

A Profile of Aetiological & Therapeutic Searches by Netizen Parents/ Caregivers of Children on the Autism Spectrum

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Abstract

Autism is a growing tragedy of contemporary information age. A sizeable population of their parents is computer savvy, knowledgeable and active denizens on the new virtual reality available on world-wide web. They spend several hours on the computer keyboard asking questions, seeking answers, sending messages or exchanging notes between themselves or other professionals in virtual chat rooms, internet groups or through personal emails. The present study seeks to empirically profile the frequency, intensity and extensity of thematic concerns/searches by an organized group of internet netizens dedicated to autism. Content analysis of transcripts derived by data mining 3436 email exchanges of the netizens in the studied sample is classified/presented under three heads: (a) spread of information themes/choices; (b) etiology based issues/transactions; and, (c) themes related to therapy or treatment of individuals with autism. The highest number of discussions center around the theme of therapies/treatments applicable for persons on the autism spectrum (N: 1697; 49.39 %). This is followed by online concerns of the group members on behavior problems or its management (N: 1488; 43.31 %) in their children. Their etiology based explorations cover four categories: (a) Biological; (b) Environmental; (c) Sensory; and, (d) Diet related causes of autism. Content analysis reveals as many as 238 types of treatment related key-words as discussed by members in the internet group. They are classified as nutrition-based, sensory, and education-behavior based therapies, Alternate Medical Systems, bio-medical therapies, and Instrument based therapies respectively. The implications of the study are discussed in the context of parental quest for understanding the continuing challenge and enigma called autism

Key words: Internet groups – Content analysis.

Autism is increasingly becoming the tragedy of contemporary information age. The kids with autism inhabit their inner worlds as their parents/caregivers desperately search for an understanding of its ever elusive causes and therapeutic management in the outside world. Many modern day parents are computer savvy active denizens of the new virtual reality available on the world-wide web. They spend several useful hours dabbling on the computer keyboard asking questions, seeking answers, sending messages or exchanging notes between themselves or other professionals in virtual chat rooms, internet groups, or through personal emails. These voyages are made over and above their regular and routine consultations with friends and well wishers,

doctors, hospitals, rehabilitation professionals, and others in the real world. Their preoccupations and queries relate to the unfortunate predicament of their children. There are major and recurrent themes of information needs and exchanges that are shared by these netizens.

Various e-based diagnostic, counseling and therapeutic services, either professional or otherwise, charged or freebie, are increasingly becoming the order the day. Subscriber based Virtual Expert Clinics close the gap between high demand for special needs services and the limited accessibility and high existing costs of such services. These services provide planning, training and problem solving strategies to assist parents, caregivers, educators and professional service

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providers. Some e-therapy sites offer paid and/or freebie services via synchronized chats, others use emails alone. Online communication is fast, easily accessible from home, cost effective, time efficient, etc. Of course, this form of therapy also carries certain disadvantages. It is not suitable for every one's needs. It cannot be intensive and it cannot respond immediately and effectively in crisis situations. Internet groups related to persons with disabilities, including autism has become a reality in India. Several internet users (called denizens) make use of groups and networks like Autism India Network, Autism India Group on Yahoo, India Developmental Disabilities, Autism India, Help Autism, India_autism_forum, India_autism_forum2, etc. A few examples of such groups based abroad is 'ASD Friendly', 'www.aspergersnw.org', 'AutismSpot', 'The Autism Connection', 'The Autism Depot', 'www.templegrandin.com', 'Auties.org', 'autismkey.net', 'lakeautismgroup@yahoogroups.com', etc. These groups or forums have their own entry/exit services, policies, and philosophies. Several interested or affected individuals, parents, caregivers, professionals and others seek and enter into membership into these groups. They are then regularly posted with information, introductions, discussions, articles, essays, or other details on the subject matter of autism. They are also given an opportunity to post their own questions, experiences, requirements for the peer group to respond through an effective moderator.

Aims & Objectives

It is the objective of this study to

- a. Empirically profile the frequency, intensity and extensity of diagnostic, etiological and therapeutic concerns by a group of internet netizens regarding their children with autism;
- b. Attempt a qualitative and quantitative profile in the patterns or content of their concerns as expressed by the target sample/s on or regarding their children with autism.

