Researching with Specially-abled children: An experience

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Abstract

Any research that is undertaken is a time consuming process that requires an immense amount of hard work. Moreover, if the research conditions are not conducive, the journey becomes excruciating. While there are many difficulties that a researcher can face, gathering data from participants plays a major role in conducting research. The inability of the participant to give the required information can be on account of numerous reasons- most of which are easy to overcome. But, in research conducted with specially-abled children, the situation becomes more challenging. In this paper a case study conducted on one such participant is presented.

Keywords: specially-abled, autism, case-study

Introduction

A case study is defined as the research methodology that is requires in-depth investigation: of one single individual, a group of people sharing similarities, or an event about which information is being gathered. Generally, case studies can be either descriptive studies or explanatory studies based on their reporting procedure. Explanatory case studies are useful for exploring the cause of a certain phenomenon in order to find the underlying principles that govern it. Therefore, the case study method requires an in-depth, longitudinal data collection of an instance or event, that is, the case. Case studies are therefore, systematic process for analysing events, data collection, analysis and finally the reporting of results. Consequently, the case study method enables the researcher to gain a more focused conceptualization of the process that is being studied. It forms a solid foundation for future research towards problem solving. This is possible since the case study model of data collection and analysis prove useful for both generating as well as testing hypotheses.

A Case Study can therefore be surmised as:

- an empirical inquiry investigating real-life scenarios/problems
- requires a certain amount of quantitative analysis along with a qualitative data collection,
- by extension required numerous modes of data collection
Case Study as a Research Strategy

Any usefulness of qualitative research procedures remains a point of debate among practitioners. The same holds true for case study method of data collection, analysis and interpretation. Miles (1979), criticizing the method stated that the procedure’s utility is partial at best on account of its usefulness only in the initial exploratory phase of a longitudinal research project. But others such as Yin (1981) who are in favour of the case study method are of the opinion that case studies have numerous uses and are limited just on account of the lack of understanding about its various applications including the types of research questions best addressed and the type of case study design. Furthermore, Yin (1984) identified three conditions that determined the type of research programme indicated. These include the type of research question that governs the study, the degree of investigator control to keep the study on track; and, the amount of focus that can be given on the contemporary researchable events.

Therefore, the case studies provide prospective researchers with both the historian's primary and secondary documentation as resources, and also add direct observation procedures, and systematic interviewing of the respondents of the study to its annals of data gathering tools. It is thus useful for a wide range of data documentation procedure that includes but, is not limited to artefacts, interviews and observations—individual, focus group as well as a larger number of participants.

Objectives

The objectives that govern the present study include the following:

- To understand the psychology and behaviour of the case in the overall context
- To collect multidimensional information about the case understudy
- To explore the developmental history of the case
- To acquire knowledge about the family and parental history
- To focus attention on understanding the emotional and intellectual behaviour of the child
- To understand the socialization processes and social history of the case

Procedure:

As one of the stated objectives of this report is to collect multidimensional information about the case understudy, the methods deployed to achieve these are:-

1. Personal interviews
The Problem: Autism

Autism refers to a neurological disorder indicated by impaired social interaction, communication, restricted and repetitive behavior among those afflicted with it. Usually the symptoms start appearing before the child turns three years. Autistic individuals’ brains are unable to undertake information processing as a result of altered synaptic connections of their nerve cells. The symptoms develop gradually, but in rare cases the autistic children at first develop normally and then undergo sudden regression. The individuals whose cases are detected early on can be provided both behavioral as well as cognitive intervention depending on the requirement of the autistic child to make them aware of self-care procedures and social, and communication skills that are important to negotiate adulthood. Very few cases of recovery are reported among autistic children and those who reach adulthood need assisted living all through their lives. Like most issues there is a raging debate about whether autism should be accepted as a difference or a cure should be found for those individuals afflicted with the condition.

Social Development

Children afflicted with autism exhibit certain traits that make them incapable of adjusting to social interactions. This becomes evident in the early days and includes inability to respond to social stimuli such as smiling or looking at other people around them. Furthermore, they tend not to respond to their names. They do not make much eye contact, and choose not to take turns during group playing with other toddlers. Also, small movements that indicate a healthy psychomotor development among infants such as pointing out to different objects, are found lacking among autistic children. Three- to five-year-old autistic children exhibit very limited social understanding, do not approach others spontaneously, cannot imitate or respond to emotions, or incorporate non-verbal communication in their play. However, they are able to form strong bonds with their primary caregivers. Children afflicted by high-functioning autism suffer in greater intensity by frequent bouts of loneliness compared to their non-autistic peers. Contrary to popular belief autistic children do like the company of their primary caregivers but are usually unable to express this need adequately. Consequently, these children find it difficult to make friends and maintain friendships; this continues to adulthood as well since the autistic children never get a chance to develop the negotiation of social interaction. Erroneously, this lack is reported in many instances as aggressive and violent behavioral patterns; this in reality is the autistic child’s only mode of expression of his/her emotions.
Communication

Autistic children face impairment in their communicative abilities as well. Many of them fail to develop natural speech patterns that are necessary for daily communication. These start appearing from the very moment that children generally start speaking. Some of the features that are a red herring for autism include delayed onset of babbling before comprehensible speech development, unusual gestures that are akin to ‘jazz hands’, liminal responsiveness on being engaged by the caregiver, and vocal patterns that are inconsistent with the model set by the primary caregiver. As time progresses, over the next few years of natural language acquisition, autistic children tend to use more gestures and less speech to express themselves, do not use a lot of consonant sounds, or make word combinations that are indicative of language development. They are unable to make meaningful requests or share their experiences with the caregiver. Moreover, they tend to repeat words spoken by others, also known as echolalia; or pronounce in the reverse which in turn sounds like gibberish.

