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House Tree Person Test: Need for Indian Norms

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The House-Tree-Person (HTP) is a projective technique developed by John Buck, which was originally an outgrowth of the Goodenough (Florence Goodenough) scale utilized to assess intellectual functioning in an individual. The HTP was developed in 1948, and updated in 1969. Buck believed that through drawings, individuals objectified unconscious difficulties by sketching the inner image of primary process. In the HTP, the patient is asked to draw houses, trees, and persons, and these drawings provide a measure of self-perceptions and attitudes. As with other projective tests, it has flexible and subjective administration and interpretation [1].

The primary purpose of the HTP is to measure aspects of a person's personality through interpretation of drawings and responses to questions. It is one of the robust tests to assess psychopathology. It is also sometimes used as part of an assessment of brain damage or overall neurological functioning about the cognitive function of the subject such as agnosia and apraxia because they require skills and visual spatial, spatial orientation, attention, concentration and accurate perception of the visual stimulus lends motor functions [2].

Drawings are a function of culture and thus, are influenced by determinants of socio-cultural background of an individual, language, teaching style as well as socio-political and economic demographic variables. Thus, any projective test, including the HTP, is interpreted in the contextual framework of variables like age, sex, cultural and sub-cultural background of the person. Drawings are also known to vary as a function of geographic shift, especially so, as cultures also present with differing local norms and colloquial practices, from one region to another. Buck [1] assumes that patients objectify the unconscious conflicts by drawing the inner images of primary processes. Buck also explains that when an individual draws a house, tree and a person- it leads to eliciting emotions in an individual which is a determinant for the underlying affectional states.

The HTP test has established standardised interpretive determinants however, it must be noted that the test is culture fair and has considerable influences of the culture. Though the House Tree Person test has been used in the Indian subcontinent for over 50 years, there has been no effort to Indianize the scoring and interpretation. Every projective test outcome is understood to be influenced as a function of various factors such as personality development, intellectual capacity, interpersonal dynamics and largely also, culture which influences the level of exposure and perception of environment. Putting the House Tree Person in the Indian context, it is crucial to consider how the various characteristics of the drawings change from patient to patient. Apart from the Indian context, it is also prudent to consider that there are several elements of the House Tree Person that are also influenced by the new age lifestyle changes that have been a function of time and globalisation.

The qualitative scoring of Indian HTP protocols have the potential of producing richer and better understanding if the interpretations can be carried out in the light of the cultural significance of the HTP characters. Since psychopathological risks and underpinnings are also a function of the cultural norms, it is thus, necessary to keep in mind and also consider for crucial cultural factors that may enhance the understanding of projective techniques, inclusion the HTP test. Several underpinnings and interpretive elements are either not applicable to house, tree and person drawings made by Indian patients or the

characteristics are missing in the international House Tree Person manual that hold value of significance in the Indian context.

On the basis of clinical practice, it is a common finding to observe the following in Indian HTP protocols:

House Elements

- Houses, as opposed to interpretation protocols, may also be drawn as huts, with thatched roof or with traditional markers of *Rangoli* and *toran* as decors- and would not hold for any pathological underpinnings given that they are a norm in the traditional framework of India. Houses may also be drawn as flat (without roof), as skyscrapers or buildings as they are the normative in the present twenty first century.
- Sometimes farmlands and cattle may be also be drawn as part of the house, especially so by either those who are folks from the countryside or are immigrants from rural areas. This may be normative in the rural Indian backgrounds.
- Another common characteristic that may be found in the rural households would be patients drawing cow-dung cakes on the courtyard area of the yard of the house. This may not classify as a psychopathological marker as often the yards or front porches are made of cow-dung to keep away infections.
- Drawing of temples and other religious institutes are also a common traditional norm in the Indian society where belief in religious are a common practice.
- Another important consideration would be to note that absence of chimneys, fireplace, attics may be normative and not considered for interpretation among Indian protocols.

Tree Elements

- Drawing a mango, *peepal*, coconut or palm tree is common as these are common references of trees for Indian patients. It is interesting to note how which is 'common' changes from state to state depending upon the topographical regions.
- It is yet common for Indian patients to draw a *tulsi* (basil) plant as it has cultural and religious significance. This plant is frequently found to be made in the courtyards or somewhere on the window sill of flats and is regarded as an auspicious plant that people pray to.
- Patients also make a banyan or a *neem* (Indian lilac) tree with threads around it because these two trees are considered auspicious and prayed to.
- Coconuts are also commonly drawn by Indian patients and the coconut water symbolizes cleansing.

Person Elements

- One of the most common elements found in the person character are related to the dressing of the person. It is common for Indian patients to draw a male dressed in dhoti, kurta-pyjama; or a female dressed in sari, salwar -kameez. It is also a common observation to see Indian patients draw culturally relevant dressing elements such as the *pagdi* (turban), *topi* (cap) on the male or bangles, *bindi* and *mangalsutra* on the female.
- The person, most likely the female, may also be holding kitchen accessories like the spoon or cooking utensil which is a symbol of the gender roles specified by culture.
- The size and shape of the trunk of the body may also vary as drawn by the Indian patients as the physiological make up varies in the Indian subcontinent.
- Traditionally, it is common-practice to see patients from the rural background draw males with a hookah which has been a part of the normative traditional rural life.
- Human figures may also be drawn holding mobile phones which would generally be accepted given the normalcy of smartphones as part of everyone's life (*it would generally be expected in the younger population to draw so*). The same holds true for ipads and laptops.

Based on the clinical experience drawn, we have authored a book discussing these nuances in detail with every characteristic of the house, tree and person in *House Tree Person Test: Drawing Styles and Interpretation: An Indian Perspective*. This book is an additional resource to the HTP manual that can be used to better interpret and understand the underlying psychopathological risks in Indian patients. It is an attempt to bridge the need for Indian norms and interpretive standards that have been amiss in the clinical practice [3].

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Child Development: An Overview for the busy psychiatrist

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ABSTRACT

Child Development and milestones are vital aspects of history taking when it comes to child and adolescent psychiatry. The article here aims to provide the psychiatrist an overview of child development and various milestones and the age at which they are achieved. The article aims to give the clinician details of these milestones as applicable in clinical practice and enables the clinician to use the same in history and assessment of children and adolescents with psychological problems.

Keywords: children, development, child development.

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INTRODUCTION

Development involves a persistent change and acquisition of different skills for optimal functionality in a social environment. It is a continuous process from birth to maturity. Growth indicates overall well-being and status of chronic diseases. The knowledge of normal growth, development and behaviour is significant to effectively monitor child's progress. It helps to identify delays or abnormalities in development and counsel parents and caretakers, thereby optimize the growth and development of each child. It helps to understand how mutual forces interact within the parent-child relationship, within the family and between the family and society at large. A thorough knowledge and understanding of the normal development is very much crucial to anyone concerned with the care of children. Growth and development have been a traditional "concern" of primary health care providers. Family physicians, Paediatricians and Psychiatrists must know the normal and its variations before one can identify the abnormalities.

Developmental delay is when a child exhibits significant delay in the acquisition of milestones in one or more domains of development- gross and fine motor; speech and language; cognition; personal and social development or in activities of daily living. Global developmental delay can be defined as significant delay in two or more developmental domains. Delay is said to be significant with discrepancy of 25 % or more from the expected rate or a discrepancy of 1.5 to 2 standard deviations from the norm. The extent of delay can be classified as mild if functional age is 33% below chronological age, moderate if functional age is 34–66% of chronological age, and severe if functional age is 66% below chronological age.

A child with the clinical picture of global developmental delay is not necessarily destined to have intellectual disability. Deviance occurs when a child acquires milestones outside of the typical sequence as in cerebral palsy in which the infant rolls over early secondary to increased extensor tone.

When a child displays widely differing rates of development in different developmental domains, it is termed as 'Dissociation'. For example, children with Autism Spectrum Disorder have typical gross motor

development but significantly delayed language development. 'Developmental Regression' occurs when a child loses already acquired skills or milestones. It is often associated with inherited metabolic disorders and serious neurological problems.

Developmental disorders include a wide range of conditions that result from physical and / or cognitive impairments. They are mostly reported by parents and school teachers in the developmental period of the child. These problems are related to delayed milestones, inappropriate feelings, unsatisfactory interpersonal relationships, school learning problems, physical symptoms or fears related to problems at school. The focus on developmental-behavioural issues reflect changing priorities in traditional health care for children and helps consolidate a distinct fund of medical knowledge.

NORMAL DEVELOPMENT

Development as a phenomenon represents the progression towards maturity- physical and mental. Often the terms 'Growth and Development' are used together. Growth is increase in size and is measured using physical parameters. Development is a continuous and multi-faceted process by which child achieves competency to perform complex activities and tasks. It can be sub-divided into:

1. **Physical Development:** acquisition of gross and fine motor skills
2. **Language Development:** transition from vocalization to understanding and use of language for communication.
3. **Cognitive Development:** acquisition of mental abilities such as learning, memory, concrete thinking and abstract reasoning.
4. **Social and Emotional Development:** establishing the pattern of behaviour and way of dealing with others.

A thorough knowledge of the normal development forms an underlying base of the study of abnormality. At the same time, one should also be conversant with the normal variations, not amounting to disease.

THE PRINCIPLES OF NORMAL DEVELOPMENT

The principles of normal development can be summarized as follows:

1. Development is a continuous process starting from stage of conception until maturity. The process of development starts in- utero and continues after birth.
2. The sequence of development is the same in all children. It is the rate of development that varies from child to child. For example, a child has to learn to sit before he can learn to walk. However, the age at which children learn to sit and to walk differs widely.
3. Development is closely related to the maturation of the nervous system. For instance, a child can learn to walk only when his nervous system is ready for it.
4. Specific individual behavioural responses come in place of generalized activity. For instance, a young infant excitedly moves his trunk, arms and legs when he sees something interesting whereas the older infant merely smiles and reaches out for the same.
5. Development progresses in the cephalocaudal direction. The development of head control is a preliminary step before learning to walk without support. The infant can manipulate his hands before he can walk.
6. The primitive reflexes, such as walking reflex, have to be lost before the corresponding voluntary movement is picked up.

FACTORS INFLUENCING CHILD DEVELOPMENT

Adaptation to one's surrounding environment and prevalent culture is essential for normal development of the child. Environment at home, neighbourhood and school has a profound influence on a child's potentials. Both child's biological endowment and learning experiences are important in the complex

processes of child development and behaviour. Nature and nurture are intimately and intricately intermingled, and are inseparable. The age of the mother & father are amongst the pre-natal factors that affect child development. Cerebellum begins to grow later than the rest of the brain but completes its growth sooner and poverty along with poor maternal nutrition during pregnancy negatively impacts inter-neuronal connections inside the cerebellum. Late preterm infants have poorer neurodevelopmental outcomes compared to term infants.

THE PARAMETERS OF DEVELOPMENT

Parameters of development include the below-mentioned:

1. Physical growth
2. Motor development- gross and fine motor, balance and movement
3. Language and communication development
4. Adaptive (Non-verbal) development
5. Personal – social development
6. Hearing and vision

MILESTONES

They are a set of functional skills or age specific tasks that most children can do in a certain age range. Taking into account individual variability in child's development, a normal age range is given on milestone checklists. They help to check how a child is developing. Using milestones as the sole method for assessing development is not recommended because of its potential inaccuracy. Thus, parental recall of milestones is demonstrated to be less accurate. However, knowing the appropriate milestones is a key to good history taking. Reliability of the measure increases when milestones are significantly delayed. Written questionnaires are preferable to asking questions during a consultation.

PHYSICAL GROWTH

Physical growth is the most apparent change during infancy. Apart from growth, many organs acquire maturity and functionality in terms of multiplication of cells and pattern formation. The important parameters of physical growth include weight, height and head circumference. At birth, mid-brain is the most developed part of the brain. Cortex acquires dominance by 6 months of age resulting in disappearance of some primitive reflexes. Areas of brain responsible for hearing and vision are well developed at birth. Gross motor development follows thereafter while higher cognitive functions come later, after birth.

GROSS MOTOR DEVELOPMENT

Gross motor development implies various milestones related to sitting, standing, crawling and walking. These developments are closely related with maturation of the brain. Hence, the ability to move erect and letting the limbs move across the body's midline is the result of a balance between flexor and extensor tone, diminution of obligatory primary reflexes and evolution of protective and equilibrium responses. When the newborn baby is pulled to the sitting position, there is complete head lag. When half pulled up, he or she will raise the head. The back is uniformly rounded, when in sitting position. The head lag decreases with maturation, so that by 12 weeks it is only slight and an infant gains head control by 28 weeks, raising it spontaneously off the couch and repeatedly. Also, by 24 weeks, when made to sit, he / she can sit propped up with straight back. After a month or so, the infant sits on the floor with arms forward for support. By 40–44 weeks he / she can sit steady and can manipulate objects at hand. The infant can sit by the self in a chair by 15 months.

He / she can bear all his weight by 24 weeks. At 36 weeks, they stand holding on to furniture and can pull themselves up to the standing position, but cannot let them-self down. At 44 weeks the infant can lift one foot off the ground and can walk holding on to the table at 48 weeks. At 13 months, he / she can walk without any support. At 15 months, the infant starts to creep upstairs. Also, the infant can get into the standing position independently. At 18 months, he / she can walk up and down stairs without help. At 2

years they can pick up an object on the floor, without falling, can run and walk backward. They go up and down stairs with two feet per step. At three the infant can balance self on one leg for a few seconds. He / she can go upstairs one foot per step, and downstairs two feet per step and can ride a tricycle. At four, he / she can go downstairs one foot per step and also learns to skip on one foot. At six, the infant can skip on both feet.

FINE MOTOR DEVELOPMENT

The disappearance of the certain primitive reflexes and acquisition of accommodative abilities between 2 and 3 months of age allow infants to look at their hands and touch one hand with the other furnishing simultaneous information to the senses of vision and touch, and thereby, provides a foundation for later visual motor skills.

Between 2 and 3 months of age, infants look at their hands and join them together. As visual acuity improves, infants begin swiping at objects in front of respective shoulder. By 6 months of age, they reach persistently toward objects in the midline, at first with both hands and then with one. By 40 weeks, they can pick up a small object using finger and thumb together. By 13 months, they can build a tower of two 1-inch cubes and by 15 months, they can pick up a cup and drink from it without spilling much. At 18 months, the infants can turn two or three pages of a book at a time; they learn to turn them singly by the time they reach the age of 2 years. By 2½ years, they can thread beads, and by 3 years, the infants can build a tower of 10 cubes, draw and paint. They learn to fasten buttons, dress and undress themselves.

LANGUAGE AND COMMUNICATION DEVELOPMENT

Infants communicate with their mother by smiling, laughing, screaming, throwing temper tantrums, vocalizing and by watching her as she speaks. They vocalize one word with meaning by 10 months of age. The infant responds to 'No' and obeys orders, waves bye-bye and plays pat-a-cake. The child grasps jargons by 15 to 18 months. In most cases, they intend to ask 'wh' questions. They also achieve grammatical correctness gradually as they talk. At 2 years, they understand two-step commands while at 3-5 years, they tend to answer "wh" questions.

SOCIAL /ADAPTIVE DEVELOPMENT

Most of the children express their readiness for toileting between the ages of 18 and 24 months which is evident by interest in sitting at the toilet seat, ability to get to the toilet and pull down pants, and having a word for urination and stooling, dislike of being soiled or wet. Voluntary control of micturition begins after 15-18 months of age. Most children are reasonably dry by day at 18 months. Toilet training is generally accomplished by 3 years. The day time bladder control is achieved earlier as compared to night time control. In general, pre-schoolers display behavioural problems like nightmares, night terrors, sleepwalking, or sleep talking. There occurs dramatic slowing of rate of growth amongst pre-schoolers making them selective with their dietary choices. It signifies their emerging sense of self.

SENSORY AND MOTOR MATURATION

Infants need to actively coordinate- (1) Level of arousal, (2) Sensory stimuli and (3) Voluntary control of fine and gross motor movements to learn about social and inanimate world. During early infancy, certain neurophysiologic and neuroanatomic changes allow to regulate the state of arousal and along with mutual regulation with the caregiver, it forms the basis of social and emotional development.

SOCIAL-EMOTIONAL DEVELOPMENT

Psychosocial and Emotional development is characterized by a distinct blend of increased self-respect and freedom with increased social emotional reciprocity and self-awareness. Young pre-schoolers display multitude of emotions without an ability to regulate them resulting in impulsive reactions. This manifests as behavioural acting out (e.g. temper tantrums) or emotional sensitivity. A sense of pride is reflected in every new tasks and celebration in even little achievements. Late pre-schoolers are able to execute basic but effective coping strategies successfully.

COGNITIVE DEVELOPMENT

Jean Piaget's Theory of Cognitive Development

This theory provides a valuable guidance about cognitive development in an infant. A central ideology of Piaget's work is that cognition changes in quality as well as quantity.

According to this theory, infants are active learners as they modify their behaviour in response to environmental needs. They integrate information and also accommodate themselves to environmental responses called as 'schemas'.

When faced with a novel situation, the infant can create a new or change an existing schema to "accommodate" or "assimilate" the new information. These adaptations, across different stages lead eventually to maturity.

Cognitive development during the sensorimotor period (birth to 2 years of age) can be organized into six stages. Each stage represents a temporary equilibrium between the infant's skills and the environment's challenges.

1. Birth to one month: reflex actions which may be modified by experience
2. One to four months: active movements of body to produce new situations
3. Four to ten months: concept of environment and self as exclusive and relation of body actions with objects.
4. Ten to twelve months: uses discovered strategies of the body to create known and new situations.
5. Twelve to eighteen months: formulates new strategies and manipulates objects
6. Eighteen to twenty four months: uses concepts to achieve desired results.

Pre operational thought stage from two to six years: Seeing things from someone else's viewpoint is difficult. Child cannot understand constancy and permanency of objects.

Concrete operational stage from six to twelve years: Memory and logical thinking is helped by the child's ability to add learnt concepts to his thinking process like mathematics, reading.

Formal operational stage, above twelve years: Abstract thought develops. Power of deduction emerges.

Erikson's Psychoanalytical Theory

According to this theory, the child's sense of basic trust develops through the successful negotiation of infantile needs. A toddler will be engaged with thoughts of acquiring autonomy while a late-adolescent on establishing meaningful relationships.

