Model of Simultaneous Counselling and Training Parents of Children with Special Needs to Nurture Parent-Child Interactions

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Abstract

Parents differ in their way of being with their children, in turn affecting the development of their child. With the addition of a 'diagnosis' or label to their child, they oscillate between how much leniency to give and how much strict they should be. With the diagnosis, there is a considerable shift in the *parenting styles* and hence, their *coping styles*; this affecting the focus child *and* their typical peers. In addition to children with autism, who had impaired parent-child interactions (less affection and more overprotection and authoritarian controlling); their siblings may be at risk for such problems too (Gau SS, *et al*.,2010). Parents of these children themselves undergo stresses and other psychological disorders like depression. Families participating in ABA experienced elevated depressive symptoms, much like any family raising a child with an ASD. ABA intensity related to maternal depression and personal strain. (Schwichtenberg A, Poehlmann J.2007)

The current paper endeavours to outline a need for counselling parents regarding everyday issues, expectations from the child etc along with providing focussed training on effective strategies and techniques for the parents themselves in order to make them feel empowered and independent, while helping in their venting day to day frustrations; with the aim of nurturing parent-child interactions. Increasingly it has been seen that the parents getting support are more resolved and rated as higher in Cognitive Engagement and Supportive Engagement in play interactions, reflecting greater verbal and nonverbal scaffolding to enhance the child's play and attention to activities and greater reciprocity and mutual enjoyment (Wachtel K, Carter AS.2008). Providing the parents with only one of the two (counselling or training) may not cater to their needs; for effective intervention the parents need a mix of both counselling (for their own emotions, balancing them and motivating them) as well as training them (to understand their child's in a unique manner and in light with the diagnosis and equipping them to take care of these and helping in his/her growth). Narratives of parents are recorded at different intervals of their engagement with Potentials and shifts in their narratives studied. Lastly, the proposed foci of counselling and training are delineated to observe the shifts in their narratives during the counsellings and the parent trainings.

Keywords: Autism parenting, coping styles, parent counselling, parent training

Introduction

The news of a new born brings tears of joy to the newly made parents in most of the households. They use their own understanding, instinctual knowledge about how to 'parent' the child and the journey begins with the application of this understanding and their own life experiences. Their own parenting styles (authoritarian, permissive, authoritative) of dealing with these parenting challenges have a major role to play in the development of their child as well as the whole family system.

Time and again researches on child development have proved that parenting not only impacts the early development but also effects the later years of life. Sensitive parenting behaviours predicted increased and faster rates of cognitive-language, social development and initiating skills. (Landry SH, *et al.,* 2001) **.**

Through observations and interactions with parents it is also suggested that 'over-protective/over-controlling' parenting styles adversely impact learning cycle. This maybe since, the *incidental learning* is reduced as the child gets to learn and understand only what is the presented knowledge *(intentional learning)* rather than learning by doing (trial and error). Parent's ways of coping with everyday challenges shapes their child's overall development.

All this confusion regarding parenting and the art of parenting itself is further complicated when parents feel their child might have a disability. They run from pillar to post to know if and why their child is not developing 'normally'. A professional 'Diagnosis' seems to bring an alteration in their parenting style. Mostly, parents feel a state of shock and immense grief with the diagnosis and the 'labelling'. This in turn adversely impacts parent's mental health which is substantiated by various researches highlighting great strains on the family and the well-being of parents. (Koegel *et al.,* 1992; Dunn *et al*., 2001) (Nor Zaidah AH *et al*., 2004).

As compared to children with other neuro-developmental disorders e.g. general delay *(Beck and colleagues (2004)* and Down's syndrome (Fisman *et al.,* 2000), the complex nature of Autism Spectrum Disorders (ASD) includes profound behavioural disturbances and impairment in social interactions. This leads to higher degree of parental stress and mental health issues affecting their ability to regulate their child's behaviour (Hoppes and Harris 1990; Kasari and Sigman *1997*; Sigman *et al.,* 1986) (Horowitz 2004). Also, mothers of children with autism described themselves as unable to pursue personal goals (Holroyd 1974; Milgram and Atzil 1988; Tunali and Power 2002).

With the diagnosis, it's not just the child who is affected but the parent too undergoes too many emotions and strives for their own emotional stability and of the whole family. They go through cycles of emotional upheavals- denial, grief, guilt, and acceptance. Qualitative researches demonstrated that parents of children with ASD had to face isolation from social circle and "Living in a world of our own"

emerged as the essence of the parents' experiences (Woodgate RL, *et.al.,* 2001). Another similar study suggests that raising a child with ASD puts tremendous strain on families due to competing family commitments, lack of professional (health and education) awareness, and discrimination because of social rejection leading to initial social withdrawal with later reintegration into social networks (Divan G, *et.al.,* 2012).

