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Role of neurological and neuropsychiatric comorbidities in the long-term outcome of severe paediatric feeding and eating disorders - A caregiver perspective

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SUMMARY

Aim: To examine the long-term outcome of severe paediatric feeding and eating disorders as perceived by their caregivers in relation to predominant areas of comorbidities in the neurodevelopmental and behavioural field.

Methods: A sample of 103 patients (ICD-10 F98.2, age below 7 years, all previously referred for a four-week inpatient eating intervention between 2009 and 2016) was followed up by a parent questionnaire with the target parameters being age-appropriate eating and long-term improvement (Likert scale 1-10).

Four comorbidity subgroups were compared: 1) neurological comorbidities ("Neuro-group", n=28), 2) behavioural comorbidities ("Psy-group", n=24), 3) developmental delay without severe neurological or behavioural disorders ("DD-group", n=22) and 4) without any neurodevelopmental or behavioural disorders (non-DNP-group, n=29).

Results: After a mean follow-up period of 3.5 years (n=103), the non-DNP-group (normal development and low rate of comorbidities) achieved the best outcome. The Neuro-group had the least age-appropriate eating behaviour on follow-up, while their caregivers experienced good life satisfaction and surprisingly low burden of disease; they were similarly satisfied with previous treatment as caregivers of non-DNP-group. Caregivers of Psy-group described a better outcome than those from the Neuro- and DD-group, however lowest satisfaction and felt highest burden of the child eating problems.

Conclusion: Feeding and eating disorders are persisting for a long time in children with disabilities. It seems that caregivers of children with neurological disabilities adequately lowered their outcome expectations and developed better coping strategies. This stays in contrast to caregivers of children with behavioural disorders.

Keywords: Infantile eating disorders; Developmental disabilities; Behavioural disorders; Cerebral palsy

Abbreviations: ARFID: Avoidant-Restrictive Food Intake Disorder; ASD: Autism Spectrum Disorder; CP: Cerebral Palsy; DD: Developmental Delay; GERD: Gastroesophageal Reflux Disease; GMFCS: Gross Motor Function Classification System; ICF: International Classification of Functioning, Disability and Health; Non-DNP: Comorbidity Group without Developmental/Neurological/Psychological Diagnoses

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INTRODUCTION

Co-occurring medical or mental conditions are common in children with severe paediatric feeding and eating disorders of infancy or early childhood. The risk of developing a feeding or eating disorder is increased in children with intellectual or physical disabilities, [1,2] autism spectrum disorders [3] and genetic syndromes, further in premature born children [4]. Neurological impairments manifesting as oral motor difficulties and dysphagia often coexist in children with cerebral palsy and other neurodevelopmental disorders [2,5-7] It is often unclear whether the avoidant-restrictive food intake problems can be explained by the comorbid disabilities or are just associated. Therefore, the pathological food-intake behaviour cannot exactly be classified as "Avoidant-Restrictive Food Intake Disorder" (ARFID) because the criteria D of ARFID according to DSM V cannot exactly be determined in these children [1].

With regard to this heterogeneous group, it is not surprising that a more precise classification remains challenging. Different approaches to classify children with feeding or eating disorders or to define subgroups have been undertaken. Subgroups based on symptoms as in the revised classification, DC:0-3R [8], and in a later approach from Kerzner B, et al. [9] were defined. Both include leading symptoms like food selectivity, restricted appetite/infantile anorexia and fear of eating/posttraumatic feeding disorder. Although the important role of of comorbidities is evident in children with eating problems, only two studies formed subgroups with respect to comorbidities where cases were not assigned to one group exclusively but in the majority to a combination of disorders. In the study by Burklow KA, et al. [10] the cases were most frequently assigned to the comorbidities "structural-neurological-behavioural" (30/103) and second to the "neurological-behavioural" group (28/103). Neurological diagnoses included developmental delays, which were present in 75% of the study population. The study sample of Rommel N, et al. [11], on the contrary, contained only 11% (69/603) neurodevelopmental disorders, whereas gastroesophageal reflux disease was predominant with 60% of the cases (228/380). Interestingly, oral motor problems were present in 61% (427/700) while only few children showed behavioural comorbidities (18.1%; 127/700).

