

Attitudes of Social Workers to Complementary and Alternative Methods of Interventions for Children with Autism in Kerala, India

Tomáš Hudec, Stanislava Ševčíková

Abstract

The authors present the topic of professional social workers and social pedagogues' attitudes and practice towards complementary (healthcare, psychotherapy, special education) and alternative (ayurveda, homeopathy, music therapy, yoga, meditation) medicine for children with autism spectrum disorders in Indian Kerala. Field research was conducted directly in the Indian state of Kerala with professional social workers using a qualitative research strategy in the form of semi-structured interviews. The aim of the study was to gain better understanding of the cultural context and specific features of psychiatric social work in India.

Keywords: Attitude – Autism – Complementary methods – Alternative methods – Social Work – Social Pedagogy.

Postoje sociálních pracovníků ke komplementárním a alternativním metodám intervence dětí s autismem v Kerale, Indii

Abstrakt

Autoři prezentují problematiku postojů a praxe profesionálních sociálních pracovníků a sociálních pedagogů ke komplementární (psychoterapie, speciální pedagogika) a alternativní medicíně (ajurvěda, homeopatie, terapie hudbou, jóga, meditace) s dětmi s autismem v indické Kerale. Výzkum byl realizován přímo v indické Kerale s profesionálními sociálními pracovníky kvalitativní výzkumnou strategií formou polostrukturovaných rozhovorů. Cílem studie je získat lepší porozumění kulturního kontextu a specifických rysů psychiatrické sociální práce v Indii.

Klíčová slova: Postoj – Autismus – Komplementární metody – Alternativní metody – Sociální práce – Sociální pedagogika.

Introduction

As the pace of new knowledge accelerates in many disciplines of present-day society (Ferguson, 2003), traditional systems face a need to respond to new challenges, which involves the need also to cope with a certain degree of risk (cf. Beck and Beck-Gernsheim 1996, Ševčíková, Navrátil, 2010). In the presented study we interview social workers operating in the Indian state of Kerala in order to find out how social workers view traditional systems of complementary and alternative medicine in addressing autism and children's autistic manifestations. Happé (1995) assume that autistic manifestations are present across our civilisation despite the fact that they may never have been diagnosed by doctors and professionally addressed, especially where social services and healthcare are not accessible for the whole population.

The authors first conceptualise the basic notions in the particular culture, and continue by defining autism spectrum disorders as well as the concept of family, complementary and alternative medicine, and, last but not least, social work. We shall subsequently present the applied research methodology and provide an interpretation of the data obtained through the presented qualitative research among social workers in Kerala, India.

Culture

The present work represents a cross-cultural study, and therefore the authors begin by defining culture. The generally accepted concept by Grewal (2010) and Geertz (2000) considers culture as a shared system of meanings, and these meanings channel the behaviour of all members of a culture group. Murphy (1986) states that for culture to exist, the human brain must be able to generalise and arrange the perceived categories into meaningful units. According to White (in Murphy, 1986), human culture is a set of symbolic acts. For old customs and symbols to be reflected and new possibilities to be allowed to enter an original culture, a certain amount of “mental flexibility” is required (cf. Murphy, 1986). Some authors, including Mamtani (2011) believe that in mental health matters, these meanings influence the way we perceive and intervene in a mental disorder, and this subsequently influences how the disorder develops in its cultural settings. Mamtani (2011) uses the term *universalist* approach, whereas some other approaches regard mental illness as a purely social construct or rather the opposite, a biological disease with uniform symptoms and manifestations across the world.

Autism spectrum disorders

Autism spectrum disorders (hereinafter ASD) have been studied in a similar way by anthropology. Grinker (2007) makes the distinction that ASD as a disorder (the physical structure of the brain and behavioural patterns) is universal, while as an illness it is culturally constructed (the set of symptoms perceived as pathological or strange). Western social science reaches the same conclusions in the work of Eyal (2010). In his work he shows the changing cultural perception of ASD in the history of Western psychiatry and social services.