Repetitive behavior

Autistic individuals display many forms of repetitive or restricted behavior that are categorized by the Repetitive Behavior Scale-Revised (RBS-R) under the following sub-groups:

- **Stereotypy** among autistic children indicate repetitive movement like the incessant flapping of hands, making unintelligible sounds, rolling one’s head continuously, and rocking the body almost violently.
- **Compulsive behavior** comprises intended actions and appears to follow set patterns for undertaking mundane tasks. It includes the reorganizing of objects in stacks or lines almost compulsively.
- **Sameness** indicates a resistance to change exhibited by the autistic child. Often such specially-abled individuals insist that the furniture not be moved. They also react violently if interrupted when in the middle of something.
- **Ritualistic behavior** entails an unvarying pattern of habitual activities, including unchanging menu or a dressing ritual that the autistic child follows on a daily basis. This is similar to the repetitive behaviour of sameness and often understood interchangeably.
- **Restricted behavior** indicates the specially-abled child’s limitedness of focus, interest, or activity, like preoccupation with only a single television program, specific toy to play with, or the same game with the primary caregiver. Any deviation from the norm leads to violent behaviour in the autistic child.
- **Self-injury** is quite high among such children and includes self-injuring movements that include poking the eye, pulling ones’ skin, biting hands and fingers, and in extreme cases head-banging. A study conducted in 2007 reported that causing injury to oneself was a major problem among autistic children and it affected almost 30% of children with ASD.

While no single repetitive or self-injurious behavior is specific to autism only, symptoms of autism tend to increase in frequency and intensity of the fore-mentioned behavioral patterns. In the following section, the case of a single child is presented.
Case Selection

This case-study relates to a boy named V. Hemanth. The child at present is 10 years old. I came across him at the Sadhana Institute for the Mentally Challenged. This place caters to the needs of special children. They believe in the use of yoga therapy and speech therapy for helping the differently-able children under their care. Hemanth has been attending the school now for 5 years.

Hemanth’s Basic Details

- Name: V. Hemanth
- Date of birth: 29th November, 2004
- Age: 10 years
- Father’s Name: S. Venkat
- Mother’s Name: T. Kirthana
- Religion: Hindu
- Language known: Mother tongue (Telugu)
- Height: 3’8’’.
- Weight: 30 k.g.
- Level of Autism: Moderate
- Enjoys: Food, Music, Scribbling

Family History

Hemanth’s parents are both well educated. His father is an M. Com and his mother a B. Com. His father is a government job holder and his mother is a home maker. In spite of this, their family condition is not too well off as their monthly income is only about Rs. 10,000/-

Discussion

Hemanth’s autism is of the moderate kind. It means that he exhibits a few of the ASDs (Autism Spectrum Disorder) syndromes. Initially his parents were unable to comprehend their son’s erratic behaviour. At one moment he would be the symbol of peace while the very next moment would transform him into a messenger of pieces. He had a habit of lining up his toys and repeating a few words in his mother tongue- which is his only known language. Hemanth’s condition had been identified when he was 4 years old. He has been a part of Sadhana now for two years during the time span of which his condition has improved slightly.

His psychomotor skills are very ill developed. He cannot use his fingers and hands properly. Initially he could not even grasp objects. But now after intensive practice of the past 1 year, he can now put in 5 pebbles in a
bottle without much of an effort. But to go beyond the 5 is taking longer to accomplish. Consequently, his hand-eye coordination is also improving with each passing day.

By nature Hemanth is a complete recluse. It was very difficult to interact with him. The only people he interacts with, is his parents. At present, his trainer has been able to make some headway with her relationship with Hemanth. Now, at times he listens to her. But he did not want to be photographed. He was too shy. Also, if I was around, his behaviour underwent a sea change. When I observed him from afar, he was busy playing with his toys and other pieces. But whenever I went to join him, he became totally reticent. He simply clammed up and refused to behave according to his normal pattern.

**Conclusion**

Within the short time period that I could interact with Hemanth, I could not do a lot for him. The first and second day was spent in completing the formalities and just getting to make him comfortable with me around. It is very problematic to interact with them given the sensitive temperament these children have.

Yet one thing which worked for Hemanth to an extent was the playing of music. At the behest of his trainer, I played a few songs on my mobile phone. I do not know how far he could comprehend those, but he reciprocated by swaying to the music.

Maybe, along with music, the incorporation of some sort of dance will be beneficial for him as well. He already does a little bit of yoga. With the proper care and guidance from the trainer, this should not be much of a problem either.

As a novice researcher, the experience though, an eye opener was quite painful for me: especially, as I realized my ineptness in helping Hemanth. It was not possible for me to spend much time with him. I felt like an intruder in his world. To interact with him at any depth for a longer time period gave me a sense of actually treating him like a mere case and not a living, breathing, feeling individual. The next step of this case-study observation is to design an action plan for the participant’s foray into language learning through the use of study materials sensitive towards the needs of specially-abled children.

**References**