On the other hand, we know from multimorbid children with disabilities that treatment nowadays are usually not built on ICD diagnoses but on goals based on the International Classification of Functioning (ICF), expecially on functional aspects during daily living and participation including the environment and using a client-centred approach based on the expectances and goals of the caregivers and if possible the patients themselves.

In consideration of the heterogeneous presentations of study samples in the literature, comparing outcomes of children with eating disorders is impeded. Moreover, the long-term outcome has scarcely been examined with a follow-up period of more than a year [5,12,13]. Existing literature often focuses on specific patient characteristics or differing outcome measurements, predominantly tube weaning, weight gain or nutrition input as described in a recent meta-analysis of Sharp WG, et al. [13]. They describe outcomes of multidisciplinary interventions of 593 patients (age range, 15.7-48 months) in eleven studies, also including two randomised-controlled trials of 454 tube dependent patients 71% (95% CI, 54%-83%) were weaned during intervention and finally, 80% of 414 patients by follow-up (95% CI, 66%-89%). A decrease in disruptive mealtime behaviour, parental stress and an increase in food intake have been seen, whereas weight gain was low, mainly due to the frequently performed "aggressive", rapid tube weaning until discharge [13].

Most studies so far focussed on the above stated “objective” outcome whereas parental perception of the outcome has not been looked at. It is however crucial to understand caregivers as they play crucial roles in decision making, defining therapy goals and treatment; their appraisal has of high importance for children with complex chronic disorders.

This study aims to describe the different long-term outcomes of severe paediatric feeding and eating disorders from the parents’ perspective with regard to neurological, neurodevelopmental and psychological comorbidities.

METHODS

From a consecutive sample of 253 patients with the diagnosis of severe feeding or eating disorder in early childhood (ICD-10 F98.2 “Other feeding disorders of infancy”) who had undergone an intensive multidisciplinary inpatient treatment at the age of under 6 years between 2009 and 2016 [14].

The patients had previously received four weeks of inpatient treatment in a parent-child setting by an interdisciplinary team of paediatricians, child psychiatrist, psychologists, speech therapists, physiotherapists, occupational therapists, social worker, curative teachers and nurses at a specialized centre for social and developmental paediatrics.

Data sources/Measurements

Patient characteristics during inpatient stay - retrospective patient chart review (Time T1): Following data were extracted from medical records: Gender, age at hospital admission, number and type of comorbidities (according to ICD-10), perinatal period (gestational age, birth weight, APGAR scores), level of developmental delay according to developmental age *vs*. chronological age (severe, medium, slight or no delay), level according to Gross Motor Function Classification System (GMFCS 1 to 5) in children with cerebral palsy, z-score of body-mass-index, successful tube weaning (yes/no) [15,16].

Long-term outcome from parent perspective (Time T2): Parent Questionnaire on recent status and outcome of feeding/eating disorder, Burden of Disease and Life Satisfaction.

A sixty-eight item questionnaire for caregivers was applied. The questionnaire consisted of the diagnostic questionnaire for feeding and eating problems developed including tube feeding in German by Wilken and Jotzo16.

Further, we included questions on anthropometrics (weight, height), a standardised questionnaire on the parents’ life satisfaction (LiSat-11), two questions on the burden of disease experienced by the primary caregiver and the family and finally, feedback questions on the long-term outcome in general and in specific areas with respect to previous intensive inpatient treatment. We focus on the analysis of following items in the parent questionnaire:

Target parameters:

1. Score of long-term outcome after the inpatient treatment: "Eating improved in the long term after this inpatient stay." (10-point Likert scale: 1 "strongly disagree" to 10 "strongly agree.")
2. Score of age-appropriate "normal" mealtime behaviour: "From my point of view, my Treatment satisfaction in retrospect: “I am satisfied with the result of the inpatient eating therapy.” (10-point Likert scale)

Further questions were:

“Is your child fed by tube/PEG?” (Yes/No, not anymore/No, never.)

