

Overcoming the Issue of Language Barriers with Cantonese Speaking Families When Researching the Impact of Developmental Disability

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1. Abstract

Cross-cultural studies in East-Asia are needed in educational psychology research because past-studies have found that having a child in the family with a developmental disability can induce feelings of stress, impose major psychological and social adjustments, increase the burden of care and place the entire family at risk. Chinese participants have been under-represented in family studies for some time and language issues have been identified as a recurrent barrier to research participation by Chinese samples. The three major reasons for non-participation are the lack of translated materials, feeling intimidated by English, and the lack of translation of key words. To increase participation in survey research projects, it is clear that first one must remove language barriers. The Impact on Family Scale [1] is a measure that has repeatedly shown good construct validity in assessing the impact of chronic illness on family functioning. Like many health status questionnaires, the Impact on Family Scale was developed in an English-speaking country. The aim of the present study was to develop a Hong Kong Chinese version of the Impact on Family Scale for parents of children with autism to make it culturally viable for Cantonese speaking and

traditional script reading participants.

2. Keywords: Impact on Family Scale; Traditional Chinese; Autism Spectrum Disorders; Hong Kong SAR

3. Introduction

3.1 Motivation

Although autism spectrum disorders (ASD) have been recognized since the 1940s in Western countries [2], ASD is not generally well understood by the Asian community [3,4]. Adapting to the birth of a child with a developmental disability (such as ASD), which frequently requires life time care in countries with limited support services, has been reported to result in a series of stressful events for parents [5,6]. The present study originated from a growing awareness of the needs of Hong Kong Special Administrative Region (Hong Kong) Chinese parents of children with ASD by Kathleen Tait who conducted investigations in 2014 and 2015, into the coping strategies of Chinese families raising a child with ASD in this region. Cross-national surveys, which analyze an

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experience that takes place within one country, (for example the impact on families raising a child with ASD), while comparing the way that experience is perceived across many different nationalities, have become increasingly popular [7,8]. However, international survey research involving Hong Kong Chinese populations has been plagued with chronic low response rates [9,10]. After a meta-synthesis of 2341 articles, [11] suggested that survey participation rates were the lowest among Asian Americans compared to that of any other ethnic group.

3.2 Problem Identification

Chinese participants have been known to be under represented in family studies for some time [12] and language issues have been identified as a recurrent barrier to research participation by Chinese samples [13]. The major reasons for non-participation were lack of translated materials, feeling intimidated by English, and the lack of translation of key words or terms [11]. Given that only 3.5% of the Hong Kong Chinese population use English as their usual language [14], someone who does not speak English very well may use this to hide a refusal to complete a survey presented in English. To increase participation in survey research projects, it is clear that first one must remove language barriers and preferably use specific dialects.

4. Background

There are currently two Chinese writing systems in use in Chinese speaking regions, namely simplified Chinese and traditional Chinese. The simplification movement of Chinese characters first emerged in the early 1990s, and the simplified script widely implemented today was the version created during the writing reform initiated by the central government of Mainland China in 1956 for easing the learning process in both recognition (reading) and production (writing) [15]. Today the majority of Chinese speaking regions, including Mainland China, Singapore and Malaysia, use the simplified script, while the Hong Kong and Taiwan continue to use the

traditional script.

To understand what the participants from another culture have to say about a topic, it is necessary to know something about the sociolinguistic background they come from. Hong Kong SAR is a very homogeneous society linguistically, with over 98% of the population being Cantonese speaking [16]. The early literacy experience of most Hong Kong Chinese people from the age of three, when they start learning the Chinese character system in kindergarten, until they enter secondary school, is Cantonese. Even though their secondary and tertiary education is most likely to have been mixed mode (i.e., Cantonese and English), Hong Kong Chinese people's educational experience is firmly rooted in a Cantonese. Further, outside of school, their life-world is predominantly Cantonese: family life, movies, menus, the media, signage, etc. are all offered in the medium of Cantonese. Living in a Cantonese-speaking environment, Hong Kong Chinese have little need to use English outside of their work, where they may only use it for writing and some teaching environments.

Cross-cultural and international collaborative studies in Hong Kong are needed in educational psychology research because past studies have found that having a child in the family with a developmental disability can induce feelings of stress, impose major psychological and social adjustments, increase the burden of care and place the entire family at risk [17]. In a recent study, [18] assessed the needs and responses of 75 parents following the diagnosis of childhood autism and found that the parental concerns included a possible delay in diagnosis and dissatisfaction in the lack of communication by the healthcare team post-diagnosis. For studies in which quantitative measures are used, it is necessary to translate these measures into the language of the culture being studied. This is not a simple process. In order to study the quality of life of people with diverse cultural backgrounds, research instruments must be

reliable and valid in each culture studied [19].

