Autism in Vietnam: the case for the development and evaluation of an information book to be distributed at the time of diagnosis

Ko Chung Ying
Graeme Browne
Southern Cross University
Marie Hutchinson
Southern Cross University
Andrew Cashin
Southern Cross University
Bui Vu Binh
Hanoi Medical University

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Autism in Vietnam: The Case for the Development and Evaluation of an Information Book to be Distributed at the Time of Diagnosis

Ko Chung Ying, Graeme Browne, PhD, and Marie Hutchinson
Southern Cross University, Health & Human Sciences, Lismore, Australia

Andrew Cashin, PhD
Southern Cross University, Nursing, Lismore, Australia

Bui Vu Binh
Hanoi Medical University, Nursing & Midwifery, Hanoi, Vietnam

Autism is not generally well understood by the community in the West or in Asia. A diagnosis of autism is distressing for all families. When families receive the diagnosis they are often not able to fully appreciate what it means or process the information given to them. Booklets exist in English that contain relevant autism related information but few have been evaluated. In Vietnam, parents do not have ready access to autism related information. This paper makes the case for offering a Vietnamese language information resource/booklet for parents to be distributed at the beginning of the diagnostic process and evaluating its usefulness. In developed countries autism has been recognised since the 1940s (Kanner, 1943). More recently it is being increasingly recognised in children with average and above intelligence. In Vietnam, a Western view of autism is just developing. Consequently community resources are undeveloped. The community, in general, and health services for children, in particular, have a rudimentary understanding of autism. This paper discusses a Western understanding of autism, autism in Vietnam, and suggests one possible strategy for addressing the educational needs around autism in Vietnam.

Autism is a way of being in the world characterised by a triad of impaired behaviours that are the basis of diagnosis. The triad consists of impaired social skills, communication, and behavioural flexibility, which are manifested as restricted interests, activities, and behaviours (American Psychiatric Association, 2000). The behavioural triad is underpinned by the cognitive triad of impairment: abstraction, theory of mind and linguistic processing of information (Cashin, 2006; Cashin & Barker, 2009).

Autism internationally affects between 0.6 and 1.6% of the population (MacDermott, Williams, Ridley, Glasson, & Wray, 2008; Baron-Cohen et al., 2009; Centre for Disease Control and Prevention, 2007). It is of note that prospective studies report higher prevalence (Cashin, 2006; Cashin & Barker, 2009). It would appear a claim that internationally one percent of the population has autism is sustainable.

Understandably, parents are distressed when their child receives a diagnosis of autism. This distress arises from both the diagnosis and a lack of a simple and definitive understanding of what it means to the child and family (Dale, Johada, & Knott, 2006; Gray, 1994; Howlin & Moore, 1997). This distress is compounded because the diagnosis of autism is not straightforward.

In general, children with autism will exhibit the behaviours by their second birthday (McConkey & Cassidy, 2010). For this study the authors interviewed 72 parents of children with autism regarding their recollections of the problem in their child’s speech and behaviour as well as communication difficulties by the age of 18 months (McConkey & Cassidy, 2010). Nevertheless, receiving an accurate diagnosis of autism is a long and arduous journey. One reason for this is that parents of children with autism may hesitate to seek help. Another is the lack of awareness and knowledge of clinicians about autism or misdiagnosis arising from a confusing range symptoms that are commonly shared with other disorders (Howlin & Moore, 1997; McConkey & Cassidy, 2010).

LITERATURE SEARCH

A search of databases, including CINAHL, ERIC, MedLine, PsycARTICLES, and PsycINFO was undertaken: “Auti*,” “book,” and “parent*” were the terms for the first search, which revealed 324 articles; all but three were book reviews; “Auti*” and “Vietnam” were the terms for the second search. The
12 articles found by this search are discussed in this article; “Autism,” “pamphlet,” and “parents” were the search terms for the third search; no articles were found using these terms.

Interestingly, there seems to be a large number of English language books and booklets developed to help parents of young children diagnosed with autism. Although the books and booklets received mostly positive reviews no formal evaluation of the usefulness of these books was found.