Method

The sample for this longitudinal study was derived from an internet group for autism in India. The group is in existence over four years. All online transactions occur in this virtual group only in English. One of the authors is an observing and

passive member of this group. The current membership strength of this internet group is over 1500 denizens. During its first year, the number of registered members and their online transactions was meager. Data collected during that period was not considered for inclusion in this study. An overall of 3793 email transactions between the members was collected and individually recorded in the form of written transcripts from the period between January, 2005 and December, 2007. Within this figure, there were 357 repeat emails that were discarded. The final inclusion comprised 3436 emails as the sample for content analysis in this investigation.

Content analysis (or textual analysis), as defined in this study, involves a set of procedures for collecting and organizing the non-structured email information into a standardized format that allows one to make inferences about the target phenomenon (Krippendorff, 2004; Berelson, 1971; Holsti, 1969). It is aptly recognized as 'study of recorded human communications, such as, books, websites, emails, paintings and laws' (Babbie, 2005). Content analysis of the transcribed emails was carried out in terms of the most typical themes, notes, messages, information, queries, answers, or other forms of information exchange happening between/within members of the internet group. The shared messages between members of the internet group were recorded on daily basis using non-participant objective observation methods. The transcript pro-forma recorded the title of message, thematic concern/content, date/s of their postings and the continued frequency or duration of messages on that given topic of discussion. The names of netizens, notes of self introduction, often congratulatory and/or acknowledgement mails were not recorded for ethical reasons. Content analysis of the netizens' concerns from the transcripts was carried out in three broad domains: (a) spread of information themes/choices; (b) etiology based issues/transactions; and, (c) themes related to therapy or treatment of individuals with autism. All exchanges and discussions between the virtual group members were classified as such.

Results and Discussion

The results of content analysis of transcripts derived by data mining email exchanges of the netizens are classified and presented under the following three heads:

(a) Spread of Information Themes/Choices

Out of the 3436 emails eventually included for content analysis in this study, the highest number (N: 1697; 49.39 %) of discussions centered on the theme of therapies or treatments for persons with autism. This is followed by emails on self introductions (N: 1684; 49.01 %) by the netizens, and exchange of individual/institutional contact addresses (N: 1679; 48.78 %). The information needs of parents/caregivers querying availability of services/professionals is reported in several studies (Peshwaria, Menon, Ganguly, Roy, Pillay and Gupta, 1995; Garshelis and Mc Connell, 1993; Gowen, Christy and Sparling, 1993; Bailey, Blasco and Simeonsson, 1992; Bailey and Simeonsson, 1992).

This is followed by online concerns of the group members about behavior problems (N: 1488; 43.31 %) in their children and its

management, consulting (N: 1464; 42.61 %), or seeking peer approval on the diagnosis/therapeutic practices being followed by them (N: 1224; 35.62 %). The internet group discussions offer a splendid opportunity for the denizens to share experiences, ventilate doubts, or deliberate on ongoing day-to-day problems being faced by them in the rearing and caring of their children with autistic disorders. About a third of the discussions by the members pertain to exploring the possible cause/s of the condition (N: 1089; 31.69 %) in their children. The group is also equally preoccupied in seeking mutual clarifications about the diagnosis in their children (N: 1087; 31.64 %). This is particularly true of new entrants into the group who describe the individual signs and symptoms of their wards/children and posting questions whether they signify anything related to disorders on the autism spectrum.

Sl. No.	Information Themes	N	%	Rank
1	Advocacy	601	17.49	15
2	Behavior Problems	1488	43.31	4
3	Causes	1089	31.69	7
4	Conferences & Seminars	838	24.46	11
5	Consulting	1464	42.61	5
6	Contact Addresses: Institutions or Individuals	1679	48.78	3
7	Courses	272	7.92	18
8	Diagnostic Clarifications	1087	31.64	8
9	Enquiries	984	28.64	10
10	Greetings & Congratulatory Messages	1030	29.98	9
11	Information on Forthcoming Events	623	18.13	14
12	Information on Relevant Websites	581	16.90	16
13	Introductions/Welcome Notes	628	18.28	13
14	Notes, News, Views & Reviews	830	24.16	12
15	Peer Approval	1224	35.62	6
16	Self Introductions	1684	49.01	2
17	Send Articles	328	9.55	17
18	Therapies, Treatments & Techniques	1697	49.39	1
	TOTAL	3436		

Table 1: Spread of Information Themes Discussed by Netizens.

There are a sizeable number of social greeting and congratulatory messages exchanged between the members (N: 1030; 29.98 %). These greetings relate to local festivities, commencement of year/s, seasonal salutations, etc. These exchanges lubricate the social dynamics and lend a tone of informality to the interactions between members of the virtual group. Despite the fact that the internet group

smacks of members who are highly educated and belong to the elitist class of intellectuals, it is seen that their concerns have not yet reached the level of active or belligerent advocacy (N: 601; 17.49 %) for the cause of autism in the country. There are fewer exchanges on information related to websites (N: 581; 16.90 %), books and articles (N: 328; 9.55 %) or

about online/offline curses related to the field of autism disorders.

