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Review Article

A systematic review on parent mediated intervention programmes for children with autism spectrum disorders in India

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ABSTRACT

The relevance of identifying effective interventions and rehabilitation of children with autism spectrum disorders (ASD) increases day by day due to the growth, especially in India. One strategy which has been found to be effective to meet the requirements of children and adolescents with ASD is parent-mediated programmes. However, since most studies of this kind have been undertaken in high-income nations, the present research will explore the effect of parent-mediated intervention programmes in India, a country with a high incidence of developmental disabilities. A fast systematic review employing databases such as PUBMED, psycINFO, Medline, Web of science, and Google Scholar was conducted to assess Indian research on PMI for children with ASD published before February 2022. Studies that were included in the review covered research involving those between the ages of 1 and 18 who were diagnosed with ASD. The 354 research papers were collected, and 11 studies satisfied the criteria for inclusion, including randomised controlled trials and pre-and post-intervention studies. The current research reviewed the articles in terms of the efficacy of parent-mediated interventions (PMI) and their feasibility and acceptability. Studies show that PMI helps improve interactions between parents and children as well as children's social, communication, motor, and cognitive skills. They also help parents learn more about how to teach their children and improve their children's language and academic skills. The overall conclusion of the systematic review was that PMI helps improve parent and child skills.

Keywords: ASD, PMI program, Systematic review, Feasibility, Receptivity, Potential contents

INTRODUCTION

Autism spectrum disorders (ASD), a subset of developmental disabilities, and account for 4.2% of all disabilities related to mental disorders. ASD is normally diagnosed between the ages of three and five years; a recent systematic study showed a global mean prevalence of 1%. This equates to approximately 4 million children in the country who have an ASD. Autism is a spectrum, not a single diagnosis, and is frequently viewed as a range of symptoms in which children display varying degrees of difficulty with communication, social interaction, repetitive behaviours, and a lack of creativity. Young children with ASD often pose a challenge to parents and other family members with behavioural issues due to their struggles with social communication and socialisation in general. However, recent research has indicated that early intervention programmes work, even though such claims are doubtful and replication has been a challenge.[1-4] Early intervention has taken several forms, often involving parents, but not necessarily always. Some such

programmes include applied behaviour analysis (ABA), which employs "discrete trial" training to assess children's learning. The TEACCH project (Treatment and Education of Autistic and associated communication handicapped Children) focuses on using visual signals, communication routines, and individual activities to structure classroom settings.[5,6]

CHALLENGES FOR MANAGEMENT OF ASD

Despite the benefits of interventions for children on the autism spectrum, there are several challenges yet to be overcome for such interventions to be applied. Due to the early manifestation of ASD, children are prevented from a young age from being able to develop their skills, and this can lead to lifelong disability. The treatment gap that exists within rehabilitation services leaves only 10-15% of children receiving the help that they need.[6,7] Socio-economic level is yet another factor which plays a role in seeking treatment. Parents from a lower socio-economic status are less likely to seek treatment as compared to parents from a middle or upper socio-economic group.[6] And even when help is sought, it is often delayed, with a significant time gap between the initial onset of symptoms and the first treatment contact. Reasons attributed to the low rates of professional help seeking include a lack of awareness and stigma, poor availability and access of resources, negative attitudes towards seeking treatment, and an excessive reliance on self-treatment.

Parent-focused intervention approaches revolve around identification, reduction, and intervention of skill deficits, behavioural excess, and deficits in children with ASD, along with addressing parental concerns, stress, etc. However, these approaches often fail to provide a comprehensive intervention for both parents and their children with disabilities in general and ASD in particular.

Recently, the trans-disciplinary model of intervention for developmental disability has emerged as a new paradigm in disability management as a result of growing awareness of the shortage of disability professionals. This has the potential to also help address the significant individual differences in the development and emergence of ASD symptoms. Such a trans-disciplinary model would involve a master therapist to address the other therapeutic needs in liaison with or consultation with other multi-disciplinary specialists. The primary therapist would know the child in detail. Having a comprehensive idea of the child, he can be a better planner or understand the real needs or areas to be targeted for the child's fast progress.