TABLE 1 – DEVELOPMENTAL MILESTONES IN FIRST 5 YEARS OF LIFE AS PER DEVELOPMENTAL DOMAINS

| Age | Gross Motor | Fine Motor | Language | Social/Adaptive |
|-----------------|---|--|---|---|
| 1 month | Lifts head when prone | Visually fixes to midline | Vocalizes | Regards faces, social smile at 6 wks |
| 2 months | Holds head steady while sitting, Can lift head 45° and extend arms forward when prone | Can follow across midline, grabs clothes | Coos, Smiles in response to face, voice | Social smile, Stares momentarily at spot where object disappeared |
| 3 months | Pulls to sit, with no head lag, Brings hands together in midline | Grasps rattle | | |

| | | | | |
|------------------|---|--|---|--|
| 4 months | Can raise head and chest when prone, no head lag, rolls front to back | Hands together, objects to mouth, Reaches for objects, Palmar grasp gone | Responds to voice, squeals | Stares at own hand |
| 6 months | Sits without support | Reaches for toys, ulnar grasp , Transfers across midline | responds to name, imitates sounds, Monosyllabic babble | Stranger anxiety |
| 8 months | Can stand if held , Crawls, pulls to a stand | Thumb-finger grasp | Mama/dada (nonspecific), Inhibits to “no ” Follows one-step command with gesture | Waves bye-bye at 8.5 months , Bangs 2 cubes, Uncovers toy (after seeing it hidden) |
| 9 months | Cruises | | Jabbers | Plays patty-cake |
| 10 months | Cruises at 11 months | Pincer grasp | Mama/dada (specific) , Points to objects , Follows one-step command without gesture | Plays peek-a-boo |
| 12 months | Walks alone or with support | Throws, Turns pages of book | Few words plus mama/dada Speaks first real word | Drinks from a cup, Egocentric symbolic play (e.g., pretends to drink from cup) |
| 15 months | Walks well, walks backwards | Scribbles, can make tower of 2-3 cubes | Points, follows simple commands | Hugs parents, uses spoon/fork, removes clothes |
| 18 months | Runs, walks upstairs, kicks ball | Tower of 3-4 cubes | Knows 10 words | Feeds self, helps brush teeth, pts to body parts , Uses stick to reach toy |
| 2 years | Runs well, Walks up and down Stairs 1 step at a time, opens doors, climbs on furniture, throws a ball overhead, jumps | Initiates pencil stroke, tower of 6 cubes | 2-3 word phrases, 25% of speech understandable | Listens to stories, parallel play |
| 2.5 years | Walks on toes | Tower of 8 cubes | Knows name, 50% of speech understandable | Dry at night, toilet trained between 2-3 yrs |
| 3 years | Rides tricycle, Goes up stairs with alternating feet, stands on one foot momentarily | Imitates construction of bridge of 3 cubes, Copies a circle and imitates a cross | 3 word phrases, knows age and gender, 75% of speech understandable | Plays with others, shares toys, partially dresses self |

| | | | | |
|----------------|---|---|--|---|
| 4 years | Hops on one foot, throws ball overhand, cuts out pictures with the help of scissors | Copies a square and a cross, uses scissors, draws a man with 2-4 parts besides head, can identify longer of the two lines | Tells a story, asks questions, knows full name, 90% of speech understandable | Interactive play, role play, dresses self completely, brushes teeth on own |
| 5 years | Rides a bike with training wheels, Skips. | Copies a triangle, ties shoes, names heavier of the two weights, prints name, draws a person (6 parts) | Names 4 colors | Fluent speech, goes to toilet alone, can say alphabet Plays competitive games with rules |

THE DEVELOPMENTAL HISTORY

A history of prenatal and perinatal factors is most relevant to the understanding of the child's development. A detailed history from conception to the present must be sought. It must include the 'risk factors' for cognitive and physical development, for disabilities like—blindness, deafness, subluxation of the hip, cerebral palsy, intellectual disability and genetic conditions, such as degenerative disease of the nervous system, schizophrenia and manic-depressive psychoses.

While calculating test performance appropriate to a child's age, a baby born low birth weight appropriate for gestation must be distinguished from the baby who was small-for-date so as to decide whether or not to account for the prematurity. The history must include environmental factors which affect development like the rate of development, the familial pattern of development, the amount of exposure, emotional deprivation, parent-child interaction, child abuse, and malnutrition. The mother's observations must be taken into consideration to supplement history of achievements. It is useful to determine whether one's own assessment tallies with the mother's inputs of the child's development.

DEVELOPMENTAL AND BEHAVIOURAL SURVEILLANCE AND SCREENING

Developmental screening is the administration of brief, standardized, formal tool for identification of children at a risk for developmental disorders. In contrast, developmental surveillance is defined as a flexible, longitudinal, continuous, and cumulative process for identifying children who may have developmental problems and is performed at every well-child visit. Surveillance through proper history and physical examination should occur at every well-child visit. Primary care clinicians often use informal techniques that are usually weak in reliability and validity, to identify developmental delays or behavioural problems resulting in under-referral of children. Clinicians must know the standardized assessment measures with appropriate levels of specificity and sensitivity that can either be self-administered in waiting or examination rooms or administered online before an appointment.

As per American Academy of Paediatrics (AAP), a good screening tool is the one with sensitivity and specificity in the 70-80% range. It is meant to suggest 'at risk' children and not for making diagnoses. It should be done by a centre that provides medical services to the family. Evidence-based care has shown significant improvements in a child with special health care needs. The principle followed is the same as used in other health conditions. The use of standardized tools over an informal judgement is highly recommended for detection of the degree of abnormality of a child's behaviour and development. It helps the caregiver to discuss age matched activities and provide developmentally appropriate opportunities. Those children who could not pass the screening test should be followed up closely and subjected to additional assessment by means of early intervention referral. "wait and see" approach is strongly

condemned. Considering the fact that isolated developmental delay is seen in less than 1%, only those children with relevant history or physical examination should be subjected to metabolic screening.

Assessing milestones is a challenge in pre-schoolers complicating the task of screening them for developmental delay. The most likely areas of developmental concern to be identified in pre-schoolers are delays in expressive or receptive language skills, fine motor or gross motor coordination skills and rate of acquisition of early learning concepts. The American Academy of Paediatrics recommends that screening for developmental delay should occur at least three times at well-care visits for children between infancy and age 3 years. Obstacles for successful and wide spread implementation of screening tools include time, expertise and awareness of significance of early identification and intervention. Referral is indicated for any child about whom the parents have voiced a concern. An expert is likely to assess development of only referred children. Hence a rough developmental screening should be scheduled in each infant and young child visit.

DEVELOPMENTAL PREDICTION

One should be familiar with the limits of developmental assessment before commencing to assess development. It is only with great difficulty that one can differentiate between normal and abnormal in the early infancy. The profound effect of environmental and other factors in future makes it difficult to predict intelligence of the child accurately only on the basis of developmental assessment in infancy

EARLY INTERVENTION

Early intervention is targeted at providing well defined opportunities to develop, providing special services to children and their families and to practice skills appropriate to child's developmental level. It should aim for an all-round development. An active coordination between the health care professionals and local early intervention programs is essential to encourage and facilitate the optimal development of children. Early intervention results in improved outcomes in most of the children. Different health care professionals can train parents about how to provide early intervention.

REGULATORY ISSUES

Toilet training, eating and sleeping are the most commonly sought regulatory issues by parents. High level of understanding and patience is required on behalf of parents. It is always advisable to issue written advice for parents and clinicians are expected to remain up to date regarding what parents are reading.

ADVISING ON KINDERGARTEN READINESS

Motor abilities, language development and pre-academic or academic skills constitute assessments for kindergarten readiness. Also, the domains like child's attention, social abilities, self-regulation predicts success in school. These are more difficult to assess than pre-academic and motor abilities. Child should be encouraged to know his or her telephone number and address for his safety.

CONCLUSION

The current challenge faced by the primary health care professionals is to identify developmental and behavioural disorders in children in the course of providing health care to them. This can be made possible by means of universal health care concepts of surveillance, screening and evaluation. A strict vigilance on behalf of primary health care provider is expected for identifying those children who require further evaluation and referral. A systematic and algorithmic approach can help in early identification and ongoing monitoring of a child's development. A standardized objective screening tests with acceptable levels of sensitivity and specificity should be used in this regard. A clinician-guided, systematic approach

can help in its successful implementation. The child identified with developmental or behavioural concerns can begin the process of diagnostic evaluation and subsequently, begin treatment for the identified conditions. A change in the approach of primary care clinicians towards families is essential to make early intervention a reality.

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The Effect of Resilience on the Psychological Well Being of Orphan and Non-Orphan Adolescents

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ABSTRACT

Background: Resilient individuals are usually able to maintain their physical and psychological health and have the competence to recover quickly from stressful events. The present study provides insight into vulnerable segment of the population and helps to identify the factors contributing to their wellbeing & modifying them. Thus following this view, the objectives of the study was to examine the level of Resilience and psychological wellbeing among orphan and non-orphan adolescents; and to examine the influence of resilience on psychological wellbeing of orphan and non-orphan adolescents

Methodology: The participants were 30 orphan and 30 non-orphan adolescents (15 males & 15 females in both group), aged 13-18 years and were administered Child and Youth Resilience Measure and Ryff's multi-dimensional Psychological wellbeing scale.

Results: The findings revealed that there is no significant difference in the level of Resilience among orphan and non-orphan adolescents where as there is significant difference in the Positive Relations with others among Orphan and Non orphan adolescents in the level of Psychological wellbeing. In relation to orphan adolescents, there is no significant influence of Resilience on psychological wellbeing of orphan adolescents whereas among non-orphan adolescents there was significant influence of Resilience on psychological wellbeing.

Conclusions: Further studies in diverse populations are warranted to ascertain the effects of Resilience on Psychological well being in adolescents.

Keywords: Resilience, Psychological wellbeing, Orphan, Non- Orphan adolescents.

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INTRODUCTION

Richardson and his colleagues [1] stated resiliency to be the process of coping with disruptive, stressful, or challenging life events in a way that provides the individual with additional protective and coping skills than prior to the disruption that results from the event. Resiliency has been linked with positive mood, positive self-esteem, feeling of self-efficacy, secure relationships [2-4]. According to researchers [5], psychological well-being is being able to feel good about one self and to be able to function effectively which involves having a sense of control over one's life, to be able to exploit one's potential, having a sense of purpose in life and experiencing positive relations with others. It has been found that secure attachment with parents, healthy peer relationships and a protective social environment help the person to resolve the problems with confidence; also develops various self-competencies as social-emotional skills, cognitive and occupational abilities and others [6-7]. Thus, resilient behaviour significantly contribute in psychological well-being of individuals that lead them to cope effectively with various situational contexts of life [8].

Resilience theory is a process of balancing the protective factors against risk factors [9-10], and the gradual accumulation of emotional strength as children respond successfully to challenges in their families, schools and communities [11].

Well-being is dynamic concept that includes subjective, social, and psychological dimensions as well as health related behaviours [12]. Ryff's model Psychological well-being theory states that the goal of life is about living virtuously instead of just feeling good.

Katyal [13] investigated- the resilience among orphan and non-orphan children. The study was carried out in orphanages and schools in Chandigarh, Panchkula and Ajitgarh (Mohali) in India. The sample consisted of 50 orphan children (25 from each orphanage) and 50 non-orphan children (25 from each school) aged 12-18 years. Standardized tools were used. Results indicated that there was significant difference in resilience of orphan and non-orphan children, with orphan children having higher resilience than that of non-orphan children mainly develops due to development of close and warm social bonds and friendships with peers in orphanages. Sreekanth and Verma [14] conducted a study comparing stress and psychological well-being among orphan and normal adolescence (40 orphans and 40 non orphans) in Adilabadh district, Telangana state, through accidental sampling. Stress scale by Sinha and PGI General Well-Being scale by Verma and Verma were used for measuring the level of stress and psychological well-being of orphan and normal adolescence. The study revealed that compared to normal adolescents, orphans are significantly more stressed and performed weakly in the areas of psychological wellbeing probably due to lack of parental care or lack of guidance, facilities, and negligence in orphanages. Also, orphans are neglected from fields of education, daily needs of adolescents, sports activities, lack of love and affection, compare to normal adolescents.

The present study will be helpful in understanding and would provide insight into vulnerable segment of the population. This will also help in identifying the factors contributing to their wellbeing & modifying them. The present study would help in identifying the factors affecting their Psychological wellbeing. It will also help to develop effective intervention program to enhance the level of resilience and psychological wellbeing among them, providing psycho-education to parents and care givers. Most of the researches are conducted on western population suggesting a need for the present study from Indian context. The study would also add to the existing review of literature.

The aim of the study was to determine the effect of Resilience on the Psychological wellbeing of orphan and non-orphan adolescents. The objectives were to examine the level of resilience among orphan and non-orphan adolescents, to examine the level of psychological wellbeing among orphan and non-orphan adolescents, to examine the influence of resilience on psychological wellbeing of orphan adolescents and to examine the influence of resilience on psychological wellbeing of non-orphan adolescents

METHODOLOGY

The present study is based on survey method and is empirical in nature. The primary data was collected from orphan and non-orphan adolescents from Bangalore.

Hypotheses

- There is no significant difference in the level of resilience among orphan and non orphan adolescents
- There is no significant difference in the level of psychological wellbeing among orphan and non orphan adolescents
- There is no significant influence of resilience on psychological wellbeing of orphan adolescents
- There is no significant influence of resilience on psychological wellbeing of non - orphan adolescents

Variables

Independent Variables: Adolescence (orphan and non-orphan)

Dependent Variables: Resilience, Psychological wellbeing.

Research Design: The research design employed for this study was non-experimental co-relational research design. Parametric statistics - Pearson's product moment correlation and Multiple Regression, Independent sample t-test and one-way multivariate analysis of variance (MANOVA) were used for analysing.

Sample: Following purposive sampling technique, a total sample of 30 orphan adolescents (15 males and 15 females) and 30 non orphan adolescents (15 males and 15 females), living in Bangalore between the age group of 13–18 years were selected,

Inclusion Criteria:

- Male and female adolescents in the age range of 13-18 years
- Urban / sub-urban
- Delinquent/ under trial orphan adolescent

Exclusion Criteria:

- Single parent child.
- Adolescents with mental and chronic physical illness
- Residing in hostel or with any guardian

Tools for Data Collection:

- The 54 item scale Ryff's multi-dimensional Psychological wellbeing scale (1989) developed by Carol Ryff, measures the 6 dimensions of psychological well-being [15].
- The Child and Youth Resilience Measure (CYRM)-28 is a measure of youth resilience for the youth populations (aged 10-23) which has three sub-scales of individual capacities/ resources, relationships with primary caregivers and contextual factors that facilitate a sense of belonging [16].

Ethical Considerations: Informed consent was taken from the parent/guardian and the sample and confidentiality was ensured. It was ensured that no physical or emotional harm was caused to the participants during and after the research. None of the samples were forced to be a part of the research. The data obtained shall be used only for academic purpose. The participants were allowed to leave the research work if he /she wished to.

RESULTS

The table below shows a comprehensive overview of the descriptive statistics.

Table 1: Descriptive Statistics of Resilience and Psychological wellbeing in Orphan and Non orphan Adolescents.

| Orphan & non-orphan adolescents | N | Mean | Std. Deviation | Kurtosis | Skewness |
|---------------------------------|----|--------|----------------|----------|----------|
| Resilience | 30 | 115.55 | 13.472 | 0.208 | -0.903 |
| Autonomy | 30 | 34.83 | 5.927 | 1.377 | 0.717 |
| Environmental Mastery | 30 | 36.20 | 5.461 | -0.425 | -0.017 |
| Personal Growth | 30 | 34.43 | 6.958 | -0.516 | 0.612 |
| Positive relations with Others | 30 | 35.38 | 6.722 | -0.737 | 0.276 |
| Purpose of Life | 30 | 36.22 | 7.820 | -0.697 | 0.051 |
| Self Acceptance | 30 | 39.25 | 7.410 | -0.515 | -0.092 |

In the table 1, descriptive statistics of Resilience and Psychological wellbeing in Orphan and Non orphan Adolescents are shown. For the total number of respondents, (N= 60), a group of samples of 30 orphan adolescents and 30 non orphan adolescents were selected. The table shows the mean score, skewness and kurtosis value of Resilience and the variables of psychological wellbeing which are identified to be between the range of -1.96 to +1.96, hence the distribution is normal.

Table 2: Independent Sample t-Test – Level of Resilience among Orphan and Non-Orphan adolescents

In the table 2, Independent sample t test scores for the level of Resilience among Orphan and Non orphan adolescents are shown. For this research sample ($n=60$), the group of Orphan adolescents ($M = 116.27$, $SD = 13.913$, $n = 30$) has higher Resilience than the group of Non orphan adolescents sample ($M = 114.83$, $SD = 13.215$, $n = 30$), $df= 58$, $t = -0.409$, $p = 0.988$ and is not significant at 0.05 level. Therefore $p > 0.01$, hence the null hypothesis is accepted and alternate hypothesis is rejected. Hence there is no significant difference in the level of Resilience among orphan and non-orphan adolescents. This can be due to the reason that the sample was from urban population and both orphan and non-orphan adolescents had proper education and their skills in communication, problem solving skills, and their confidence level was nurtured with immense care. It was also noted that both the groups of orphan and non-orphan had close and warm social bonds and friendships with peers in orphanages and back at their house. Generally, in urban setting, parents take care of their children a lot and also make them involve in many extra curriculum activities which makes them more trained to face challenges. Not only non orphan adolescents, but even in orphanages, various workshops, activities, visiting's, are conducted and children are exposed to challenges and guidance is given in every step which makes the orphan adolescents being equally resilient to non orphan adolescents.

| Dependent Variable | Independent Variable | N | Mean | Std. Deviation | t | df | Significance |
|--------------------|----------------------|----|--------|----------------|--------|----|--------------|
| Resilience | Orphan | 30 | 116.27 | 13.913 | -0.409 | 58 | 0.988 |
| | Non orphan | 30 | 114.83 | 13.215 | | | |

Table 3: Descriptive Statistics and Levene's Test of Homogeneity level of Psychological wellbeing among Orphan and Non orphan adolescents

| Dependent Variable | Adolescents | Mean | Std. Deviation | N | Levene's Test Of Equality Of Error Variances | | |
|---------------------------------------|-------------|-------|----------------|----|--|----------|--------------|
| | | | | | F | df1, df2 | Significance |
| Autonomy Score | Non Orphan | 35.00 | 6.384 | 30 | 0.530 | 1,58 | 0.470 |
| | Orphan | 34.67 | 5.536 | 30 | | | |
| | Total | 34.83 | 5.927 | 60 | | | |
| Environmental Mastery Score | Non Orphan | 37.20 | 4.475 | 30 | 2.702 | 1,58 | 0.106 |
| | Orphan | 35.20 | 6.211 | 30 | | | |
| | Total | 36.20 | 5.461 | 60 | | | |
| Personal Growth Score | Non Orphan | 34.50 | 5.824 | 30 | 6.042 | 1,58 | 0.017 |
| | Orphan | 34.37 | 8.036 | 30 | | | |
| | Total | 34.43 | 6.958 | 60 | | | |
| Positive Relations with Others Scores | Non Orphan | 37.47 | 6.801 | 30 | 0.348 | 1,58 | 0.557 |
| | Orphan | 33.30 | 6.058 | 30 | | | |
| | Total | 35.38 | 6.722 | 60 | | | |
| Purpose Of Life Scores | Non Orphan | 37.13 | 6.771 | 30 | 2.909 | 1,58 | 0.093 |
| | Orphan | 35.30 | 8.766 | 30 | | | |
| | Total | 36.22 | 7.820 | 60 | | | |
| Self Acceptance Scores | Non Orphan | 39.87 | 7.276 | 30 | 0.028 | 1,58 | 0.869 |
| | Orphan | 38.63 | 7.613 | 30 | | | |
| | Total | 39.25 | 7.410 | 60 | | | |

In the table 3, the results of descriptive statistics and Levene's test of homogeneity for the level of Psychological wellbeing among orphan and non-orphan adolescents are shown.

For the research sample ($n = 60$), the Levene's test of Equality of Error Variance of the dependent variables is homogeneous (Autonomy: $p = 0.470$, Environmental Mastery: $p = 0.106$, Positive Relations with others: $p = 0.557$, purpose of life: $p = 0.093$ & Self acceptance: $p = 0.869$) except the Personal Growth ($p = 0.017$) which indicates that it is not homogenous.

Table 4: Box's Test of Equality of Covariance Matrices, Wilks' Lambda Multivariate Test –level of Psychological wellbeing among orphan and non orphan adolescents

| Independent Variable | Wilk's Lambda Value | F | Hypothesis df | Sig. | Partial Eta Squared (ω^2) | Dependent Variable Box's Test of Equality of Covariance Matrices | | | |
|-----------------------------------|---------------------|--------------------|---------------|-------|------------------------------------|--|-------|--------------|--------------|
| | | | | | | Box's M | F | df1, df2 | Significance |
| Orphan and Non-orphan Adolescents | 0.828 | 1.834 ^b | 6.000 | 0.110 | 0.172 | 42.093 | 1.781 | 21, 12372.78 | 0.015* |

In the table 4, The Box's M Test of equality of co-variance matrices signifies that assumption of equality of co-variance matrices is significant (Box's M = 42.093, F = 1.781, df = 21, 12372.787, $p = 0.015$ which is < 0.05). The Multivariate test results shows that Orphan and non-orphan adolescents (Wilks' Lambda Value = 0.828, F = 1.834, df = 6.000, $p = 0.110$, $\omega^2 = 0.172$) has no significant influence on dependent variable.