Within the field of family impact studies, stress and coping as a result of raising a child with ASD, a lack of representation by Chinese parents in the literature maybe because there are a limited number of measures available in languages other than English. Currently, a validated measure of family impact from this target culture does not exist. The aim of this study was to prepare the Impact on Family Scale (IFS), a tool designed by Stein & Jessop [1] for use in a different cultural and language context. Specifically, we aimed to translate and adapt this tool to make it culturally viable for Cantonese speaking and traditional script reading participants. The cross-cultural adaptation of a familial impact status self-administered questionnaire for use in a new country, culture, and/or language necessitates use of a unique method, to reach equivalence between the original source and target versions of the questionnaire. It is now recognized that if measures are to be used across cultures, the items must not only be translated well linguistically, but also must be adapted culturally to maintain the content validity of the instrument at a conceptual level across different cultures. Attention to this level of detail allows increased confidence that the impact of raising a child with a developmental disability (such as ASD) is described in a similar manner in multinational trials or outcome evaluations. The term cross-cultural adaptation is used to encompass a process that looks at both language (translation) and cultural adaptation issues in the process of preparing an instrument for use in another setting.

4.1 The Present Investigation

According to the results of the 2012 Census figures, the population of Hong Kong was registered to be 6,857,100, while the overall prevalence of autism in this region was reported to be 3800 (0.055%) [16]. This is supported by the World Report on Disability (World Health Organization, 2011), which indicated that 5.49 children in every 10,000 are diagnosed with

autism in Hong Kong (0.054%). The diagnosis of a developmental disability (such as ASD) in a child can trigger a range of emotional responses in parents and across family systems.

Family studies are especially important in the context of the traditional values in Hong Kong because Chinese family members consider themselves to be responsible for taking care of each other [20]. This is known as filial piety [4]. In Confucian philosophy, filial piety means that an individual should be capable of supporting and taking care of their parents in their old age. Children with a moderate to severe impact disability (which can may be the case with ASD) may face obstacles in the fulfillment of their filial piety duties to their aging parents [21]. Chinese parents of children who have significant impact disabilities do consider that their children represent disruptions to the flow of filial piety (FP) exchanges [22]. They understand that the “natural” progression of reciprocity that should flow from birth into ancestry is unlikely to ever be reclaimed. Consequently, raising a child with a disability in a Chinese family is likely to increase that family’s perceived demand and longevity of caregiving responsibilities. The measurement of the meaning that raising a family member with ASD holds for Hong Kong Chinese parents and their view of their family life will not only assist parents with their own psychological distress, but can guide the provision of much needed education and support services that can strengthen family coping and positive adjustment [23].

The Impact on Family Scale (IFS) [1] is a measure that has repeatedly shown good construct validity in assessing the impact of chronic illness on family functioning [24]. It has also been found useful in gauging the impact on families raising children diagnosed with behavioural difficulties [25], behavioural tic disorders [26] and autism [6]. However, like many health status questionnaires, the IFS was developed in an English-speaking country. While the IFS has been translated into five European

languages (e.g., Spanish by Stein and Jessop [27] Italian by Kolk [28] Turkish by Bek [29] , Brazilian-Portuguese by Barbosa & Gavião, [30] and French by Boudas [31] to the best of our knowledge, the IFS has not been translated into any Eastern languages. Specifically, the IFS has not been translated into Hong Kong Chinese (also known as Traditional Chinese). Thus, the aim of the present study was to develop a Hong Kong Chinese version of the IFS for parents of children with ASD.

5. Materials and Methods

5.1 Participants

The total sample for this study consisted of 137 parents from Hong Kong Chinese families who were rearing at least one family member who had been diagnosed with ASD between the ages of 3–18 years. This age group was chosen as it relates specifically to the school age years and thus, should highlight a range of information, educational and support needs by families. Informed consent was obtained from all individual participants included in this study.

5.2 General Description of the Children with ASD

Two different kinds of data were obtained. Firstly, general demographic data was collected about the child (e.g., gender and age of the child, age of diagnosis, and birth order). Refer to Table 1. The mean age of the children was 8.12 years (SD 3.59), and the mean age at diagnosis was 4.33 years (SD 1.99). Parents rated their child as functioning at either an average (20%) or below average (25%) intelligence level. The majority (55%) of parents indicated that they just did not know.