The current study aims to highlight too that parents have several unmet needs hence, require equal or more amount of support, direction, training and catharsis for their own self, as the child with neuro-developmental disorder needs. Parents of neuro-typical children themselves feel so much of confusion and self doubt but parents with children who have 'diagnosis' have to deal not only with the stigmas of the society or the name-blame gaming but often feel incompetent to ascertain their own child's needs and seem confused about what to do, their instinctual knowledge of being a parent doesn't help their child to learn skills and thus leaving them with a feeling of helplessness or heightened stress. With all these confusions and the vulnerable emotional state the parents are in, they often strain the nurturing parent-child relationships and hence the call for our model. Our philosophy and work model came from the fact that parents benefit from the interventions which not only help the child but support the whole family system. Research also strengthens our belief that by training parents with effective coping mechanisms and providing them a platform to build social support system for themselves, we may help reduce psychological distress (Nor Zaidah AH *et al.,* 2004) (Bristol and Schopler 1983; Wolf *et al.*, 1989). It thus seems imperative to provide the parents with a platform for counselling and also to train them to feel equipped to take care of their own child.

Methodology

Aim: To ascertain the importance of an eight sessions Focussed Parent Training (FPT) Programme as a part of Eye-to- I© 'Multi Level Parent Counselling Model'.

Participants: Two groups each of 15 parents of children in the age group of 3-12 years, diagnosed with ASD/PDD, receiving therapeutic interventions at 'Potentials Therapy Centre'.

Further Inclusion Criteria for Control Group required the parents/ primary care giver accompanying the child and being part of at least 3 of the 6 levels of counselling interventions of the said model. For Intervention group- Parents/ Primary care giver were specifically required to attend 'formal' parent training level along with any other 2 levels of the model. Parents of children (undergoing therapy at the centre) who have not been at the centre for more than 3 months and not attending weekly /monthly feedbacks of their child were excluded from the study.

Research Design

Narrative/deductive analysis was used to examine the change in narrative themes of the participants' pre and post training intervention. In line with the existing literature, themes relating to (i) understanding of their child and their felt stress (ii) Parents mechanisms of coping (iii) Managing their own child, were picked. The present study is partly an retrospective study and the themes pre intervention were arrived at using the intake interview and observation notes made of the parents. These observation notes included parents' general affect and body language, during their initial (at the centre) interaction with their children, therapists and other parents visiting the centre. To collect the current status data (post counselling intervention), a set of open ended questions were made which would help elicit the current view and experiences through their narratives in the interview. A comparison of the themes –initially, at varying intervals (depending on data availability) and current themes was made. Also, comparison of the shift in themes of parents who participated in the FPT sessions as compared to those who did not, was made.

Procedure

 (i)   The participants satisfying the inclusion exclusion criterion were assigned into the two (control and intervention) groups.

 (ii) A set of open ended questions were framed, based on the literature review, and inturn keeping in mind these questions, answers/themes were retro-spectively retrieved from the recorded parental interviews at the time of intake, and observations made by the assessment team, of the parents' interaction (style and language content) with their child.

 (iii) The records of formal meetings and the informal interactions with the thera-pists were looked into.

 (iv) As the parents were interacted with for current understanding, the same sets of questions were asked and shifts in the narratives observed.

 (v)   Comparison was done for the narratives of both the group of parents.

Intervention

All participants in the study were accessing the 'Eye-to I © parent counselling model' (Kukreja, S. *et al.* 2013). The model is as attached in appendix. The intervention group specifically attended the FPT which is explained hereunder:

Parent Training (Focussed Parent Trainings)

To equip the parents and make them feel more in control of their own child's needs and everyday management technques; and inturn creating better understanding of their child; a series of 8 parent training worksops were carried out. These included two and a half hours per week of the training workshops

spread over two months. each session had extensive theoretical plus application training involving role plays, making aids to help their own child and clarifying their doubts and queries, aimed at boosting their self morale as well as empowering them to be an effective yet nurturing parent to their children's specific needs.

The workshops included topics such as : 'Narrations', 'Visual Scheduling and visual cards', 'Being a non-instructive play-partner, 'Builiding a leisure time skill', ' Emotional Regulation', ' Social stories', 'Enhancing Language' etc. Alongwith the workshops, homeworks are also given wherein the parents carried forward the learnings to home, applied it with their child, made aids for the same and in the next sessions discussed both their achievements (and more so their child's) and the concerns they faced.