Table 5: MANOVA (Tests of Between-Subjects Effects) –level of Psychological wellbeing among Orphan and Non-orphan adolescents

| Source | Dependent Variable | Df | Mean Square | F | Significance | Partial Eta Squared (η_p^2) |
|-----------------------------------|--------------------------------------|----|-------------|-------|--------------|------------------------------------|
| Orphan and Non Orphan Adolescents | Autonomy Score | 1 | 1.667 | 0.047 | 0.830 | 0.001 |
| | Environmental Mastery Score | 1 | 60.000 | 2.048 | 0.158 | 0.034 |
| | Personal Growth Score | 1 | 0.267 | 0.005 | 0.942 | 0.000 |
| | Positive Relations With Others Score | 1 | 260.417 | 6.278 | 0.015 | 0.098 |
| | Purpose Of Life Scores | 1 | 50.417 | 0.822 | 0.368 | 0.014 |
| | Self Acceptance Score | 1 | 22.817 | 0.411 | 0.524 | 0.007 |

In the table 5, The test Between-Subject Effects result describes that there is no significant difference in Autonomy ($p = 0.830$); Environmental mastery ($p = 0.158$); Personal Growth ($p = 0.942$); Positive Relations with Others ($p = 0.015$); Purpose of life ($p = 0.368$); Self acceptance ($p = 0.524$) among Orphan and Non orphan Adolescents as $p > 0.05$. Therefore, the null hypothesis is rejected and alternate hypothesis is accepted. Hence there is significant difference in the level of Psychological wellbeing among Orphan and Non orphan adolescents.

The variable "Positive Relation with others" indicated significant difference which may be due to the fact that non orphan adolescents experience warm, satisfying, and trusting relationships with peers and family members whereas in case of orphan adolescents, they have very few close and trusting relationships with others, they find difficulty to open up and feels isolated in interpersonal relationships. Researchers [17] believed that adolescents living in the intact families with their parents are found to have a better scholastic achievement, conduct, psychological adjustment, self-esteem and social competence which lower their

psychological distress. Whereas adversities such as lack of parental and familial support initiate a major change in the lives of children [18] and can also interrupt their healthy psychological functioning [19].

Table 6: Pearson Product Moment Correlation Test – Resilience on Psychological wellbeing among orphan adolescents

| Resilience Score | Mean | Std. Deviation | N | Pearson Correlation | Sig. (2-tailed) |
|--------------------------------------|--------|----------------|----|---------------------|-----------------|
| Resilience score | 116.27 | 13.913 | | | |
| Autonomy score | 34.67 | 5.536 | 30 | 0.075 | 0.693 |
| Environmental mastery score | 35.20 | 6.211 | 30 | 0.176 | 0.353 |
| Personal growth score | 34.37 | 8.036 | 30 | -0.113 | 0.550 |
| Positive relations with others score | 33.30 | 6.058 | 30 | -0.237 | 0.206 |
| Purpose of life score | 35.30 | 8.766 | 30 | -0.046 | 0.811 |
| Self -Acceptance score | 38.63 | 7.613 | 30 | 0.050 | 0.794 |

In the table 6, For this research sample ($n = 30$), the Resilience and Autonomy($r = 0.075$, $p = 0.693$); Environmental Mastery ($r = 0.176$, $p = 0.353$); Personal growth($r = -0.113$, $p = 0.550$); Positive Relations with others ($r = -0.237$, $p = 0.206$); Purpose of life ($r = -0.046$, $p = 0.811$); Self acceptance ($r = 0.050$, $p = 0.794$) of the sample is not significant at 0.05 level as $p > 0.05$. The results null hypothesis is accepted and hull hypothesis is rejected. Hence it revealed that there is no significant influence of Resilience on the psychological wellbeing of orphan adolescents. It indicates that this may be due to the circumstances prevalent in their orphanages where they develop resiliency in their behavior but they lack guidance and are neglected from the field of education, daily needs of adolescents, sports activities and many others [14]. Research indicates that Orphans have higher internalized problem compared to non-orphan adolescents and thereby influencing the psychological wellbeing. It is also seen from research studies that orphan are higher in resiliency but lower in psychological wellbeing when compared to non-orphan adolescents [13].

Table 7: Pearson Product Moment Correlation Test – Resilience and Psychological wellbeing

| Variables | Mean | Std. Deviation | N | Pearson Correlation | Sig. (2-tailed) |
|--------------------------------------|--------|----------------|----|---------------------|-----------------|
| Resilience score | 114.83 | 13.215 | | | |
| Autonomy score | 35.00 | 6.384 | 30 | 0.300 | 0.108 |
| Environmental mastery score | 37.20 | 4.475 | 30 | 0.579 | 0.001 |
| Personal growth score | 34.50 | 5.824 | 30 | 0.473 | 0.008 |
| Positive relations with others score | 37.47 | 6.801 | 30 | 0.513 | 0.004 |
| Purpose of life score | 37.13 | 6.771 | 30 | 0.467 | 0.009 |
| Self -Acceptance score | 39.87 | 7.276 | 30 | 0.491 | 0.006 |

For this research sample ($n = 30$), the Resilience and Autonomy ($r = 0.300$, $p = 0.108$) is significant at 0.05 level. Therefore $p > 0.05$, there is no significant relationship between Resilience and Autonomy score among the non-orphan adolescents. Whereas, the Resilience and Environmental Mastery ($r = 0.579$, $p = 0.001$); Personal growth ($r = 0.473$, $p = 0.008$); Positive Relations with others ($r = 0.513$, $p = 0.004$); Purpose of life ($r = 0.467$, $p = 0.009$); Self acceptance ($r = 0.491$, $p = 0.006$) of the sample is positively correlated and is significant at 0.05 level. Therefore $p < 0.05$, there is significant relationship between Resilience and Environmental Mastery, Personal Growth, Positive Relations with others, Purpose of life and self-acceptance scores among the non-orphan adolescents whereas there is no significant relationship between resilience and autonomy.

Table 8: Multiple Regressions – Resilience on Psychological wellbeing

| Predictor Variable | Beta Standardized Coefficient | Sig. | R | R Square | Df | F | Sig. |
|--------------------------------|-------------------------------|-------|-------|----------|-------|--------|-------|
| Autonomy | 0.300 | 0.108 | 0.300 | 0.090 | 1, 28 | 2.761 | 0.108 |
| Environmental Mastery | 0.579 | 0.001 | 0.579 | 0.335 | 1,28 | 14.121 | 0.001 |
| Personal Growth | 0.473 | 0.008 | 0.473 | 0.223 | 1,28 | 8.048 | 0.008 |
| Positive Relations with others | 0.513 | 0.004 | 0.513 | 0.263 | 1,28 | 9.985 | 0.004 |
| Purpose of life | 0.467 | 0.009 | 0.467 | 0.218 | 1, 28 | 7.808 | 0.009 |
| Self Acceptance | 0.491 | 0.006 | 0.491 | 0.241 | 1,28 | 8.897 | 0.006 |

For this research sample ($n = 30$), the dimension of psychological well being - Autonomy ($\beta = 0.300$, $p = 0.108$) is not a significant predictor for resilience among non-orphan adolescents. For this research sample ($n = 30$), the dimension of psychological Well Being-Environmental Mastery ($\beta = 0.579$, $p = 0.001$); Personal Growth ($\beta = 0.473$, $p = 0.008$); Positive relations with others ($\beta = 0.513$, $p = 0.004$); purpose of life ($\beta = 0.467$, $p = 0.009$); self acceptance ($\beta = 0.491$, $p = 0.006$) is a significant predictors for resilience among the non-orphan adolescents. Therefore, the null hypothesis is rejected and alternate hypothesis is accepted. There is significant influence of Resilience on Psychological wellbeing of non-orphan adolescents. The results indicate that Environmental Mastery, Positive relations with others, personal growth, purpose of life, self-acceptance will be able to predict relationship with resilience among the non-orphan adolescents.

Resilience is considered as one of the indicators of psychological well-being of the individuals [20]. Ryff and Singer [15] argue that resilient individuals are generally able to maintain their physical and psychological health and have the capacity to recover more quickly from stressful events. Researchers also found that adolescents living in the intact families with their parents have a better scholastic achievement, conduct, psychological adjustment, self-esteem and social competence lowering their psychological distress [17].

CONCLUSION

Implications of the study

The findings of this study would help in throwing light into certain neglected fields like education, daily need of adolescents, physical activities, lack of love and affection. Hence, assisting in enhancing the qualities lacking in the field, can help in effective Resilience and psychological wellbeing of both orphan and non-orphan adolescents. The results have implication for the government and other agencies to develop programs with holistic approach for orphans through various NGO's.

The present study is limited in its scope due to the small sample size of 60 participants. Rural population was not taken into account, was limited to school going adolescents (English medium & Kannada medium) and did not cater to non-educated adolescents for diversity of responses which in turn limits it from generalisation to the population.

Scope for Further Research

The findings of the present research holds that Resilience is not the only factors to measure Psychological wellbeing and factors other than Resilience are required for further research. The present study is based on Bangalore region, thus the study can be widened in terms of the geographical area so that the sample size could be increased and can represent the wider section of the society.

Conclusions

The relevance of the present study in Indian context caters to adolescents, who characterized by immense and drastic changes in physiology, emotional maturity, psychological and social factors as well as the roles and responsibilities of the individuals. The present research indicated that though there was no difference in the level of Resilience among orphan and non-orphan adolescents, there were differences in orphan and

non-orphan adolescents with respect to Positive relations with others in the level of psychological wellbeing. It revealed that Resilience has no influence of on the Psychological wellbeing of orphan adolescents. Whereas, Resilience had significant influence on the psychological wellbeing of non-orphan adolescents (Environmental Mastery, Personal Growth, Positive Relations with others, purpose of life, Self-acceptance). Research evidences suggest that cultural resources like families, schools and societies help the individuals to become more resilient whereas lack of all these supportive and protective factors tend to weaken inherent potential of the individuals to deal with unfavorable circumstances but may increase the level of autonomous dealing with adversities.

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Youth's Presentation of Themselves on Instagram and Facebook with respect to Body image focusing on appearance

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ABSTRACT

This study was done to investigate youth's presentation of themselves on Instagram and Facebook. Participants (N-266) were told to fill an online questionnaire which consisted of 31 multiple choice questions with choice of answers differing from question to question. Youths were studied on frequency of posting pictures, appearance related things done before or while posting pictures, their expectations from others, comparison and engagement on Instagram and Facebook. It was observed that participants use filters to enhance their looks in the pictures. Participants reported that they do not feel pressured to look good in their posts and they don't compare themselves with others. The amount of engagement in these platforms increases after posting pictures of themselves to check all reaction a post gets.

Keywords: Instagram, Facebook, youth, body image, appearance.

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INTRODUCTION

There are lot of social and cultural factors that affects person's body image. Society often constructs our behaviours and beliefs, such as personal developments, physiological and psychological interactions, and the common perception of our bodies as a reflection of self-worth. Body image struggles have been prevalent for many centuries now, with the rapid constant shifts in ideal body types. In the past, norms were typically set by cultural beliefs, genders, or social factors. Despite these being prevalent today, changes in the fashion and media industries are other influences at hand [1]. On account of the evolution of society today, text messaging, emails, social media, and other technological advancements have dominated people's face to face interactions. Although technology provides the convenience of connecting with others easily, its association with the media has resulted in a "platform of delivery in which we intercept and interpret messages about ourselves, our self-worth, and our bodies"[2].

The phrase body image was first coined by the Austrian neurologist and psychoanalyst Paul Schilder (1935) in his book 'The Image and Appearance of the Human Body (1935)' [3].

The Oxford dictionary meaning of body image is "The subjective concept of one's physical appearance based on self-observation and reactions of others". Another definition says, "Body image is how one views themselves in the mirror or in their mind. It incorporates memories, experiences, assumptions, comparison of one's own appearance and overall attitudes towards their height, shape and weight" [4].

An individual's impression of their body and appearance is also assumed to be a product of ideals on social media. Majority of the users choose to create a positively biased self-presentation [5].

Today in the world of internet, social media platforms like Instagram and Facebook are most popular among Indians with 201 million Facebook users and 46 million Instagram users of which 90% of Facebook and 85% of Instagram users are under the age of 45 years [6].

Instagram and Facebook are platforms that allow users to share personal photos, videos and information due its popularity in personal photo sharing among young people. These photos and videos may be used as appearance feedback seeking platforms. In case of photos, this often consists of posting 'idealized' images through the use of camera angle, filters, digital manipulation software like Photoshop; developing a personality identity through self presentation has been cited as an important aspect of social media [7]. Social media lets anyone enter the beauty pageant. Teens can cover up pimples, whiten teeth and even airbrush with the swipe of a finger, curating their own image to become prettier, thinner and hotter.

All this provides an illusion of control: "If I spend more time and really work at it, I can improve at being beautiful". "I don't get to choose how I'm going to leave my apartment today," one young woman told. "If I could, my body would look different. But I can choose which picture makes my arms look thinner" [8]. Several studies have been done in relation with social media and body image. A study found that cultural pressures via media may lead to development of negative body image (body image and eating-disorder). Media images of 'thin' females and 'muscular' males represent idealized version of physical attractiveness [9]. Study on Irish females revealed that women are aware that they are experiencing negative body image self-impression because they try to imitate the models they see in digital media [10]. Similar studies have been done on effects on body image by social media's, T.V.'s effect on eating disorders. However, there are limited studies on how social media affects appearance related comparisons, expectations and assumptions. The data relevant to these studies is even more limited in the Indian context.

METHODOLOGY

This study attempts to investigate youth's frequency of posting pictures, things done before or while posting pictures, expectations, comparison and engagement on Instagram and Facebook. Method

Participants

Participants (N= 266) were from the age group of 15 to 24 years (M=18.82) of which 142 were females (M=18.37) and 124 were males (M=19.25). Participants were from different regions of Mumbai. Participants who said that they never post their own pictures on Facebook and Instagram were excluded (18 participants).

Material

A self prepared questionnaire including 31 questions mainly concentrating on following four aspects:

- i. Frequency of being engaged in photo sharing on Instagram and Facebook.
- ii. Appearance related things done before or while posting pictures on Instagram and Facebook.
- iii. Consequences if any (like comparison, pressure to look good, etc.) while posting picture on Instagram and Facebook.
- iv. Frequency of checking reactions after posting their own pictures on Instagram and Facebook.

The questions were multiple choice questions with choice of answers differing from question to question.

Procedure

The survey was done online using Google Forms; it was based on random participation. The Google form link was sent to various people through WhatsApp and email. Consent of participants was taken at the beginning of the form. Each form of the survey took about 15-20 minutes for the participants to fill. After filling of all the forms by the participants, question-wise analysis was done of the responses recorded.

RESULTS

All the participants (N-266) used Instagram or Facebook, and majority of them used both (72.9%). All the participants were those who posted pictures on these platforms. It was observed that 36.8% of the participants change their profile picture once in three months and 35% of the participants post their pictures monthly. The common reason given for posting pictures was to let others know more about themselves (39.5%). Some other reasons were to feel more acceptable in the virtual world (19.9%), to assure that even

they are updating themselves with the modernizing world (32%), to get more people to like and comment on them through the pictures (8.6%). 75% participants use filters to enhance their looks in the pictures. 53.4% participants said they do not use cosmetic/Grooming products on themselves to look good in pictures. More than half of the participants said they give importance to their looks in the picture more than occasion or people in the pictures (57.2%).

Participants reported that they did not compare themselves with others (74.5%) or feel pressured to look good in the pictures (54%) nor do they plan their looks in advance (50%). They did not spend time thinking about looks while posting pictures. (41.7%). Participants also said that they give same amount of importance to physical appearance even if they are definitely not going to post the picture.

Majority of the participants check their Instagram and Facebook more frequently after posting pictures (66.9%). Participants also expected certain people to like or comment upon their picture (53.4%) and also check who all have liked their post (55.2%). 33.9% boys accepted that they go to gymnasium to do exercise or follow diet to look good in the pictures whereas only 5.0% of the females accepted it.

DISCUSSION

The survey was done concentrating on four major aspects which are:

- i. To find out how often people engage in photo sharing themselves on Instagram and Facebook.
- ii. Appearance related things people do before or while posting the pictures.
- iii. Consequences if any (like comparison, pressure to look good, etc.) while posting picture.
- iv. iv) Frequency of checking reactions after posting their own pictures on Instagram and Facebook.

It was found that posting pictures is common in participants than changing profile picture, major reason for posting was letting others know more about themselves. In doing so, it is seen that participants do not use cosmetic/grooming products on themselves before taking the picture (50.3%) but the need to look good is still there which is satisfied by apps. 75% of the participants accepted using filters to enhance their looks in the picture. In a UK based study on males found 57% boys feel pressured by social media to look good (Ads add to boys' body-image pressure, 2016) and in a survey done by dove, it was found that pressures from social media doubles for adolescent girls between the ages of 13 to 18 years old [11]. Socio-cultural model puts forward that society promotes physical attractiveness and beauty for both males and females through social media. This is in alignment with the results of the study as the need to attain these beauty standards is clearly seen.

These networks are effective medium and more celebrated in 21st century and are believed to manifest episodes of real life. In this manifestation, people use filters to portray oneself in appealing manner. Participants do not use cosmetic/grooming before taking the picture, which reflects that these apps itself are designed in such a way that it replaces and satisfies the need of such products. The enlarged sense of media personalization and tendency to use the Internet for social purposes has led millennials to get increasingly invested in developing an idealized online self that they can present to the world [5-7].

Participants also reported that they give same amount of importance to physical appearance even if they are definitely not going to post the picture. Though participants said that they did not feel pressured to look good or think about looks while posting, 75% of them do use filters to enhance their looks in the pictures. Hence, there is discrepancy in what they say and how they behave. Possibly same is the case of real life and virtual world. Studies have also shown that perhaps comparison does take place on social media through self enhancing posts. People upload self-enhancing post and see such contents from others on their feeds. This could lead to social comparison with oneself and with these images and feel inferior [12].

More than half of the participants (66.6%) agreed that they check who have liked their post. 53.4% participants expect specific people (such as friends, family etc.) to like and comment on their post. 55.3% participants check who all have liked their post. Recent study discovered a strong connection between Facebook and the brain's reward centre, called the nucleus accumbens. This area processes rewarding

feelings about things like food, sex, money and social acceptance. The feeling on receiving positive feedback lights up this accumbens part of the brain. This is likely to get an individual hooked to these platforms [13]. Certain amount of difference was found between boys and girls when asked if they went to a gymnasium or followed diet to look good in the pictures. 33.9% boys accepted that they go to gymnasium or follow diet to look good in the pictures whereas only 5.0% of the females accepted it. The importance men placed on muscle and weight may be traced back to the 'bulked-up action heroes', along with the brawny characters in many video games, present an anatomically impossible ideal for boys, much as Barbie promotes proportions that are physically impossible for girls. The main causes of male body issues include 25% being teased about their weight, while 33% specified social media as the source for self-consciousness [14]. The pursuit of an idealised online self could however provide a dangerous playground for adolescents and young adults who may end up with low self esteem and negative body image. Often people feel isolated and rejected when their expectations are not fulfilled.

CONCLUSION

There were no major discrepancies found in the replies of males and females. So, it can be said that social media affects both the genders in nearly equal manner. However, if we take a positive look, the figures which indicate influence of social media on youth are still average and not on very higher sides. Also, some other figures like 74% participants do not compare themselves with others, 54% participants do not feel pressured to look good in the pictures, etc show that still there is light, social media has not completely overpowered youth. This study acknowledges requirement of further research in this area with regards to differences in response of different age groups, cultures, economic status and also if factors like self-esteem is affected along with any other negative consequences.

Practical implication and suggestions

In today's age of filters, people are bombarded with idealized beauty images and people seeking social approval through social media, there is need to help youth go beyond their appearance and to assess their own strengths. As looks are temporary, virtues are permanent. At larger level, there is a huge need to reach out to children and youths through institutions like schools and colleges; training students, parents and teachers to emphasise on health, hygiene, neatness and skill set rather than merely external looks; and surmise to identify themselves more with their blue ribbons (high qualities) rather than transitory looks.