5.3 General Description of the Parents and Families

Secondly, information was collected about the respondents. Respondents varied considerably in age (range: 23-68 years, mean: 46 years). The majority of the respondents (n=111, 81%) were mothers. With regard to marital status, most of the respondents (84.3%) reported living with a partner. Of the participants who had partners, 58.5% of those partners

worked full time. Respondents were asked to indicate their annual household income, however very few parents completed this question. The next step involved collecting data on the parents' perception of the impact of their child's disability on family behaviour via the use of the Traditional Chinese version of the Impact on Family Scale (TCIFS).

Table 1: Demographic Information of the Participants (N = 137)

Age	Sub	Gender		Birth Order		Average age at diagnosis
		Total	Male	Female	1 st	
3	10	8	2	7	3	2.8
4	12	11	1	11	1	2.92
5	7	6	1	6	1	3.71
6	19	16	3	17	2	4.11
7	20	15	5	16	4	4.7
8	17	12	5	12	5	4.69
9	14	11	3	11	3	4.14
10	13	11	2	13	-	5.54
11	3	3	-	3	-	4.33
12	4	2	2	2	2	5.25
13	7	6	1	5	2	4.86
14	1	1	-	1	-	3
15	1	1	-	1	-	3
16	2	2	-	1	1	5
17	5	4	1	5	-	5.8
18	2	1	1	2	-	6.5
Total	137	110	27	113	24	-

6. Procedure

Strategy 1: Recruitment at five community support services for Children with ASD in Hong Kong

The first strategy was to recruit parents indirectly via three NGO (private) special schools and two acupuncture clinics serviced by Chinese medicine practitioners for children with Autism/ASD. Teachers/practitioners nominated the children who were diagnosed with autism/ASD for inclusion in this project. In total, 150 packages with surveys and self-addressed stamped envelopes were sent out to parents of children with ASD. Thirty-eight completed participant consent forms were returned from one of the largest private schools for students with ASD in

Hong Kong SAR (the Autism Partnership School). These 38 participants constituted the pilot group and were interviewed as they completed the pre-final TCIFS. As there were no requested changes or adaptations to the pre-final TCIFS, this version became the final translated version of the TCIFS. A further 58 participants (recruited via Strategy 1) requested that a hard copy survey be posted to them. In total, from the 150 packages, 96 completed TC Impact on Family surveys were returned.

Strategy 2: Recruitment at Autism Information Conference for Parents in Hong Kong

The second recruitment strategy was to approach participants directly at local NGO, (free entry) parent information seminars on ASD that are held annually in Hong Kong during Autism Awareness Week. Two hundred copies of a flyer explaining the project, and giving a web link for either (a) on-line participation, or (b) details for a mail-out data collection method, were distributed at this event. Seventy-five expressions of interest were either, handed to the first author at the conference, or were posted, e-mailed or faxed to the first author within the following week. Seventy-five hard copy final versions of the TC-IFS then posted out to interested participants. This strategy resulted in a total of 41 returned TC-IF surveys. The outcome of recruitment strategies 1 and 2 resulted in a return of 137 completed TC Impact on Family surveys, achieving a response rate of just under 40 %. It has been reported in the past that a response rate of 31% should be considered as a good return rate for survey research conducted in Hong Kong [32]. In addition, Kramer, Schmalenberg, Brewer, Verran & Keller-Unger [33] suggest that response rates of 40% or more have acceptable psychometric properties for unit-specific scales.

6.1 The Measure

The original version of the Impact of Family Scale (IFS) was designed to measure impact of pediatric chronic physical illness on the family (such as asthma, seizure disorder, heart disease, and diabetes mellitus)

and had 24 items. The IFS (short version) has been used to assess the impact of chronic illness on family functioning [24]. It has also been found to be useful in gauging the impact on families raising children diagnosed with behavioral disabilities [25], behavioural tic disorders [26] and autism [6]. The factor structure of the IFS has been examined extensively. In 1980, Stein and Riessman reported that following a factor analysis of the preliminary scale, items relating to siblings and those with low factor loadings were eliminated. A total of 24 items were retained with a four-factor solution (financial burden, family/social impact, personal strain, mastery) and a total score was also generated for the scale. However, in 2003, Stein and Jessop recommended the use of a revised 15 item IFS (short version). A recent study using the Traditional Chinese translated IFS scale (TC-IFS) has investigated the factor structure and has reported on the sound face validity of the TC-IFS [34]. According to Williams [24] the IFS is one of the most frequently used measures of a family member's perception of the effect of a child's disability in both clinical and health service research across numerous diagnostic groups.

