not invite participants to discuss the reason why they think the particular words are regarded as offensive. We can only speculate on the reasons for finding the language offensive, as discussed above. Further studies through interviews or focus group discussion to explore reasons for why particular words are deemed offensive could shed further insight into this area of research.

Declaration of Interest

We declare that there is no conflict of interest.

Acknowledgement

We would like to thank Hong Kong Down Syndrome Association and all participants for their support to this study.

References

1. Halmari H. Political correctness, euphemism, and language change: The case of 'people first'. *Journal of Pragmatics* 2011; 43:828-40.
2. Down JL. Observations on an ethnic classification of idiots, 1866. *Ment Retard* 1995;33:54-6.
3. R-Word: Spread the word to end the word 2011 [10 May 2013]. Available from: <http://www.r-word.org>.
4. Collier R. Person-first language: Laudable cause, horrible prose. *CMAJ* 2012;184:E939-40.
5. Hodgson J, Hughes E, Lambert C. "SLANG"-Sensitive Language and the New Genetics-an Exploratory Study. *J Genet Couns* 2005; 14:415-21.
6. S. 2781 (11th): Rosa's Law. *Pub Law*, 2010:111-256.
7. Yam WK, Tse PW, Yu CM, et al. Medical issues among children and teenagers with Down syndrome in Hong Kong. *Downs Syndr Res Pract* 2008;12:138-40.
8. Condit CM, Dubriwny T, Lynch J, Parrott R. Lay People's Understanding of and Preference Against the Word "Mutation". *Am J Med Genet A* 2004;130A:245-50.
9. Giordano B. The impact of genetic syndromes on children's growth. *J Pediatr Health Care* 1992;6:309-15.
10. Skotko B, Levine S, Goldstein R. Having a son or daughter with Down syndrome: perspectives from mothers and fathers. *Am J Med Genet A* 2011;155A:2335-47.
11. Gombrich R. Buddhist Karma and Social Control. *Comparative Studies in Society and History* 1975;17:212-20.
12. Barlow-Stewart K, Yeo S, Meiser B, Goldstein D, Tucker K, Eisenbruch M. Toward cultural competence in cancer genetic counseling and genetics education: Lessons learned from Chinese-Australians. *Genet Med* 2006;8:24-32.
13. Wakefield C, Meiser B, Homewood J, Barlow-Stewart K, Tucker K. A comparison of community, clinician, and patient preferences for naming a cancer-related mutation. *Clin Genet* 2007;71: 140-7.
14. Chapple A, Campion P, May C. Clinical terminology: anxiety and confusion amongst families undergoing genetic counseling. *Patient Educ Couns* 1997;32:81-91.