(b) Etiology Based Issues/Transactions

The etiology based concerns of the internet group members as reflected in their emails pertaining to possible causes of autism was next taken up for analysis. This causal domain

analysis revealed as many as 341 possible causes emerging from the transcripts as being perceived, reported and discussed by the 1089 internet group members (31.69 %). The area wise causal perceptions of the netizens are classified into four categories: (a) Biological; (b) Environmental; (c) Sensory; and, (d) Diet Based respectively (Table 2).

Biological	N	Environmental	N	Sensory	N	Diet Based	N
Allergies	28	Accidents	12	Auditory	30	Alpha Protein Deficit	13
Amygdala Neurons	14	Bad Parenting	6	Gustation	7	Diet disturbances	67
Autoimmune Disease	22	Birth Trauma	7	Hypersensitive	21	Enzyme Dysfunction	23
Brain Abnormalities	18	Emotional Trauma	10	Hyposensitive	9	Food Allergies	32
Chromosomal	16	Excess Hygiene	7	Olfactory	5	GFCF	111
Familial	8	Folic Acid	6	Tactile	7	Leaky Gut Syndrome	42
Food Additives	29	Perinatal Environment	4	Vestibular	4	Nutritional Deficiency	26
Genetic/Heredit	11	Pesticides	14	Visual	3	Poor Nutrition	27
Lead	33	Pollution	12				
Maternal Antibodies	7	Poor Stimulation	19				
Mercury	18	Prenatal Environment	11				
Mercury Toxicity	78	Refrigerator Mother	7				
Metabolic Disturbances	19	Social Factors	9				
Missing Brain Protein-Cdk5	8	Stress	11				
MMR Vaccine	99	Ultrasound	7				
Oxidation Stress	10	Watching TV	27				
Pesticides	16						
Synapse Disconnection	4						
Teratogens	13						
Toxicity	6						
Viral Infection	12						
Vitamin Deficiency	24						
N	22		16		8		8
Sum	493		169		86		341
Mean	22.4		10.6		10.7		42.6
SD	22.9		5.8		9.6		31.9
Sumsq	22139		2281		1570		21701
Variance	528.2		33.1		92.2		485.5

(SS-BG: 6330.8693; df: 3; MS: 2110.29; SS-WG: 19398.6307; df: 50; MS: 387.97; F: 5.44; p: 0.002572)

Table 2: Spread of Etiology Themes Discussed by Netizens.

There is obviously greater preoccupation of the internet group members on perceived/reported biological causes for disorders on the autism spectrum (N: 22), followed by environmental cases (N: 16) and equally on sensory and diet based causes (N: 8) respectively. However, within these causal domains, discussions on GFCF (Gluten Free Casein Free) diet stands out as the most discussed theme among all the supposed

causes of the netizens (N: 111; 10.19 %), followed by chat about MMR vaccines (N: 99; 9.09 %), mercury toxicity (N: 78; 7.16 %), diet disturbances (N: 67; 6.05 %), etc. On the whole, the group is less attentive to remediable environmental and/or sensory issues related to individuals on the autism spectrum. These differences are also found to be statistically significant ($F: 5.44; p: <0.002$).

(c) Treatment/Therapy Based Issues / Transactions

Many members in the studied internet group are apparently more interested on treatment/therapy based issues (N: 1697) than upon etiology based concerns (N: 1089) related to autism. Content analysis of available transcripts revealed as many as 238 types of key therapeutic or treatment related terms being highlighted or discussed by the members in the internet group. They are classified as nutrition based therapies, sensory therapies, education-behavior based therapies, Alternate Medical Systems, bio-medical therapies, and Instrument Based Therapies respectively.

Sl.no	Category	Types	N	Percent
A	Nutrition-Diet Based Therapies	51	459	27.05
B	Bio-medial Therapies	24	337	19.86
C	Education-Behavior Based Therapies	40	287	16.91
D	Sensory Therapies	50	199	11.73
E	Alternative Medical Systems	40	189	11.14
F	Medication/Drug Therapy	24	133	7.84
G	Instrument Based Therapies	9	93	5.48
	Total	238	1697	

Table 3: Spread of Therapeutic Themes and Choices Discussed by Netizens.