Results and Discussion

The present study highlights the importance of the 'parent training' in bringing about a change in the narratives of the parents and comparing these with the narratives of parents who underwent other tiers of 'Eye- To I's © Parent counselling' model, (Kukreja, S. *et al*., 2013)., but not the formal training [Formal meeting (workshops) - tier 2] of the model.

The emerging trends in the narratives, body language and affect of parents of children diagnosed with ASD/PD had many similarities despite the diversity in socio-demographic backgrounds. The derived themes for both the groups from the initial discussion/interview at the time of intake in the centre seemed to be similar, pointing towards: '*Heightened stress and lack of understanding about their child (HS)*', '*Maladaptive coping mechanisms (MC)*', '*Professional Dependence for child management (DCM)*'- *Externally depending on professionals to manage their children.*. Some of these salient features seem quite recurrent in their narrative samples:

"I can't take it anymore. *(MC)*. I can't leave my child but I don't know what to do with him*". (DCM).*

"He is very lazy and hence doesn't listen *(HS)* I give him a tight slap and he does his work *(MC.)*

"I don't know why he is like this? *(HS)* Am I not a good person and is God punishing me?" *(HS).*

"He is fine with you here. But with me he just doesn't cooperate, I can't go out anywhere". *(DCM).*

"I have been told he will become 'normal'. How many sessions will it take for him to be a normal child. He will become a doctor?" (HS and MC).

"I am going to Dubai now. Can you send someone for at least 1-2 years (full time); I am ready to bear all the expenses. I can't manage him. (DCM)".

"My life is a mess (MC). Ek aap hi ho jo isse theek kar sakta ho" (DCM).

"Muje to life kya enjoy karni hai, (MC) aap bas isse theek kardo. Jab ye normal ho jayega ab to tab hi I will live my life. (DCM)

The narratives point towards an exhausted set of parents who are dried out of energy and zeal for life. They seemed more anxious and withdrawn; evident from their body language while interacting with other parents/therapists. The narratives reflect either very low expectations from their children owing to their 'disability' or in the others, shows over-raised expectations. Some appeared confused owing to misleading theories about the disorder, leading to heightened stress.

It was observed that with the '*Eye-to I's © parent counselling model',* both the sets of parents showed remarkable shifts in their narratives reflected in their changed interaction style with their child, their affect and body language.

Out of thirty parents, fifteen parents received interventions at the all six proposed tiers (that is inclusive of the formal meeting tier- having participated in the Focussed Parent Training ,FTP, Workshops. Rest of the fifteen parents could access only certain tiers because of their availabilty and accessibilty and definitely not the FTP's.

The results reflected a change in narratives of both the groups. They showed themes like Optimism *(O)* and Relieved *(R)* . However, the intervention group reflected a third theme of being Empowered *(E)* , whereas the control group still reflected varied extent of external dependence theme to manage their child *(DCM).*

Although many parents could not receive the counselling interventions at all the levels of our model, shifts in the themes of their narratives were observed. Although, total time for which the child undertook therapy did not appear as a strong indicator of model effectiveness, it cant be overlooked that parents who are coming regularly for longer duration of therapy are getting more opportunities of relating with others. The interactions which started with the formal sharing of information about their children have been extending beyond the discussion of children. Parents were seen even helping each other develop hobbies and help with the same or would also be observed stepping out of the centre (till the time child was in sessions) for having coffe, snacks etc., sharing the achievements of their children and being able to see their children's skill areas as well besides deficits.

After accessing the interventions, emerging themes from the narratives are *'Optimism (O)'*, *'Relieved (R)'* for both the groups but added was the '*Empowered (E)'* theme for the treatment group. Some of the narratives samples of parents in the control group:

The narratives of control group included excerpts like:

" Yesterday some guests came over and he sat down at the dining table without troubling me" *(R)"*.

" Yesterday he created so many sounds I could even hear him say 'hmm' almost as if saying yes to me'. I hope he soon starts atleast communicating with me." *(O)*

" He is showing a lot of improvement *(R)*, I want to take him out to the park *(O)* but what if he starts shouting there too, what will I do? *(DCM)*"

" Thanks to all of you, she has started taking so many changes in her routines (R) but now that we are shifting to U.S. can you help her through this major change? (DCM).

" Earlier when we had to go out anywhere I had to sit out on the steps with him all the time. Yesterday, he and I sat together on the dining table for the first time (R) and he was observing other children around. If you could just teach him how to now interact with these kids (O and DCM)?"