6.2 The Translation Process

The guidelines proposed by Beaton, Bombardier, Guillemin & Ferraz [35] were used for the cross-cultural adaptation of the 15 item IFS [1]. This method has been successfully used in the past by the American Association of Orthopaedic Surgeons (AAOS) Outcomes Committee when they coordinated the translation of the different components of their outcomes battery [36]. This process was also used by Boudas [31] to translate the 15 item IFS into French.

Stage 1 – Initial Translation

The first stage in adaptation is the forward translation. The IFS (15 item short version) was translated into Traditional Chinese (TC) by two independent native TC translators. The bilingual translators whose mother tongue was TC produced two independent

translations.

Translator 1 (T1) was a female PhD (education studies) student working as a senior research assistant on several projects with the first author. As a result, Translator no 1 was aware of the concepts being examined in the IFS. This was necessary to provide equivalency from a more clinical perspective and a more reliable equivalency from a measurement perspective (Beaton et al., 2000).

Translator 2 (T2) took on the role of the naïve translator. T2 had a background in gifted education and he was neither aware of nor informed of the concepts being quantified in the IFS. The second translator needs to be less influenced by an academic goal in order to offer a translation that reflects the language used by the population, often highlighting ambiguous meanings in the original instrument (Guillemin, Bombardier & Beaton, 1997). Each translator produced a written report of the translation that they completed, identifying any challenging phrases or uncertainties.

Stage 2 – Synthesis of the Translations

The two translators and the first author, who took on the role of recording observer, synthesized the results of the translations. Working from the original questionnaire as well as the (T1) and (T2) versions, a synthesis of these translations was first conducted (producing one common translation (T – 12). A written report, carefully documenting the synthesis process, noted each of the issues identified by the individual translators and how they were resolved. The next stage was completed using this T-12 version of the IFS.

Stage 3 – Back Translation

Working from the T-12 version of the IFS and totally blind to the original version, two new translators (BT1 and BT2) then translated the T-12 back into English. This is a process of validity checking to make sure that the translated version is reflecting the same item content as the original versions [37]. The back translations of the T-12 were produced by two

secondary school teachers (i.e., a music and a history teacher) who had been living in Hong Kong and working at an International Secondary School for 19 and 23 years respectively. Their mother tongue was English, neither was informed of the concepts that were being explored, nor did they have any background understanding of Autism. This was to avoid information bias and to avoid eliciting unexpected meanings of the items in the translated document (T-12) [38].

Stage 4 – Expert Committee

The next step is to form a committee. The composition of the committee is important to achieve cross-cultural equivalence. According to Beaton [35], the committee should comprise of methodologists, educational professionals, language professionals and the translators (forward and backward). The expert committee's role is to consolidate all versions of the IFS and to develop what will be the pre-final version of the IFS before pilot testing. At the time of the study the first author was working as an Associate Professor at a university in Hong Kong. The expert committee comprised of the Associate Dean of Research, an Assistant Research Professor, the Head of the Language Centre of that university (who were all bilingual) and the first author (whose mother tongue is English).

The committee approach although useful is regarded by some as weak, because it does not necessarily control for shared misconceptions [39]. The reason being that a committee participant may be reluctant to criticize another participant's suggestions especially if there is a perceived inequality of power in the group. This is particularly the case in Asian communities where positions of status are highly regarded and where it would not be acceptable for a junior to correct his/her senior colleague. As a result, none of the translators (T1, T2, BT1, BT2) attended the expert meeting. However, the materials that were at the disposal of the committee included the original English version of the IFS, each translation (T1, T2,

BT1, BT2) along with all of the corresponding written reports from each of the four translators which explained the rationale of each decision at earlier stages. Consensus was reached by the expert committee on all 15 items.

Stage 5 – Test of the Pre-final Version

According to Beaton [35], the final stage of the adaptation process is a pretest and ideally between 30-40 persons should be used. The pilot test of the Traditional Chinese (TC) version of the IFS (TC-IFS) sought to use the pre-final version with participants from the target setting (i.e., Hong Kong Chinese parents raising school aged children with autism/ASD). In the present study, 38 parents completed the pre-final version of the TC-IFS. Each participant completed the survey via an interview so that they could be probed about what he or she thought was meant by each question item and the chosen response. This interview process ensured that the TC adapted version of the IFS retained its equivalence in an applied setting. There were five interviewers, who were bilingual, enrolled in a Master of Education program of study, and who had completed the Educational Research Methods and Data Analysis units which involved being trained in face to face interview techniques.

