What do clinicians and clinical researchers need to know about psychosocial and neurocognitive constructs?

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This commentary is on the original article Payne by et al. on pages 813–819 of this issue.

Neurofibromatosis type 1 (NF1) is a genetic disorder characterized by abnormalities in (neural) cell differentiation, growth, and apoptosis, and also by a high prevalence of social problems.[1] Payne et al.[2] investigated associations between scores on the Social Responsiveness Scale, Second Edition (SRS-2), the Social Skills Improvement System – Rating Scales (SSIS-RS), and several other instruments measuring aspects of social functioning in children with NF1. The study compiled and linked data from four NF1-treatment centres in Australia and the USA in order to increase knowledge about behavioral end-points for clinical trials with NF1. The treatment centres assessed multiple aspects of social functioning using several different instruments. Upon reading the paper, one wonders whether different measures of social functioning can be used interchangeably as behavioral end-points after pharmacological or behavioral interventions.

Payne et al. found strong correlations between the scores on the SRS-2 and the SSIS-RS. SRS-2 and SSIS-RS scores were also significantly related to adaptive social skills and behavior (as measured by the Adaptive Behavior Assessment System and the Scales of Independent Behavior), and to measures indicating attention-deficit/hyperactivity disorder symptomatology. The authors did not claim that the significant associations indicate that the different instruments can be used interchangeably in clinical trials, although results might suggest this to clinicians and clinical researchers who lack detailed knowledge of psychosocial constructs.

The SSIS-RS rates children's social skills, specifically their communication, cooperation, assertion, responsibility, engagement, empathy, and self-control. The SRS-2 rates behaviors associated with autism spectrum disorder, including reciprocal social communication and interactions, restricted interest and repetitive behavior symptoms. The overlap in total scores for both instruments may be due to specific overlap in communication, cooperation, assertion, and responsibility from SSIS-RS, and reciprocal social communication from SRS-2. Nonetheless, these two instruments clearly tap into different aspects of psychosocial functioning, and similar arguments could be made about the overlap with other instruments. The fact that core psychosocial impairments are expressed in a wide range of social behaviors seems to have led to the addition of many non-specific items in existing instruments, and development of new instruments measuring daily life or 'global' social functioning.

Whereas a plea for more attention to psychosocial outcome measures may seem pedantic to medical professionals who deal with matters of life and death, there are examples from clinical trials using neurocognitive outcomes in NF1 that underline its importance. New forms of medication showed neurocognitive improvements in NF1-animal studies, but these effects could not be replicated in studies with human patients.[3,4] Obviously, it is a big challenge to mimic animal cognition in humans, but the lack of effects could possibly be attributed to the choice of instruments measuring neurocognitive functioning in human patients. A parallel exists with Payne et al. only weak relations were found between psychosocial functioning and measures of general intelligence. Based on the existing literature, stronger associations with specific aspects of cognition (e.g. executive functioning) may be expected.[5]

In order to be able to use instruments interchangeably, it is important that they have the same measurement potential. For example, in NF1, the outcomes on different instruments measuring autistic traits (where Payne et al. found the highest proportion of severely impaired scores) should be compared. The most important message, however, is that children with NF1 demonstrate problems in many different aspects of social functioning. In clinical trials with social functioning as the behavioral end-point, the choice of instrument(s) should be informed by this knowledge. At this stage, it would not be wise to pick one instrument over the other. Either use multiple instruments or compile the different aspects of social functioning as different dimensions in one instrument measuring global social functioning.

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