" We have to go for a marriage today, can you please accompany us? He will be better with you around !" *(DCM).*

Narratives of the intervention group:

" She and I made boondi raita yesterday *(R)* Next I will add aloo in the raita sequence". *(E)*

" Yesterday , when I started to play with him, he looked at me in the eye and smiled.(R) We played the same game together and I could help him bring variations." (O and E)

" He would not be able to take changes in the route. I gave him the narrations before the event yesterday and for the first time he did not throw any tantrums".(R and E)

" We could move beyond his obsessions for 'fan' and spin other toys. Spinning is atleast better than merely sticking on to fans. (R and O)

The parents' repeated negative thoughts about their child, their own self and the life condition consistently reinforced the need to provide not only 'parent counselling' but to have a model that helps empower the parents, making them feel more in command and competent, thus hoping to strenghten the parent-child relationship. It was believed emotionally struggling parents will not be optimal support for their children and hence the therapeutic gains will be comprimised. With the added 'Parent training' tier, the parents would feel more empowered to take care of their own child's needs. This would also show better therapeutic results for the child, with the same kind of strategies being used across situations

and by different people, including the parent. Thus, adding Relief and Optimism to their repetoire of newly re-found self worth.

Karst JS, *et.al.* (2012), suggested that the pervasive and severe deficits often present in children with ASD are associated with a plethora of difficulties in caregivers, including decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. The same was observed in our sample.

While efforts were made to make available all the 6 tiered services to the parents as was feasible, not all parents were able to access all 6 tiers. Certain levels seemed more accessible for parents (typically the informal meetings and the regular, formal feedback meetings); whereas others could not be accessed because of various factors. The findings highlighted that *all* parents (both groups) felt more relaxed even with informal feedbacks and discussions after accessing intervention at level one because of the reduction in their apprehensions and confusions. Out of the 15 parents who attended the parent training workshops, 14 shared they felt more at ease and better empowered seeing the things falling in place, which earlier seemed like an impossible ordeal.

It was observed that all the 15 parents in the intervention group (who attended the workshops) not only participated in this level, they also accessed all the 6 tiers of the 'Eye- to- I © Parent Counselling Model'. On the other hand, the parents in the control group attended 3-4 out of the 6 tiers only. It is contemplated whether the shift in themes of the parents in intervention group post intervention is due to the FPT's impact alone, or due to their having attended all the tiers of the model. There is a 100% participation in all tiers of the model by the intervention group. This in itself can be a by-product of the FPT. It may be argued that, as they have been part of the FPT's, they have been able to expand the horizon, empower their own selves and in turn their children. Once they have done so, they are able to step out with more confidence than the other parents and hence able to tap tier 5 (being able to stand for the rights of their child and also point out to the family members the reason behind the so called 'maladaptive behaviours) or tier 6 (forming small SHG's-with one another or letting the child explore the world, being confident of self that they will be able to manage their child. Or, as they are obtaining all 6 tiers, are they able to feel more empowered and better relieved.

Many of the parents weren't able to access the Formal training tier due to some practical limitations of being a working parent or having other priorities at home or financial constraints. To reduce these concern efforts were made by the organisation to help by adjusting the timings / training dates depending upon the availability of a group of parents or reducing/forgoing the cost for parents who needed it and facility of child-minding while the parent was in the training. Yet not all parents were able to utilise this tier.

Therefore, another factor that may be duly viewed to reach any conclusion is in relation to the readiness of the parents to attend the FPT. Though the research shows a positive shift in the narrations and body language of the parents in the control group, what was not assessed before their participation in the FTP is, what was the level of stress they were at *that* stage, i.e. immediately before a new FPT group was beginning, hence an opportunity to attend. Whether the intervention group was already at that level where-in they were coping well enough with stress levels enough to motivate them to participate in the training whereas may be the control group parents were still so stressed out that they couldn't pull themselves to this workshop and hence there existed already a disparity in their level of stress and coping to take next steps to bring about a change. To make true analysis an empirical data with rigrous statistical analysis needs to be gathered in regards to this dimension and comparing it with their control group counter parts.

Though there needs to be more empirically researched analysis, the current research finds that indeed parents need support and guidance for not only their children but for their own mental well-being and empowerment; and even informal levels of support are helpful. Researches also quote that there is a need for support programmes to target family and relationship variables as well as ASD children and their behaviours, in order to sustain the family unit and improve quality of life for parents and caregivers as well as those children (Jonathan A. et.al, 2012). Our research sufficiently points that parents definitely benefit with the integration of both counselling and training, but the extent to which Focussed parents training is a sole catalyst in bringing about this change is to be further researched upon.

Conclusion

The paper suggests the importance of having an effective counselling plus training intervention for not just the children but also the parents. Hence, ensuring a holistic approach (spread across social systems) for the development of child by targeting also the parental emotional well-being along with strengthening the parenting skills.

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