A brief overview demonstrates the multiple benefits of parent-mediated intervention programs. To name a few, improved communication skills, fine-motor skills, increased social skills in terms of pro-social bonding, competence across emotional and cognitive domains, behavioural and emotional engagement with parents, siblings, peers, and improved academic skills.

A study done by Hume, Bellini, and Pratt (2005) showed that there are numerous strategies which are not being put into practise which lead to a lower intensity of engagement than expected, even though parental domain was one of the most effective methods to help a child's growth.[8]

The paper aims to survey empirical research conducted in India that uses a parent mediated intervention (PMI) framework to address issues arising from ASD. Further, the research will explore the scope for developing and testing PMI interventions keeping in mind previously used content, structure, and feasibility of programmes that explicitly integrate existing evidence-based therapeutic components for empowering children and their parents.

This review looked at parent-mediated intervention programmes for children with ASD in India. Within the selected reviews, we compiled the outcomes of the intervention in parent and child behaviour or skills.

Search strategy

We used the PRISMA reporting frameworks.[9,10] PubMed, Medline, PsycINFO, Web of science, and Google Scholar were searched exhaustively for pertinent papers.

The first search phrases included "Autism" or "Autistic" or "ASD", "Parental training" or "Parent mediated programmes", or "parent intervention programmes", as well as "India" (Additional publications were discovered by examining the references of the retrieved papers).

Two reviewers (1st and 2nd authors) independently examined the literature using a priori prioritisation and sequential exclusion approaches to ensure the information's quality and correctness. Where there were disagreements between the two reviewers, a third reviewer (the third author) weighed in to resolve them. In total, 2.8 percent of articles (6/215) contained disagreements. Articles that were duplicated have been removed.

Inclusion criteria

This review included studies that: Aimed at parents of children and adolescents with ASD aged 1 to 18 years; ASD was diagnosed using: DSM-IV, DSM-5, or the international statistical classification of diseases and related health problems, tenth revision (ICD-10); research carried out in India. Studies published in English language, full text articles available through an indexed in an international scientific journal prior to March 2022.[11-13] Used an experimental design, which could be a randomized control trial (RCT), quasi-randomized trial, or a pre-post intervention study, with outcomes assessed at baseline and end line. Reported on outcomes for child

or parent. Involved parents of children with ASD as trainers.

Data management and analysis

Two reviewers separately screened the title and abstract for relevance to the study according to the inclusion criterion (1st and 2nd authors). A third reviewer resolved any discrepancies (3rd author). First and second reviewers did full text screenings of eligible manuscripts and collected data on a Microsoft excel data extraction sheet (version 2013). The sheet captured study details such as the title, year of publication, aims of the study, sample, intervention used, and major findings. The data from all eligible research was synthesised, and the conclusions were summarised using a narrative synthesis.

RESULTS

The initial database search identified 337 publications, from which 17 additional abstracts were acquired through manual search, leading to a total of 215 articles. The 139 duplicate articles were found, leaving 215 abstracts for examination. While screening the abstract, 204 articles were excluded either because the key term search did not match (n=33), or the title and abstract did not match the inclusion criteria (n=29), or the full text did not match the inclusion criteria (n=18), the article failed to specify ASD assessment tools (n=21), the article was not implemented in India (n=25), no child or parent outcome was reported (n=30), and training programmes did not involve parents (n=26). Those that passed the full text review (n=13) were included in the final analysis.