Family

Present-day family is described as the process in which the members of a family construct the perception of their roles (Baviskar, 2010). The Indian family shows certain specific cultural features, the extended family in India is a “joint family”, with joint obligations, joint estates and subordination of the individual to family interests (Henderson, 2002, Sharma, 2007). Other characteristics are strong religious and caste affiliations. Another aspect of the Indian family, *izzat*, i.e. maintaining the reputation of one’s family, has specific implications for people’s conduct towards the mentally ill, and the overall

importance of family life for Indians has implications not only in the care provided by the family but also in the Indian *healthcare and social care sectors* (Juthani, 2001).¹

In India, a family with a member with ASD is affected very strongly. Family pride suffers with the breaking of numerous social rules in everyday situations (Grewal, 2010). According to Grewal, parents may tend to hide their child with ASD because of public shame.² Juthani (2001) describes how the family members approach the allopathic professional – doctor. They rely on him/her as a positive figure once they gain confidence in him/her. Parents in India tend to make decisions on behalf of their child, even when they are adults, and they expect the allopathic professional to show respect for their culture and religion, including a belief in the supernatural causes of the disorder.³

Complementary and alternative medicine

For the purposes of this study, the commonly used term “complementary and alternative medicine” (hereinafter CAM) is also covered by the single word “intervention” (as defined in Thackery, 2002) – it is a notion which is broader than “treatment” or “medicine” and includes healthcare, religious practices, psychotherapy, special education, etc.

CAM has been defined as “a group of diverse medical and healthcare systems, practices, and products that are not generally considered part of conventional medicine” (National Centre of CAM, NCCAM, 2008). “Complementary” is used in conjunction with and an alternative to “conventional intervention” (CI). Considering the great heterogene-

¹ In Baviskar's (2010) study, “family” comprises of the closest caregivers of a child with ASD. Having a child with even mild ASD has serious consequences for the family. The attitude of the family to the child has several psychological phases (Thorová, 2006). As for the services and interventions chosen, the family is initially susceptible to shortcut solutions and crisis behaviour. Following this, for various reasons, family life is strongly affected, more than in the case of other developmental disabilities (Twoy, 2006). Therefore, a sensitive approach to family members is of crucial importance. The family itself uses various coping strategies. For Asian families in general, the most important coping strategies observed were religious coping and relation-based coping.

² They may not be able to find a spouse for the child's siblings. Interaction with other family members, including the extended family, is often denied to the child. On the other hand, the extended Indian family can provide the parents with extensive support, for example by showing understanding for the situation, acceptance and tolerance (Mamtani, 2002).

³ When looking specifically at Kerala, a state in South India, a great intercultural variety can be observed (Raj, 2008). On the other hand, Kerala's society can be described as conservative (in comparison to the rest of modern India), preserving many ancient Indian traditions, especially in the world of religion, family and lifestyle (Raj, 2008). Kerala stands out as the world's Ayurvedic centre and home to various local approaches to mental health – from holistic traditional medicine to tribal medicine and spiritual healing. The concept of the “Kerala model” has been described in the literature (McKibben, undated) – the state of Kerala has become well-known for its huge investment in human resources. This means that most Kerala citizens have access to allopathic psychiatric care, education, and in cities special education. The rising middle class has gained access to private medical care, including psychological support and hi-tech facilities.

ity of CAM, and all the more so in the context of a different culture, we shall first look at the definitions surrounding the conventional approach to ASD.⁴

Social work and Social Pedagogy

According to the IFSW General Meeting and the IASSW General Assembly, it is defined as follows: "Social work is a practice-based profession [...] that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing." (International, 2007, Musil, 2013). Social work as a profession originating in industrialised countries aims at understanding spiritual, cultural and ethnic specificities and respecting diversity in the areas within its mission (cf. International, 2007). In the Czech area eligible for the social work are people after studying mostly the area of social work, social pedagogy or special pedagogy (more Act No. 108/2006 Coll.). There is a similar situation and similar conditions for the both professions also in other parts of the world.

