

ORIGINAL ARTICLE

Effectiveness of an Information Booklet on Opinion among Caregivers of Children with Autism

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Abstract

Autism spectrum disorders (ASDs) are neurological disorders that affect social interaction and speech, such as difficulty in responding to social interactions or recognizing non-verbal communication. Opinion of the caregivers plays a very important role in the care of children with autism spectrum disorders and will have a negative impact on child development. The objective of this study was to find the effectiveness of information booklet on Opinion among Caregivers of Children with Autism. The booklet was developed in English for the caregivers of children with autism.

Method: Thirty caregivers were included in the study. The tools were developed based on the content coverage of the information booklet. The caregivers were given a seven-day period to read the information booklet. A quasi-experimental design was used, with a single group pre-test and post-test. The caregivers were chosen using a purposive sampling method. After the pre-test, the caregivers were given the information booklet. After the information booklet was distributed, the post-test was given on the seventh day.

Results: The influence of the information booklet was inferred to have a major positive effect on the subjects in all four dimensions of opinion.

Introduction

Autism spectrum disorder (ASD) is a severe neuro developmental condition.¹ This neuro developmental disorder begins in childhood and may persist in adulthood.² Characteristic symptoms include impaired interaction and social communication, as well as restricted, stereotyped behaviour, activities and interests.^{2,3} The frequency and severity of symptoms vary widely among children with ASD, and over time, the treatment recommended by clinicians also varied. ASD affects around 1 in 100 people.³ Autism spectrum disorder (ASD) is a major problem for public health.²

This may be due to inadequate infrastructure, lack of professionals, overall lower levels of schooling, disability-related stigma, conventional parental roles in childcare, underlying cultural elements, and competition for national spending resources.⁴ Receiving an autism spectrum disorder (ASD) diagnosis has a significant impact on a person and their families.³ Parents of children with ASD face various obstacles that lead to significant problems relative to other parent groups.⁵ Studies show that these parents were more stressful than parents of normally developing children.⁵

As a result, family members of children with autism are often thought to be suffering from detrimental psychological consequences. Some parents experience disbelief, deep sorrow and depression, as well as self-blame and shame, while others feel powerless, inadequacy, rage, shock, and guilt. This shows that caregivers of children with autism develop negative opinion towards their children with autism as they grow.⁶ These negative attitudes among caregivers may have a negative impact on the prognosis of the child with autism. In addition, there is mounting evidence that chronic disease and disability have a detrimental effect on families and family functioning.⁷

Although the disorder is not uncommon, most children with autism are not been diagnosed, even in urban India, and are not receiving the services. This exists in many countries. In India, very less level of awareness and huge levels of discrimination are increasing the need for public education services on the treatment of children with Autism Spectrum Disorder. Therefore, preparation for the education of caregivers in India is urgently needed.

In the Indian sense, not much work has been done focusing on the challenges and hardships of parents and how a parent can best deal with them. In a country like India, where autism awareness is still increasing and resources are scarce, the position of the service provider is best exemplified as a multifaceted knowledge provider, leader, supporter, and guide.

There is a great need for caregiver education. Effective intervention program for education must therefore be planned and implemented. Parents find it challenging to understand and care for the children and also require support for sustaining the energy through long years of raising a child with ASD.⁴ Parents of children with Autism Spectrum Disorder (ASD) face various obstacles that lead to significant problems relative to other parent groups.⁵ Parents need reliable information because they play a vital role in their choice and implementation of the treatment and management.¹ This is achieved by health professionals who provide parents and caregivers with guidance and data on appropriate and evidence-based interventions.⁴ Parents can approach for help and support for themselves and for their children.³ Written information provided should be effective, transmissible and attractive to help caregivers.⁸ Evidence has shown that the presence of parents improves the therapy's effectiveness over time.¹ Written information like information booklets, have been shown successfully

in the context of preoperative anaesthesia,⁸ language stimulation for children with mental retardation⁹ and insignificant other areas.

Participating in parent education programmes has a positive impact on parents. Parental tension is reduced, parental leisure and recreation time is increased, and parental confidence about the treatment of children with autism is increased through learning about the essence of the condition, its causes, management, and home-based therapies. Parent education programmes, in particular, have proved to be more successful and have earned higher satisfaction scores from parents. Researchers are currently working to increase the quality and efficacy of parent education programmes to improve outcomes for all families that participate. According to research, the most valuable assistance parents can get from clinicians is right after the diagnosis. Facilitated information is one potential support system for parents. This type of support may increase parent's ability to take care of their children, thereby bringing out positive opinion towards the children with autism.⁶

Caregivers are now widely recognised as the single most valuable resource for every child and must be included in the service delivery and planning process. Given that children spend the first few years of their lives under nearly constant parental control, parents may serve as primary educators by teaching their children in a variety of natural ways during the day. The focus of intervention programmes is shifting from child-centred to family-centred.¹⁰

Parents and caregivers of children with autism must be positive and relaxed to support their children. This research aimed to develop an information booklet for caregivers of children with autism. The book was designed to help parents cope with the difficulties that children with autism face daily at home.

