

Children with autism spectrum disorder in the canton of Zurich – Evaluation of daily life, early interventions, and need of support by professionals

N. Schneider, M. von Rhein, O. Jenni, C. Schaefer

University Children's Hospital Zurich, Child Development Center Zurich, Switzerland
 Children's Research Center, Zurich

Introduction

Autism spectrum disorder (ASD) received increasing attention in Switzerland and gained additional political relevance through the report by the Federal Council in 2018¹. It is well known that parents of children with autism are often greatly burdened by the intensive and challenging care of their child². Therefore, an early diagnosis and initiation of early therapeutic interventions is crucial for the development and quality of life of children with autism and their families³. A quote from a mother as an example of the burden: «Das erste, was mir in den Sinn kommt, ist Stress, ziemlich permanent. Es gab schon Phasen, wo es ruhiger war, aber dann kam immer der nächste Punkt und es war wieder stressig.» However, little is known on the families' perspectives regarding diagnostic workup, early interventions or their everyday life. But what specifically are the experiences and needs of affected families?

Patients & Methods

The population is based on a central register of all children with special educational measures before kindergarten entry in the canton of Zurich. 147 children with an autism diagnosis between 2014-2017 could be found in this database. Out of these 147, we conducted a survey among 57 families focused on the diagnostic workup, early interventions and their everyday life followed by more detailed interviews on these topics with 20 of them. The autistic children ranged in age from 5.7 to 12.0 years (mean: 8.9 years). 88% of them were male and 12% were female, which is comparable to what can be found in the literature. We chose a mixed method design for the evaluation, in which both quantitative and qualitative data were collected and analysed in a single study.

Results

Diagnostic workup

Most parents (83%) were first concerned about their child's development before the age of 2.5 and the majority (77%) first contacted the paediatrician for this reason. Parents mainly (77%) reported concerns in the area of language. Most often, the diagnosis was made by the University Children's Hospital Zurich (58%). Parents waited an average of 3.7 months for the diagnostic work up. The mean age of diagnosis was 3.7 years (SD: 0.8). The average satisfaction with the diagnostic workup on a scale from 0 (unsatisfied) to 10 (very satisfied) was 7.3 (SD: 2.5) (Fig. 1). Reasons for low satisfaction were the long waiting time before diagnostic workup and thus a later diagnosis. Furthermore, parents expressed their need for a closer follow-up after the diagnosis.

Figure 1

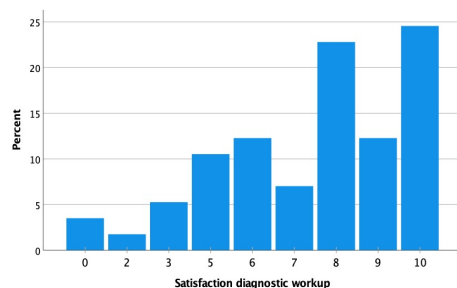


Figure 1: Satisfaction with the diagnostic workup

Daily life

More than half (54%) of the parents stated that they feel challenged in everyday life, 28% cope well and 18% feel exhausted (Fig. 2). 39% of parents evaluated their family support as medium and 19% as poor. Slightly more than one-third of parents (37%) rated the environment's understanding as moderate and 23% as little. More than half (55%) reported that they had to reduce (25%) or even quit (30%) their job due to the increased care requirements for their child. The average satisfaction with the parental role in general on a scale from 0 (unsatisfied) to 10 (very satisfied) was 7.7 (SD: 2.2). Reasons for low satisfaction were lack of support including financial support as well as lack of understanding from the environment.

Figure 2

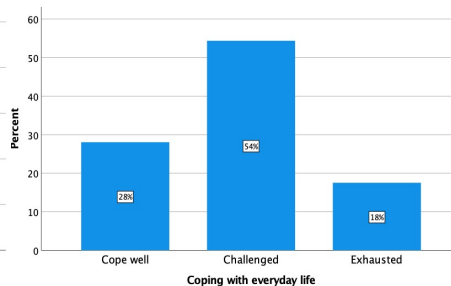


Figure 2: Coping with everyday life of parents with an autistic child

Positive aspects:

However, some parents also appreciate the positive aspects of the disorder: «Aber es ist auch ein Geschenk, er kann ein Geschenk sein. So wie unser Sohn ist und diese Details, die er sieht und diese Freude an den kleinen Dingen. Manchmal denke ich, es ist wie so ein Kind, dass nie gross wird. Es ist immer so wie mit einem 2- oder 3-jährigen, der sagt, oh so schön die Blume. Das höre ich von meinem Sohn jetzt noch. Schau mal Mama, was für ein wunderschöner Tag. Das ist schön eigentlich. Er lebt wirklich ganz im Moment.»

Conclusions

- An early diagnosis is important not only for the autistic child, but also for the parents.
- The diagnosis changes the life of the family and therefore they need support by professionals after the diagnosis.
- **Autism is more than just a medical problem:** families with an autistic child are confronted with a wide range of challenges