Methodology

The research design required an inductive and qualitative research design. Semi-structured interviews were used to collect data, which provided a deeper insight into attitudes in a limited number of cases. In the research, the authors established the sample population as a number of social workers and one psychologist who intervene

⁴ A phenomenon worth mentioning is the prominent position of the ancient Indian medical system of Ayurveda (Kurtz, 2008), homeopathy as a German alternative medical system widely used in India, followed by alternative approaches such as music therapy, meditation and yoga. These are the most widely used complementary interventions in India. Families in the West increasingly resort to CAM, evidence of which is brought out by research in multicultural Western countries (e.g. in Klitzke, 2010). The factors subject to study include mainly doubts about conventional interventions, in particular fear of side effects accompanying psychiatric medication (Hanson, 2009), frustration stemming from slow progress and hope for complete curing for those suffering from ASD, and also belief in the causes. In research into CAM this belief has been found to be related to culture; those resorting to CAM use these methods because they are "congruent with their values, beliefs and philosophical orientations" (Astin, 1998). In India, the position of CAM is hugely influenced by India state incentives for the use of indigenous medicine under The Department of Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy (or CAM in our sense) the equilateral triangle (Hausman, 2002) present in the Indian healthcare system – Ayurveda, homeopathy and allopathy. This approach is applied by physicians and affiliated professionals, and can be described as Western and evidence-based. Thorová (2006) defines it as the "mainstream" in the allopathic approach. Some of the practices of the conventional approach are, especially in the West, controlled by various governmental regulatory authorities.

in families with a child with ASD (other than community social workers) who were not present in training and non-allopathic clinical settings (such as Ayurvedic).⁵ The respondents were collected using the “snowball method” (Gilbert, 2001). The respondents in the research were six social workers, psychiatric professionals of similar age, with a balanced gender distribution, each with a university degree.⁶

Reality of field research

While the social workers involved were familiar with and approved of the basic western concepts of perception of autism (the triad, comorbid conditions and organic background), in the research they added a description of children with ASD, defining them as *socially closed* (see Thorová, 2006). The thus-outlined form of the disorder is just one type of autism, with an emphasis on the impairment of social relationships (Daley, 2004). Surprisingly, along with the organic cause, the respondents also mentioned psychogenic causes – faulty parenting and under-stimulation. They described the changing lifestyle of modern Kerala, with its growing economy, increasing emigration (the “Gulf syndrome?”), etc., which were denoted as *globalisation influence* in the research⁸.

Basic job roles were described as education, skill training and psychoeducation. Training was characterised as *homebased training*, in which parents are trained to train children at their homes, and it seems to consist of the standard skill training and teaching procedures (e.g. applied behavioural analysis (ABA), structured learning, etc.). Training was seen as an essential element, and medication only rarely used and not regarded as very important for ASD treatment.

⁵ For transcripts, some of the time-saving techniques described by Hendl (2005) were used, including the “summary the protocol” of the semi-structured interview pattern. This “segmentation process” (Hendl, 2005) was detailed by Nvivo 7 software. The topics which arose from the respondents’ answers were subsequently coded and subjected to more general conclusions, identifying the specified codes across the respondents’ answers.

⁶ Standardised tests were inconceivable due to the demanding foreign cultural context and specificity of the topic (ASD and social work) (see Hirschhorn, 2005). The limitations of the qualitative research included the external validity question, as the Kerala culture and healthcare system are unique and different from the cultural perception of a researcher from the Czech Republic. One of the authors opened the research by conducting interviews directly in Kerala, with the respondents using “Malayalam English”.

⁷ The Gulf syndrome is labour migration to the Persian Gulf States which allows families in Kerala and other parts of India to live in a relative wealth including, for example, the construction of new housing. Children grow up in families consisting mainly of mothers and grandmothers.

⁸ The respondents did not have a clear idea of what CAM (or alternative treatments or other concepts used in the allopathic research) meant, and often were hearing about it for the first time. Many of them would not use this term for indigenous Indian interventions. After a discussion with the respondents about what CAM can mean, we usually concluded that it was an *intervention different from our own*, one which was not “allopathic”. Only one respondent claimed that “his” intervention is also with Ayurveda and homeopathy as the equilateral triangle system of medicine in India (Hausman, 2002).

Nevertheless, the respondents referred parents to a psychiatrist from time to time, which meant an additional financial burden for the patients in India. Families were also referred to other services, thereby making the intervention for children with ASD a complex act (cf. Daley, 2004). Social workers also provided psychosocial help for parents, mostly counselling and support groups. The respondents mostly claimed that religion did not play a major role in their professional work.

Social workers endeavoured to look at the families in their natural environment, behaviour and context. Frustration and non-acceptance of diagnoses were described as factors influencing the families' decision on treatment, patients' depression was also mentioned.