There is very little research on educational intervention in an awareness booklet for parents of children with autism. There is a significant need for educational intervention for the caregivers. The use of tertiary treatment in the diagnosis process is beneficial. The caregivers, on the other hand, are in charge of guiding the children and assisting them in gaining skills in various areas of life. As a result, parents need an information booklet as a source of information about how to care for children with autism.

In light of the above, the present research examined the caregiver's opinion towards the treatment of children

with autism. Furthermore, the current research aimed to create and evaluate the efficacy of self-instructional content in the form of an information booklet for the treatment of children with autism on the level of opinion, which will aid in determining how instructional materials can be prepared and used effectively by caregivers.

Materials and Methods

Development and validation of the information booklet: A comprehensive literature review was conducted to determine the different aspects of autism treatment. The information was delivered in a straightforward manner and in a logical order. The contents of the information booklet were validated by experts from various disciplines for applicability, feasibility, significance, suitability, and validity. Expert recommendations of reassurance. The experts' suggestions for the information booklet were properly implemented, and the information booklet was finalised.

Research design: One group pre-test – post-test design was adopted for the study. The study was carried out in a tertiary care hospital dedicated for the mental health and neuro science speciality, located in Bangalore, Karnataka, India.

Sample: Thirty caregivers of children with autism were selected using purposive sampling technique.

Inclusion criteria: Caregivers who attend the outpatient and inpatient services of the chosen institution's child psychiatric centre, as well as those whose children have been diagnosed with autism after a thorough examination.

Exclusion criteria: Caregivers who had completed some advanced training in the care of autistic children.

Tool: It consisted of a socio-demographic data schedule and an opinion questionnaire on the care of children with autism.

A: Socio-demographic data schedule: It consisted of basic sociodemographic details of the caregivers.

B. Opinion questionnaire on the care of children with autism: The opinion questionnaire contained 30 items

divided into five categories: strongly agree, agree, unsure, disagree, and strongly disagree. This scale was written in the form of sentences. There were four dimensions to the size. Caring, indifference, approval, and punitive were among them. Items under care and approval were positively worded, and items under acceptance were positively worded. Score 5 denoted strongly agree, 4 for agree, 3 for undecided, 2 for disagree and 1 for strongly disagree. Scores were reversed for the negative items. 13 items were negative and 18 were positive items. The interpretation was that the higher the ranking, the more favourable the opinion. Scores <75% indicated most favourable opinion, scores 50% -74% indicated favourable opinion and scores <50% indicated unfavourable opinion. The content validity was done and the reliability was ($r=0.9961$) highly significant.

Method of data collection: Caregivers of children with autism who were attending outpatient and inpatient child psychiatric centre at a tertiary care centre in South India were included. The sample was selected for the study based on the purposive sampling technique. The caregivers were approached to see if they were interested in participating in the research. After a brief introduction to the subject, the caregivers were given the information booklet. The caregivers were given a seven-day period to read the information booklet. At the end of each booklet, a feedback form was attached and was given to the caregivers for writing their feedback on the booklet. After one week, caregivers in outpatient settings were assigned a follow-up date, while caregivers in inpatient settings were reached by the researcher after one week. A follow-up interview was conducted after seven days. The feedback forms were collected by the researcher. All the caregivers gave their feedback about the booklet. During the follow-up session, the caregivers were given time to discuss their doubts and clarifications. The concerns of the caregivers were addressed.

Results

Effectiveness of the information booklet on the opinion scores

Table 1: Comparison of pre and post test scores on opinion based dimensions

n = 30

Sl. No	Opinion dimension	Test time	Mean scores	% of mean	Opinion gain	Standard deviation	t- value	P value
1	Caring (OD1)	Before	33.93	84.82	02.80	04.28		
		After	36.73	90.82		02.53	04.79	0.000
2	Neglect (OD2)	Before	24.76	70.74	03.80	04.65		HS
		After	28.56	81.61		03.47	06.14	0.000
3	Acceptance (OD3)	Before	37.13	82.51	03.47	05.65		HS
		After	40.60	90.22		03.25	04.48	0.000
4	Punitive (OD4)	Before	19.86	66.22	03.17	04.19		HS
		After	23.03	76.77		03.50	04.39	0.000
5.	Total score	Before	115.68	77.12	13.24	18.78		HS
		After	128.93	85.95		12.76	19.82	0.000

