

Psychological and social factors in informed consent for patients with autism

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Psychological and Social Factors in Informed Consents for Patients with Autism: Case Studies on Treatment (Psychopharmacology), Genetic Testing and Research Participation

Name:

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Informed Consent for Research Participation

Pellicano, Dinsmore and Charman (2014) investigated the views of various stakeholders with respect in involving autistic persons and the general community in research on autism. In their findings, the group found that medical researchers were more confident while engaging autistic individuals and their communities. However, the communities had the opposite view of the researchers. This was attributed to the lack of involvement of the concerned communities in giving views, leading to skepticism and low willingness to consent to research studies.

Informed Consent for Treatment (Psychopharmacology)

Robotham et al. (2011) examined the levels of understanding and perceptions on the need to conduct randomized controlled trials among professionals, users and care givers concerned with provision of intellectual care, including care for autism cases. There was poor understanding of the principles attributable to randomized controlled trials among care givers and users, but understanding was higher among professionals. The authors noted that lack of understanding has negative implications on social validity of random controlled trials.

Informed Consent for Genetic Testing

Chen, Xu, Huang and Dhar (2013) conducted research into the levels of

awareness, attitudes and experiences among a sample that comprised parents of children who were undergoing genetic testing owing to their condition. More participants were in support of genetic testing research, mainly citing early intervention and motivation, identification of the causes of the condition, and family planning as their motivations. Competence of medical staff handling the tests was highlighted as a major concern among participating parents. Minority groups in the sampled population appeared to have lesser understanding of the importance of the procedure. At the psychological level, researchers are encouraged to learn the needs of such individuals to encourage their participation.

References

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