

The Pivotal Role of Parents in Documenting Early Development

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To assess trends and potential atypicalities in various developmental domains of children with a late diagnosis of developmental disabilities [e.g. autism spectrum disorders (ASD), Rett syndrome, fragile X syndrome] clinicians and researchers partly rely on retrospective information provided by the parents. Although caregivers have often been regarded as “naive” or “biased” informants when documenting or delineating their children’s specific abilities, the study by Kern suggests that “the benefit of studying parental reports may out-weigh the limitations.”^[1] In fact, numerous studies report a high concurrent validity of parental interviews/questionnaires/checklists with standardized assessments, for example when documenting on the early speech-language and communicative development.^[2,3] On the contrary, parental reports are also limited in their applicability as they do not allow for a documentation of the frequency with which children use particular vocabulary types, nor of the phonological development, and so on.^[3] In terms of retrospective data, we face additional limitations such as (a) the time lag (especially in case of conditions with a late clinical manifestation); (b) the awareness of diagnosis at the time of the interview; and (c) memory bias. Especially when documenting the onset of a particular behavior, specific aspects of regression, or frequencies of atypicalities, parental reports soon reach their limits.^[4,5] But how can we circumvent these problems? One way of analyzing early behavioral abnormalities and their developmental trends in detail

is the assessment of family videos recorded at a time when parents were not aware of the neurodevelopmental disability of their child. Retrospective video analysis has proved to be a valuable and practical instrument for identifying behavioral features that are hard to capture otherwise.^[5-7] Yet the retrospective video analysis also has its limitations, and a combination of both video analysis and parental reports is still the subject of controversy. Both methods have their strengths, including the fact that they are based on observations made in natural settings. On the contrary, studies (e.g.^[5]) have shown that video footage reveals more accurate data than parental questionnaires, especially when there is a long lapse of time between the interview and the period of interest. Video analyses allow precise descriptions of observable phenomena, although behavioral patterns missing in the assesment are not necessarily absent.^[5-7]

Recently, prospective studies in high-risk populations - especially in the field of ASD - have been breaking new ground. But when dealing with, for example, late-onset and rare genetic disorders we still, and almost exclusively, rely on parental reports and video recordings. Family videos are still fundamental for a better understanding of the early development of affected children.^[5-7] I am convinced that only in a joint endeavor parents, clinicians, and researchers will unravel a series of mysteries and thus enable an earlier detection of and earlier intervention in many conditions with a (presently) late diagnosis.

References

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