There are 51 subtypes of nutrition-diet based therapies mentioned in the transcripts such as, Almond, Aloe Vera Juice, Brown Barley, Brown Rice Therapy, Calcium, Carbohydrate Diet, Cod Liver Oil, EFA (Essential Fatty Acids) Therapy, Feingold's Diet Therapy, Feldenkraiz Therapy, Fish Oil Therapy, Gluten and Casein Free Diets, Multivitamin Therapy, No Phenol Diet, Omega-3 Fatty Acids, Rice Milk, Vitamin Therapy, Zeolite Therapy, etc. About 50 subtypes sensory therapies were discussed including, Animal Assisted Therapies, Aroma Therapy, Arts Based Therapy, Auditory Integration Therapy, Brushing Therapy, Craniosacral Therapy, Dance Therapy, Deep pressure, Deep Sound Therapy, Drum Therapy, Group Touching Therapy, Holding Therapy, Hydrotherapy, Laughter Therapy, Movement Therapy, Music Therapy, Phototherapy, Rolfing, Swimming Therapy, Therapeutic Massage, etc. Several education-behavior based therapies (N: 40) considered in the group discussions included Applied Behavior Analysis (ABA), Assertiveness Training, Biofeedback, Cognitive Behavior

Therapy, Conductive Education, Floor Time Intervention, Discrete Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI), Face Talk, Facilitated Communication, Family Therapy, Family Focused Early Language Approach Program, Home Schooling/Teaching, Hypnotherapy, Portage Program, Prompt Therapy, Relationship Development Intervention (RDI), Social Skills Training, Verbal Behavior Intervention (VBI), etc.

There is copious discussion in the group on the pros and cons as well as possibilities or potentials of about 40 different Alternate Medical Systems in the treatment of autism. A few examples of this category included Acupressure, Acupuncture, Ayurveda, Biosys or Magnet Therapy, Brain Gym, Chinese Medicine or Quigong, Chiropractic Treatments, Dr. Oswal's G Therapy, Faith Healing, Hair Analysis and Treatment Protocol, Homeopathy, Love Therapy, Meditation, Miracle Therapy, Nature Cure, Naturopathy, Neuro-Linguistic Program, Pranic Healing, Reiki, Siddha Medicine, Spiritual Medicine, Tibetan Medicine, Unani, Yoga, etc. Among the bio-medical therapies (N: 24) were included in the discussions protocols or program to treat Candida Albicans, Antibiotic Treatment, Chelation, DAN Doctors, DMG, DMPS Therapy, Detoxification, Fertility Treatment, Live Cell Therapy, Maggot Debridement Therapy/MDT/Larva Therapy, Stem Cell Therapy, etc. Simultaneous discussions were carried out on the experiences of interacting members related to their use of various drugs/medications like Adderal, Benedryl, Botox Injections, Carbamazepine, Cucurmin, Pemoline, Encephobol, Learnol Plus, Olanzapine, Mentat Tonic, Nystatin, Phenol Injections, Piracetam, Prozac, Quetiapine, Resperidol, Ritalin, Secretin, Senetin, Straterra, etc.

There was exchange of information and discussions between the denizens on Instrument Based Therapies (N: 9), such as, Advanced Biomechanical Rehabilitation, Electrical Stimulation, Therapeutic Electrical Stimulation, Foot Nerve Therapy, Light Sound Therapy, Neurofeedback, Neuro-developmental Therapy, Vibroacoustic Therapy, Video Therapy, etc. Nutrition-diet based therapies (N: 459; 27.06 %) was the most talked about theme of members in the internet group followed by discussions on bio-medical therapies (N: 337; 19.86 %), education-behavior based therapies (N: 287; 16.91 %),

sensory therapies (N: 199; 11.73 %), alternate medical systems (N: 189; 11.14 %), medication/drug therapy (N: 133; 7.84 %), and instrument based therapies (N: 93; 5.48 %) respectively.

Conclusions

In sum, the present study opens the internet, web world and virtual reality as an increasingly new or exciting vista/dimension for investigation of social group dynamics in the field of disability rehabilitation. Parents, caregivers and advocates for the cause of children with special needs do not merely exist in the real world alone. There is a growing population of computer savvy service providers as well as receivers with an equally growing redoubtable knowledge base which seeks to answer uncensored anything or everything one wanted to know from the virtual world. However, considering the expanse of themes and discussions on autism by the members in the studied virtual group, it is seen that there is likelihood of one to get lost in the quagmire of information overload unless one is discerning in the quest for understanding the continuing challenge and enigma called autism.

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