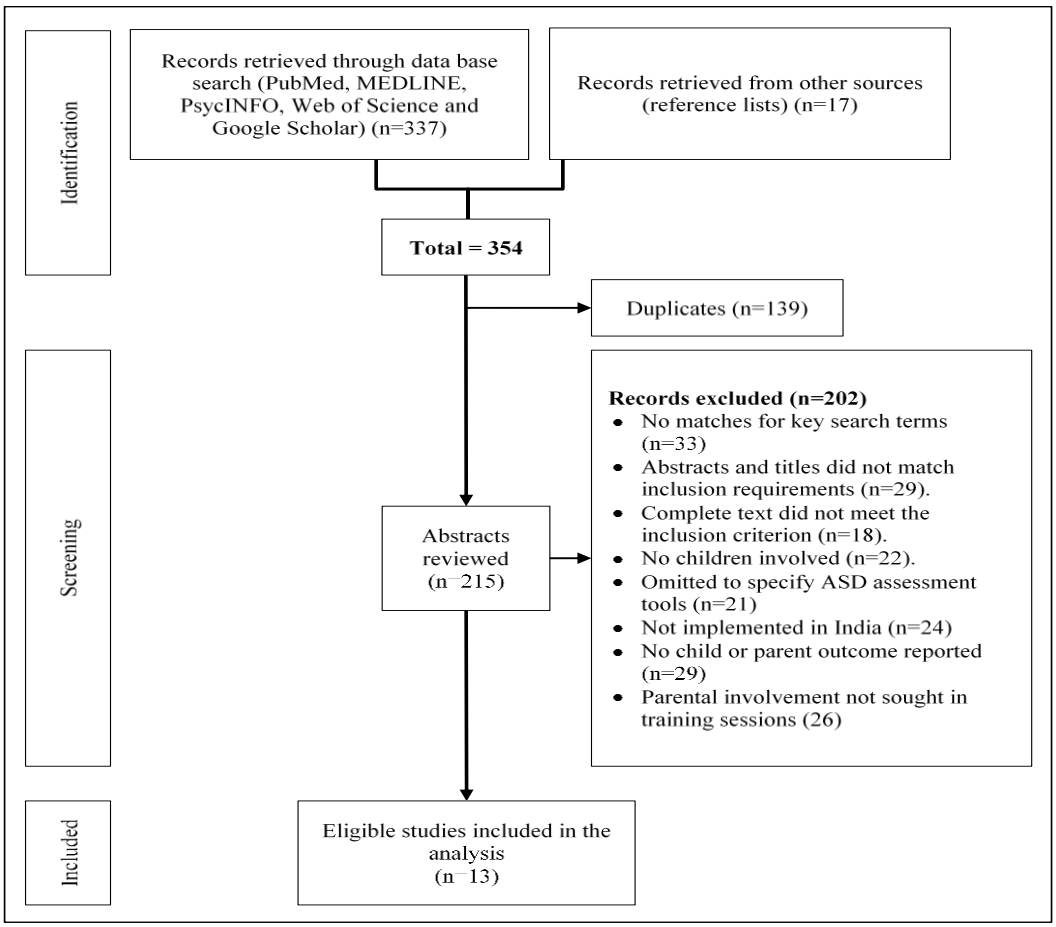

Figure 1: Flow diagram of study selection for the systematic review.

We first analysed data relating to ASD, treating it as a theme, and then organised the findings into subthemes within this theme. The findings were classified into eight subthemes: i) research characteristics, ii) examination of potential contents, a) parent-related potential contents and child-related potential contents, iii) examination of programme feasibility and acceptance, iii) examination of programme structure, iv) examination of dual outcomes, a) parent-related outcomes and b) child-related outcomes.

Research characteristics

The final analysis included eleven studies during the period of January 2012 to January 2021 involving parents of children or adolescents with ASD. Thirteen research studies were carried out in India, and one study was carried out simultaneously in both India and Pakistan.[14]

Examination of potential contents

Parent-related potential contents

Several intervention programmes involve the adaptation of standardised interventions in western settings with appropriate cultural adaptations. PASS, pre-school Autism communication therapy (PACT), psycho education profile intervention (PEP-R), and Caroline curriculum for infants and toddlers with special needs (CCITSN) were standardised programmes that were adopted into cultural contexts and implemented by involving health workers or parents.[17,21,22] Out of thirteen studies on ASD, only five studies assessed the impact of parent-mediated training programmes on parental knowledge.