7. Results

7.1 Semantic Adaptation of the IFS into Traditional Chinese

The only point requiring discussion regarding the semantic and content equivalence of the Traditional Chinese version of the IFS occurred at Stage 5 of the translation process. The issue debated at Stage 5 focused on the term to be used for the disability known as autism or ASD. There is no Traditional Chinese term for autism or ASD. Consequently, it was decided that as all of the participants in this study were going to be accessed through community support services which required a diagnosis of autism or ASD at point of entry, the TC term for special needs instead of autism/ASD would be used.

Participants were asked to give their perception of being interviewed on this topic and their opinion of the semantic quality of the TC version of the IFS. The key themes for this cohort were that: the TC-IFS questions were clear and easy to understand; the issues raised in the TC-IFS were important to the participants; parents also mentioned that they would appreciate some Government initiated innovation to increase Hong Kong community awareness about individuals with disabilities. Sample participant responses are outlined below.

I was very afraid of facing this situation. It is not easy to talk about raising a child with a disability in Hong Kong. I am pleased that this Professor is asking us about our life. Yes, the survey questions were easy to understand, I know what to say. Will the Government know the answers? (Interviewee No 5).

Because of my son, I understand the importance of this interview. So that is one thing that I would say is a positive thing. You're trying to help others. The questions? Yes, their meaning is clear (Interviewee No 26).

This is rare (being interviewed in Traditional Chinese about family impact). No one ever asks me how I am, or even how my child is, not even the social workers. The Government should promote more to let the people understand more about these problems. The questions are good. Anyone can know how to answer (Interviewee No 8).

8. Conclusion

Understanding the importance of including parents of Chinese heritage in cross cultural family impact research is increasing both inside and outside of Mainland China and Hong Kong [40]. However, in the past, when undertaking research with another culture, western research has been criticized for using survey instruments in English [41]. The choice of the language of the survey should not only consider participants' proficiency level, but should also take into consideration which language is normally used in discussing the research topic among the participants,

as well as the impact of the language on the study. The task of establishing equivalence of cross-cultural instruments is both challenging and rewarding [42], and with a reported increase in the number of multicultural research projects conducted, the need to adapt health status measures such as the IFS, for use in other than the source language, is timely.

Although translation has been identified as the most common method of preparing instruments for cross-cultural research [43], there is no one perfect translation technique recommended to improve the semantic equivalence of cross-cultural instruments [39]. Further, the cost of rigorous instrument translation including translator effort, the difficulty of establishing a suitable expert committee of equal status members, the time and effort required of those committee members, as well as participant burden, is considerable. Nonetheless, ideal cross-cultural instruments can separate the variance because of true differences in the phenomena of interest, from the variance because of cultural and linguistic differences [44]. Once the true variance can be discriminated by cross-cultural instruments, interventions deemed effective in one culture can be tested and applied in a different culture.

The TC-IFS was generated through a very rigorous method of translation and adaptive procedures proposed by Beaton [35], which included pretesting with interviews using a standardized protocol, as well as negotiation between local language experts, local researchers and the developer. As a result, the back-translation procedures used to develop a traditional Chinese version of the IFS described in this study were rigorous enough to create an instrument that was both linguistically appropriate and culturally relevant. Further, the TCIFS pilot interviews revealed that the translation was understood as intended by participants. These steps helped to assure content and face validity. Researchers should expect that potential participants will be highly motivated to enroll in a study with these benefits. However, past results have

shown that as a cultural group, the Chinese population has been reticent to participate in research studies. The main reasons for non-participation by Asian American women as identified by Giarelli [45] were: lack of time, mistrust of institutions and negative experiences, lack of translated materials, feeling intimidated by English, and the lack of translation of key words or terms (p. 1055).

It is hoped that a long-term application of the present study might increase the participation of Hong Kong Chinese parents raising children with ASD in family impact research. It is also hoped that it will be possible to explore the transferability of the results of the TCIFS data in future studies. The collective group of Chinese families raising children with ASD will ultimately benefit from the individual's participation in scientific inquiry. To increase participation, in research studies for busy Hong Kong Chinese families raising a child with ASD, first one must remove language barriers in the survey instruments. Second, one must specify if the benefits for participating in research studies are directly or indirectly related to the family or cultural group. HK Chinese research participants in similar studies [46, 4] consistently expressed that a significant motivator for agreeing to participate in research projects was their desire to be of help in some way to the Hong Kong SAR community in general.