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Smoking and Peer Preference in College Students: an exploratory study

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ABSTRACT

Background: Smoking in adolescents is related to multiple factors like genetics, family variables and peer preference and influence. The aim of the following study was to study the prevalence of smoking and age of initiation college students while comparing peer preferences in smoker and non-smoker college students.

Methods: 100 college students were divided on the basis of current smoking status into two groups. These two groups were administered the Evers-Pasquale peer preference test and the Global Youth Tobacco Survey (GYTS). Sociodemographic variables were assessed using a semi-structured proforma. The data was then statistically analysed.

Results: The prevalence of current smoking was 54%. Almost 44% of college students had initiated smoking at or after 16 years of age, whereas only 4% of the entire sample had initiated smoking before 10 years of age. Close to one fifth (18.52%) of current smokers smoked daily and smoked cigarettes first in morning suggesting dependence. Students who currently smoked were most likely to engage in any activity in the company of best friends, followed by cool friends ($p = 0.0001$).

Conclusion: Smoking and peer pressure are linked and there is a need for tobacco intervention programmes to be directed at adolescent specific factors. Further research is needed to understand other factors promoting smoking like personality factors, social influence, genetic factors etc.

Keywords: Smoking, peer pressure, peer influence, tobacco, adolescents, college.

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INTRODUCTION

By 2030, tobacco is expected to be the single biggest cause of death worldwide, accounting for about 7 million deaths a year [1]. Cigarette smoking is more detrimental for health than many other forms of tobacco. Smoking is more common in nonmetropolitan areas with lower socioeconomic status and lower level education [2]. Tobacco consumption is increasing in developing countries with a lower age of initiation of smoking in adolescents [3]. A disturbing trend is seen in developing countries like India with adolescents and children initiating smoking. Though tobacco consumption is decreasing in Western countries [4], the prevalence of smoking in adolescents has increased in the last 40 years [5].

Smoking in adolescents is related to long term dependence, severity of smoking and higher morbidity and mortality [6]. Initiation of smoking is complex with contribution of social, environmental, cognitive, and genetic influences [7]. Some researchers suggest that instead of direct peer pressure to smoke, adolescents

attribute smoking to trying to conform to a group. According to selection theory, adolescents choose friends having similar characteristics like smoking. The attitudes towards smoking may be different in smokers and non-smokers. There is increasing evidence to show that peer influence is a pivotal factor in adolescent smoking. Smoking is often a way for adolescents to instantly become independent and fit in with peers who smoke. Relationship of peers with smoking is complex and may influence or deter smoking [8].

Literature suggests that 89.8% of users start smoking before 19 years of age [9]. However, there is limited evidence for differences in peer pressure and attitudes in adolescent smokers and non-smokers. In the context of the abovementioned statistic, our study addresses this gap in the existing knowledge regarding differences in peer pressure and attitudes in adolescent smokers and non-smokers in college students of age group 18-20 years. The primary aims of this study were to study the prevalence of smoking and age of initiation in urban college students, and to compare peer preferences and indicators of use in smoker and non-smoker college students.

METHODOLOGY

The study was conducted in second year degree college students in a large metropolitan city in India. A semi structured proforma containing details pertaining to socio demographic variables, The Global Youth Tobacco Survey (GYTS) [10] and the Evers Pasquale's peer preference test [11] was used. After informed consent was obtained, students (study participants) were interviewed with the peer preference test. Proformas were distributed in the classroom and returned after completing them.

A total sample of 100 was obtained from 119 second year degree college students with an inclusion rate of 84.03%. Students were divided in two groups depending on current tobacco use. Smokers were defined as anyone who had smoked at least 100 cigarettes in their life and who currently smokes cigarettes [12]. Non-smokers included never smoked and experimental smokers who were currently not smoking in the last 30 days. Thus, two groups were formed, Group A: Current smokers (n=54), and Group B: non-smokers and experimental smokers (n=46).

Ever Pasquale's peer preference test is a 12-item scale scored on a 4-point Likert rating where No=1 and Yes=4. It assesses the likelihood of the adolescent engaging in any activity in four different scenarios if they were with their best friends, cool friends, people they don't like and when they were alone. Higher score indicates greater likelihood of the adolescent conforming to situations in presence of peers. Total score is obtained with the mean of summation of scores [11].

The Global Youth Tobacco Survey was used to assess tobacco use indicators like the attitudes and opinions of adolescents to smoking. The GYTS aims to track tobacco use among youth in countries around the world, using a common methodology and core questionnaire. It also makes it possible to recognize patterns and determinants of smoking. It is a self-administered scale assessing the tobacco use indicators [10].

STATISTICAL ANALYSIS

Statistics were performed using SPSS 10 software. Group differences were analysed using unpaired t test, ANOVA, non-parametric tests and Fishers test as applicable. Two tailed p value was obtained for all statistical analyses.

RESULTS

The prevalence of current smoking was 54%. However, 64% of college students had ever smoked. Majority of the college students (64%) in 18-20 years age group had ever smoked and 54% were current smokers. Six of the ten girls in the study currently smoked, whereas 53% of the college students got pocket money between INR 300-400. Students in both groups belonged to upper and middle socioeconomic class. Almost 44% of college students initiated smoking at or after 16 years of age, whereas only 4% of the entire sample initiated smoking before 10 years of age. Despite numerical differences, groups had no significant differences in socio-demographic variables like age, gender, disposable income (pocket money) and socioeconomic status (Table

1). About 7.41% of group A and 13.04% of group B were girls. However, it did not achieve statistical significance.

The mean age of initiation of smoking was 14.34 years in group A and 15.1 years in experimental smokers in Group B. Only 7.41% of ever smokers initiated smoking before 10 years of age in our study. Most students (44%) initiated smoking at or after 16 years of age (Table 1).

Table 1: Sociodemographic profile of both groups

| Variable | Group A (N=54) Mean ± SD N (%) | Group B (N=46) Mean ± SD N (%) | Statistics | p value |
|---|---|---|------------------------|--------------------|
| Age of smoking (years) | 18.74 ± 0.78 | 18.60 ± 0.80 | t = 0.83 df = 98 | 0.407 ^a |
| Gender Male Female | 50 (92.59) 4 (7.4) | 40 (86.95) 6 (13.04) | X ² = 1.389 | 0.506 ^b |
| Socioeconomic status Upper class Middle class | 30 (55.55) 24 (44.44) | 26 (56.52) 20 (43.47) | X ² = 0.982 | 1 ^b |
| Pocket money (in INR) | 631.87 ± 230.231 | 676.580 ± 287.93 | t = 0.987 df = 98 | 0.986 ^a |

^aUn-paired t test used in the statistics, ^bChi-square test used in the statistics

It was found that 7.41% of group A and 26.09% of group B students had none of their closest friends as non-smokers. More than half (53.7%) of smoker participants reported that their parents were smokers. Both these results were statistically significant (Table 2).

Table 2: Groups and their Closest Friends as Smokers

| | Group A (N=54) N (%) | Group B (N = 46) N (%) | Statistics |
|------------|-------------------------|---------------------------|---|
| None | 4 (7.41) | 12 (26.09) | X ² = 6.4803 p = 0.039* significant df = 2 Chi square test used in calculation |
| Some | 26 (48.15) | 17 (36.95) | |
| Most / All | 24 (44.44) | 17 (36.95) | |

Close to one fifth (18.52%) of current smokers smoked daily and smoked cigarettes first in morning suggesting dependence. Though one third of Group A students did not admit to smoking daily, they expressed the desire to smoke first thing in the morning, indicating early signs of addiction. When both the groups were assessed on the GYTS (Table 3) differences in tobacco use indicators were seen. The majority of group B (non-smokers) opined that smoking made no difference in making friends for both the genders. 77.78% & 83.33% of Group A (smokers) opined that smoking makes a difference in making friends in boys and girls respectively. The difference in attitudes in both the groups was statistically significant with smokers viewing a positive effect of smoking in social circle.

Table 3 – Group data on having parents as smokers

| Parents that smoke | Group A (n = 54) N (%) | Group B (n = 46) N (%) | Statistics |
|--------------------|------------------------|------------------------|---|
| No | 25 (46.29) | 40 (86.96) | p < 0.0001* Fischer's exact test used in the calculation |
| Both | 2 (3.7) | 0 (0) | |
| Father only | 27 (50) | 6 (13.04) | |

Majority of group A i.e., 75.93% opined that smoking makes attendance of social function more comfortable, whereas only 23.91% of group B opined that same. This difference was statistically significant. Positive effects of weight reduction by smoking were opined by 81.48% of group A and 43.48% of group B respondents. This difference was statistically significant & in keeping with the other studies. 35.19% of group A and 78.26% of group B respondents thought that it is difficult to quit smoking once started and this difference was statistically significant.

When Group A was assessed on Ever Pasquale's peer preference test, it was shown that students who currently smoke are most likely to engage in any activity in the company of best friends, followed by cool friends. They were least likely to engage in any activity with people they didn't like. This difference was statistically significant ($p < 0.0001^{***}$, Bartlett stat=20.379) (Table 4).

Table 4 – Scores between both groups of Evers-Pasquale Test

| | Group A (n=54) | Group B (n=46) | Statistics |
|---------------------|-------------------|-------------------|---|
| | Mean \pm SD | | Group A p<0.0001* Bartlett's Stat = 20.37 |
| Best Friends | 3.231 \pm 0.322 | 2.465 \pm 0.58 | |
| Cool Friends | 2.746 \pm 0.397 | 2.171 \pm 0.61 | Group B p<0.0001* Bartlett's Stat = 1.298 *significant (p<0.05) |
| Don't Like | 2.366 \pm 0.575 | 1.813 \pm 0.553 | |
| Alone | 2.475 \pm 0.518 | 2.365 \pm 0.652 | |

When Group B was assessed on Ever Pasquale's peer preference test, it was observed that they were most likely to engage in any activity with best friends followed by when they were alone. They were least likely to engage in any activity when alone. This difference was statistically significant ($p < 0.0001^{***}$, Bartlett's stat = 1.29) (Table 4).

DISCUSSION

Smoking in women is not culturally and socially acceptable in India [13]. But current change in trend is seen with increased use in women in developing countries in response to marketing tactics [14]. The disposable income in terms of pocket money was and in group A & B respectively. Researchers have found that availability of pocket money is related to smoking. However, we did not find any difference in both the groups [15].

Interestingly a gender bias was seen with group A opining that boys who smoke make more friends but girls who smoke have less friends. This probably reflects the poor cultural acceptance of smoking in women [16]. It was found that 7.41% of group A and 26.09% of group B students had none of their closest friends as non-

smokers. Adolescents choose friends who are similar in characteristics and attitudes and this is seen strongly in non-smokers [7], which is consistent with our study. In Group A, 44.44% of the students had most or all of their friends as smokers. Adolescents whose more than three or almost all friends are smokers are more likely to be smokers [7]. More than half (53.7%) of smoker participants reported that their parents were smokers, which is consistent with other studies showing adolescents who smoke were more likely to have smoker parents than non-smoker adolescents.

When both the groups were compared for peer preference, Group A was significantly more likely to initiate an activity in the company of best friends, cool friends and people they didn't like. There was no significant difference in situations when students from both the groups were alone. This shows that smokers are more likely to conform and be influenced in not just in the company of best and cool friends but also when they are with people whom they don't like. Smokers were greatly influenced by peers as compared to non-smokers.

The main study limitations were that the study group does not represent the entire 18-20 years age group. Also, smoking was self-reported and not confirmed by any biochemical test.

CONCLUSION

The study results indicated that half of the students in smokers group had a dependence pattern. Smokers were more likely to have either or both parents as smokers and less likely to have any non-smoker close friend. Additionally, smokers are more likely to believe that smoking has positive effects like having more friends, making participation in social events more comfortable and causing weight loss. Approximately half to two-third of non-smokers felt that smoking makes no difference in making friends or being more comfortable. Compared to non-smokers, smokers minimized their perception of habitual smoking by underestimating the difficulty to quit. Though smokers and non-smokers maybe equally likely to participate in any situation when alone, smokers show a high likelihood of activity participation in the presence of any peer like best friends, cool adolescents and people they didn't like. Peer influence was significant in smokers. In addition to peer pressure, tobacco intervention programmes need to be directed at adolescent specific factors. Behavioural intervention and coping strategies need to be targeted at these impressionable minds. Further, research is needed to understand other factors promoting smoking like personality factors, social influence, genetic factors etc.

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Depression and Anxiety in mothers of children with autism spectrum disorders and intellectual disabilities

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ABSTRACT

Background: All parents always plan for perfect, healthy and normal babies. They never expect or think about children with disability. But if they confront with such situation in their lives, they face many emotional problems such as grief, loss, disbelief, guilt, rejection, helplessness, denial, shame, anxiety, anger and depression for a long period. Social stigma that itself attaches to the family and frustration and helplessness for not able to cure the condition leave parents sad and depressed

Methodology: The sample consisted of 60 mothers of children between ages 6 to 12 years; out of 60, 30 were mothers of children with autism spectrum disorder and 30 were mothers of children with intellectual disabilities. The data was collected from hospitals and special schools in Mumbai

Results: In the present study, it was found that depression and anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disability. The factors that lead to high depression and anxiety in mothers of children with ASD were behavioral issues in children like hyperactivity, aggressiveness, self-injurious behavior and stereotyped movements. They also have difficulties in their day to day life such as managing household chores plus looking after the child, financial problems and restricted social life.

Conclusions: The findings indicate that depression and anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disability. The results obtained are in line with hypotheses and past research.

Keywords: Depression, Anxiety, Autism Spectrum Disorder, Intellectual Disability, Parents.

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INTRODUCTION

The birth of a disabled child evokes mixed feelings in the minds of the mother and rather both parents. Guilt, sadness, anger, anguish and non-acceptance are some of the emotions that are experienced. Mothers of children with intellectual disabilities have been proven to experience higher levels of stress and depression than their spouses [1]. It has been noted that mothers of autistic children show an increased anxiety with respect to the poor social relatedness, delayed speech development, hyperactivity, behavioural problems and lack of eye contact in their children [2].

A cross-sectional study compared the psychopathology in mothers of children with autism & mental retardation. When these groups were assessed on Beck Depression Inventory (BDI), it was found that a majority of mothers of children with autism had moderate to severe depression compared to the mothers of children with mental retardation who had more of mild to moderate depression. When assessed on State Trait Anxiety Inventory, results indicated that mothers of children with autism had significantly higher scores on both state anxiety and trait anxiety scales [3].

A study was conducted [4] to evaluate anxiety, depression, alexithymia, and general psychological symptoms in the mothers of children with autism in comparison with the mothers of children with mental retardation. Forty mothers of autistic children and 38 mothers of mentally retarded children were included in the study. Results indicated that there was no difference regarding anxiety and alexithymia between the two groups. But the psychopathology in the mothers of children with autism was more frequent than in those of children with mental retardation in all sub-scales of Symptom Distress Checklist (SCL-90). The mothers of children with autism experienced more psychological distress than those of mentally retarded children.

In a study to find out the level of depression and level of stress in mothers of children with mental retardation and autism and compare them, a sample of 50 children with mental retardation with their mothers and a sample of 50 children with autism and their mothers were selected for the purpose of the study. It was found that mothers of children with mental retardation and autism suffer from same level of stress although depression is higher in mothers of children with autism [5].

Olsson and Hwang investigated the prevalence and severity of parental depression in families of children with autism and with intellectual disability without autism. Parental Depression was assessed using the Beck Depression Inventory (BDI) in 216 families with children with autism and intellectual disability. The results indicated that Mothers of children with autism have higher depression scores than mothers of children with intellectual disability without autism [6].

Mothers of children with autism spectrum disorders

A study aimed at evaluating presence of depression in a group of mothers of autism spectrum disorder (ASD) children in comparison with a group of mothers of normally developing children. Using short Beck inventory scale depression was significantly more among mothers of children with ASD than controls. The results indicated that autism is associated with burden and stress for mothers of the affected child. The demands placed by disability contribute to higher overall incidence of depression among mothers. Therefore, mothers of ASD children do need psychological interventions [7].

A semi-experimental study was performed to compare parenting related stress and depression symptoms in mothers of children with and without autism spectrum disorders. They found that mothers of children with an autism spectrum disorder generally report significantly higher levels of stress and depression than mothers of children without autism spectrum disorder [8].

A study assessed differences in parental reports of parenting stress, child behaviour problems, and dysphoria in 150 families who had children with autism, behaviour disorders, Down syndrome, or normal development. It was found that mothers of children with autism and behaviour disorders experienced statistically and clinically higher levels of dysphoria than mothers in the other two groups. In contrast, mothers of children with Down syndrome did not differ from mothers of nondisabled children on any of the measures [9].

In a review of literature, it was found that mothers of children with Down syndrome had the least impaired health and mothers of children with autism and particularly autism without intellectual impairment had the most impaired health [10]. A study was conducted to examine the relationship between stressors, social support, locus of control, coping styles, and negative outcome among parents of children with autism. Results indicated that parents of children with autism experienced more stress and were more susceptible to negative outcomes than parents of children with other disabilities [11].

Another study found higher levels of parenting stress and psychological distress in mothers of children with autism spectrum disorder (ASD) group compared to the developmental delay (DD) without autism group. Children's problem behaviour was associated with increased parenting stress and psychological distress in mothers in the ASD and DD groups [12].

A study was done to examine parenting stress and affective symptoms in parents of autistic children as compared to normally developing children. It was found that parents of autistic children reported higher levels of stress, depression, and anxiety than parents of normally developing children. Mothers of autistic children had a higher risk of depression and anxiety than that did parents of normally developing children. Also, mothers compared to fathers of autistic children were more vulnerable to depression [13].

McCabe studied the experiences of 78 parents (70 mothers, 8 fathers) of children with autism regarding their personal experiences and the experiences of their families in terms of having a child with autism. Results indicated increased stress, anxiety, and depression in mothers whereas the father tended to become less involved and somewhat more distant. McCabe also reported that having a child with autism significantly impacted the relationship between spouses in both positive and negative ways [14].

A study was conducted on symptoms of stress, depression and anxiety between parents of autistic children and parents of typically developing children. Findings suggested that parents of autistic children reported more symptom of stress, depression and anxiety than parents of clinically healthy children. Mothers of children with autism showed a significant difference in symptoms of stress, depression, and anxiety compared with fathers of children with autism [15].

Researchers studied the association between maternal quality of life and risk for depression in families of children with ASD. They found that higher autism symptomatology in the child was associated with an increased risk for maternal depression and a lower maternal quality of life [16].

Benson examined the relationship between coping and mental health outcomes in parents of children with autism. The study found that maternal use of avoidant coping (distraction and disengagement) was found to be associated with increased levels of maternal depression and anger [17].

Mothers of children with intellectual disabilities

Researchers reported that the parents of children with mental disabilities registered high depression and anxiety scores and the majority met the criteria for possible clinical depression and anxiety [18].

Nisa, Safi, and Rizvi studied the relationship of different stressors with depression among mothers of children with mental retardation. The results of the study revealed that there is a significant positive correlation between daily care stress, family emotional stress, social stress, financial stress, and depression [19].

Mitchell and Hauser-Cram [20] investigated the utilization of and satisfaction with adolescent health care services reported by mothers of children with disabilities and their relation to maternal well-being. Regression analyses were conducted to test whether utilization and maternal satisfaction with care related to maternal depressive symptoms or parenting stress [20]. Mothers with higher family income reported both lower parenting stress and fewer depressive symptoms than those with lower income levels. Mothers who reported higher usage of medical services for their adolescent in this study also reported higher levels of depressive symptoms and greater parenting stress.

A study was conducted on psychological well-being among mothers of children with cerebral palsy. They found that anxious and depressed moods in mothers of children with cerebral palsy were inversely associated with generalized self-efficacy and anxious mood was inversely associated with children's sleeping difficulties [21].

The aim of the current study was to assess the levels of depression and anxiety in mothers of children with autism spectrum disorders and intellectual impairment and compare the same.

METHODOLOGY

Participants

The sample consisted of 60 mothers of children between ages 6 to 12 years; out of 60, 30 were mothers of children with autism spectrum disorder and 30 were mothers of children with intellectual disabilities. The data was collected from hospitals and special schools in Mumbai.