Program feasibility and acceptability assessment

Overall, all the programmes were taken in a positive way and higher levels of participation and involvement were reported, indicating PMI is in general a feasible and receptive method of intervention for ASD. In the 6 studies that mentioned a dropout rate, the rate was between 5 and 56%.[17,15,21,24] Parents were motivated to join the programme due to their sense of helplessness about supporting their children. All studies demonstrated parents' proclivity to attend.[15,16,20,21,23,24,] Sengupta et al discovered that 75% of parents reported practising specified home-based tactics on a weekly to daily basis, throughout their home and play routines.[26] Parents were found to accept the various components of the intervention and had high rates of attendance and caregiver fidelity.[26]

Examination of programme structure

Examination of programme structure of the studies reviewed, eight were set in clinical/hospital environments, while one was implemented through a training centre. The delivery varied between 3-6 months. The interventions were mostly delivered by therapists, while in some studies, various providers such as paediatricians, special educators, psychiatrists, psychologists, special educators, trainers, and health workers also provided the interventions. They were mostly delivered through home-based sessions, and occasionally through one-on-one sessions. Follow-up was usually after 3 to 6 months.

Examination of dual outcomes

Parent related outcomes

All studies except two mentioned a parent outcome.[15,19] According to studies, the intervention benefited parents both personally and in terms of their interactions with their child. Personally, mental health effects seem to be positive, with a reduction in depressive symptoms, distress, and improved family coping.[21,23] In terms of parent-child interaction, improvements were seen in better synchronous interactions, improved adaptive behaviour, increased involvement of fathers, and increased acceptance of diagnosis. However, the interpretation of the parent outcomes needs to be interpreted with caution as most programmes were carried out among educated parents from families with higher incomes, which may lead to a biased generalization.[1728,29] But it also gives hope that some studies that were conducted among parents who were illiterate and from low socioeconomic classes also demonstrated the efficacy of the intervention among parents.[21]

Child and adolescent related outcomes

Nine studies highlighted at least one child related outcomes. The outcomes for children included improvements in perception, cognitive performance, and verbal skills.[16,20,23] Parent-child communication initiation was seen to improve.[18,21] One of these pre-post intervention studies showed strong effects on adaptive behaviour and behavioural problems as well, with even a reduction in the symptoms as assessed by the childhood Autism rating scale.[15,16,20,28] Additionally, mothers and facilitators reported positive impacts on child's behaviour. Changes in their children's expressive capabilities, such as beginning to point or use more words, greater comprehension of instructions and social interaction, better self-regulation, and higher engagement in self-help skills, were reported.[29]

Table 1: Characteristics of the selected study.

Study, year, place	Participants	Design	Outcome measures and results
Juneja et al (2012), New Delhi, India	Intervention, n=16. Control, n= N/A. Age: 6 years or less Diagnosis confirmed by diagnostic and statistical manual, 4th edition, text revision (DSM-IV-TR) criteria. Dropout rate: 55.55%	Pre and post study design. Customized programme designed to improve a child's attention, communication, social skills, and behaviour; A specialist demonstrated methods to parents; Parents acted as therapist; Parents expected to spend 45-90 minutes daily in one-to-one setting with child; average duration of therapy was 19.5±11.78 months	Child outcomes: Significant improvement in development quotient (p=0.015), social quotient (p=0.004), expressive language quotient (p=0.03), CARS (p=0.001), ABC (p=0.014) scores. Parental outcomes: N/A

Continued.

