

Qualitative Analysis of Counselling Approaches for Caregivers of Children with Neurodevelopmental Disorders

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ABSTRACT

About 18% of children in India (2-9 years of age) have *neurodevelopmental* disorders in rural areas and 13% in cities. Data derived from five multidisciplinary intervention centres (including monthly parental counselling) in Mumbai for children with special needs, forms the reference for this study. Evidence-based counselling practices like Behavioural Modification and Cognitive Behavioural Therapy undergo key adaptations for parents in the Indian context. The current qualitative analysis describes these adaptations (60 counselling sessions; parents of 10 representative children). Discussion includes a focus on acceptance of disability by parents; embedding counselling within all components of an intervention program; goal-driven counselling; tailored home-programs to institute sustainable management of disabilities; and counselling goals that are jointly agreed upon by counsellors and parents.

Keywords: *Qualitative Analysis, Counselling Approaches, Neurodevelopmental Disorders*

Over 200 million children under 5 years are estimated to not attain their developmental potential and 65 million of these (or 32%) are in India (Grantham-McGregor et al., 2007). The consequences are reflected in poor schooling of these children and their lower adulthood incomes. According to Census 2011, there are 158.7 million children between the age group of 0-6 years. Degree of development in emerging economies like India depends on how best communities and systems tap the potential of its younger population often referred to as the 'demographic dividend'. A significant number of children in India are affected by

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neurodevelopmental disorders (NDDs) that impair physical, mental, behavioural and social growth of children. Common NDDs include Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Learning Disability (LD) and Intellectual Disability (ID). Data to understand the burden of the problem has been scarce until a 2014 survey conducted in 4000 households in 6 regions in India showed that 18% of children 2-9 years of age have one or more NDDs in rural areas and 13% in urban settings (Silberberg, 2014). Not surprisingly, the alarming prevalence of NDDs in developing countries like India appears as a key theme across the newly framed Sustainable Development Goals.

Challenges Faced By Parents in Developing Countries

In India, apart from low awareness on NDDs, there is low acceptance of childhood disabilities by parents, resulting in limited and delayed care-seeking (Wilcox, 2007; Desai, 2012; Divan, 2012). The situation is compounded by the fact that majority of children in India having NDDs do not receive timely and effective intervention, which remains a hindrance to formulate evidence-based policies. The limited interventions that do exist are “stand-alone” or involving single disciplines (e.g. a paediatrician or occupational therapist) that cannot comprehensively address a child’s multi-faceted developmental condition.

The above environment severely affects parenting in that, parents are expected to not only take care of the child’s routine activities, but also periodically engage with a range of health and education professionals to avail effective advice or intervention. This is a stressful process for parents and their problems have been documented in studies conducted in India and elsewhere, which can be categorized as social, psychological and financial problems (Nimbalkar, Raithatha, Shah, & Panchal, 2014).

One of the most common social problems described in studies, was reduced participation in social gatherings (e.g. marriages and other ceremonies) especially in a traditional society like India. Parents perceived difficulties in going out on holidays and entertaining guests, as their attention frequently diverted towards the needs of the child. Lack of societal acceptance coupled with perceived traditional parental roles, disturbed existing social relationships. For example, if a father was seen being involved in caring for the child, he was questioned and not accepted by peers. Complaints from siblings regarding excess attention given to the child with disability were common and resulted in feelings of guilt in parents.

Psychological problems related to demands of care-giving for a child with disability. Parents experienced a wide range of stressful emotions, from mild anger to tiredness and frustration, and a constant anxiety about the future of the child. Some parents also reported having suicidal thoughts. Other parents had high blood pressure and other physiological complications due to stress. In terms of the child’s future in resource-limited environments in India, parents reported concerns on care-giving in their absence. They reported relief on observing that the child was

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learning basic skills and activities of daily living and hoped that she would be able to earn a livelihood. Some parents believed that whatever would happen with the child was bound to occur and not under their control.

With respect to financial problems, one of the parents had to provide constant attention and regular follow-up of therapy at home, which often necessitated the parent to leave his/her job. Moreover, parents also had to cater to the fees of health care providers and expenses for medications. Thus, parents incurred a substantial financial burden due to the child's disability.