Design

The proposed research is a survey design using questionnaires. It is a mixed study where open-ended questions were asked to mothers of children with autism spectrum disorder to understand their specific concerns.

Instruments

1. Beck Depression Inventory (BDI) [22]
2. The Zung Self-Rating Anxiety scale (SAS) [23]

Procedure

30 mothers of children with autism spectrum disorder and 30 mothers of children with intellectual disabilities were purposively selected from hospitals and special schools in Mumbai. The head of the psychiatry department in hospitals and the principals of the schools were contacted to provide information regarding the objective of the research, scales, principle of confidentiality and to seek their permission for the students to participate in the study. Once they agreed to allow the study to be carried out and the signed consent letters of the institute were acquired; the researcher arranged an appropriate date and time for administering the questionnaires. The data was collected using the survey method. Beck Depression Inventory (BDI) and The Zung Self-Rating Anxiety scale (SAS) were administered on each participant. The standardized instructions will be provided before the administration.

The mothers of children with developmental disabilities who were willing to participate in the study were provided with standardized instructions before the administration. They were explained the purpose and relevance of the study. After that these participants completed the paper and pencil questionnaire. After each participant was finished with the survey and the materials were collected, the participants were thanked for participating in the study. After the surveys were collected from the centres, data were scored, coded and entered into an excel spreadsheet. Data coding and entry were verified to minimize error. Verified data were then calculated on MS excel.

RESULTS

The result of the collected data was quantitatively and qualitatively analyzed. There was one independent variable- mothers of children with developmental disabilities. There were two levels of independent variable, i.e. mothers of children with autism spectrum disorder and mothers of children with intellectual disabilities. The two dependent variables were depression and anxiety. Also thematic analysis, as a part of qualitative study was done on 10 mothers of children with ASD.

Table 1: Descriptive statistics of the variables

| Variables | Mothers of children with ASD | | Mothers of children with ID | |
|------------|------------------------------|------|-----------------------------|------|
| | Mean | SD | Mean | SD |
| Anxiety | 31.96 | 7.83 | 27.16 | 5.16 |
| Depression | 11.13 | 5.6 | 5.63 | 3.29 |

The descriptive statistics of the entire data revealed that the mean value for the anxiety in mothers of children with ASD was 31.96 with standard deviation of 7.83. On the other hand, the mean value for the anxiety in mothers of children with ID was 27.16 with standard deviation of 5.16.

The statistical results of depression scores, of the overall data showed that the mean was 11.13 and standard deviation was 5.6 in mothers of children with ASD. In mothers of children with ID, the mean was 5.63 and standard deviation was 3.29. The inferential statistics used is independent t-test since it is the robust statistics. The analysis of the data was carried out using MS excel. Before performing t-test, normality and homogeneity were checked. Skewness and kurtosis values were examined on the total population to check the normality of dependent variables. Results revealed that for the scores of anxiety in ASD group, the statistics was 61.34 for Skewness and -0.09 for Kurtosis. In mothers of children with ID, for the scores of anxiety in, the statistics was 26.69 for Skewness and 0.002 for Kurtosis. These values remain in between the range of -1 and +1, which is an acceptable range for the normality range for t-test.

The value of Skewness and kurtosis for depression in mothers of children with ASD were 31.36 and -0.57 respectively. In mothers of children with ID, the value of Skewness and kurtosis for depression were 10.86 and 0.34 respectively. Since these values remain in between the range of -1 and +1, it is an acceptable range for the normality range for t-test.

Table 2: t-test for anxiety in mothers of children with ASD and ID

| Variables | Value of t | Df | Significance (one-tailed) |
|--|------------|----|---------------------------|
| Anxiety in mothers of children with ASD and ID | -2.80 | 50 | 0.0036 |

The obtained t value for anxiety in mothers of children with ASD and ID is -2.80 and the degree of freedom is 50. The obtained value is significant at 0.05 level of significance.

Table 3: t-test for depression in mothers of children with ASD and ID

| Variables | Value of t | Df | Significance (one-tailed) |
|---|------------|----|---------------------------|
| Depression in mothers of children with ASD and ID | -4.63 | 47 | 0.0015 |

DISCUSSION

The first hypothesis was that depression is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disabilities. The statistical result obtained was in line with the hypothesis and also in line with previous studies.

In a cross-sectional study, it was found that a majority of mothers of children with autism had moderate to severe depression compared to the mothers of children with mental retardation who had more of mild to moderate depression [3].

Olsson & Hwang investigated the prevalence and severity of parental depression in families of children with autism and with intellectual disability without autism. The results indicated that mothers of children with autism have higher depression scores than mothers of children with intellectual disability without autism [6].

Another study was conducted with the aim of considering anxiety, depression and any other general symptoms of mental illness of mothers of autistic children and comparing them with mothers of children with mental retardation. Rate of lack of depression in mothers of children with autism was 27.5% but for mothers of children with mental retardation it was 55.3%. It was also found that mothers of autistic children have experienced more psychological pain and discomfort than mothers of children with mental retardation. The second hypothesis was anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disabilities. The statistical result found was in line with the first hypothesis and also in line with past studies [4].

According to a study on the incidence and contributing factors in anxiety, depression and stress in parents of a child with autism spectrum disorder (ASD), nearly half of the participants were severely anxious and nearly two thirds were clinically depressed. Factors that emerged as significant in differentiating between parents with high versus low levels of anxiety and depression included access to family support, parents' estimation of family caregivers' expertise in dealing with the behavioural difficulties of a child with ASD, and parent [24].

Amanda Gane [25] explored mothers' experience of having a child diagnosed with an autism spectrum disorder. Ten mothers with children between the ages of five and nineteen were interviewed face to face regarding their experiences of caring for a child with an ASD. They described feelings of anxiety, despair, guilt and anger. Participants reported frustrations regarding their treatment by health care professionals and school systems. In addition, they spoke of the multitude of roles they had to play and relayed stories of loss in different areas of their lives as a result of mothering a child diagnosed with an ASD [25].

Ludlow, Skelly and Rohleder [26] interviewed 20 parents of children with ASD and explored their experiences, challenges faced, and what has helped them to cope. Their children's difficulties with social interactions, was a problem consistently raised by several of the parents (11 out of 20). Their children who were diagnosed with autism found it difficult to relate to others, understand others, or even tolerate the presence of others. In mothers, dependency of their children on them for care posed some anxiety, as they worried about how their children will be able to cope when they are no longer alive or able to look after them.

The open-ended questions of the study revealed similar difficulties mothers face in dealing with their children with ASD, which are pervasive problem behaviours such as self-stimulatory behaviours, stereotyped movements, self-injurious behaviour, hyperactivity, aggressiveness and poor acceptance of autistic behaviours by society and, other relatives in family. Mothers also expressed deep concern about the dependency of their children on them for care.

Koydemir and Tosun [27] attempted to investigate the impact of having an autistic child on the lives of Turkish mothers. It was found that most of the mothers of children with autism lack accurate information regarding the disability. Although there were some attempts by the mothers to get more information such as consulting school teachers and counsellors or using self-help resources, mothers indicated that they did not see themselves as fully informed about the situation. This study found that one of the consequences of having an autistic child was postponing or finishing career.

Mothers in other cultures also reported that having a disabled child prevented them to seek employment [28]. In the qualitative part of the present study same results are obtained where 6 out of 10 mothers of children with ASD reported that they have either left their jobs or they took up part-time jobs [28].

Stigma is one of the most difficult aspects of public encounters experienced by parents of children with a disability. Parents of children with autism often experience stereotyping and negative public reactions [29]. In the current study, also the mothers of children with ASD reported negative reactions from other people and exclusion from social functions.

Gona and others [30] studied challenges and coping strategies of parents of children with autism on the Kenyan coast. In their study, most parents and the professionals from rural and urban settings interviewed reported nonacceptance of the child with autism by peers, family members, relatives, and the wider community. Lack of acceptance was expressed in the form of social exclusion of the child. The need for constant monitoring of the child with autism has negative economic impact on the parents which was also reported by the mothers.

Most parents, especially mothers, have a strong commitment toward their children, spouse, and other family members. Mothers of children with autism reported more stress and fewer competencies in parenting than mothers of children without disabilities [31]. The present study showed that the characteristics of children with ASD, such as hyperactivity, self-injurious behaviours, stereotyped movements, make it difficult for mothers to deal with their children.

In the present study, it was found that depression and anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disability. The factors that lead to high depression and anxiety in mothers of children with ASD were behavioural issues in children like hyperactivity, aggressiveness, self-injurious behaviour and stereotyped movements. They also have difficulties in their day to day life such as managing household chores plus looking after the child, financial problems and restricted social life.

CONCLUSION

The current study aimed at comparing the level of depression and anxiety in mothers of children with autism spectrum disorder and intellectual disabilities and to find out which group is at increased risk of suffering from anxiety and depression. The findings indicate that depression and anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disability. The results obtained are in line with hypotheses and past research.

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Motivating factors amongst caregivers of those suffering from dementia: a thematic analysis

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ABSTRACT

Background: The current study explored the factors that motivate caregivers to continue providing care to their family member suffering from dementia. Maximum variation sampling was employed. In depth interviews were conducted with each caregiver till saturation was reached. A total of five hours of interview data was transcribed verbatim and 75 pages of the transcribed data were analyzed using thematic analysis. 18 themes were identified under the area of motivating factors.

Methodology: The data collection was done through face - to - face in - depth interviews. The sample included was adult female family members of the patient suffering from dementia. They were selected through medical and mental health professionals.

Results: Five hours of audio taped data derived from in depth interview with five caregivers was transcribed verbatim. 75 pages were analysed using thematic analysis. Most of the existing research focuses on the stress and health issues caregivers face. Little research exists about what motivates individuals to choose to provide long term care to their deteriorating family members. Seven areas were explored.

Conclusion: 18 themes were found under motivating factors. These were maternal instincts, reciprocity, responsibility towards family, lack of assistance, lack of an option, caregiver's personality, care and love, viewing caregiving as an opportunity to show concern, concern for patient's safety, patient's attitude towards the caregiver, guilt, viewing the patient as vulnerable, view of oneself, desire for normalcy, identifying with the patient, personal anxiety, final years and hope.

Key Words: Dementia, caregivers, motivating factors, thematic analysis

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INTRODUCTION

The care giving process often involves multiple tasks that may be physically, emotionally, socially, or financially demanding [1]. These individuals providing care are usually family, friends, or neighbours and are frequently key resources in the care of patients who would otherwise need institutional care [2].

Caregivers of individuals with dementia are characterized by high levels of stress, burden, drug use, depression, and physical decline. Caregiving spouses, especially wives are particularly vulnerable to negative consequences of caregiving [3]. Yet, they choose to provide long term care. Family caregivers may be motivated to provide care for several reasons: a sense of love or reciprocity, spiritual fulfilment, a sense of duty, guilt, social pressures, or in rare instances, greed [4].

Cicirelli [5] conducted a study to determine the motivating factors for adult children who provide care to older parents despite enduring incredible amounts of burden. There were two motives that Cicirelli focused on: filial obligation and filial attachment. This study was designed to clarify the relationship of obligation and attachment to both the amount of caregiving and the resulting amount of subjective burden. Adult children may come to feel that it is their duty, obligation or responsibility to help their older parents.

Caregivers who are motivated by a sense of duty, guilt, or social and cultural norms are more likely to resent their role and suffer greater psychological distress than caregivers with more positive motivations. Caregivers who identify more beneficial components of their role experience less burden, better health and relationships, and greater social support. The negative aspects of caregiving for people with dementia tend to receive most attention, but caring has also been associated with positive feelings and outcomes [6].

A study explored the relation of entrapment, shame and guilt to depression in a group of 70 carers of those with dementia. The experience of entrapment was highly related to depression. Moreover, experiences of shame relating to self-criticism, other people's expectations and the fear of their criticism were significantly related to depression, entrapment and guilt. Guilt focused on the fears of harming others, letting others down and sense of responsibility. Depression in carers may relate in part to feeling trapped in a role but also being vulnerable to criticism and feelings of inadequacy in that role [7].

Factors such as gender, age, marital status, education, ethnicity, and employment status will predict the likelihood of caregiving [8]. A study purporting to explore the impact of background characteristics, exchange patterns, motivating factors and diagnosis of dementia on caregiver reciprocity indicated that adult children of parents with dementia gave more direct instrumental and supervisory care, received more negative and fewer positive exchanges, and reported significantly lower levels of warmth and regard, intrinsic rewards of giving and balance within family caregiving when compared to adult children of parents without dementia [9].

Gender also may influence the caregiving process. A traditional perspective on women's work socializes females to assume duties which are centered in the home and reflect a sense of social obligation [10]. Traditional work roles include the belief that women must expect not only to assume caregiving duties, but also to receive minimal help from male family members.

A study looked at men in the role of elder caregivers. It was found that men reported having found emotional gratification an important motivating factor and they tended to attribute to themselves many affective traits usually associated with the female role [10]. It is seen that for the caregiver, a respite experience is one way to alleviate the negative consequences of caregiving. Caregivers in a study described respite experience as a cognitive process of getting out of the caregiver world and into their own world. In this world, they feel free from the responsibilities and the worries of caregiving—the ideal meaning of respite to these caregivers. Factors influencing the caregivers' abilities to experience this respite include the nature of the pre-illness relationship between the caregivers and their dependent family members, role expectations, the attributes of the available respite services, and time [11].

A study with Swedish population aimed at investigating connections between family caregivers' health and providing care for an ill relative. Results indicated that caregivers' beliefs, experiences of reciprocity, or non-support, along with quality of interpersonal relationships and feelings of responsibility and guilt, had a profound impact on their health [12]. Another study using thematic analysis to understand the stressors and resources of caregivers, found that caregivers' primary stressors related to day-to-day patient care and emotional support; secondary stressors included financial hardship, family responsibilities, and social isolation. Caregivers' social, relational, spiritual, and psychological resources mediated the effects of these stressors. Strengthening one resource strengthened others, but the failure of one resource hindered other resources, intensifying the burden [13].

Priorities of people with dementia can be different from those of caregivers. In a study that aimed at understanding these different needs reported that people with dementia had fewer needs compared with the reports of their caregivers and the professionals. The most frequent unmet needs reported by people with dementia, caregivers and professionals were in the areas of daytime activities, company, and psychological distress; however, people with dementia rated psychological distress as the commonest unmet need [14].

A study aimed at understanding end of life care and the effects of bereavement on family caregivers of persons with dementia assessed type and intensity of care provided by family caregivers to persons with dementia during the year before the patient's death and assessed the caregivers' responses to the death. It was found that half the caregivers reported spending at least 46 hours per week assisting patients with activities of daily living and instrumental activities of daily living. More than half the caregivers reported that they felt they were "on duty" 24 hours a day, that the patient had frequent pain, and that they had had to end or reduce employment owing to the demands of caregiving. Caregivers exhibited high levels of

depressive symptoms while providing care to the relative with dementia, but they showed remarkable resilience after the death. Within three months of the death, caregivers had clinically significant declines in the level of depressive symptoms, and within one year the levels of symptoms were substantially lower than levels reported while they were acting as caregivers [15].

A research paper aimed at reviewing literature related to the experiences of family caregivers after institutionalization of their older relatives found that family caregivers continued their caregiver roles even after institutionalization. A significant decrease was seen in the caregivers' burden after institutionalization. Depression in caregivers, however, was not significantly reduced. After institutionalization, caregivers experienced positive feelings, negative feelings, and mixed feelings [16].

A study about variables involved in predicting dementia caregiver's depression revealed that increases in caregivers' self-efficacy, frequency of leisure activities, and cognitive reappraisal significantly predicted decreases in caregivers' depression over time. It was also seen that increases in stressors were related to increases in depression over time [17].

It was thus seen that caregiving affects lives of the caregivers in innumerable ways. Caregivers experience positive as well as negative emotions towards caregiving. Various factors play a role in predicting caregiving and are responsible for motivating caregivers to care for their family members. The aim of this study was to examine how do the caregivers view their role and the situation that they are in, what motivates them to continue taking care of their family member despite the deteriorating condition and how would they feel if they were to discontinue taking care of the family member.

METHODOLOGY

Setting

The study was conducted in Mumbai, Maharashtra. The interviews were conducted at the caregivers' home. In addition to their preference of a familiar place, they were unable to leave their homes as they were looking after their family member.

Sample

The population was adult female family members of the patient suffering from dementia. The sampling was done till saturation was reached. The sample for the present study consisted of 5 caregivers. The primary inclusion criteria were female adults taking care of their family member suffering from dementia. Diagnoses had been given by psychiatrists and clinical psychologists. Those individuals whose family member had been suffering from dementia for a minimum of one year were selected. This time period allowed for an insight about what makes them continue providing care despite the deteriorating, long term nature of the disorder. The sample was obtained from referrals from medical practitioners and mental health professionals. The sample was selected using a mixture of purposive and snowball sampling methods. One caregiver was the sister of the patient, one was the daughter in law, one was the spouse and the other two were daughters. This maximum variation approach to sampling was used to help incorporate a range of participants sharing a different relationship with the patient for gaining a richer understanding of the reasons they choose to take care and the difference in the emotions they experience.

Patient characteristics: Out of the five patients, three were female and two were male. The patients were all on medication.

Measures used in the study

A brief socio – demographic questionnaire was used to obtain background information. The questions included age, relationship with the patient, education level, year in which the patient was diagnosed with dementia, family structure, whether the caregiver was currently working or not and the annual income. Participants completed the questionnaire at the beginning of the first interview. It took about 5 – 10 minutes to complete.

Interviews: The interviews were simple in depth with probes to encourage the participants to elaborate on specific aspects of their caregiving experience. Interviews began with open ended, non-directive questions.

Probes like “Tell me what happened next?” and “How did that make you feel?” were utilized to encourage the participants to talk about their experiences. All the interviews began with “What were your thoughts and feelings when your family member was diagnosed with dementia?” As the interviews proceeded, the interview questions became more focused on what motivated the care giver to continue taking care of the family member.

Procedure

The data collection was done through face-to-face in-depth interviews. The sample included was adult female family members of the patient suffering from dementia. They were selected through medical and mental health professionals. The interview was conducted in one session lasting an hour. An interview schedule was prepared to provide clarity during the interview regarding the areas to be covered. It served as an aid rather than something read out verbatim during the interview. Before any interview began, the participant was given a consent form which included the purpose of the study, assurance regarding confidentiality and how the information will be disseminated.

The consent form was read along with the participant and discussed; with the understanding that the participation was voluntary and the participant could withdraw at any time they felt uncomfortable, that the information shared would be confidential and that the interview will be audiotaped. They were given a brief socio demographic form prior to being interviewed.

In the interview session with each participant, they were asked “What were your thoughts and feelings when your family member was diagnosed with dementia?”

Subsequent conversations with the participants involved questions directed towards the motivating factors. The interview with each participant ended with a debriefing session where the participant’s experience of the interview was discussed. It was conducted in English or Hindi or a combination of both depending on the participant’s preference. Each interview was scheduled at a time convenient to the participant at their homes.

Research Design

The design of this study is qualitative, exploratory and descriptive in nature. A qualitative study aids in understanding the experiences of the sample under study and the meanings attributed to different events by them. Caregivers of individuals with dementia are characterized by high levels of stress, burden, drug use, depression, and physical decline. Caregiving spouses, especially wives are particularly vulnerable to negative consequences of caregiving. To obtain an understanding of what makes them continue taking care despite this, a qualitative research design with a contextual epistemological position was used.

Data Analysis

This exploratory and descriptive qualitative research utilized face-to-face in-depth interviews which were audiotaped and transcribed verbatim. The transcriptions were checked against original audio recording for accuracy. Five hours of data was collected, transcribed verbatim and analysed using thematic analysis which as defined by Braun and Clarke [18] is a method for analysing and identifying patterns of meaning in a data set. It illustrates which themes are important in the description of the phenomenon under study. These themes can contain manifest content and latent content.

Thematic analysis is best suited for elucidating the specific nature of a given group’s conceptualization of the phenomenon under study. It forms the implicit basis of many other qualitative methods. Braun and Clarke’s model of thematic analysis [19] was used to analyse the transcribed data. According to their model, the process of carrying out thematic analysis can be broken down into six steps, though, as with most qualitative analysis, there was constant going backwards and forwards between the different stages of the analysis to ensure high quality.