“My child's eating problems are a burden for the family.” (5-point Likert scale: "Does not apply", "Applies little", "Applies moderately", "Applies fairly" and "Applies very much")

“The eating problems burden me as a mother/caregiver.” (5-point Likert scale)

LiSat-11 item 1: “I feel my life in general is …” (6-point Likert scale: "very unsatisfied", "unsatisfied", "rather unsatisfied", "rather satisfied", "satisfied", and "very satisfied")

PROCEDURE

The first version of the questionnaire was adapted with support of the multidisciplinary team and checked for

comprehensibility in a pilot study of 8 participants and then approved by a further independent researcher. The questionnaire was sent by mail including an introductory letter and a consent form to the 253 eligible earlier patients. For the planned analysis of four subgroups, a minimal sample size of 100 participants was calculated. To reach the calculated return rate the families were reminded with a phone call and if necessary the questionnaires were sent again. If needed the questionnaire was completed in a telephone interview. For inclusion in the study a declaration of consent signed by both parents and a fully completed questionnaire were necessary. Then, baseline data were extracted and previous therapy reports were reviewed for this sample.

STATISTICAL ANALYSIS

The analysis was carried out with SPSS for Windows version 27.0 (IBM Corp., Armonk, NY). Data distribution and descriptive statistics were calculated for all variables of interest. Drop out analysis was conducted with non-parametric tests (median two-sample test and Fisher's exact). Depending on the level of measurement, the subgroups were compared either with a chi-square independence test and effect size of Cramer's V for all nominal variables, with a Kruskal-Wallis-test for all ordinal scaled variables (Dunn-Bonferroni post-hoc test and Cohen's d effect size), or with a one-sided ANOVA for all metric variables.

RESULTS

From a consecutive sample of 253 treated patients, 107 caregivers were willing to fill in the questionnaires. Four of them were excluded because of incompleteness or lack of signatures of both parents. Finally, a sample of 103 patients (46 girls and 57 boys; mean age 3;3 yrs;months at T1; mean age 6;9 yrs;months at T2) was included reaching the goal of areturn rate of at least 40% (103 of 253). The mean time interval after inpatient treatment was 3 years and 6 months (range 6 months-7 years) after inpatient treatment. A drop-out analysis revealed no systematic differences between responders and non-responders with respect to gender, age distribution during inpatient stay and at follow-up, year of treatment, and number of comorbidities. Further information is gathered in **Tab. 1**.

Tab. 1. Patient characteristics (N=103).