One limitation of the present study was the range of ages of the children of the participants. The age range was wide (between 3 and 18 years), making it difficult to make general statements about any particular age group. However, this diversity of age enabled a range of experiences to be represented within the study population. Secondly, by utilizing several recruitment strategies, this study achieved a response rate of 40%. Although, this has been identified in the literature as being a good return rate for a paper-based survey conducted with a Chinese heritage population [32, 33, 47], unfortunately, Hong Kong Chinese parents of children with disabilities are disproportionately

underrepresented in the family impact literature. In Asian communities, there are many culturally received beliefs of causation of disability grounded in filial piety, karma and ancestry [22]. Given the large dispersion of families with children with ASD living in HKSAR, the sample size utilized in the present study (N=137) might be considered to be modest. However, the stigma of a child with ASD not being able to fulfill their filial piety to their parents in a Chinese family is judged harshly by the Hong Kong society. Consequently, greater refusal to participate in research studies might be expected in surveys dealing with sensitive material which had any potential to identify that their family had a member with a disability [48-55].

There is a dearth of literature exploring how altering various factors in an experimental fashion would affect research participation in the Hong Kong Chinese culture. A follow up phase of the TC-IFS translation project has examined the internal consistency and factor structure of the Traditional Chinese version of the Impact on Family Scale in order to make cross cultural comparisons (authors, submitted). Results of that investigation indicated that the Impact on Family Scale has a strong potential to be useful for cross-cultural comparisons between the United States version [1] and the Chinese traditional script version. Understanding Hong Kong Chinese families' concerns about participation in health status research would increase ethical recruitment of individuals of Chinese descent. Culturally appropriate research will require additional resources and additional costs of time and money. However, the ultimate benefit for the Hong Kong SAR community will outweigh these costs.

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10. Declaration of interest statement

The authors and associated staff have no conflict of interest with any funding agency or in relation to use of certain survey tools.

11. Ethics and consent

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Logistical support was provided by Hong Kong SAR NGO disability organizations. Ethical approval to conduct this study was granted by the Hong Kong Baptist University Committee on the use of Human and Animal Subjects in Teaching and Research (HASC) (IRB permission number HASC/249312). Written informed consent was obtained from all participants. Anonymity and confidentiality of participants were guaranteed.

12. References

1. [Stein R, Jessop D. The impact on family scale revisited: further psychometric data. *Journal of Developmental Behaviour Pediatrics*. 2003; 24: 9–16.](#)
2. [Kanner L. Autistic disturbances of affective contact. *Nervous Child*. 1943; 2: 217-250.](#)
3. [Neik T, Lee L, Chia, N. Prevalence, diagnosis, treatment and research on autism spectrum disorders \(ASD\) in Singapore and Malaysia. *International Journal of Special Education*. 2014; 29: 1-10.](#)
4. [Tait K. Parental identification of potential communication behaviour in young Hong Kong Chinese Children with Autism. In CAISE Review No. 4. Collaboration Innovations Supporting Improved](#)

[Educational Outcomes for Students with Special Educational Needs \(SEN\). 2016;](#)

5. [Connolly M, Gersch I. A support group for parents of children on a waiting list for an assessment for autism spectrum disorder. *Educational Psychology in Practice*. 2013; 29: 293-308.](#)

6. [Tait K, Mundia L. The impact on families of children with autism in Brunei Darussalam. *International Journal of Special Education*, 2012; 27: 199-212.](#)

7. [Dyches T, Wilder L, Sudweeks R, Obiakor F, Algozzine B. Multicultural issues in Autism. *Journal of Autism and Developmental Disorders*. 2004; 34: 211-222.](#)

8. [Kogan M, Strickland B, Blumberg S, Singh G, Perrin J, van Dyck P. \(2008\). A national profile on the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics*. 2008; 122.](#)

9. [Hise R, Solano-Mendez R, Gresham L. Doing business in Mexico. *International Business Review*. 2003; 45: 211-224.](#)

10. [Rao P. International survey research: Understanding national cultures to increase survey rate. *Cross Cultural Management*. 2009; 16: 165-178.](#)

11. [Thornton L, Amorrortu R, Smith D, Mainous A, Vernon S, Tilley B. Exploring willingness of elder Chinese in Houston to participate in clinical research. *Contemporary Clinical Trials Communications*. 2016; 4: 33-38.](#)

12. [Holcombe R, Jacobson J, Li A, Moinpour C. Inclusion of black Americans in oncology clinical trials: The Louisiana State University Medical Centre experience. *American Journal of Clinical Oncology*. 1999; 22: 18-21.](#)