The first step involved data familiarisation. Since the semi - structured interview method was used; the data familiarisation began during the data collection process. After each interview, the audio of the first interview session was heard and notes were made for the second interview.

Data familiarisation continued during the transcription process. The second step was the initial coding generation step which involved line-by-line coding or of every four-five lines.

A code is a label used to describe a line (or few lines) of the transcript. Descriptive coding was used. The coding indicated something that is interesting or important about the data and it involved the researcher systematically working through the data in its entirety. The initial coding captured the essence of a segment of the text.

It was followed by search for themes based on initial coding. It involved identifying the patterns among the different codes, categorizing them into meaningful groups of codes; which resulted in emergence of themes and sub themes. This categorization was done manually on Microsoft Excel.

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RESULTS

The study was carried out to explore the factors that motivate individuals to care for their family member suffering from dementia and their experiences and emotions.

Length of responses

Five hours of audio taped data derived from in depth interview with five caregivers was transcribed verbatim. 75 pages were analysed using thematic analysis. Most of the existing research focuses on the stress and health issues caregivers face. Little research exists about what motivates individuals to choose to provide long term care to their deteriorating family members. The study also has personal relevance to the researcher. Seven areas were explored.

Thematic categorization

41 themes were identified. In the tables the areas, the emerging themes, the codes and the definitions along with examples from the data extract are provided. The areas explored were the onset and initial symptoms, feelings about the condition, feelings towards the patient, feelings about the situation that they are in, the motivating factors, the concerns and ways to cope with the situation.

Onset and initial symptoms. The area of onset and initial symptoms refers to the beginning of the illness and the symptoms presented at the time. There were four themes under this which included 1) Memory related, 2) Mood related, 3) Unusual behaviour and 4) Caregivers' views.

1.1 Memory related. The caregivers spoke about the initial phases where the patients had begun showing deterioration in memory functions. "Initially he started forgetting small things". They spoke the gradual decline in memory, the worsening of their condition. They spoke about the damage done. Caregiver 4 spoke about her mother forgetting names and people. She said: "She had started forgetting our names. She would go and ask the maids who they are and what they are doing here. She was loosening up on her memory". Caregiver 2 spoke about the realization of memory deteriorating before the diagnoses of dementia.

She said: “When we took her to the doctor he said it is dementia. But we realized that she was forgetting smaller things even before that”. Caregiver 3 spoke about how it has been getting worse. She said: “Every year it started becoming more and more. The memory loss. Now it’s very bad. He doesn’t recognize anyone. Gradually it is becoming worse.”

1.2 Mood related. The caregivers spoke about the changes in mood that the patients showed. “She was depressed”. They spoke about the mood changes that would come along every day. Caregiver 1 spoke about the patient seeming depressed. She said: “Voh depressed lagti thi. She used to be sad on most days and then sometimes would be happy.” Caregiver 3 spoke about mood issues that she saw in the patient. She said: “He has a lot of mood issues. If his mood is not there he will get irritated. He will not eat. Otherwise when he is in a good mood he will talk very nicely”.

1.3 Unusual behaviour. The caregivers spoke about the behavioural changes they noticed. They considered these strange. “Used to get very violent”. Caregiver 2 spoke about the fear she felt when the patient began to display unusual behavior. She said: “She used to keep searching for her husband who has been dead for many years now. She used to keep calling out to him and looking here and there. We didn’t know what’s happening. We thought she is going insane or something.” Caregiver 5 spoke about the changes they saw in the patient as a person. She spoke about all the behaviours that displayed now were ones they would never have imagined he would. She said: “He used to get very violent. He was a person who never got violent. Forget violent. He never even shouted. He had started giving bad words now. God knows where he got this. Maybe it was the frustration.” Caregiver 1 spoke about the strange things that the patient would say. She said: “Sometimes bolegi chor aa gaya. Mere ghar me chori ho gayi. Somebody is taking my property. Toh hum log samajh gaye ki something is there.”

1.4 Caregivers’ views. The caregivers spoke about their assumptions, understanding and realization about the onset. “Realized ki something is there”. Most of the caregivers believed that the condition began only after the death of a close one. Caregiver 1 said “After her husband’s death it all started”. Caregiver 4 spoke about being unaware initially and decided to take the patient to the doctor when she felt clueless about her behavior. She said: “She started doing very strange things. I didn’t know why. Then one day I took to the doctor. That’s when we came to know she has dementia.”

Feelings about the condition. This area pertains to the emotions and thoughts that the caregiver had towards the condition of the patient. The themes under this area were 1) Uncertainty, 2) Destiny, 3) Focus on the positive aspects and 4) Social embarrassment.

2.1 Uncertainty. The caregivers spoke about the confusion they felt. They described their emotions as surprising, shocking and scary. Caregiver 4 spoke about not expecting something like that. She said: “That time I didn’t know. You don’t expect something like that na.” Caregiver 2 spoke about it as a scary experience. She said “At that time it was scary. We didn’t know what was happening.” \

2.2 Destiny. The caregivers blamed and questioned the destiny for the condition of the patient. Caregiver 1 questioned destiny. She said: “Aisa kyu ho haga usko ke saath?” Caregiver 5 blamed destiny for this. She said: “It’s just bad luck. What to do now?”

2.3 Focus on the positive aspect. This was a novel theme in case of caregiver 5. She was emphasized on the positive aspects of the patient’s life. She said: “His has led a very healthy life for 84 years. He has everything else. Everyone loves him and treats him with kindness.”

2.4 Social embarrassment. The caregivers described the awkwardness they felt. They spoke about feeling ashamed in social situations. “Becomes very embarrassing”. Caregiver 4 spoke about the embarrassment she faced when they had guests over for lunch. She said: “She once put laddoos in the paratha stuffing and kept it on the hot plate. She came outside and thought it’ll become aloo parathas. We had guests over for lunch that day. I was so embarrassed. I didn’t know what to tell them.”

3. Feelings towards the patient. This area pertains to the emotions and thoughts the caregiver has towards the patient. The themes under this were 1) Sympathy, 2) Frustration, 3) Ambiguity, 4) Positive feelings and 5) Accusatory feelings.

3.1 Sympathy. The caregivers spoke about feeling sorry for the patients. "Bohot bura lagta hai". Caregiver 1 spoke about feeling sad and tensed. She said: "Feelings of dukh hota hai. Sad. Tension aata hai." Caregiver 2 spoke about feeling sorry the patient has become dependent. She said: "I feel bad, you know. Everyone person is a self-respecting person. And then you come to a stage where you become so dependent. It's sad".

3.2 Frustration. The caregivers described their feelings of anger, annoyance and irritation. "I get really bugged." Caregiver 1 described the annoyance she feels despite the love. She said: "Two things were there. Ek toh gussa bhi aur pyaar bhi. Kabhi kabhi I felt like giving her one slap and saying chup!" Similarly, the rest of the responses were recorded for the remaining care givers on the dimension of Feelings about the situation that they are in. This area pertains to the emotions and thoughts the caregiver has towards the situation that they are in. the themes included here were- 1) Self-pity, 2) Distress, 3) Positive feelings.

DISCUSSION

In depth interviews lasting an hour with each caregiver led to five hours of interview data; taken through maximum variation sampling. This provided a chance to hear what caregivers sharing different relationships with the patient had to say about their experiences and emotions related to the caregiving process. The caregivers vented out their emotions and expressed relief about being able to talk about it. It was both inspiring and painful to hear their experiences.

It must be noted that the caregivers were not presented with the themes mentioned in the study. Rather, the themes were derived from what the caregivers said spontaneously to open ended questions. This study's contribution is through the individual accounts that the caregivers offered related to what motivates them and what are the emotions they experience.

Analysis of the transcribed data revealed 18 themes under the motivating factors. These were maternal instincts, reciprocity, responsibility towards family, lack of assistance, lack of an option, caregiver's personality, care and love, viewing caregiving as an opportunity to show concern, concern for patient's safety, patient's attitude towards the caregiver, guilt, viewing the patient as vulnerable, view of oneself, desire for normalcy, identifying with the patient, personal anxiety, final years and hope.

All of the caregivers expressed maternal feelings as one of the reasons that motivated them. They described the patient as being child-like and expressed feeling motherly towards them. A qualitative study by Eileen da Pena on subjective experiences of daughters as caregivers of their frail elderly parents found that many participants felt that there had been a change in the daughter-parent relationship, where the daughters felt that they had somehow become a parent to their parent They described their parent as being like a child, or behaving like one, and thus eliciting "mothering" behaviors from the caregiver. Many of the caregivers shared that either they were like their mothers in some way or another, or that they had learned caregiving behaviors from their mothers which was indicated of caregiving patterns being mostly passed down through the female culture [20].

Reciprocity was another theme found. Most participants in the study expressed their need to return the care that the patient had given them at some point in their lives. They expressed feeling indebted and viewed caregiving as paying the individual back. A study conducted on informal caregiving among women found 'Caregiving is Bi-directional' as one of the themes. Participants in this study viewed caregiving as part of a large reciprocal, interactive, and dynamic partnership [21].

Responsibility towards family was an important theme that was seen in case of all participants. The caregivers stated being a family member as one of the reasons for providing care. Cicirelli [5] conducted a study to determine the motivating factors for adult children who provide care to older parents despite enduring incredible amounts of burden. There were two motives that Cicirelli focused on: filial obligation and filial attachment. It was found that adult children may come to feel that it is their duty, obligation or responsibility to help their older parents.

Lack of assistance was seen as a reason for caregiving by many caregivers. The patients often had no one else to look after them and the caregivers received very little support from their relatives in the caregiving

process. Lack of an option was a theme seen in case of many of the caregivers. They viewed caregiving as the only option and saw no other choice besides that.

The study by Mendez [21] on informal caregiving among women found that the women in the study viewed choice as irrelevant since giving care was seen as part of a larger marital agreement. The notion of “having a choice” was not seen as part of a woman’s paradigm. This theme was caregiving as a negative obligation. Caregiver’s personality was a novel theme seen in case of one of the caregivers. The caregiver spoke about her being the kind of person who tended to care for anyone in need of it.

In a study on effects of motivation, roles, coping strategies, and adaptations in relationships and personality on caretaking of elderly parents by midlife couples explored the role of personality factors in caregiving. It was seen that the factors included attitudes toward coresidency; using religious/spiritual beliefs for coping, decision making, and well-being; effect of multigenerational caregiving (taking care of children and elderly parents at the same time); marital status of the caregivers, and having a variety of roles and interests while caregiving [22].

Care and love that the participants felt for their family member suffering from dementia was seen as a major factor that motivated them to look after them. They expressed feelings of love and care and stated various reasons for feeling the same. The attachment that felt as a result of the number of years they spent together, the value they had for the relationship they shared were some of them. Some of the caregivers in the study viewed the caregiving process as an opportunity to show the patient how much they mean to them. They saw this as an opportunity to express their affectionate feelings to the patient.

Most caregivers in the study stated that their concern for the patient’s safety was a reason they looked after them. Their concern about the patient’s need for security and well-being seemed to motivate them. Some of the caregivers mentioned that the patient’s faith in them and the patient’s desire to stay with them was one of the reasons they choose to continue taking care of them. Thus patient’s attitude towards the caregiver seemed to be a theme in the motivating factors.

Eileen da Pena’s study also pointed out that fewer attempts are made to interview the care recipient. As a result, only one point of view seems to exist, and not the whole picture of caregiving [20]. Guilt was seen as a factor influencing many caregivers. Most of the caregivers’ statements were indicative anticipatory guilt. The caregivers spoke about the guilt that they would feel if they were to abandon the family member. Some of them expressed guilt regarding their actions in the past towards the patient. The impatience, frustration and anger towards the patient were some of the reasons for their guilt. Regret about not having spent enough time in the past with the family member now suffering from dementia was also seen.

In one study it was observed that caregivers who were motivated by a sense of duty, guilt, or social and cultural norms were more likely to resent their role and suffer greater psychological distress than caregivers with more positive motivations [23].

In the study on informal caregiving among women it was found that spousal caregivers provided care to their husbands regardless of the situation because of external pressures, in the form of guilt from others and self-guilt from if they there were to abandon their husbands [21]. Most of the caregivers viewed the patients as vulnerable. They felt the need to look after the family member because he or she was old and helpless. Many of the caregivers believed that they were the only ones who were capable of looking after the patient. They expressed feeling that no one else was capable of taking care of the patient as they do. This was stated as one of their reasons for looking after their family member.

A novel theme found in case of one caregiver was a desire for normalcy. The caregiver stated her desire to have a normal family. She compared hers to others and expressed that she wished she could have normal conversations with her father as others do. She saw caregiving as an alternative to normalcy. Many of the caregivers identified with the patients. They communicated their concern about old age. They expressed their anxiety about getting old and being in the state that their family member is now in.

Personal anxiety was another theme seen. The caregivers expressed their own anxieties that played a role in motivating them to look after the patient. A novel theme seen in case of one caregiver was that of final years. The caregiver expressed belief that since these were the final years of the patient they must be happy ones. She stated this as one of the reasons motivating her to take care of the patient as these last few years must be as happy as the rest of his life. One reason for this novel theme could be the relationship of the caregiver

with the patient. She was the spouse. Since the difference between their ages was not much, she probably viewed these as the final years for both of them [24].

Hope was seen as another theme. Some of the caregivers expressed hope that if taken care of the patient may get better.

A study on Hope and connection: the experience of family caregivers of persons with dementia living in a long term care facility found that hope was important and essential for family caregivers of persons with dementia. Several sub-themes were identified including: accepting where they were, living life in the moment, believing in something, standing together, and balancing dual worlds [25].

Other areas that were analysed in the study were onset and initial symptoms, feelings about the condition, feelings towards the patient, feelings about the situation that they are in, the concerns and ways to cope with the situation. The caregivers stated what they observed and felt during the initial phase of the illness. Four themes were seen under this which included aspects which were memory related, mood related, unusual behaviours and the caregivers' views. The caregivers communicated their observations about the loss of memory, irrelevant talking by the patient, aggressive behaviour which was otherwise inconsistent with the patient's personality.

The caregivers also gave an account of the feelings they had towards the condition. These included the themes of uncertainty, destiny, focus on the positive aspects and social embarrassment. A research paper aimed at reviewing literature related to the experiences of family caregivers after institutionalization of their older relatives found that family caregivers continued their caregiver roles even after institutionalization. A significant decrease was seen in the caregivers' burden after institutionalization. Depression in caregivers, however, was not significantly reduced. After institutionalization, caregivers experienced positive feelings, negative feelings, and mixed feelings [26].

The area of feelings towards the patient was also analysed. Caregivers vented out the emotions they felt towards the patients. Sympathy, frustration, ambiguity, positive feelings and accusatory feelings were the themes in this area. It has been seen that caregivers are at an increased risk for feeling angry, anxious, hostile and aggressive. As a possible result, the prevalence of violence is increased in families with dementia patients, with the overall prevalence at 17.4 percent higher than in the general caregiving population [26]. The last area studied was ways to cope with the situation. Support system, personal factors and self-care were themes under this. In a study on dementia caregiving and impact of location of residence on stress, coping, social support and health it was seen that caregivers used more social support seeking coping to deal with their caregiving stress. Caregivers who were more satisfied with support services perceived lower levels of caregiving stress and had a more positive attitude toward their health status [27].

CONCLUSION

The caregivers interviewed in the study experienced a wide range of emotions. They expressed experiencing positive as well as negative emotions. They were burdened by the demands of the caregiving process and yet they chose to continue. 18 themes were found under motivating factors. These were maternal instincts, reciprocity, responsibility towards family, lack of assistance, lack of an option, caregiver's personality, care and love, viewing caregiving as an opportunity to show concern, concern for patient's safety, patient's attitude towards the caregiver, guilt, viewing the patient as vulnerable, view of oneself, desire for normalcy, identifying with the patient, personal anxiety, final years and hope. Other areas that were analysed in the study were onset and initial symptoms, feelings about the condition, feelings towards the patient, feelings about the situation that they are in, the concerns and ways to cope with the situation.

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A Study on Quality of Life and Self Esteem in children and adolescents with Strabismus

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ABSTRACT

Background/Context: Strabismus is a condition that results in loss of self esteem and affects quality of life due to the changes it may cause in facial appearance and other factors. There is a dearth of Indian literature on children and adolescents with strabismus. The current study analyzed self esteem and quality of life in children and adolescents with strabismus.

Methods: Children and adolescents between 6-17 years attending the ophthalmology out-patient department of a tertiary general hospital and their normal siblings were identified and assessed after parental consent using a semi-structured proforma and the KINDL questionnaire. The results were statistically analyzed and presented.

Results: 35 children and adolescents with strabismus were compared to 38 siblings who were the controls. It was seen that children and adolescents with strabismus scored lower on family and social contacts quality of life scores on all subscales of the KINDL questionnaire. However, self-esteem did not differ across both groups.

Conclusion: Further larger studies in diverse populations are needed to corroborate the effects of strabismus on self esteem and quality of life.

Key words: self-esteem, strabismus, quality of life, children, adolescents.

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INTRODUCTION

Strabismus is a condition associated with abnormal binocular vision that leads to ocular misalignment, blurring, eye strain and diplopia causing a change in the normal facial appearance of the individual [1]. Studies have demonstrated that patients with strabismus patients suffer from both psychological problems and social impairments [2]. There has been an increased incidence of psychological problems like anxiety and depression correlated with strabismus that may also affect the quality of life of the patient adversely [3-4]. Strabismus is commonly seen in India and the incidence varied from 0.13%–4.7% across various studies conducted [5]. The psychosocial implications of strabismus are relevant in school going children who might be bullied and ridiculed due to the changes in facial appearance as seen in exotropia or esotropia [6].

In a Turkish study, teachers were asked about their impression about photographs digitally altered to show children with orthotropia, esotropia and exotropia and their perceptions were noted. There was a significant social bias against children with strabismus, reported even by their teachers [7]. Children with strabismus may be treated differently by their peers and even by parents during caregiving and authority figures owing to the changes in their facial appearance [8]. Strabismus may thus cause low self-esteem in the child as eye contact is important for good communication skills and children with strabismus may face a problem this area during ordinary conversations with people and in specific social situations [9]. Studies have demonstrated that children with strabismus face issues like severe difficulty in communication, difficulty coping in social situations and immense social anxiety [10]. Thus, strabismus may affect the child's quality of life both due to psychosocial factors and appearance defects even when there is no significant diminution of vision or functional impairment [11-12]. Previous studies in children and adolescents with strabismus between the age of 3-17 years have reported poorer quality of life and low self-esteem in these groups [13-14]. There is scarce literature on quality of life and self esteem in children with strabismus in India. The present study was thus aimed at studying quality of life and self esteem in children and adolescents with strabismus attending the outpatient department in a tertiary general hospital

METHODOLOGY

The study was a cross-sectional, single center study conducted in a tertiary general hospital in Mumbai. The study was conducted over a period of four months between June and September 2018. The study was conducted in children with strabismus attending the ophthalmology out patient department of the hospital. The parents of the children were explained the nature and purpose of the study and written informed valid consent from them was obtained. The children were also explained the nature and purpose of the study and where applicable assent for the study was obtained. The study cohort were patients between the age of 6-17 years having strabismus. Due to the limited time period of the study cases and controls were recruited on a first come first serve basis and no sample size calculation using power data was done.

Children and adolescents with severe cognitive or neuropsychiatric problems and major medical or surgical disorders that may cause impairments of self-esteem or quality of life were excluded from the study. Children and adolescents who have already had successful strabismus surgery were also excluded. The control group were siblings of these patients in the age range 6-18 years. respectively. Similar exclusion criteria were applied to the siblings as well. The control group chosen was chosen as siblings of the study group as most factors which affected self-esteem was assumed to be common to both groups and strabismus was probably a major differentiating factor between the two groups.

A semi-structured proforma for data collection of socio-demographic variables was constructed for the purpose of this study and administered. Data on self esteem and quality of life in both groups was collected using the KINDL Questionnaire.