**AUTISM IN VIETNAM**

In Vietnam, information related to the prevalence of autism is limited (Browne, 2009). According to the Vietnam Public Health Association there are around 160,000 identified people with autism in Vietnam, but there is no official data and no autism related books printed in Vietnamese (Brown, 2009). It has been estimated that of the children with special needs in Vietnam, about 95% of them do not receive any dedicated services (Villa, Van Tac, & Muc, 2003).

In Vietnam, the diagnosis of a child with a disability has long been considered a crisis for parents (Hatton, Akram, Roberston, Shah, & Emerson, 2003). Vietnam is an Asian country, whose culture, “shares some elements with Chinese and Korean cultures, namely centuries-long traditions of Buddhism and Confucianism” (Shin, Nhan, Crittenden, Hong, Flory, & Ladinsky, 2006, p. 749). Culturally, people commonly view “disability” as a punishment for the disabled person’s sins in a past life or for the sins of the person’s parents. Because of this traditional belief, the families of those with a disability will often feel ashamed and guilty (Kim-Rupnow, 2005; Lam, 1992; Liu, 2005). Weil (2000) described blame and guilt among family members as a common finding in families when a genetic disorder is identified. Additionally, in Vietnam the pressure and stigma of being parents of a child with a disability, considering the cultural views of causation, can result in increased parenting stress and anxiety (Huang, Kellett, & St John, 2010).

All children with autism may exhibit peculiar behaviours and unusual language and communication patterns. This brings unique challenges to mothers everywhere in public situations where some people may misunderstand or misinterpret the child’s behaviour (Estes, Munson, Dawson, Koehler, Zhou, & Abbot, 2009). As a result, numerous studies have indicated that caregivers of children with autism experience increased depression and anxiety, diminished physical health, and increased pressure in marital relationships, as well as modified lifestyles, such as restrictions of roles and activities (Cashin, 2004, Holmes & Carr, 1991; Jessop, Riessman, & Stein, 1988; Shu, Lung, & Chang, 2000; Simon, 1995, 1997).

A nongovernment organisation (NGO), Connect Asia (2009), described parents in Vietnam as being very anxious about their child’s behaviour. They identified that autism was very much a new field in Vietnam and little information was available. An Australian paediatric specialist recently reported in the Caring and Living as Neighbours (CLAN an NGO supporting children with chronic illnesses in developing countries) newsletter that families in Vietnam were shocked by the diagnosis and were uncertain what to do, but there are almost no resources available in the community (CLAN, 2010). The non-profit organisation, New Hope Resources in Vietnam, described a situation where many doctors, health professionals, and students only learned theories of autism in the absence of practice knowledge or clinical experience. These clinicians reported they didn’t know how to work with people with autism (Brown, 2009).

Understanding autism is very important for parents of newly diagnosed children to enable them to undertake their responsibilities of being caregivers. In traditional Vietnamese families, health care decisions are made by the extended family not by the parents alone (Duong Nguyen, 1985). It is the responsibility of mothers to relay information from health professionals to other family members. The extended family then uses this information to make decisions about health care.

Health literacy is an important element in decision making around health and disability. There is little information related to levels of health literacy in developing countries, and the limited evidence available indicates the levels are low (Carmona, 2006). In Australia, a developed country, results from the Australian Bureau of Statistics indicated that 60% of Australians lack basic health literacy (Nielson-Bohlman, Allison, & Panser, 2004). There is no health literacy data available from Vietnam, but anecdotal reports indicate levels are much lower than those in Australia. The case example that follows suggests there is much work to be done to build health literacy.

A child from the Montagnard mountain region in Vietnam was prescribed antibiotics to treat impetigo. Parents of the child were told to give 1 pill 4 times a day to their child for 7 days and then come back for follow-up. On the day of follow-up, the health care provider found that the antibiotic tablets had been made as a necklace (Carmona, 2006, Page 803).

Clearly there was not sufficient/appropriate information communicated to the family, which became manifested in a problem of understanding. The main focus of consideration in any health related intervention is not only relaying the information but also considering how the consumer will understand and make use of that information. Clearly the communication of accurate and culturally appropriate information to relatives and friends at the time of diagnosis is important. The provision of written information may be more reliable and also useful as a supplementary resource to the standard of verbal instructions.