Study Rationale - Need to Review Modifications in Standard Counselling Methods

Due to the larger social environment and health system inadequacies around NDDs in India and resulting constraints on parents, standard counselling methodologies like behaviour modification and cognitive behaviour therapy, undergo modifications in order to adapt to specific needs of parents (Meichenbaum, 1977). It has been observed in the aforesaid intervention setting that therapists have to mainly work on probably the most basic aspects such as making the parents understand their child's condition and accepting it. Lack of acceptance is problematic as parents tend to remain in denial and put pressure on children in order to make them perform tasks which are beyond their abilities. Parents undergo many negative emotions, which in turn affect their relationship with children. It has also been observed in therapeutic practice that in developing country settings (as in this study) with few specialized care providers and limited awareness on disabilities, counselling tends to become difficult in the initial phases of the child's condition. However, after the parents have developed a certain acceptance of the child's disability, the flow of treatment tends to improve. A key aspect is to make the parents understand that an NDD is not a behavioural concern as they often perceive, but rather a developmental deviation. A parallel effort is to make the parents focus on the current and potential abilities of the child, than the limitations imposed by the developmental condition. To that end, counselling approaches could become more structured, and goal-driven (i.e. an adaptation in behaviour modification of parents) so that children attain feasible developmental goals. Finally, an integral component of counselling is to train parents for sustainable management of disabilities to enable children to attain incremental degrees of functional independence at home and beyond the therapy centre.

STUDY BACKGROUND

Data for this study was obtained from a multidisciplinary intervention setting in Mumbai, providing services for children with NDDs. Till early 2000s, disability in India was considered as an issue requiring charity and sympathy, without any scientific, process-driven or result-oriented interventions in place. Beyond hearing aids and surgery for specific conditions like Cerebral Palsy, little else was available or delivered with confidence that parents could access. NDDs were not recognized as conditions that could be improved significantly. Parents had to move from one facility to another and from one therapist to another, without a centralized, coordinated and result-oriented process.

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The aforesaid intervention setting provides a multidisciplinary, comprehensive, goal-oriented, coordinated and measurable program under one roof. Founded in 2003, it is the largest multidisciplinary child development intervention in India, with five child development centers in Mumbai. The team headed by a Developmental Pediatrician (DP), includes an Audiologist, Clinical and Counseling Psychologists, Occupational Therapists, Physical Therapists, Remedial Educators and Speech Therapists, in addition to visiting specialists (i.e. Ophthalmologist, Neurologist, Pediatric Orthopedic Surgeon, Psychiatrist and Nutritionists). It serves 200 children daily on average and conducts 30,000 individualized treatment sessions annually on average.

At each child development centre, each child gets individual assessment and therapy, and yet in a comprehensive (trans-departmental) manner. Analysis of child's strengths and challenges, leads to the formulation of an intervention program for a defined period of time (e.g. 6 months). Each child is re-evaluated after the intervention to see whether the goals have been met and a revised intervention program is developed, if needed. All intervention programs are referred to as Individualized Therapy-Education Program (IT-EP). Under IT-EP, every child's parents, family members and school officials are counseled every month to maximize impact. Thus, each child receives a complete end-to-end and outcome-oriented intervention for developmental concerns.

An estimated 315 children with developmental concerns receive IT-EP at the five child development centres. Apart from the compulsory monthly session of parental counseling under IT-EP, counselling is embedded within the protocols of all its components i.e. occupational therapy, physiotherapy, speech therapy and remedial education. Individual counselling sessions are also conducted with children on a case-to-case basis.

STUDY OBJECTIVE

The objective of the study is to describe the adaptations in standard counselling methods, through a secondary qualitative analysis of information obtained from a sub-sample of parent and individual counselling reports.

METHODS

Information recorded in counselling sessions of a sample of ten children was included for qualitative (content) analysis. Data pertaining to 5-8 monthly parental counselling (PC) sessions or an approximated average of 6 sessions per child was included. Each counselling session between a Psychologist and one or maximum two caregivers, was 45 minutes in duration. Thus, information from 60 PC reports for the 10 children was thematically analyzed. In addition, five of these children received 7 individual counselling (IC) sessions on average (Range: 2-12). It was necessary that the selected children 'represent' the larger clientele of children with developmental concerns receiving IT-EP. Since the study objective was to describe adaptations in counselling methods, it was necessary to ensure that these adaptations were executed for a heterogeneous profile of children. According to the findings of the Pew research centre study

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(based in Washington, D.C.), variables considered by the study team to obtain a representative sample included: child's age, gender and family monthly income (Venkataramakrishnan, 2015). Apart from these the other factors included: marital status of parents, family members usually attending the counselling session and diagnostic condition of the child. Table-1 of Appendix A presents the distribution of sampled children according to these variables.