Family and CAM was regarded as communicating vessels. A family with a child with ASD receives frequent recommendations for CAM from other people (family members and friends) or some allopathic doctors, together with hope for a quick solution and failure to pay attention to the recommendations of medical practitioners in a wide range of possibilities for patients in what is called *doctor shopping*. The respondents further reflect *cultural reasons*, and the latter can be further divided into *positive* (health concept, strong religious belief, and the tradition of the first visit⁹ to CAM) and *negative* (stigma, feelings of sin, and ignorance). Other cultural reasons for refusing allopathic medicine in Kerala that were frequently mentioned were *fear of side-effects* and *the effect of traditional views*¹⁰ (as described by Juthani, 2006). One of the respondents also mentioned the insensitivity of the poor to behavioural abnormalities (Daley, 2004).

As for cultural differences, unsurprisingly, only one respondent expressed the opinion that CAM was related to religion in one way or another. The respondents agreed that conventional/allopathic medicine was *global* while CAM was local and that clinical experience is as important as scientific evidence¹¹.

The attitudes of the respondents suggested interest in new knowledge of CAM. The respondents admitted to not having a deep knowledge of the matter. Their evaluations were coded as *differentiated* – when faced with various CAM modalities, they shaped their opinion on the basis of evidence available and risk-benefit evaluation of each particular CAM type. Yoga, meditation and music therapy were appreciated by all the respondents (although one of them maintained that meditation was not practicable

⁹ In India, allopathic doctors, and social workers in the same way, often receive patients/clients who know nothing about allopathic medicine at all. They consider themselves bound to educate patients/clients in topics that would be generally understood in Europe; for example, the meaning of mental illness and psychiatry.

¹⁰ A patient looks for purely Ayurvedic answers or spiritual explanations (for example, bad Karma, etc.), and these beliefs influence the parents of a child with autism (stigmatic discouragement from visiting a doctor, etc.). Paradoxically, the Indian mother tends to be the first to understand that an allopathic intervention is appropriate and must win the family over for the visit to an allopathic doctor.

¹¹ However, the respondents did not see themselves as fully allopathic workers and drew a line between themselves and psychiatrists. As social workers, they provide training while doctors focus on allopathic medication. The reason behind this strategy seems to be the "stigma attached to psychiatry, all the stronger in non-metropolitan areas like the research site, i.e. the northern region of the state of Kerala".

for ASD). On the other hand, they did not agree on the usefulness of Ayurveda and homeopathy. The respondents saw training as a necessity, referring to the fact that alternative and complementary systems provided only herbal medication, and their providers sometimes discourage patients from visits to allopathic social workers, and that holistic medication was not strong enough.

The respondents found spiritual help and spiritual healing to be controversial issues in relation to families with a child with ASD. Four respondents believed that spiritual help and healing could help parents cope, and two claimed that they were able to help children with ASD themselves. Spirituality is perceived as interfered with the intervention of social work. The respondents claimed to be secularised and non-partial as required by the codes of social work ethics. Criticism in relation to spiritual help and spiritual healing was expressed while nonetheless showing the strong personal religious identity and faith which had so often been described as existing in Indian culture, and all the more so in Kerala. The idea of a spiritual cause of ASD was also strongly opposed.

As for their own personal health problems, CAM or conventional medicine was evaluated and chosen from a broad range of unorganised providers, without perceiving any conflict between alternative and conventional treatment. The situation of social care and healthcare in India was perceived as a space where providers with balanced influences offer their services. This balance of influences is mirrored in the Indian public healthcare policy and the system of higher medical education. This arrangement can be described by the fitting term *health bazaar*¹², i.e. a place where families tend to practice *doctor shopping* (Daley, 2004). At the bazaar, social workers also offer their services, strongly believing in scientific evidence and quality and the necessity of their services, although free of any uncompromising medically orthodox attitudes as in the case of some psychiatrists. This “practice” was a behavioural attitude pattern discernible in the answers of all the respondents, except for one who sincerely described it as his own evaluative pattern. In that pattern, the respondents attribute zero or poor knowledge to the parents, present their own personal *opinion* to them or reveal the negatives and positives of a CAM variant, then stress *what is necessary* (such as training provided in accordance with the clients’ beliefs). Then they allow the parents *to have freedom of choice*. If the parents choose a CAM modality, social workers *permit* that modality and afterwards *make it complementary* to existing treatment by offering them training in applied behaviour analysis (ABA) and structured learning to use these in parallel with CAM¹³.