There is information available on the Internet, for example, SPIRAL (Selected Patient Information in Asian Languages; Tufts University Hirsh Health Sciences Library, 2011) unfortunately there is limited access to online resources for the average Vietnamese family and the therapies recommend by SPIRAL are not available in Vietnam.
INFORMATION PROVISION AT TIME OF DIAGNOSIS

There is no available Vietnamese research (in peer-reviewed literature) to inform a discussion of the parents’ experience. There is limited literature generally on parents’ experience of a diagnosis of autism. Therefore this argument is informed by a wider range of literature that includes other disabilities and from a range of developing and developed countries.

During the process of diagnosis, parents of children with disabilities, in general, and autism, in particular, experience stress not only related to the diagnosis but also related to the process of receiving the diagnosis (Dale, Johada, & Knott, 2006; Gray, 1994; Howlin & Moore, 1997). Factors that contribute to the parental dissatisfaction at the time of diagnosis are the content of shared diagnostic and related information, the way they receive the information, the manner and attitude of the health professionals as well as the provision of explanatory written materials, such as pamphlets and booklets designed for families (Brogan & Knussen, 2003).

In a UK study of 107 parents of children with Cerebral Palsy, Baird, McConachie, and Scrutton (2000) found 46 parents (43%) were dissatisfied with the information content they received at diagnosis. The study used semi-structured interviews to explore the parents’ experience. Almost all the 107 parents in the study said they thought that receiving a booklet or some written information about their child’s condition would have been helpful.

In an Austrian study exploring parents’ recollection of the appointment where their child received a diagnosis of Cystic Fibrosis, Jedlicka-Kohler, Gotz, and Eichler (1996) found that parents, because they were stressed upon hearing the diagnosis, retained limited amounts of information given to them by the diagnosing physician. The study recruited parents of 29 children to be involved in the study; the parents of 27 children (n = 46) completed the questionnaire. The 20-item questionnaire was developed in-house and was designed to obtain parents’ subjective estimates of what they understood and retained from their initial discussion with their diagnosing physician. The parents reported that the diagnosis was communicated orally, without written material. Generally there was time given to the appointment that included counselling and time to ask questions, which were encouraged. Despite the efforts of the diagnosing physician, the parents reported that they retained only portions (M = 76%) of the information. A group (n = 15, 33%) reported that they retained less than 50% of the information. Interestingly the parents who retained less than 50% of the information also reported being most shocked by the diagnosis. The poor retention of information was reported by parents to be a result of fear (83%), despair (56%), disappointment (30%), and guilt (30%) (Jedlicka-Kohler, Gotz, & Eichler, 1996). Although this is an Austrian study with parents of children diagnosed with Cystic Fibrosis, it is reasonable to assume the experience of Vietnamese parents of children diagnosed with autism may well be similar.

A postal survey of 1300 parent members of autistic societies in the UK, conducted by Howlin and Moore (1997), focused on parents’ views of the diagnostic process. This study found that dissatisfaction with the quality of information was frequently reported by the parents. In relation to the provision of basic information, many families reported that they would have benefitted from written material. They said things like, “It would have helped us considerably if we had been provided, from the start, with a set of leaflets explaining the basic things parents need to know about—such as, a statement of special educational needs, respite care … It took us a long time to find out this sort of information” (Howlin & Moore, 1997, p. 160).

Results of the study by Howlin and Moore (1997) illustrated that the parents of these children were likely to seek help or advice about 6–7 months after they realized that their children had problems. However, only 101 (7.8%) of the total 1295 children received a diagnosis at the first consultation and 63% (519 children) obtained a diagnosis subsequent to the secondary consultation. On average, delays in obtaining a diagnosis, from when families first became concerned and began seeking professional help were between 3.81 and 4.42 years (Howlin & Moore, 1997). Whilst the Howlin and More study was in 1997 in Britain, emerging data from developing countries would suggest that the findings remain contemporary in a Vietnamese context (Action for Autism, 2010).