Each counselling report included information on parental views and attitudes and level of acceptance of the child's condition; information on counselling approach followed; explanation of IT-EP to the parent and the need for adherence to IT-EP counselling methods adapted to the specific child and parent, based on the child's condition and parent's specific constraints and follow-up on improvement and/or concerns in the child.

Following section on study inferences, obtained through qualitative analysis of the above information, describes the adaptations in the counselling methods.

INFERENCES

Review of adaptations in counselling methods has been discussed under the following broad themes, as reflected in the information obtained from the counselling reports:

Acceptance of the child's condition

First few counselling sessions tend to focus on parental acceptance of the child's condition, which as discussed earlier, is limited in developing country contexts like India. To that end, the 'Negotiation and bargaining principle' is adopted. This process aims to reach a consensus between the parent and the counsellor on activities that are 'acceptable' and 'unacceptable' in the routine life of the child, given the nature of the child's condition. Consequences of both kinds of activities are discussed. A 'deal' is made between the child and the parent and accordingly parents are counselled to encourage specific activities and discourage others. This adaptation has been experientially constructed by the IT-EP team.

Adherence to IT-EP

The structure of IT-EP enables regular bi-directional communication between all developmental therapists (for e.g. between the Psychologist and the Occupational Therapist and others). Thus, a therapist/counsellor can substantively explain the child's progress to the parent and what needs to be done in order to meet pre-determined goals. Moreover, the IT-EP goals per se, are also communicated to the parent during counselling sessions to ensure that parents understand the reasons behind these goals. It is observed in developmental and general paediatric practice, that this is in contrast to other clinical settings in India where parents are often not aware of therapeutic goals. Explaining consequences of attaining (or not attaining) every goal leads to parents seeing a purpose in their child's therapy and anticipate progress milestones, which in turn impacts their adherence to IT-EP.

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Dynamic DOs and DONT's

The counselling team has formulated “best practices” for parents in order to positively impact developmental concerns in children (e.g. hyperactivity). Parents are counselled to adhere to these practices during the child’s routine and that the effectiveness of IT-EP would also depend on their adherence to best practices.

The best practices focus on minimum exposure to electronic gadgets and reduction of television viewing, especially animation; avoidance of food with preservatives and additives; increased physical activity or outdoor play in the evening; and increase night sleep. The counselling team refers these practices as “DOs and DONT’s”. However, the instructions are dynamic and reviewed during every parental visit— either for therapy, counselling or follow-up with developmental paediatrician. Parents express routine concerns in adhering to these practices and alternative strategies are suggested to them by the IT-EP team. These practices are based on evidence around unhealthy daily habits that predispose a child to developmental concerns, particularly inattention and hyperactivity (Quach, 2011; Arnold, 2012; Gentile, 2012; Pontiflex, 2013; Smith, 2013). In addition, parents are also encouraged to maintain a daily diary to note the child’s routine concerns (e.g. not sitting at one place, throwing objects etc.), which is reviewed by the counsellor during every monthly parental counselling session. The diary functions as a monitoring tool between IT-EP and parents and actively involves parents in the therapeutic process.

Goal-Driven, Outcome-Oriented Approaches

The aforesaid inferences indicate a ‘goal-driven, outcome-oriented’ approach to counselling where an analogy could be made to a prescribed drug-regimen that needs to be adhered to, by the patient. IT-EP therapists have experienced that parents need to be directed on occasions, in order to meet therapeutic goals. They have opined through their counselling sessions that while therapeutic goals need to be jointly made between the IT-EP team and the parents, there are occasions when parents need greater instruction. For example, parents with children having Autism Spectrum Disorder, often tend to give in to the demands of the child when he/she is not able to verbalize. However, this reinforces a child to meet his demands in a developmentally inappropriate manner. Therapists note these parental behaviours in the counselling sessions as well as the DPDs and encourage parents to extensively communicate with their child on a daily basis, so as to gradually enable their child to verbally express her demands. Such ‘regimented’ approaches are essential within the stated format of the IT-EP. They ensure that parents have well-defined expectations from the therapy received, as well as the IT-EP team (including counsellors) has clear expectations from parents in terms of their compliance.