The KINDL questionnaire is a standardized measure of quality of life and self-esteem in the age group of 3-18 years. It has good reliability and validity with Cronbach's alpha of 0.70. It consists of 24 likert – scaled items associated with six dimensions viz. physical well-being (eg. during the past week I felt ill), emotional well-being (eg. During the past week I felt good about myself), family (during the past week I felt fine at home), friends (during the past week I got along well with my friends) and everyday functioning (school) (during the last week I enjoyed my lessons). The items in the scale give 5 responses from 'Never' to 'All the time'. The proxy version Kid/Kiddo KINDL parents for 6-17 years of age was used in this study.[15-16] The questionnaire was administered by a qualified psychiatrist (HM) who was also an author in the study.

Ethical clearance for the study was obtained from the Institutional Ethics Committee. The data was analyzed using SPSS statistical software version 17 and descriptive statistics for the ages like mean and standard deviation along with the unpaired t test to compare scores on the scale were used.

RESULTS

The study subjects were 35 children and adolescents having strabismus and 38 of their normal sibling that functioned as the control group. In the study group there were 20 females and 15 males having strabismus. In the control groups there were 21 females and 17 males. In the strabismus group, there were 24 (68.57%) esotropes and 11 (31.43%) exotropes. Headache, eyestrain and difficulty in reading were the common symptoms associated with squint seen in majority of the patients (n=20, 57.14%). The mean age of the study group was calculated to be 11.60 ± 4.3 years and that of the control group was 10.73 ± 3.8 years. No epidemiological data could be ascertained due to the sample size.

On assessing the study and control groups on the KINDL questionnaire, it was seen that children and adolescents with strabismus scored significantly lower on family and social contact scores of quality of life than the control group (Table 1). Physical and emotional well being subscale scores showed no differences between the group and surprisingly the two groups did not differ on self esteem scores. The self esteem scores were high indicating good self esteem in the strabismus and control groups.

Table 1 – Comparison between study and control groups

| KINDL Questionnaire Subscales | Strabismus Group (n=35) Mean \pm SD | Control Group (n=38) Mean \pm SD | t value | p value |
|-------------------------------|--|---------------------------------------|---------|---------|
| Physical Well Being | 74.10 \pm 17.75 | 69.07 \pm 23.11 | 1.036 | 0.3036 |
| Emotional Well Being | 69.29 \pm 17.31 | 75.33 \pm 15.34 | 1.5804 | 0.1185 |
| Family | 59.82 \pm 16.49 | 70.06 \pm 14.39 | 2.8324 | 0.0061* |
| Social Contacts | 52.32 \pm 12.69 | 63.98 \pm 16.14 | 3.4141 | 0.0012* |
| Self Esteem | 66.78 \pm 11.29 | 65.29 \pm 13.61 | 0.5067 | 0.6141 |

All calculations done using the Unpaired t test (*significant $p < 0.05$)

DISCUSSION

The study demonstrated that quality of life is significantly worse in strabismus. Many studies in past have shown results on similar lines [17-18]. These studies attribute this reduced quality of life to just not only the functional impairments caused by strabismus, but also due to psychosocial disturbances caused by bullying or cosmetic disfigurement caused by strabismus [18]. There have been studies that have demonstrated that strabismus surgery improves quality of life in children and adolescents irrespective of the functional impairment due to the cosmetic changes and improvement in facial features [19].

In our study Family and Social Contact aspect of the quality of life were significantly reduced in children and adolescents with strabismus. The child with strabismus often may face discrimination at school and/or home and this possibly leads to some form of psychosocial disturbance [20]. A study has shown that 84.17% of the parents used to feel that other people notice their child's strabismus during interaction, 91.67% parents considered strabismus as a form of facial disfigurement while 61.67% parents felt that their children would have difficulty in interacting with their own peer group and in making friends [21]. The two groups however did not differ on self-esteem scores. Parents filling in the questionnaires for both children may have had a bias that led to the same. The perception of self esteem is highly varied and this also may have affected the scores [22].

In this study decrease in quality of life could not be purely attributed to the strabismus and but there may have been multiple factors at play. The limitations of this study were a small sample size, a relatively short time period of 4 months and the cross-sectional nature of the study. Further larger studies in diverse samples are need to corroborate and give impetus to the findings of this study.

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A Cross-sectional study to explore Sexual dysfunctions among male Hypertensive Patients attending Medicine OPD of Tertiary care centre, Western India

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ABSTRACT

Background: Sexual dysfunction has been traditionally attributed to psychogenic origins and managed by mental health professionals and urologists. However, advances in pathophysiology research point to a vascular origin of the problem in the majority of patients, possibly due to atherosclerotic lesions in the genital arteries that result in decreased blood flow. During management of Hypertension; even the highly skilled physicians fail to raise the question of sexual dysfunction as they have never been accustomed to do it in their routine practice.

Aim: The study has two aims- (i) to evaluate sexual dysfunctions in male patients of Hypertension and (ii) comparison of sexual dysfunctions and other variables between case and control group.

Methodology: Consecutive 200 Hypertensive patients were included in the study. Individuals with comparable age served as a control group. Detailed socio-demographic variables, substance history and treatment history for hypertension obtained using a semi-structured Performa. Subject's sexual dysfunctions were assessed by ASEX (Arizona Sexual Experience Scale), IIEF (International Index of Erectile Dysfunction), PEDT (Premature ejaculation diagnostic tools).

Result: Of the 200 hypertensive patients, 74(37%) participants reported erectile dysfunction, 16(8%) participants reported premature ejaculation, while among 200 normotensive participants, only 8(4%) reported erectile dysfunction, 15(7.5%) reported premature ejaculation. Of the hypertensive participants studied, 23% had severe, 8% had moderate, 6% had mild erectile dysfunction. Frequency of erectile dysfunction increase with advancing age.

Conclusion: The present study has revealed that erectile dysfunction was a major problem, with a higher prevalence among hypertensive men than normotensive men. Age was considered statistically significant predictors of erectile dysfunction.

Keywords: Sexual dysfunctions, International Index of Erectile dysfunction, Arizona sexual experience scale, Premature ejaculation diagnostic tools, hypertension.

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INTRODUCTION

Sexual dysfunction represents a common condition in the general population placing a major burden on patients' and their sexual partners' quality of life. Sexual dysfunction has been traditionally attributed to psychogenic origins and managed by mental health professionals and urologists. However, advances in pathophysiology research point to a vascular origin of the problem in the majority of patients, possibly due to atherosclerotic lesions in the genital arteries that result in decreased blood flow. During management of

Hypertension; even the highly skilled physicians fail to raise the question of sexual dysfunction as they have never been accustomed to do it in their routine practice.

In 1993, a meeting of the Consensus Development Panel on Impotence at the National Institutes of Health defined erectile dysfunction (ED) as the persistent inability to attain and maintain a penile erection adequate for satisfactory sexual performance [1]. Recently, many analyses of hypertensive patients suggested that the prevalence of ED in hypertensive populations is high [2-3]. However, epidemiological data used to be relatively scanty to prove that hypertension was really a potential risk factor for ED.

Sexual dysfunction is a frequently encountered problem in patients with hypertension and may occur either as a side effect of some types of antihypertensive medications or as a component of the dysmetabolic syndrome of high blood pressure [4]. The prevalence of ED is significantly higher among men with hypertension than in general population [5-9]. A decrease risk of premature ejaculation (PE) has been reported in men with treated diabetes, while no association was found with hypertension, cardiac disease, hypercholesterolemia and peripheral or central neuropathy [10].

Few studies have been done on this topic in India and hence doing such a study in our setup will be helpful in identifying sexual dysfunctions in hypertensive male patients and treating this aspect of the disease as well.

METHODOLOGY

A cross sectional case-control study which was carried out on patients with clinical diagnosis of Hypertension who were referred consecutively from medicine department in a tertiary health care centre in Ahmedabad. The study was conducted on Hypertensive patients between 30 to 70 years of age during a period from September 2018 to May 2019. Ethical clearance has been taken from the institutional ethics committee. The subjects have been recruited on the basis of written informed consent.

A detailed questionnaire addressing their socio-demographic characteristics, general medical history with special emphasis on hypertension history (i.e., duration of hypertension, type of treatment and presence of any complications). Sexual function was assessed with Arizona sexual experience scale (ASEX), Premature ejaculation diagnostic tools (PEDT) and International index of Erectile Function (IIEF). A Gujarati and Hindi translation of ASEX, PEDT and IIEF was used to assess the sexual function.

The ASEX scale is a five-item rating scale that quantifies sex drive, arousal, penile erection, ability to reach orgasm, and satisfaction from orgasm. Possible total scores range from 5 to 30, with higher score indicating more sexual dysfunction. A total ASEX score of ≥ 19 would have sexual dysfunction [11].

The PEDT scale is a five-questions rating scale. The total PEDT score ranged from 0 to 20, with higher score indicating more premature ejaculation. A total score of ≥ 9 indicates premature ejaculation [12].

The IIEF and its scoring system were found to be a reliable and valid measure of the five relevant domains of sexual function in men, including erectile functions (EF), orgasmic function (OF), sexual desire (SD), intercourse satisfaction (IS), and overall satisfaction (OS). The IIEF items – EF, IS, and OF – are considered to reflect predominantly physical functions, and SD and OS to reflect mainly psychological functions.

The responses to questions 1–5 were rated on a 5-point scale. [14,15]; the total IIEF score ranged from 0 to 25, the higher score indicating the better sexual function. Patients were classified as having no (22 to 25), mild (17 to 21), moderate (12 to 16), or severe (1 to 11) ED; a higher score indicates better function [13-15].

Inclusion criteria:

1. Hypertensive male (age 30 to 70) attending Medicine outpatient department at tertiary health care centre in Ahmedabad.
2. Patients who are currently sexually active (married or unmarried) and suffering from Hypertension.
3. Patients who have been diagnosed with Hypertension for a period of 6 months or more.

Exclusion Criteria:

1. Not willing to provide informed consent for the study.
2. Patients having any other acute comorbidities and Major Depression, Anxiety and Psychotic spectrum disorders and their treatment.
3. Patients who have diabetes along with hypertension.

STATISTICAL ANALYSIS

Chi square test has been used to determine the association between categorical variables. The P value of less than 0.05 has been considered statistically significant.

RESULTS

Table 1: Comparison of sexual dysfunction assessed by ASEX scale between Hypertension cases and Normotensive control group

| ASEX score | Hypertension case | Control | P value <0.00001 |
|--|-------------------|------------|---------------------|
| Sexual Dysfunction (≥ 19) | 58 (29.0) | 4 (2.0) | |
| Normal (<19) | 142 (71.0) | 196 (98.0) | |
| Total | 200 (100) | 200 (100) | |

Table shows the comparison of ASEX score between the cases of hypertension and control group. Here the P value for correlation between sexual dysfunction and hypertension is less than the significance level of 0.05, which indicates that the correlation coefficient is **significant** which means that sexual function is significantly impaired in hypertension in comparison to control group. Here 29% of hypertensive cases have sexual dysfunction, whereas 2% of controls have sexual dysfunction.

Table 2: Comparison of erectile dysfunction assessed by IIEF scale between Hypertension cases and Normotensive control group.

| IIEF score | Case | Control | P value <0.00001 |
|--|------------|------------|---------------------|
| Erectile dysfunction (≤ 21) | 74 (37.0) | 8 (4.0) | |
| Normal (>21) | 126 (63.0) | 192 (96.0) | |
| Total | 200 (100) | 200 (100) | |

Table shows the comparison of IIEF score between the cases of hypertension and control group. Here the P value for correlation between erectile dysfunction and hypertension is less than the significance level of 0.05, which indicates that the correlation coefficient is significant which means that erectile dysfunction is significantly present in hypertension in comparison to control group. Here 37% of hypertensive cases have erectile dysfunction, whereas 4% of controls have erectile dysfunction.

Table 3: Comparison of premature ejaculation assessed by PEDT tools between Hypertension cases and Normotensive control group.

| PEDT score | Case | Control | P value 0.851663 |
|--|------------|------------|---------------------|
| Premature ejaculation (≥ 9) | 16 (8.0) | 15 (7.5) | |
| Normal (<9) | 184 (92.0) | 185 (92.5) | |
| Total | 200 (100) | 200 (100) | |

Here the P value for correlation between premature ejaculation and hypertension is more than the significance level of 0.05, which indicates that the correlation coefficient is insignificant which means premature ejaculation is not significantly present in hypertension in comparison to control group. Here 8% of hypertensive cases have premature ejaculation, whereas 7.5% of controls have premature ejaculation.

Table 4: Comparison of severity of erectile dysfunction assessed by IIEF score between Hypertension cases and Normotensive control group.

| Severity of erectile dysfunction by IIEF score | Case | Control | P value <0.00001 |
|--|------------|------------|------------------|
| Severe (1-11) | 46 (23.0) | 1 (0.5) | |
| Moderate (12-16) | 16 (8.0) | 6 (3.0) | |
| Mild (17-21) | 12 (6.0) | 1 (0.5) | |
| None (22-25) | 126 (63.0) | 192 (96.0) | |

Nearly 23% of hypertensive men reported severe ED; 8%, moderate ED; 6%, mild ED. 0.5%, of normotensive men reported severe ED; 3%, moderate ED; 0.5%, mild ED.

Table 5: The difference IIEF-5 scores among hypertensive and normotensive men by factor such as age, educational level, socioeconomic class, smoking status and duration of hypertension

| Variable | Hypertension Case | Normotensive men | P value |
|---|-------------------|------------------|----------|
| Age group (years) | | | |
| <40 | 1 (0.5) | 1 (0.5) | <0.00001 |
| 40-59 | 17 (8.5) | 2 (1.0) | |
| >=60 | 56 (28.0) | 5 (2.5) | |
| Education | | | |
| Uneducated | 14 (7.0) | 1 (0.5) | 0.3616 |
| Primary | 22 (11.0) | 1 (0.5) | |
| Secondary | 18 (9.0) | 2 (1.0) | |
| Higher secondary | 4 (2.0) | - | |
| Graduate | 16 (8.0) | 4 (2.0) | |
| Socioeconomic class | | | |
| Lower class | 20 (10.0) | 1 (0.5) | 0.43899 |
| Lower middle class | 26 (13.0) | - | |
| Middle class | 6 (3.0) | 4 (2.0) | |
| Upper middle class | 16 (8.0) | 3 (1.5) | |
| Upper class | 6 (3.0) | - | |
| Smoking status | | | |
| Substance | 25 (12.5) | 3 (1.5) | 0.833224 |
| Non-substance | 49 (24.5) | 5 (2.5) | |
| Duration of hypertension (years) | | | |
| 1-2 | 16 (8.0) | NA | NA |
| 3-4 | 20 (10.0) | | |
| 5-6 | 8 (4.0) | | |
| 7-8 | 10 (5.0) | | |
| 9-10 | 14 (7.0) | | |
| >10 | 6 (3.0) | | |

Table 5 presents the differences and comparisons in IIEF scores between hypertensive and normotensive groups by socio-demographic factors. Frequency increase with advance age. A significant association was found in both hypertensive and normotensive men with ED score in respect of their age. (P<0.00001).

DISCUSSION

Hypertension is often cited as a risk factor for sexual dysfunctions, especially for Erectile dysfunction. In the present study over all prevalence of erectile dysfunction in patients with hypertension alone was 37%, while in normotensive was 4%. The present study reported some degrees of erectile dysfunction. Overall prevalence for Premature ejaculation in patients with hypertension was 8%, while in normotensive was 7.5%. The results of our study supported the results of other study conducted by Mittawae et al. in Egypt, which showed that among 800 patients with hypertension alone, the overall prevalence of ED was 43.2% [16]. Other multicentre Spanish study [17] reported a prevalence of 45.8% of ED in 2130 patients with hypertension. A few other studies have reported different prevalence rates of ED in hypertensive men, which were higher than the prevalence in our study. Case-control study in Qatari hypertensive and normotensive men, reported a prevalence of 66.2% [18].

Study limitations:

- The present study using IIEF has certain limitations. A prevalence estimate of the IIEF questionnaire may not cover all the domains of sexual dysfunction. The study may not include all the targeted population.
- We could not find the direction between different substance like (Alcohol, nicotine, cannabis etc.) and sexual dysfunctions, that is whether substances cause sexual dysfunctions or vice versa.
- Factors which we did not consider: Age, Substance use (Alcohol, Cannabis, Smoking), Psychological assessment (Stress, Depression, Anxiety), Anti-hypertensive drugs and any chronic medical illness.

CONCLUSION

The present study has revealed that sexual dysfunctions, especially erectile dysfunction was a major problem, with a higher prevalence among hypertensive men than normotensive men. Age was considered statistically significant predictors of erectile dysfunction.

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*Case Report***Asperger's Syndrome with depression and substance abuse:
First-time presentation and diagnosis in a 64-year old man**

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ABSTRACT

Autism spectrum disorders (ASD) rarely are brought to clinical notice in geriatric population. This case is of a 64 years old gentleman with high-functioning ASD (diagnosed as Asperger's Syndrome) presenting for social/ communication deficits affecting his personal life and career, resulting in depression and substance abuse. His family was skeptical about his symptoms. He was successfully treated for depression and substance abuse; CBT, psychoeducation, individual therapy, social skills training were done to help him cope with his ASD symptoms. Family therapy was done to improve the family's understanding of ASD and bonding with him. After 1 year of treatment, he is thriving in all aspects – better family relations, career management and personal emotional well-being. This opens up a discussion regarding undiagnosed ASD in older adults and elderly, comorbidities, the resulting community mental health burden which goes neglected, and therefore the need for more vigilant detection, and treatment options.

Key words: Asperger's Syndrome; autism spectrum disorders; geriatric; older adults; diagnosis; comorbidities

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INTRODUCTION

When we think of autism spectrum disorders (ASD), it generally evokes pediatric and adolescent first-time presentations; elderly population exclusively seeking help for what turned out to be ASD with secondary mental health concerns are few and far between. Adult/ geriatric ASD generally come to clinical notice when they present with subsequent psychiatric issues like depression, anxiety, psychosis, substance abuse or co-morbid neurodevelopmental conditions like attention deficit and sensorimotor dysfunctions [1]. The following case is of a first-time diagnosis of Asperger's Syndrome (AS) with depression and substance abuse in a 64 years old man.

CASE REPORT

A 64 yearS old gentleman Mr. X came along with his family to Psychiatry services OPD with chief complaint that he felt sad as he couldn't understand how to socially interact correctly. Since childhood, he has had poor eye contact, limited facial expressions, poor ability to make friends, meagre understanding of sarcasm, jokes and double meanings, little capacity to empathize and disproportionate displays of anger (he is perceived to be angrier than he feels). He has never been good at expressing his emotions, understanding non-verbal communication, interpreting body language or intuiting social communication. He has a habit of making circling gestures on surfaces (e.g. table) with his fingers, especially when he is agitated/ attempting to focus on something he finds unpleasant. He says he was never bothered till recently regarding his social inadequacies; he felt he was slightly eccentric but never had fear of being socially rejected (rather, he felt

most people did not share any common interests with him and therefore he preferred not to interact with them). He was academically brilliant in Physics and Mathematics in school. He had an arranged marriage at the age of 18 years. He stayed away from family for his job for almost 35 years. Last 3.5 years, he has been staying with family. Since then, he has constant tiffs with his family over his behavior where they tell him he is intentionally being obtuse and not making an effort and he explains that he is just not able to understand when they say one thing and mean another. He asks for short clear instructions, has a very narrow comfort zone and has a certain rigidity in managing his work and daily life. The other members of his family (wife, 2 children), in contrast, are very social, and felt he is socially (and physically) clumsy, avoidant of people and situations where a lot of small talk is required and that he tended to be lost in his own world. Mr. X said he communicates better with the family over written medium than face to face as then he doesn't have to attempt to interpret their tone, facial expression etc. However, he did have meaningful emotional relations with his family, satisfactory sexual relationship with wife as well as 2 close friendships that have sustained over 30 years. He is working as a software consultant in a video game development company and on enquiry, he said he chose this field because he had excellent skills in terms of this kind of software development (otherwise he thinks he had a limited skill set) and it requires minimal interactions with people, so he feels at ease. He tended to avoid meeting clients, again to escape small talk. He preferred focused detailed conversations on topics of his own interest where he could speak very well and at length. He has quite limited fields of interest in which he spends all his time - coding, pure mathematics, listening to 1980s' pop music and collecting those records, playing the piano and the violin. The family reported that he would exclusively pursue these activities at home, especially if he was unhappy. They felt he was faking this communication problem as he did not like socializing/ giving them time and therefore constantly blamed him. His birth and development history and family history, as far as known, was unremarkable. He was hypertensive and hypercholesteremic and was maintained on amlodipine 5 mg and atorvastatin 10 mg since the past 7 years; there was no significant history of medical issues/ organicity otherwise.