13. [Tu S, Chen H, Chen, A, Lim J, May S, Drescher C. Clinical trials: understanding and perceptions of female Chinese-American cancer patients. *Cancer*. 2005; 104:2999-3005.](#)

14. [Census and Statistics Department of Hong Kong. Population aged 8 and over by usual language. 2012;](#)

15. [Zhao S, Baldauf R. Simplifying Chinese characters: Not a simple matter. In J. Fishman & O. Garcia \(Eds.\), *Handbook of Language and Ethnic Identity: The success and failure continuum in language and ethnic identity efforts*. New York: *Oxford University Press*. 2011; 168-491.](#)

16. [Census and Statistical Department of Hong Kong, 2013.](#)

17. [Huang X, Zhang R, Xing Y. Needs of 71 families of children with autism. *Chinese Journal of Special Education*. 2009; 90: 51-59.](#)

18. [Tait K, Fung F, Hu A, Sweller N, Wang W. Understanding Hong Kong Chinese families' experiences of an Autism diagnosis. *Journal of Autism and Developmental Disorders*. 2016; 46:1164-1183.](#)

19. [Munet-Vilar'o F, Egan M. Reliability issues of the family environment scale for cross-cultural research. *Nursing Research*. 1990; 39: 244-247.](#)

20. [Chan S, Lee E. Families with Asian roots. In E. W. Lynch & M. J. Hanson \(Eds.\), *Developing cross-cultural competence: A guide for working with children with families*. Baltimore, MD: *Brookes*. 2004; 181-257.](#)

21. [Tait K, Mundia L, Fung F. Raising young children with Autism Spectrum Disorders in Hong Kong: The impact of cultural values and stigma on Chinese parents' coping strategies. *International Journal Advances in Social Sciences and Humanities*. 2014; 2:07-15.](#)

22. [Hu X, Wang M, Xiao F. Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research*. 2012; 56: 30-44.](#)

23. [Tait K, Mundia L. A Comparison of Brunei and Hong Kong \(SAR\) student teachers' self-efficacy in implementing inclusive education practices:](#)

[Implications for teacher education. *Asian Social Science*. 2013; 10: 51-60.](#)

24. [Williams A, Piamjariyakul U, Williams P, Bruggeman S, Cabanela R. Validity of the revised Impact on Family \(IOF\) scale. *Journal of Pediatrics*. 2006; 149: 257–261.](#)

25. [Sheeberl B, Johnson H. Child temperament, maternal adjustment and changes in family life style. *American Journal of Orthopsychiatry*. 1992; 62: 178-185.](#)

26. [Woods D, Himle M, Osmon D. Use of the impact on family scale in children with tic disorders: Descriptive data, validity, and tic severity impact. *Child & Family Behavior Therapy*. 2005; 27: 11-21.](#)

27. [Stein R, Jessop D. Measuring health variables among Hispanic and non-Hispanic children with chronic conditions. *Public Health Reports*. 1989; 104: 377–384.](#)

28. [Kolk A, Schipper J, Hanewald G, Casari E, Fantino A. \(2000\). The Impact on Family Scale: a test of invariance across culture. *Journal of Pediatric Psychology*. 2000; 25: 323–329.](#)

29. [Bek N, Simsek I, Erel S, Yakut Y, Uygur F. Turkish version of impact on family scale: a study of reliability and validity. *Health and Quality of Life Outcomes*. 2009;7: 4.](#)

30. [Barbosa T de S, Gavião MBD: Evaluation of the Family Impact Scale for use in Brazil. *Journal of Applied Oral Science*. 2009; 17:397–403.](#)

31. [Boudas R, Jégu J, Grollemund B, Quentel E, Danion-Grilliat A, Velten M. Cross-cultural French adaptation and validation of the Impact On Family Scale \(IOFS\). *Health and Quality of Life Outcomes*. 2013;11: 1.](#)

32. [Flower-dew J. Problems in writing scholarly publication in English: The case of Hong Kong. *Journal of Second Language Writing*. 1999; 8: 243-264.](#)

33. [Kramer M, Schmalenberg C, Brewer B, Verran J, Keller-Unger J. Accurate assessment of clinical nurses' work environments: Response rate](#)

[needed. *Research in Nursing & Health*. 2009; 32: 229-240.](#)

34. [Tait K, Sweller N, Carter M, Fung, F, Hu A, Djajic, J. A Preliminary Study of the Internal Consistency and Validity of the Traditional Chinese Adaptation of the Impact on Family Scale. *International Journal of Special Education*. 2018; 33: 77-93.](#)