Adhering To Home Program

Parents are encouraged to continue activities within the IT-EP, at home. However, given the resource-limited environment in case of most parents, therapists counsel parents to optimally use

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available opportunities and resources. For example, parents are encouraged to engage the child in household activities that improve concentration for e.g. stringing beads, punching holes in card-paper and putting a shoe-lace through the holes or sorting beans of different kinds such as *rajma*, *chana* and other pulses (the latter also strengthening fine motor skills). Contextually relevant opportunities are discussed with counsellors and advice is tailored accordingly to the situation of each parent.

It has been observed by therapists that contextually-relevant advice also implies tapping on contextual advantages. For example, domestic chores are often assigned to children in Indian homes as compared to their Western counterparts. In case of children with developmental disorders, these tasks can play important roles to improve a sense of responsibility and self-esteem in children. Counsellors thus encourage parents to assign simple household tasks to their children. The improved motivation thus, translates into greater undertaking of academic responsibilities among children, for example: initiating and completing school home-work.

Harnessing Relationships

Counsellors encourage parents to engage children with difficulties in socialization, in telephonic conversations with relatives. This builds turn-taking abilities in children and helps in role-modelling of appropriate behaviour. Parents are also encouraged to support their children with writing difficulties, to draft short letters to relatives and build their self-confidence. This can be achieved by involving siblings and other elders, grand-parents or relatives. Thus, family members apart from parents help ‘mentor’ the young child with an NDD. Thus, the options available to a child in terms of the range of people that can mentor her, are more than that in typical Western settings where family structures are less branched out.

Standard Advice but Emphasized Under IT-EP

Within counselling for parents having children with NDDs, certain aspects are included in a range of therapeutic settings in both developed and developing countries. Some examples include: not forcing the child to do an activity that he/she dislikes; providing multiple breaks during an activity; consistently and positively reinforcing the child and encouraging children to set a daily time-table in order structure their routine and enable greater self-regulation.

These aspects are not specific for the Indian clientele of parents, however they assume greater relevance. For instance, it has been observed by practising developmental therapists and counsellors under IT-EP, that children with disabilities are vulnerable to being forced by parents in order to complete tasks (e.g. home-work or a domestic or self-help task). In addition, parents have informed counsellors that children improve their concentration and interest in studying or other activities that were previously disliked, due to ‘time-breaks’ given by parents during the activity. These time-intervals help parents to determine the child’s ‘saturation point’ and make a note of the same in their diary and bring it to the notice of the counsellor, which ultimately helps the counsellor to set goals in IT-EP to further improve the child’s concentration.

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Standard guidelines for counsellors but emphasized in the Indian context have also been documented in literature (Dalwai, Nimbalkar, & Kanade-Modak, 2015). These include informing parents of the four areas of child development (i.e. motor, language, social and adaptive); the value of seeking early identification and intervention by multidisciplinary professionals in minimizing later life complications; the inappropriateness of comparing the performance of a child with special needs, with other siblings; the focus that needs to be given to build the child's self-esteem and thereby positively reinforce her strengths and support her challenges.

Perception of Parents on Counselling Advice

Qualitative content analysis was conducted on parental feedback of counselling sessions for the children included in the study. Parents reported benefit; for example, in case of parents having a child with hearing impairment, regular use of a hearing aid was not focused by the parents. During a counselling session, the parents were explained the consequences of not regularizing hearing aid use and explained the ways in which hearing aids can be incorporated into a child's routine, to ease their adoption by the child.

Parents reported challenges with certain aspects of counselling advice. For example, parents found it difficult to maintain the daily diary to record routine concerns of the child. Concerns were often repetitive and parents did not regard the process as productive. Parents also experienced in difficulties in scheduling the child's activities. For example, encouraging the child to use evening time for outdoor play and complete all academic work prior to that, implied attempting to break a long-standing habit. A related challenge was increasing the child's sleep hours at night and discouraging sleep in the afternoon. In such cases, the thrust of counselling is to find contextual ways to increase adherence to advice.

ANALYSIS

Strengths

This analysis focuses on describing adaptations in standard counselling approaches tailored for the Indian clientele of parents having children with special needs, which could be relevant to similar socio-cultural contexts in other developing countries having limited awareness around disabilities and scarce effective interventions.