Characteristics		Value
Gender, n (%)	Female	46 (44.7)
	Male	57 (55.3)
Age, mean in y; mo. (SD) (range)	Inpatient stay (T1)	3;3 (1;11) (0;4-8;10)
	Follow-Up (T2)	6;9 (2;10) (1;11-13;6)
	Time Point of Follow-Up, mean in years; months (SD) (range)	3;6 (1;11) (0;6-8;11)
	Comorbidities, mean (SD)	5.36 (3.1) (0-17)
Medical Concerns, n (%)	Neurological disorders	35 (34.0)
	Cerebral palsy (GMFCS mean 4.5)	20 (19.4)
	Motor, language or cognitive developmental disorders	77 (74.8)
Level of Developmental Delay	Slight or None	46 (44.7)
	Medium	33 (32.0)
	Severe	24 (23.3)
	Autism spectrum disorder	9 (8.7)
	Psychological-behavioural disorders	27 (26.2)
Other	Congenital malformations, deformations and chromosomal abnormalities (Q00-99)	58 (56.3)
	Chromosomal abnormalities (Q90-99)	21(20.9)
	Down syndrome	9 (8.7)
	Congenital malformations of the circulatory system	7 (6.8)
	Congenital malformations of oesophagus	3 (2.9)
	Cleft palate	3 (2.9)
	Endocrine, nutritional and metabolic diseases (E00-89)	17 (16.5)
	Diseases of the digestive system	12 (11.7)
	Gastroesophageal reflux disease	3 (2.9)
Perinatal Period	Prematurity (< 37 wks.) (n=92)	49 (53.3)
	Low Birth Weight (<2500 g) (n=88)	45 (51.1)
Z-Score of BMI, mean (SD) (range)	Inpatient Stay (T1) (n=97)	-1.38 (1.64) (-7.00-3.00)
	Follow-Up (T2) (n=90)	-1.15 (1.76) (-4.70-3.60)
	Tube feeding at one point of life, n (%)	61 (59.2)
	Tube feeding during inpatient stay (T1), n (%)	45 (43.7)
	Tube weaned during inpatient stay (T1), n (%)	5 out of 45 (11.1)
	Tube weaned at Follow-Up (T2), n (%)	26 out of 45 (57.8)

Subgroup analysis

Definition of subgroups: The subgroups are based on three predominant areas of comorbidities according to ICD-10 in order to compare their role on the outcome of ARFID diagnoses as shown in **Tab. 1**.

The first group contains 28 children (27.2%) with neurological diagnoses ("Neuro-group"), mainly cerebral palsy (G80.x), epilepsy (G40.x) and also spinal muscular atrophy (G12). Twenty-four children (23.3%) with prevailing psychological or behavioural diagnoses (F00.x to F98.x) additionally to the eating or feeding disorder were assigned to the second group ("Psy-group"). The third subgroup comprises 22 children (22.7%) with notable developmental delays including genetic syndromes and metabolic disorders without additional neurological or psychiatric diagnoses ("DD-group" i.e. neither "Neuro" nor "Psy"). Finally, a group of 29 patients (28.2%) with normally developing children without neurological and psychiatric/behavioural disorders ("Non-DNP-group" i.e. no developmental/neurological/psychiatric comorbidity) was assembled.

Characteristics

Age at inpatient stay differs significantly between groups ($F(3.99) = 4.11$; $p = 0.009$). Pairwise comparison shows a significant difference between the Non-DNP-group with a mean age of 2.46 (SD 1.63) and the Psy-group with a mean age of 4.1 years (SD 1.36; $p = 0.005$). Mean age of Neuro-group was 3.0 yrs. (SD 1.8 yrs. and of the DD-group 3.4 yrs. (SD 2.0).

On average, 6.4 (SD 3.1, range 1-18) diagnoses according to ICD-10 were given per patient. A significantly lower number of diagnoses was assigned to the Non-DNP-group with a mean of 4.1 (SD 2.14) in contrast to the other groups ($F(3,99) = 7.766$; $p < 0.001$) (mean/SD: Psy-group 7.83/2.93, Neuro-group 7.54/3.27, DD-group 6.23/2.71).

Group differences in the degree of developmental delay are highly significant ($\chi2(6) = 66.82$, $p < 0.001$, $V = 0.57$) as indicated in the subgroup characteristics.

The level of care rated by the official health insurance system in Germany differs highly between subgroups ($F(3,99) = 25.40$; $p <0.001$) in the following ascending order: Non-DNP-group (mean 1.38), Psy-group (2.71), DD-group (3.41) and finally Neuro-group (4.5). This is consistent with the high mean GMFCS-level of 4.5 of children with cerebral palsy in the Neuro-group.

The average gestational age was generally low (34.7 weeks; SD 5.5). For the non-DNP-group, a non-significant trend towards lower birth weight and gestational age has been observed. 67.9% of Non-DNPs (19 of 29, Missing 1) were premature born in contrast to a range of 40.0 to 57.1% in the other groups. Low birth weight (<2500 g) was most found in Non-DNP-cases (18 of 29, 66.7%, Missing 2) and only in 41.2 to 45.8% of the other groups.