At the time of presentation, he had low mood, poor sleep, easy fatigability and irritability. Regarding his communication difficulties, he was angry with the family for failing to understand him as they knew he finds general chit-chat very boring; he felt astonished that this issue is so important to everybody and hence was impairing his life so much, and frustrated with himself because it was beyond his capabilities to overcome this. These symptoms had been there since 3 years but has intensified since about 1 month after a professional setback that happened as a fallout of his poor social skills (he felt he had a healthy debate with a client whereas the client felt that he was very loud and angry and so escalated the matter to the company HR department). He was afraid of losing his career which is a dearly held vocation for him, and so had some crying spells and feelings of helplessness and worthlessness. Over last 2 years, he had become addicted to nicotine (cigarette smoking, 8 sticks/day) and alcohol (whisky, binge-pattern, 2-3 QTR/ sitting, 2-3 times a month) in pursuit of relief from his depressive symptoms. He came to Psychiatry services to find out whether he really had a communication/ social skills problem, and if yes, how he could improve it as he felt it was upsetting his life and consequently, him; he also wanted to be de-addicted from nicotine and alcohol. He had never undergone any evaluation for these issues in the past.

Of salience in mental status examination, he had poor eye to eye contact but established a good rapport and sustained attention during interview, had stereotypical hand movements, low mood, ideations of helplessness, worthlessness but intact judgment and insight 5/6. He was diagnosed (see Table 1) with Asperger's syndrome (F 84.5), moderate depressive disorder (F32.1), alcohol harmful use (F1x.1) and nicotine dependence (cigarettes, uncomplicated) (F17.210) [as per ICD-10] and treated accordingly (see Table 2).

Presently patient says his AS diagnosis has brought him relief from guilt regarding his social awkwardness and improved self-esteem as he continues to work actively to better it.

DISCUSSION

An American study pegs the prevalence of AS in young adults at 0.7 % -1.9 % [7]. No concrete epidemiological data could be found regarding its prevalence in geriatric or adult global/ Indian population.

Though the epidemiology of ASD in Indian children is being studied regularly (latest pooled percentage prevalence 0.09-0.11), recent studies and meta-analyses alike have lamented the lack of high-quality epidemiological data regarding ASD in Indian adult population and it is surmised that due to it, they would have a substantial undiagnosed mental health burden [8-10].

It is not unusual for people with AS to have mental health issues due to their poor interpersonal and communication skills. Often clinically undetected, especially in context of adult population, it can lead to depression, mood disorders, anxiety, worsening of self-isolating behaviors, poor self-esteem, suicidality, psychosis, addictions and other sundry mental and behavioral disorders. Being shunned by family and society only leads to further aggravation as they cannot form any gainful emotional relationships, have difficulty with employment and a poorer quality of life. Even if they have average IQ, they may still have co-morbid attention deficit, hyperactivity, and variable neurological deficits. Mr. X did actively want to seek help for the social/communication deficit and the following depression and addictions; unlike him, even though it is common to seek help for the secondary mental health disorders, very few manage to understand and seek help for the core ASD symptoms [1,8, 11-12].

Once diagnosed, treating such cases can have challenges in terms of limitations in treatment options and long duration of untreated condition. If the person is high-functioning, CBT has been tried with some modicum of success [13], as seen here. Else, treatment should entail multi-disciplinary collaboration with psychopharmacology, supportive psychotherapy/ education, de-stigmatizing and improving family's approach towards the patient, polishing up social skills through specific training, occupational therapy for sensory/ fine motor issues if present, as well as treating the secondary psychiatric complications. Each case ought to be approached eclectically, and if there are cognitive deficits, lack of employment or social support, they should be helped to avail government concessions/ aid and additionally referred to social services or agencies that work with ASD persons for life-long social, occupational, financial and legal support as necessitated [1,8,11,14-15].

Proactively sensitizing family and community regarding ASD might go a long way in increasing detection, treatment and reducing the community mental health burden. For high-functioning ASD, specially screening adults with low global functioning and employees of STEM [science, technology, engineering, mathematics] theoretical and research fields (as selected AS individuals tend to gravitate towards these niche fields) can prove fruitful [14]. As mental health professionals working in India, to understand better the scope of adult ASD from epidemiological, management and research point of view, we should widen our traditional child-centric focus to include adults, working and geriatric populations.

TABLE 1: Differential diagnosis (as by ICD-10) [2]

| Asperger's syndrome | Anxious [avoidant] personality disorder | Schizoid personality disorder | Anankastic personality disorder |
|--|---|--|---|
| Consists of childhood onset, more in males, physical clumsiness, qualitative multiple impairments of using non-verbal behaviors/ gestures, restricted repetitive stereotyped patterns of behavior/ interest/ motor mannerisms without any clinically significant delay in language/ cognitive milestones | Consists of pervasive pattern of tension, belief one is personally unappealing, excessive preoccupation with being criticized in social situations, unwilling to be involved unless certain of being liked, avoiding interpersonal contact due to fear of rejection all becoming prominent early adulthood. | Consists of pervasive pattern of detachment from social relationships, lack of interest in family/ sexual relationships, flattened affect, lacking close friends any confidantes, taking pleasure in almost no activity, prone to internal fantasizing, all becoming prominent in early adulthood. | Consists of pervasive pattern of perfectionism, excess caution, preoccupation with details, neatness, excessive conscientiousness, rigidity and unreasonable stubbornness, sometimes insistent and unwelcome thoughts, all becoming prominent in early adulthood. |

| | | | |
|--|---|---|--|
| <p>LIKELY DIAGNOSIS IN THIS CASE AS: Childhood onset Male gender No delay in communication milestones Poor eye contact Limited facial expression Unable to make friends due to lack of communication skills despite desire to do so, but very content to be by himself pursuing his interests Academically gifted in physics and math, and later career points to 'high-functioning' Very narrow focus of interest Lack of social reciprocity Physically clumsy Stereotyped mannerism in form of circular movements with fingers</p> | <p>NOT LIKELY DIAGNOSIS AS IN THIS CASE: Childhood onset Avoids social activities as he finds communicating tedious but he has no fear of social rejection/ embarrassment Is quite obtuse to criticisms about his social behaviour Finds others boring if they do not talk about something that interests him, rather than having any sense of hypersensitivity to negative evaluation</p> | <p>NOT LIKELY DIAGNOSIS AS IN THIS CASE: Childhood onset Has lasting close friendships Cares adequately about family relationships Enjoys sexual relationship with wife Immensely enjoys activities falling into his area of interest No significant fantasizing</p> | <p>NOT LIKELY DIAGNOSIS AS IN THIS CASE: Childhood onset Though rigid, has no preoccupation with neatness/ perfectionism No insistent/ unwelcome thoughts Also, anankastic personality disorder does not entail communication difficulties.</p> |
|--|---|---|--|

Table 2: Management and recovery progression

| REFERRALS | | | | |
|--|---|---|---|--|
| General medicine: continue medications for hypertension and hypercholestermia. Ophthalmology: existing refractive error confirmed; has corrective spectacles ENT: nil active Neurology: nil active; good cognitive functioning Occupational therapist: no major sensory/ fine motor issues Clinical psychologist: Diagnostic: IQ by Wechsler's Adult Intelligence Scale: 132; Therapeutic: later for CBT, social skills training Genetic screening was not done due to family's reluctance. | | | | |
| INVESTIGATIONS | | | | |
| CBC, blood sugar levels, Hb1Ac, liver and renal functions, thyroid functions, serum vitamin B 12, D3, homocysteine levels, and MRI brain were all within normal limits | | | | |
| MANAGEMENT AND RECOVERY | | | | |
| Condition | At first presentation | After 2 months | After 6 months | After 1 year |
| Depression | HAM-D * score: 24 (moderate depression) Tab Escitalopram 10mg HS | HAM-D score: 15 (mild depression) Tab Escitalopram 10mg HS | HAM-D score: 06 (no depression) Tab Escitalopram 10mg HS | HAM-D score: 01 (no depression) Tab Escitalopram 5mg HS |

| | | | | |
|--|---|---|---|---|
| Alcohol abuse | Tablet Lorazepam 2mg HS Abstinence advised | Tablet Lorazepam 1 mg HS Did not opt for anti-craving medications Abstinence maintained | Tapered and stopped Lorazepam Maintaining abstinence No craving Avoids vicinity of alcohol | Maintained abstinence No craving Has attended events with alcohol, but no craving/ consumption |
| Nicotine dependence (cigarette) | Consuming 8 sticks/day Patient expressed willingness to cut down by himself; refused medications | Consuming 5 sticks/ day Increased craving especially after prolonged social interactions | Consuming 2 sticks/ day Craving much reduced Using ginger candy/ fennel seeds to substitute cigarette | Maintaining total abstinence since 2 months No craving (feels motivated by a sense of accomplishment after quitting both alcohol and nicotine) |
| ASD | ISAA score: 103 Psychoeducation for patient and family done CBT started | ISAA score: 100 CBT continued Family therapy done Social skills training started | ISAA score: 94 CBT continued Social skills training continued | ISAA score: 82 (improved in eye contact, social smile, responding to social cues and taking turn in interaction, reduced delayed response, reduced aggression/ temper tantrums/ exaggerated emotions) CBT over Social skills training 'brush-up' sessions still continued but less frequently |

*HAM-D = Hamilton's Depression Rating Scale: Given by Hamilton in 1960, well-known, 17 item, globally used scale with good psychometric properties (internal reliability 0.46-0.97, inter-rater reliability 0.82-0.98, test-retest reliability 0.81-0.98) to rate severity of depression. Interpretation: 0-7: no depression; 8-16: mild depression; 17-23: moderate depression; 24-52: severe depression. [3]

**ISAA = Indian Scale for Assessment of Autism: given by National Institute for the Mentally Handicapped in 2009, used widely in Indian studies, with acceptable psychometric properties (inter-rater reliability 0.83, test-retest reliability 0.89) to rate severity of autism. Interpretation: <70: no autism; 70-106: mild autism; 107-153: moderate autism; >153: severe autism [4-6]

*** ISAA was used here as, in its manual, there is no age limit mentioned but it is mentioned that this can be used for all persons with autism; studies have shown that it has been used in adults previously; [4,5] rating was done after observing and interviewing patient as well as interviewing his wife and mother (86 years, cognitively sound).

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*Case Report***Shared Psychotic Disorder: A case of “Folie a deux” with a delusion of pregnancy**

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ABSTRACT

Shared psychotic disorder (Folie a deux), is a rarely seen and poorly understood psychiatric disorder. It is characterized by the transfer of delusional belief from one primary patient, who already suffering from a psychotic disorder, to another, the secondary patient. Here we present a case, of daughter of schizophrenic mother who has shared psychotic disorder with belief delusion of pregnancy. It was easily diagnosed but a bigger challenge for management purpose.

Keywords: Shared psychotic disorder, folie a deux, delusion of pregnancy.

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INTRODUCTION

Shared psychotic disorder (PSD), also known as ‘Folie A Deux’, is a rare clinical disorder which was first coined by French Psychiatrists Charles Lasegue and Jean-Pierre Falret in 1887 so it is also called Lasegue-Falret Syndrome [1]. It has various names under umbrella of SPD such as psychosis of association, shared paranoid disorder, communicated insanity, contagious insanity, induced delusion disorder, psychosis of association, double insanity, induced insanity, insanity by association, induced psychotic disorder, folie a deux, folie a trios, folie a quatre, folie a cinq and folie a famille [2].

The nature of this disorder is a transfer of delusional belief from one person (inducer, the primary patient) to another (recipient, involved, induced partner or secondary patient). The primary patient is known as the ‘dominant’ or ‘principle’ partner and the secondary patient, who is influenced by the primary patient, is known as ‘submissive partner’ or associate [3]. The disorder commonly occurs within families, and it is most commonly seen between husband and wife, between two siblings and as well as mother and daughter and also noted in other close relationships. It is commonly seen in female than males to both primary and secondary partner. In SPD patient usually accompanied by delusional symptom and delusions shared are usually persecutory in nature, followed by grandiose delusion. Hallucinations are more commonly seen in inducer. The one of the precipitating or risk factors of this illness are both patients usually live in close proximity and they are always isolated from the outside world and its influences [4]. Average age of onset for disorder in both primary and secondary patient is in the adult age group [5], however may affect any age of population [6]. Regarding causes, natural history and prognosis of the syndrome are still unclear.

There are four types of folie a deux: (a) Folie impose’e; (b) folie simultane’e; (c) folie communique’e; and (d) folie induite [7]. Folie impose’e is the most common form of folie a deux, in which the primary case is typically dominant and forceful. The secondary case is usually dependent, highly suggestible and in this delusion always disappears after separation. Folie simultane’e is the simultaneous appearance of identical psychoses in two predisposed persons who have a long, intimate association and in this delusion never

disappear after separation. Folie commune'e involves the transfer of psychotic delusions after a long period of resistance and in which delusion typically persists despite separation. In folie induite, new delusions are added to old ones under the influence of another deluded patient.

Diagnostic and Statistical Manual of Mental Disorders (DSM) of previous version, SPD was popularly known as 'Folie a Deux,' In the current DSM-5 diagnostic criteria, this diagnosis has been removed and grouped under the umbrella of 'Delusional Disorders' owing to the fact that the belief in question might normally be widely shared amongst people of the same culture. In International Classification of Diseases-10 diagnostic criteria (ICD 10) however, 'SPD' still remains relevant. Like most psychiatric phenomenon SPD was also the theme of a well-known movie, 'Cries and Whispers' [8], by Ingmar Bergman, in the movie a nurse is inexorably drawn into the psychosis of her patient. Before this syndrome was assigned by a researcher, William Harvey in 1651 who described a case of 'phantom pregnancy' associated with folie a deux in two sisters who both believed that they could frequently feel the movement of the child as they occupied the same bed [9]. In our case mother and daughter both are having delusional belief of pregnancy. SPD treated both inducer and recipient with a psycho-pharmacological approach with antipsychotic drugs [10].

CASE REPORT

The mother 'X' 59 years old divorced female and her daughter 'Y' 41 years old unmarried female. Both were brought to our hospital by relative, with history of disturbed behavior. Patients are not leaving with each other, even though they used to sleep at different bed but very close.

Mother 'X' had diagnosed case of schizophrenia for more than 20 years. Her symptoms were relapsed due to non-compliance with medications since the past 2 years. She complained of suspiciousness towards neighbor, and believes that her neighbors want to marry their daughter with her husband. Also believe that her husband is in higher position, a doctor by profession, said she is pregnant of 6 months duration and occasionally anger outburst. For her illness she was started on tablet haloperidol 10mg at bed time, tablet olanzapine 5mg twice per day and benzhexole 5mg in morning.

Her daughter 'Y' 41 years old, unmarried female, she is eldest among siblings. She is very close to her mother and always shared most of the time with and supported her mother. Day by day her bonding with mother increased. Patient is also dependent personality traits such as always depends on her mother and used to sharing all activities with her mother. She gradually developed same delusion of pregnancy. She also believes that she is also pregnant like her mother and her husband is also a doctor by profession and she is 6 months old pregnant but actually patient is unmarried. No history of sexual contact with any male and she are submissive to their pregnancy. No history of psychiatric illness in past, she had no history of substance abuse and medical illness, she had normal delivery and birth milestone achieved normal. She is graduated in psychology but never employed since long. Her physical examination was normal. On mental state examination, she revealed anxious mood, delusion such as belief in pregnancy and erotomanic delusion such as believe that their husband are in a higher position, a doctor by profession, her cognitive functions were intact. After complete assessment, a physical examination including a gynecological, no abnormality seen. Pregnancy test was done; there is no evidence of pregnancy seen. Complete laboratory work up such as complete blood cell count, liver and kidney function test was done, it was within normal limits. She was diagnosed SPD and her mother with schizophrenia.

Both patients were separated from each other and kept in different ward. She was given tab risperidone 2mg at bed time and tab lorazepam 1mg for her anxious mood and sleep. Patient was referred to psychologist for psychotherapy also given psycho-education. She was reassessed after one month patient 'Y' showed rapid improvement and she gave up her delusion of pregnancy as well anger outburst. They were discharged on two different dates to provide reinforcement of the improvement obtained. On follow up after the next one month mother 'X' well settled on medications and dramatic improvement was seen in their delusion, later it was completely subsided.

DISCUSSION

In our case report as reported in literature delusion developed in context of close relationship with another person, occurs within the family member majority in blood relatives, such as mother and daughter. In literature it is mentioned that 72 percent of primary cases and 54 percent of secondary cases were female in SPD, and in our case both are female. Other risk factors are stressful life event, in our case father of patient 'Y' divorced her mother 'X'. As a daughter 'Y' never had contact with her father after divorce and mother is only parent, so social isolation may be possibility of development of her SPD. Various studies reported that the pre-psychotic personality of the individuals affected by shared psychosis and our patient is dependent, insecure, and passive in social life. That's why our case met current operational criteria for SPD and supports this diagnosis. Temporal evidence shows that delusion of pregnancy was transferred to daughter 'Y' from mother 'X'. Patient 'Y' showed remarkable improvement after separation from mother 'X'. In our case, belief of pregnancy were associated with erotomanic delusion, believe that their husband are in higher position, a doctor by profession.

This case illustrates a subtype of folie imposee, which is the most widespread and classical form of the disorder. In this subtype delusion of the person with psychosis is transfer to a person mentally sound and the delusion of the recipient disappears after separation. Dependent personality traits in the secondary person 'Y' was reported in this case report. The literature revealed that the affected person was mostly female and younger than primary person, on our case primary person mother and secondary person is her daughter. Patient 'X' who had maintained long term close symbiotic relationship with her daughter 'Y', make it compatible with these findings. Also reported that 'separation from the primary source' is the first step of the treatment and in our case we got remarkable result, our patients gave up delusion of pregnancy after separation from primary source her mother who is schizophrenic since long. In the presented case, the diagnosis of SPD was supported by an usually close relationship between these individuals, one being dominant 'X' and other submissive 'Y' between mother and daughter respectively. The symptoms started to remit when separation from 'Y' so longer separation would benefit the induced individual in the presented case. Due to lack of insight of illness and failure to seek treatment, there are chances of aggravation of symptoms so it's bigger challenge for psychiatrist regarding management of such cases.

SPD is a rare and poorly validated psychiatric illness. If it is not properly diagnosed, the patients may face unnecessary investigations and procedure that are costly and not mandatory. Proper diagnosis of this disorder can result in successful treatment outcome by separation from primary source and if needed psychopharmacology. Psycho-education and separation from primary source result in drastic improvement of belief in secondary source. Genetic transmission of such shared psychotic illness from mother to daughter so in future further test for gene transmission should be considered.

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Scope of the Journal & Instructions to the Authors

Indian Journal of Mental Health (Journal) is the official publication of the Desousa Foundation that considers for publication manuscripts that must be prepared in accordance with 'Uniform requirements for Manuscripts submitted to Biomedical Journal' developed by Journal Editors (2006). The uniform and specific requirements of the Indian Journal of Mental Health are summarized below. The journal will be published twice a year with one or two supplement issues every year. It is also the official journal of the Global Society for Digital Psychology and has a dedicated section on Digital Psychology which shall publish articles in keeping with the aims and objectives of the society. This is in addition to articles on psychology, mental health, psychiatry, psychopharmacology and psychiatric social work as well as occupational therapy that are also published in the journal.

THE EDITORIAL PROCESS

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