HS= Highly Significant p< 0.01 df =29

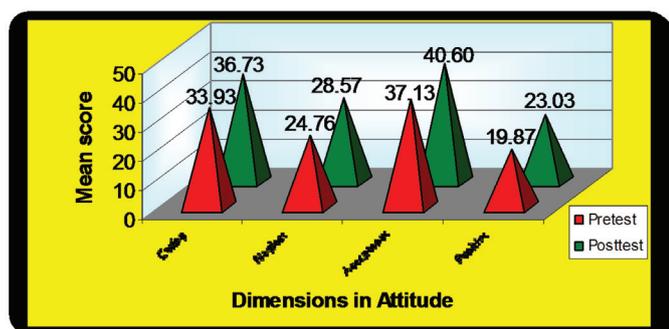


Figure 1: Dimension wise comparison of mean score of the opinion of caregivers.

Before the intervention, the caring dimensions was in high (Mean percentage 84.82), followed by Acceptance (Mean percentage 82.51), Neglect (Mean percentage 70.74) and Punitive (Mean percentage 66.22). A similar pattern was observed even after the intervention i.e. the highest mean percentage was observed in the Caring domain (90.82), followed by Acceptance (90.22), Neglect (81.61) and Punitive (75.77). The paired t-test revealed that the gain in the opinion score was statistically significant in overall (t = 19.82, p<0.001) as well as in all the domains i.e. Caring (t = 4.76, p<0.001), Acceptance (t = 6.17, p<0.001), Neglect (t = 4.48, p<0.001) and Punitive (t = 4.39, p<0.001).

The impact of the information booklet, which was provided to caregivers of children with autism, was

inferred to have a substantial positive effect on the subjects in all four dimensions. The pre-test mean score for the second dimension neglect was 24.76, with a mean percentage of 70.74 percentage, and the post-test mean score was 28.56, with a mean percentage of 81.61 percentage, an opinion gain of 3.8, a paired t value of 6.14, and a p-value of 0.000, which was highly significant. In the third dimension acceptance, the score of the pre-test was 37.13, mean percentage was 82.51% and mean score of post-test was 40.6, mean percentage was 90.22%, opinion score gain was 3.47, paired t value was 3.25 and p-value was 0.000, which was highly significant. In the punitive dimension, the mean score pre-test was 19.86, 66.22 % was the mean percentage and the mean score of post-test was 23.03, 76.77% was the mean percentage, opinion gain was 3.17, paired t value was 4.39 and p-value was 0.000 which was highly significant.

It was inferred that the caregiver’s opinion moved towards the favourable direction in the caring and acceptance indicating that there was a development of a positive opinion of the caregivers. Also in neglect and punitive, the negative opinion was reduced and the scores moved towards the favourable opinion. Thus the information booklet provided to caregivers was effective. Hence it was concluded that caregivers gained a substantial amount of favourable opinion in all four dimensions.

This study finding was similar to that of the study conducted by Probst P (2003) in which the post-test satisfaction score had shown a high degree of satisfaction and the positive effects towards the child care were identified due to the manual based educational programmes conducted for the parents of children with autism.¹¹

The current study highlights that after the post-test, the majority of caregivers had a favourable attitude towards the children with autism. This indicates that the information booklet was successful in enhancing the caregivers' attitudes about the treatment of children with autism. Due to inadequate awareness of autism among family members and caregivers, they may develop an unfavourable attitude towards their children. If parents and caregivers have sufficient awareness, they will be able to better understand their children's challenges and cultivate a favourable attitude about the treatment and care of their children with autism. Children with autism and their families face a great deal of stigma and prejudice. Specialist resources are scarce, concentrated in urban areas, and out of reach for majority of the population. Building a sense of community should be one of the intervention strategies.

Conclusion

The mean total of the opinion of the caregivers increased from 115.68 to 128.92 with a mean gain of 13.24 which indicates an increase in the opinion scores in the post-test. Thus the information booklet was effective. Thus the information booklet will improve caregivers' opinion towards the treatment of children with autism, according to this report. As a result, it can be inferred that the information booklet was successful in enhancing caregivers' opinion of how to care for children with autism and in strengthening supportive relationships. It also aided in the development of a positive opinion towards the treatment of children with autism among caregivers. Caregivers who read the information booklet to their children will help them make long-term behavioural changes, enhancing their quality of life. Family caregivers are responsible for assisting children with autism's core deficits, and nurses who work with both children and caregivers may be able to help via education. It was also expected that the number of information booklets and guides for caregivers of children with autism would increase and that they

would be made available to all vulnerable caregivers. There is also a need to broaden goals and priorities to accommodate various socio-cultural languages.

Conflict of Interest

None.

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