Study, year, place	Participants	Design	Outcome measures and results
Nair et al (2014), Trivandrum, Kerala, India	Intervention, n=52. Control, n=N/A. Age: <6 years. Diagnosis confirmed by diagnosed by a pediatrician Dropout Rate: N/A	Pre and post study design. Developmental and speech therapists helped mothers assemble low-cost training kits based on the developmental age of the child, gave initial training in the basic behavioural technique to address the three autism symptom clusters at home. Follow-up support was given either on a weekly, fortnightly or monthly basis. Each clinical session lasted between 15 and 20 minutes.	Child outcomes: amelioration of severity of autism symptoms, and acquisition of social skills, receptive language and expressive language (all p=0.001) parental outcomes: N/A
Brezis et al (2015), New Delhi, India	Intervention, n=40 3 consecutive cohorts of participants, who came in in Jan (n=16), July (n=12), and Sept (n=12), 2012, Control, n=N/A. Diagnosis confirmed by: information N/A Dropout rate: N/A	Pre and post study design. Home based intervention techniques for improving socialization, communication and behavioural problems administered on parents and its impacts on parental stress and knowledge about ASD studied.	Child and family outcomes: increased self-reflection, an increased ability to project beyond here and-now, and sense of empowerment that stems from better understanding of ASD along with better behaviour management.
Louis et al (2015), Vellore, Tamil Nadu, India	Intervention, n=15. Control, n= 15. Age: between 30- 60 months. Diagnosis confirmed by Diagnostic and Statistical manual, 4th edition, text Revision (DSM-IV-TR) criteria. Dropout rate: N/A	Randomised controlled trial; fathers in treatment group had to observe how the therapist interacted with the child, then engage the child on a one-to-one basis and finally demonstrate to the therapist how they would approach the child at home. This intervention program was followed for 6 months after which children were reassessed. For control group home program provided in a written format that would be used at home by the primary care giver.	Child outcomes: positive impact on the child's communication, understanding of play and also social skills, better communication intent, respond constructively to social cues and simple activities of daily living.
Patra et al (2015), Chandigarh, India	Intervention, n=18. Control, n=N/A. Age: between 30-60 months Diagnosis confirmed by Diagnostic and statistical manual, 4th edition, text revision (DSM-IV-TR) criteria. Dropout Rate: N/A	Qualitative and quantitative methods pre-post design; module was presented to the parent's group in 12 parts, each session lasting about 2 hours at a fortnightly interval. Impact of this module on parent stress and knowledge was then assessed using structured questionnaire.	Child outcomes: Home based intervention techniques for improving socialization, communication and behavioural problems.
Krishnan et al (2016), South India	Intervention, n=77. Control, n=N/A. Age: toddlers Diagnosis confirmed by ICD-10 diagnostic criteria. Dropout rate: N/A	Pre- and post-Intervention study. 12-week, five days a week, intervention program and regular practice at home was collected from the database of a teaching hospital.	Child outcomes: It is feasible to provide an effective parent mediated early intervention for mild to severe Autism they improve developmental age significantly develops play behaviours decreases symptoms of autism improves other abilities like

Continued.