¹² Term by Tomas Hudec, following to Daley (2004) term “doctor shopping”. In India seems to be a looking for medical care more like shopping at a bazaar than in a supermarket with clear rules)

¹³ In cases where the parents did not follow social workers’ recommendations and omitted training, then the respondents, if they did not directly rule out the possibility of freedom of choice on the parents’ side, talked about psychoeducation, in one case *diplomatic psychoeducation*, an effort to be made sensitively by social workers, having regard for cultural values and the system of belief. Three other respondents showed *respect for the belief system*: “and another thing is that if you’re a strong believer and you believe, the child will benefit;

Despite this process, the respondents admit that they do not discuss this issue with parents very often and that they basically do not actively recommend or promote CAM unless the topic is raised.

Although many respondents feel a need for collaboration with other professionals in the form of discussions about clients and for designing integrative interventions, this collaboration is rather absent.

In the study, there was also found that the respondents in Kerala do not have any specific knowledge about CAM; they merely contemplated interventions which we labelled as structured learning or ABA). According to the respondents, scientific evidence should form the foundation of a professional worker's intervention. Psychoeducation is seen by them as the *conveying of facts and strategies for treatment of children with ASD*. The respondents in the research also agree that some of the attitudes they cannot work with are related to *cultural values and religion*.

Social workers in Kerala regard some other interventions (such as those provided by spiritual healers) as available in the "open space" of the Indian *health bazaar* (for more on this, see also Daley, 2004). In the evaluation of CAM by social workers, from among what is offered on this market they choose effective solutions for the treatment of their own diseases, and they also rely on literature, their colleagues and personal experience. The respondents in the research perceive families using CAM as a subject to the *cultural values* they have adopted, which also determine their help-seeking strategies, and regard them as somewhat lost in despair over their situation and unawareness of the possibilities available on the *health bazaar*.

In this context, the respondents offer their services without coercion or exhausting disputes with clients. When families broach the topic of alternative medicine, social workers apply a specific approach to dealing with such families in order to avoid losing their clients. They respect choice, culture and feelings of the parents with children with ASD and attempt to bring in their own point of view, reach a compromise and make CAM a *complementary* matter. On the other hand, the respondents – social workers in Kerala, use psychoeducation to attract clients to their concept of ASD, its treatment, prognosis and possible gains.

I can't stand against their belief system. I will tell them – you should continue training, in any case you should not stop this if you want to go to a religious practitioner (especially spiritual healers and help)". Empirical research has shown that spiritual support in general and spiritual healing in particular are an important category for social workers' clients. This can be explained by the nature of the local culture and local religions. Sensory integration therapy is another intervention used in Kerala, and finally, vitamin supplements and special diets can be mentioned as examples of alternative "biological treatment", surprisingly in use by several Kerala allopathic facilities.

Conclusion

The authors discussed the attitudes of professional social workers to complementary and alternative medicine for children with autism spectrum disorders. However, since a great number of people living in Kerala are rooted in traditional structures, especially the traditional Indian medicine of Ayurveda and the Hindu, Jain and Muslim or Christian religions, the social workers express their respect the clients' beliefs regarding the religious causes and treatment of autism; the social workers usually offer allopathic treatment as an extension of the options available. When looking at whether social workers act ethnocentrically, it should be noted that they act very sensitively and do not endeavour to convince their clients – families with children with ASD – to change their religious views. The social workers' perception of complementary and alternative medicine depends on their own view of the possibilities of such medicine and its offer and was within tolerance limits in the research sample. There was an effort to avoid losing parents as clients (and to avoid a culture clash), to behave in a specific way, which is described as "practice". The results of the study could be helpful in further psychosocial work and understanding of clients from a different cultural context, in the deepening of clearance of meanings in mutual communication.

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Contact:

Dipl.-Theol. Univ. Stanislava Ševčíková, Ph.D.

Soukromá psychoterapeutická praxe, www.psychoterapie-brno.com

E-mail: stana.sevcikova@gmail.com

Mgr. Tomáš Hudec

Camphill na soutoku, Terezín

E-mail: Hudectomas@post.cz