Viewpoint Article

Factors influencing Parental Decisions of participation in a Neuropsychological study on Neurodevelopmental Disorders

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Research recruitment and attrition on subjects are challenges for all population groups, methods, and designs and across all disciplines [1]. Moreover, recruitment and consent for participation in clinical studies are understood to be important to a nation as well [2]. While we generally see data published and its results on the consented participants, very little is written of the reasons for non-consent of the participants in a clinical neuropsychological study.

The goal of this paper was to examine the factors that delineate the consenting versus the non-consenting subjects for a neuropsychological study involving parents of children with Neurodevelopmental Disorders (NDD) and those who are typically developing (TD).

NDD arises due to impairments in the developing brain and/or central nervous system [3]. They originate during the developmental period and are characterized by a delay or disturbance in the acquisition of skills under various domains such as motor, sensory, speech, and language, social & cognition; presented in heterogeneous conditions such as Attention-Deficit-Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Vision Impairment (VI), Epilepsy (Epi), Neuromotor Impairments such as Cerebral Palsy (NMI-CP), Hearing Impairment (HI), Speech and Language Disorders and Intellectual Disability (ID) [4].

A neuropsychological study assesses the brain functions and skills using a battery-based approach [5]. Many areas of cognitive ability such as memory, reasoning, problem-solving, verbal and nonverbal skills, intelligence are few of the many that a study attempts to tap. It involves performance-oriented tasks that are ipsative or normative in scoring.

In a neuropsychological study, compared to TD children and their parents, the consent from the parents of children with NDD poses greater barriers in obtaining their consent for a study. While recruitment of parents/carers for children with NDD is time-consuming [6], it imposes an extra burden to participate in a study apart from the health-care, parenting, and family issues, a child with NDD poses [1].

In a very brief cross-sectional two group survey design, we found a profile of factors emerging from the two sets of parents. The sociodemographic details of all the parents who were contacted in-person or on the telephone, were similar. They were professionals/post-graduates, in a nuclear family type and from high socioeconomic status families (on the basis of the locality they were staying) with children in the age group of 6 to 8 years.

All the parents contacted were with known and appropriate references only. They were told in detail about the nature and the need for the study, the time required for the session, the assessment method, and the assistance to research it would provide. As many as 19.64 % (N=11) TD parents and 16.42 % (N=13) NDD parents refused to participate in the study. The reasons for their interest and non-interest were probed once the decision was told to the author. They are compartmentalized into appropriate categories as adapted from Hoberman et al. (2013) and presented in Table 1. Some parents have mentioned more than one reason for their participation in the study. It depicts the factors influencing NDD parents mostly is what is of usefulness to the child if they consent to participate and they requested a copy of the developmental assessment report along with psychoeducational inputs if any. The NDD parents were concerned with the time taken for the administration of the tasks. On the other hand, TD parents were

interested to participate on the basis of the importance and benefit to research and the children with NDD. The main reasons of non-consent among NDD parents were the risk to the child involved, not wanting to discuss the issues of the child again with the researcher and the non-benefit to the child directly. Interestingly and contrary to the research questions raised initially on the NDD parents having barriers to participation, a high number of TD parents who are contacted had misconceptions regarding the misuse of their child's information and assessment report while being very busy to participate in such studies.

Table 1
Profile of factors influencing consent for a neuropsychological research study from the parents of both the groups

Factors Influencing Consent/Non-consent for Research Study	Consenting Parents of the two groups		Non-consenting Parents of the two groups	
	NDD parents (n=54)	TD parents (n=45)	NDD parents (n=13)	TD parents (n=11)
The benefit to the child (second opinion through the investigator, copy of the assessment report, psycho-educational inputs)	27	04	00	00
The benefit to others/research	08	21	04	00
Risk of the study (document of declaration/consent/assent misuse, personal information of a child or parent misuse, checking if proforma has information other than what has been declared, Audio-Visual use)	04	02	04	09
Importance of the study	00	06	00	00
The concern of study hampering their clinical care for the child (treatment centers delay or denial of care due to assessment in the case of NDD children)	00	00	02	00
Time taken for the administration of the study (30 to 45 mins preferred)	19	07	03	04
Place of testing (convenience)	08	28	00	00
Friends / other family members participating in assisting in participation/worried about the comparison of results with friends and family	00	32	03	01
Referral by any trusted health professional/center to participate in the study	04	02	00	00
Tasks used for the study	00	04	03	01

Adapted from Hoberman et al., 2013 [7]

These findings are preliminary and with a smaller size of sampling and cannot be generalizable to larger NDD cohorts or to other disorders. However, it definitely gives us a pointer towards factors to be understood for consent or decline of participation in such studies. Further, drawing a profile of parents might assist in tapping the accurate cohort for research while reducing attrition rates.

Extensive clinical registries are a norm for all clinical studies in the west, which should be implemented not just for drug trial cases but also for psychological studies. A form with signed approval to be contacted for research purposes at the institutions/hospitals from the patient/parent in-charge would help provide valuable data to propel valid research results. Further, such a registry at all institutions and hospital set-ups could be made available for research purposes. We strongly propose the same through this paper.

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