No significant group difference was found for 5-minute Apgar score, gender, follow-up period, and age at follow-up.

Both time points evaluated indicated a mean BMI z-score below average with -1.38 at T1 and -1.15 at T2 (T1 *vs.* T2 n.s.). No statistical intergroup difference in both time points was found.

Target parameters

General long-term outcome: From the parents' point of view, the outcome results were heterogeneous (**Fig. 1**). The long-term outcome at follow-up (T2) was described as positive by 57.3% of the parents (scale scores 6-10 out of 10). The ratings on long-term outcome varied significantly among groups ($p = 0.01$; $H = 11.27$; $n = 102$). In pairwise comparison, the best group on average, the Non-DNP-group (Median 8), differed greatly from the group with lowest ratings, the Psy-group (Median 5, $p = 0.006$; $r = -3.3$).

Age-appropriate eating: A large proportion of children have by no means achieved age-appropriate eating by follow-up ((mean 4.04 out of 10; s. **(Fig. 2)**). 37.6% of the children were still rated with the lowest scale value (score 1 out of 10). On the other hand, merely 22.8% of the children were described as eating appropriately for their age (scale scores 8-10 out of 10). General differences were found between the subgroups ($p = 0.001$; $H = 16.26$; $n = 101$). The Neuro- (Median 1) and the DD-group (Median 2) showed the least age-appropriate mealtime compared to the Non-DNP cases with significantly better results (Median 6, $p < 0.001$ and $p = 0.044$).

Other items of the parent questionnaire

At follow-up 61% of the parents have been rather satisfied with the result of the former inpatient treatment **(Fig. 3)**. A general difference between groups was found ($p = 0.038$; $H = 8.44$; $N = 100$) with pairwise differences in between the most satisfied group, the Non-DNP-group (Median 9), and the Psy-group (Median 5; $p = 0.05$) with the lowest results. The ratings of the Neuro-group were similar to the Non-DNP-group (Median 8, Interquartile range 8; DD-group: Median 5.5).

During the inpatient stay, tube feeding was performed in 45 out of 103 cases. At follow-up, 12 out of 13 patients (92.3%) of the Non-DNP cases were successfully tube weaned, compared to less than half of the initially tube-fed children in all other groups (Neuro: 7 of 17; Psy: 2 of 6; DD: 5 of 9). However, requirements for statistical testing were not met.

On average, three years after the inpatient stay, the burden of disease was still high for many of the families and primary caregivers. 35.4% of the families and 39.2% of the primary caregivers continued to be negatively affected by the child's eating disorder (scale scores 4-5 out of 5; N = 96) while only 40% of the parents or caregivers are not or only slightly burdened (scale scores 1-2 of 5). Again,

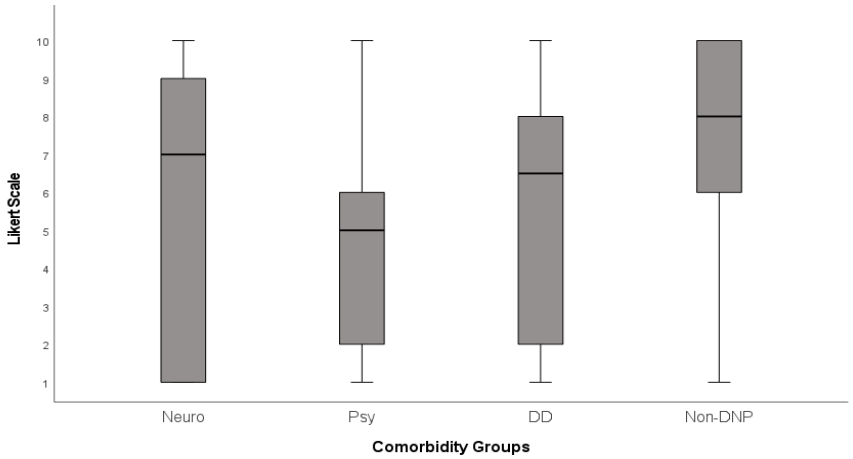

Fig. 1. Rating of "Long-term Outcome" from parent perspective (T2) by subgroup on a Likert scale (1 "strongly disagree" – 10 "strongly agree").