35. [Beaton D, Bombardier C, Guillemin F, Ferraz M. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*. 2000; 25: 186–3191.](#)

36. [McConnell S, Beaton D, Bombardier C. The DASH Outcome Measure: A User's Manual. Toronto, Ontario: *Institute for Work & Health*. 1999;](#)

37. [Leplège A, Verdier A. The adaptation of health status measures: methodological aspects of the translation procedure. International use and performance of health-related quality of life instruments. *Oxford Rapid Communication*. 1995;93: 101.](#)

38. [Guillemin F, Bombardier C, Beaton D. Cross-Cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *Journal of Clinical Epidemiology*. 1993; 46: 1417-1432.](#)

39. [Maneesriwongul W, Dixon JK. Instrument translation process: a methods review. *Journal of Advanced Nursing*. 2004; 48: 175-186.](#)

40. [Limkakeng A, Phadtare A, Shah J, Vaghasia M, Wei D, Shah A, et al. \(2013\) Willingness to Participate in Clinical Trials among Patients of Chinese Heritage: A Meta-Synthesis. *PLoS ONE*. 2013; 8:e51328.](#)

41. [Lu Y, Gatua M. Methodological considerations for qualitative research with immigrant populations: Lessons from two studies. *The Qualitative Report*. 2014;19: 1-16.](#)

42. [Wang W, Lee H, Fetzer S. Challenges and strategies of Instrument Translation. *Western Journal of Nursing Research*. 2006; 28: 310-321.](#)

43. [Morita R, Arakida M, Osborne R, Nolte S, Elsworth G, Mikami, H. Adaption and validation of the Japanese version of the Health Education Impact Questionnaire \(heiQ-J\) for the evaluation of self-management education interventions. *Japan Journal of Nursing Science*. 2012; 10: 255-266.](#)
44. [Yu D, Scudds R, Scudds R. Reliability and Validity of a Hong Kong Chinese Version of the St. George's Respiratory Questionnaire in Patients with COPD. *Hong Kong Physiotherapy Journal*. 2004; 22: 33-39.](#)
45. [Giarelli E, Bruner D, Nguyen E, Basham S, Marathe, P, Dao, D, et al. Research participation among Asian American women at risk for cervical cancer: Exploratory Pilot of Barriers and Enhancers. *Journal of Immigrant and Minority Health*. 2011; 13: 1055 - 1068.](#)
46. [Tait K, Mundia L, Fung F, Wong C. The impact of traditional Chinese beliefs, stigma and local school service provision on the coping strategies of parents of children with Autism Spectrum Disorders in Hong Kong. *Journal of the International Society for Teacher Education*. 2014; 18: 16-25.](#)
47. [Meredith R. The Elephant and the Dragon: The Rise of India and China and what it means to all of us. New York: *W.W. Norton & Co*. 2008;](#)
48. [Dehn L, Korn-Merker E, Pfafflin M, Ravens-Sieberer U, May T. The impact on family scale: Psychometric analysis of long and short forms in parents of children with epilepsy. *Epilepsy and Behaviour*. 2014; 32: 21-26.](#)
49. [Grollemund B, Guedeney A, Vazquez M-P, Picard A, Soupre V, Pellerin Pet al. \(2012\). Relational development in children with cleft lip and palate: influence of the waiting period prior to the first surgical intervention and parental psychological perceptions of the abnormality. *BMC Pediatrics Journal*. 2012; 12: 65.](#)
50. [O'Connor, B. SPSS and SAS programs for determining the number of components using parallel analysis and Velicer's MAP test. *Behavior Research Methods, Instrumentation and Computers*. 2000; 32: 396-402.](#)
51. [Ravens-Sieberer, U, Morfeld M, Stein R, Jessop D, Bullinger M, Thyen U. The testing and validation of the German version of the impact on family scale in families with children with disabilities. *Psychotherapy and Medical Psychology*. 2001;51: 384-393.](#)
52. [Stein R. Caring for Children with Chronic Illness. New York: *Springer*.1989;](#)
53. [Stein R, Riessman C. The development of an Impact-on-Family Scale: Preliminary findings. *Medical Care*. 1980;18: 465-472.](#)
54. [Tabachnick B, Fidell L. Using Multivariate Statistics \(4th ed.\). Needham Heights, MA: *Allyn & Bacon*. 2007;](#)
55. [World Health Organization. World Report on Disability. WHO Press: *Geneva*. 2011;](#)

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