The analysis underscores goal-driven counselling as well as mutually tailoring therapeutic goals with parental abilities and contexts. Such an 'adapted, yet action-oriented approach' has only been recently discussed in literature. A study on agreement between counsellors and clients on goals of counselling in a school setting highlighted that young people are concerned with improving their self-confidence, and this was different from the concerns described in counsellors' reports; thus indicating that counsellors should be mindful of clients' particular goals (Rupani et al., 2014). Another study demonstrated greater effectiveness of intensive tailored counselling to help smoking parents recruited into cessation support programs, to quit smoking,

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as compared to standard approaches such as use of self-help brochures (Schuck et al., 2014). The Contextual Action Theory (CAT) describes an integrated framework to understand human action, which is relevant in the present analysis, to the practical issue of adherence to counselling advice (Domene, Valach, & Young, 2015). This theory proposes that action can be viewed from three different perspectives: ‘manifest behaviour’ or the readily observable sequential behaviour involved in executing an activity. For example, when a frustrated parent angrily describes her problems in engaging her hyperactive child to sit and study, she listens and argues with the counsellor or may even yell at her. In that sense, manifest behaviour appears to be a process of ‘action and reaction’. However, the second perspective focusing on ‘internal processes’ or subjective cognitive and emotional mechanisms that the parent experiences during her attempts to engage the hyperactive child, also determine her manifest behaviour in narrating her difficulties to the counsellor. Finally, human action is also influenced by ‘social meaning’ or norms, rules and conventions which affect the ways in which people explain their actions to themselves and others, including counsellors.

According to a research article published at Eastern Illinois University (2003) there has been evidence of describing cultural features of psychological problems like depression which results in a need to tailor counselling methods for Indian clientele. More recent evidence has also cited that standard approaches like cognitive behaviour therapy are combined with other therapeutic methods for treating depression in Asian Indian immigrant women in the United States and the process is tailored according to individual client needs (Tewary, Jani, & Anstadt, 2012). The evidence also emphasizes on multicultural training for practising social workers using adapted cognitive behaviour therapy, in order to become more cognizant about cultural factors affecting depression in such clients.

Thus, in view of these recent scientific advances, there is a greater need to incorporate adaptations in standard counselling approaches so as to foster framing of ‘collaborative’ counselling goals that are not purely driven by clients or directed by counsellors. To the authors’ knowledge, the present qualitative analysis is one of the few studies that explain adaptations in parental counselling methods for children affected by developmental disorders, in an urban Indian setting, which demonstrate a mix of counsellor-driven as well as tailored approaches to meet therapeutic goals mutually agreed between the counsellor and the caregiver. A multidisciplinary intervention setting at the aforesaid centre in Mumbai, is one of the few such intervention models in urban India and thus, the qualitative insights obtained from the counselling sessions within this model, provide key pointers for conducting further, quantitative and more rigorous studies.

LIMITATIONS

This study had a limited objective of elaborating the modifications in standard counselling methods, to suit the Indian clientele. Resource and time limitations also precluded conducting in-

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depth interviews or focused group discussions with counsellors to know their beliefs and views on how do these adaptations operate during parental counselling sessions and the degree of their effectiveness. The study did not have the methodological strength to assess effects of adaptations in counselling methodologies on variables such as parent satisfaction, adherence to IT-EP, parental care-giving and developmental outcomes. A quantitative study including all children with NDDs receiving intervention at the aforesaid five multidisciplinary intervention centres in Mumbai, will have to be conducted, to generate a sufficiently large sample and critical variables, to review effectiveness of tailored counselling approaches. That would be a vital piece of evidence, to inform interventions for children with neurodevelopmental disorders in India and other developing countries.

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Appendix A

Table-1, Profile of children

| Variable | Distribution of Children |
|--|---------------------------------|
| Age of the child (n = 10) | |
| Less than 5 years | 3 |
| More than 5 years to 12 years | 7 |
| Gender (n = 10) | |
| Males | 8 |
| Females | 2 |
| Monthly income range (n = 10) | |
| Upper income (more than INR 33,000) | 1 |
| Middle income (INR 16,000 to 33,000) | 8 |
| Lower income (less than INR 16,000) | 1 |
| Marital status of parents (n = 10) | |
| Married | 9 |
| Single parent | 1 |
| Family members usually attending PC (n = 10) | |
| Mother only | 4 |
| Mother and Father | 5 |
| Mother and other relative | 1 |
| Diagnostic conditions (n = 10) | |
| Autism Spectrum Disorder (ASD) or ASD features | 3 |
| Attention Deficit Hyperactivity Disorder (ADHD) or ADHD features | 4 |
| Learning Disability | 2 |
| Global Developmental Delay (GDD) | 1 |