Study, year, place	Participants	Design	Outcome measures and results
			perceptual- Fine-motor, cognition, language, social/emotional. Parental outcomes: N/A
Rahman et al (2016), Goa, India and Rawalpindi, Pakistan	Intervention, n=32. Control, n=33. Age: 2-9 years. Diagnosis confirmed by diagnostic and statistical manual, 4th edition, text revision (DSM-IV-TR) criteria. Dropout rate: 9.23%	A single-blind randomised controlled trial; One-on-one clinic or home sessions between a health care provider and a parent with the child present. Health care providers were assisted by semi-structured scripts. Six months of one-hour sessions every two weeks (12 sessions)	Outcomes: feasibility of adapting and task-shifting an intervention used in a high-income context to low- and middle-income countries.
Divan et al (2019), Kolhapur, Rural India	Intervention, n=19. Control, n=21. Age: 2-9 years. Diagnosis confirmed by diagnostic evaluations were conducted using the INCLEN diagnostic tool for autism spectrum disorder [Juneja et al 2014] Dropout Rate: 15%	Two arm single (assessor)-blinded randomised Controlled trial; The " PMI for autism spectrum disorder plus" (PASS plus) treatment included one-on-one home sessions between the parent and a lay health worker.	Child outcomes: large treatment effects on proximal outcomes of proportion of parent synchronous responses and proportion of child communication initiations with parent; mutual shared attention and co-morbid symptoms. Parental outcomes: improve parental mental health.[2723]
Padmanabha et al (2019), Chandigarh, India	Intervention, n=21. Control, n=19. Age: 3-12 years Diagnosis confirmed by diagnostic evaluations were conducted using Dropout rate: N/A	Parallel group, pilot, randomised controlled trial; This was a 12-week pilot randomised controlled study with parallel groups. Throughout the research period sensory intervention group received sensory interventions at home by parents/ caregivers in addition to regular therapy; the standard therapy group received speech therapy and applied behaviour analysis from professionals.	Child outcomes: reduction of hyperactivity, motor-stereotypies, auditory sensitivity in those who underwent sensory interventions. Home-based sensory interventions feasible in developing country and suggested to beneficial role in ASD. Parental outcomes: N/A
Manohar et al (2019), South India	Intervention, n=26. Control, n=24. Age: 2-6 years. Diagnosis confirmed by Diagnostic evaluations were conducted using a DSM 5 criteria. Dropout rate: 6%	Pilot randomized controlled trial with two parallel arms; the intervention based on naturalistic developmental behavioural approach, focusing on joint attention, imitation, social and adaptive skills was structured to be delivered in five outpatient sessions over 12 weeks. All children were followed up at 4, 8 and 12 weeks.	Child outcomes: children showed significant improvement in relating to people, imitation skills, visual response, and overall autism severity. Parental outcomes: reported more improvements across parental stress.
Sengupta et al (2020), Urban India	Intervention, n=57. Control, n=N/A. Age: 1-6 years Diagnosis confirmed by Diagnostic evaluations were conducted using a DSM 5 criteria. Dropout rate: N/A	Quasi-experimental pre-post study design; project ImPACT (Ingersoll and Dvortcsak, 2010)- a parent-mediated naturalistic developmental behavioural intervention (NDBI) for young children with ASD shown to improve social communication, engagement and play was adapted	Child outcomes: Improvement in children's social communication skills. Parental outcomes: urban Indian parents found the intervention feasible and acceptable, were able to demonstrate the strategies taught and perceived. Parental outcomes: In addition, parent

Continued.

Study, year, place	Participants	Design	Outcome measures and results
		and subsequently implemented at a child development center in an urban setting in India to meet the needs of the community	stress levels decreased after completion of intervention.
Sengupta et al (2021), Mumbai, India	Intervention, n=12. Control n=N/A. Age: between 1-6 years Diagnosis confirmed by diagnostic evaluations were conducted by pediatrician/child-psychiatrist/child psychologist. Dropout rate: N/A	quasi-experimental pre-post study design with a mixed methods approach; the Project ImPACT (Ingersoll and Dvortcsak, 2010), an evidence-based NDBI, has been previously successfully adapted for use in an Indian context as a 6- week centre-based model (Sengupta et al), and has been termed the Ummeed parent training rogramme (UPPA), aims to train parents to promote social communication, play, and language acquisition for children with ASD between the ages of 1-6.	Child outcomes: improvement in child's social communication skills, social engagement, expressive language, understanding directions and social imitation, play skills. Parental outcomes: Many parents perceived enhanced sense of confidence in their abilities to understand and support children's skills, across situations and settings.
Sengupta et al (2021), Urban India	Intervention, n=22. Control, n=N/A. Age: between 2-9 years. Diagnosis confirmed by diagnostic evaluations by pediatrician/child-psychiatrist/child psychologist. Dropout rate: N/A	A concurrent mixed-methods pre-post research design; the world health organization-caregiver skills training program, a parent-mediated early intervention facilitated by non-specialist providers piloted in urban India was evaluated using mixed-methods for feasibility and effects on child and caregiver outcomes.	Child outcomes: Improved developmental outcomes on communication, social interaction adaptive behaviours. Parental outcomes: improved caregiver skills knowledge, reduction in stress.

DISCUSSION

The evidence seems to indicate that PMI training delivered has benefits in improving parent knowledge, parent child interactions, and multiple outcomes for children, including social, emotional, cognitive, and motor benefits. However, lack of methodological rigour due to lower number of randomized controlled trials, lack of standardized measures, undefined population makes it difficult to generalize the findings. Going ahead, studies should rectify this in order to make sure that a beneficial intervention strategy can be applied to the target population.