As discussed above there has been little research into the effectiveness of information provided to parents after a diagnosis of autism. What limited evidence there is seems to indicate that parents value written information resources. In a study evaluating the usefulness of an Autism Spectrum Disorder resource kit (called the Keyhole Rainbow Resource Kit) mothers reported that they found the kit helpful to their child and themselves personally (McConkey, MacLeod, & Cassidy, 2009). The resource kit had been developed by a parent-led voluntary organisation, Autism Northern Ireland and contained information booklets and other aids. The study used a combination of structured interviews and self-completion questionnaires to investigate the responses of 29 mothers to the kit. Data were collected before and after the mothers were provided with the resource kit. Findings indicated that all the participants appreciated receiving the kit. Participants also reported that they would recommend the kit to other families. Only two participants found that the kit was not really helpful for them. The above study used the Vineland Adaptive Behaviour Scales and the Gilliam Autism Rating Scale for the assessment of the child’s developmental level and autism characteristics. The Parenting Stress Index and the General Health Questionnaire were used to investigate stress and the general health of mothers. Results indicated there was a small drop in the number of the child’s behaviour problems (M = 4.9 to 4.1) reported at follow up, and that there was a significant change, with those problems “getting better” within three months of receiving and implementing the resource kit (t = 3.96, p < 0.01). In addition the parents reported significant
improvement in problems related to play (t = 2.6, p < 0.05), relations with others (t = 2.12, p < 0.05), and difficulty imitating (t = 2.21, p < 0.05). Parent stress did not change, but there was a significant change on the parent-child dysfunction subscale (t = 3.69, p < 0.01). There was no change in the general health of the mothers pre- and post-implementation of the kit.

In a study evaluating another autism resource kit, developed by parents and clinicians and aimed at parents of newly diagnosed children, findings indicated that the resource was needed and filled a gap (Mulligan, Steel, MacCulloch, & Nicholas, 2010). This Canadian study used data from two parent focus groups (n = 9) and one clinician focus group (n = 4). The booklet was mailed to the participants and the focus groups took place approximately three months later. The participants reported that the resource was accessible, useful, and accurate. Both groups reported that the resource filled a gap in assessment and practice around autism in Canada (Mulligan et al., 2010). Although further evaluation is yet to be published, this small study supports the need for written information to be distributed as part of the diagnostic process.

**RECOMMENDATIONS FOR PRACTICE**

As a parent, receiving a diagnosis of autism is often distressing. When parents receive the diagnosis, often they are not ready to think about the meaning to their child and their family. Resource booklets are a rational response to helping parents at this time, and there are many available in developed countries. Unfortunately research into their usefulness to parents is limited. The limited evidence that exists seems to indicate these booklets are valued by parents.

Autism as a diagnostic construct is a new and rapidly evolving entity in Vietnam. Although it has been estimated there are 160,000 people identified as being on the autism spectrum in Vietnam, with a population of 87 million people, it would be reasonable to expect (at an estimate of 1% of the population) that there would be 870,000 people on the autism spectrum. No causative factor has been found for autism and diagnosis remains based on behaviour.

In Vietnam there are many culturally received beliefs of causation grounded in Karma that are perhaps less helpful and informative for parents than that offered by a Western understanding of autism. Vietnam, in many ways, is very different culturally from the West. For the resource to be useful it would need to be written in Vietnamese and use culturally appropriate information and examples.

The time of diagnosis of autism is a stressful time for parents and families. Booklets are commonly used in the West and the limited evaluation of them seems to indicate they are helpful to parents. The authors of this paper propose that the provision of written information in the form of a book offered to parents at the time of diagnosis would be useful. There would also be a ripple effect, with the book becoming a community tool, not only to parents but also clinicians, early childhood teachers, and other health workers, and providing the most up to date knowledge related to autism. This knowledge spread through the community will promote inclusion. Increasingly there are Internet resources that offer information to parents of children newly diagnosed and there are emerging evaluations of these websites. Unfortunately in developing countries such as Vietnam, computer access is nowhere near universal so these websites are not available to many parents.

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**REFERENCES**