There are several studies that have looked at parent training programmes that have been found to be effective in improving motor, personal, communication, and social skills and have looked at acquiring skills through co-operative, experimental, and participative strategies.[9] However, many such programmes could not be part of the review even though they aligned with the PMI framework as they did not significantly emphasise the parental engagement component as an integral component. This is an indication that the limited number of articles which passed the inclusion criterion indicates that the programmes which focus on Parent-mediated intervention strategies are in a preliminary stage and need to be redefined in terms of their position on a local and global scale.

The drive by the government of India to involve the differently abled community across national and international programmes is often limited by a lack of empirical studies, even though there are multiple organisations that utilise parental involvement in therapeutic settings. The approach of applying PMI programmes in the nation by incorporating parental literacy components into them can be a relatively low-cost yet effective therapeutic programme for the Indian population of children with ASD.

Reflections on prospects and potentials for integrating parental and child outcomes in PMI

According to our review of the published literature, we believe that the demographic dividend represents an under-utilised opportunity to mobilise parents as change agents through parent-mediated intervention programmes that can include components of parental and child outcomes distributed equally, as well as support group building for their counterpart parents, other parents with children with ASD. Incorporating mental health components for parents of children with ASD into PMI programmes has numerous benefits, including a focus on mental health literacy and the goal of increasing

help-seeking inclinations. Because PMI programmes emphasise overall skill development and the reduction of excess behaviours, they can be an extremely effective way to engage children, parents, and, if possible, other family members in the cause of educating parents and increasing awareness, resulting in not only empowerment for participating parents and children, but also significant cascading effects on others who are the intended recipients of such programmes and support groups.

Additionally, unlike isolated information, education, and communication activities, a PMI approach can have a broader impact because it involves training children via their parents in a variety of skills and competencies related to daily functioning, self-care, and communication skills, as well as their sustained commitment to the overall wellbeing and rehabilitation of such children. Parents and interested teachers, mentors, or family members could be trained to deliver such a programme, obviating the need for mental health professionals to invest time and effort directly. Additionally, incorporating rehabilitation, disability literacy, and other related topics under the umbrella of parent-assisted interventions is a worthwhile exercise because it strengthens parents' capacity to care for their own health as well as the health of their family and children. Tasks that need to be done in the long run by research funding agencies, action researchers, disability and rehabilitation practitioners, policymakers, and implementing bodies in India include looking into their effectiveness and feasibility and getting help from both governmental and non-governmental groups to make them happen on a big scale.

Exploring content, structure and feasibility of the PMI

The reviewed literature shows that PMIs are received well, with parents admitting the benefit of the intervention strategies and the drop-out rates promisingly low. The review shows the optimal duration of the interventions should be at least 25 hours per week. Most of the research also highlights the use of concentrated one-on-one interventions. The programmes are especially feasible for supplementing service insufficiency for the population with autism spectrum disorder and can be applicable for beneficiaries from low-resource environments, as earlier diagnoses are now possible and the intervention strategies can be expanded to be developed for children under the age of three.

Limitations

The review has some shortcomings. It was limited to five databases: Medline, PubMed, PsycINFO, Web of science, and Google Scholar, plus a few Indian publications. Some supplemental searches required visual scanning of titles and then abstracts, while others required a search tool. The additional search was limited to 2010 to date, but some journal websites did not yet have the latest issues online. Unpublished dissertations and theses not uploaded to Shodhganga could not be reviewed. In addition, the search did not include all Indian publications. It only looked at a few that were relevant (like community, applied, and clinical psychology).

CONCLUSION

It is possible to conclude that there is a severe global and Indian shortage of such programmes that could aid in addressing the dual goals of child development and parental mental health. The study demonstrates that participants from low-resource areas are disproportionately underrepresented in international parent-mediated intervention studies conducted on a global scale. The study further reveals that out of eleven studies reviewed, four studies established enhanced parent-child communication: There were three studies showing that children were initiating more conversations; five studies showed that children had better social and communication skills; four studies showed that parents had a better understanding of how to teach their children; and four studies showed that children had better motor and cognitive skills.

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