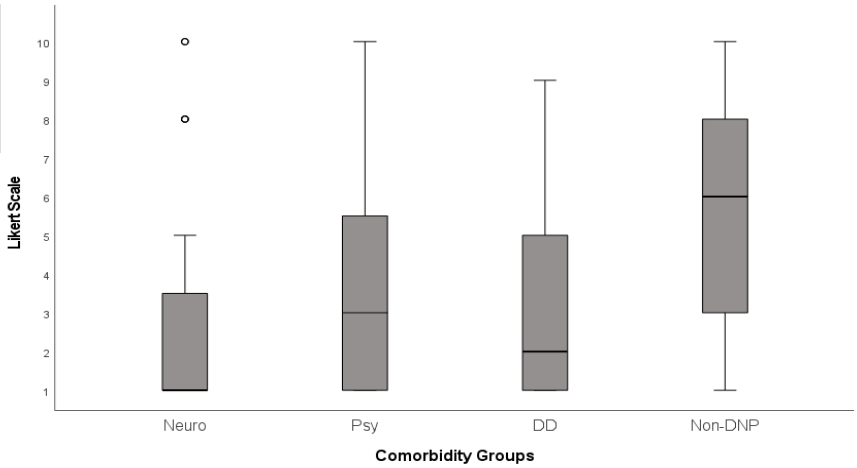

Fig. 2. Rating of "Age-appropriate Eating" from parent perspective (T2) by subgroup on a Likert scale (1 "strongly disagree" – 10 "strongly agree").

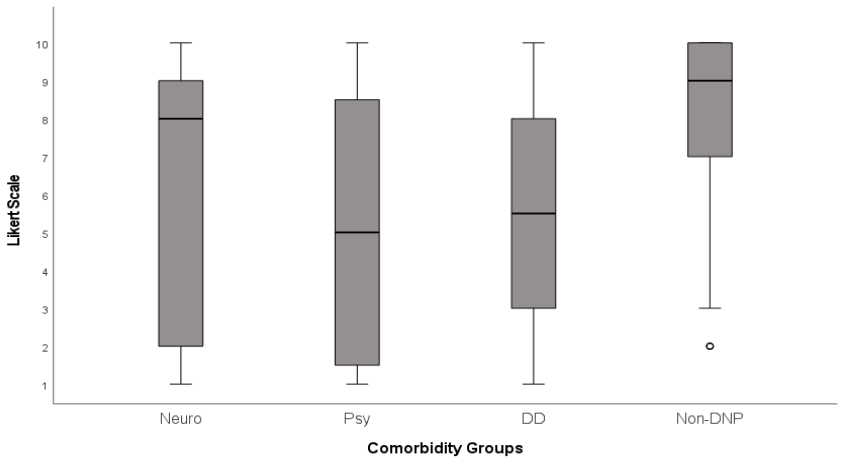

Fig. 3. Rating of "Satisfaction with treatment result" from parent perspective (T2) by subgroup on a Likert scale (1 "strongly disagree" – 10 "strongly agree").

significant group differences were found (H = 8.1; p = 0.044; mean ranks: Psy 60.9, n = 19; DD 53.1, n = 22; Neuro 45.4, n = 28; Non-DNP 39.2, n = 27). The most stressed families were among the children in the Psy-group with the highest mean rank and differing significantly from the least stressed group, the Non-DNP group in post-hoc analysis (z = 2,66; p = 0.046).

The caregivers' general life satisfaction (item 1 of LiSat-11) was good with a mean of 4.79 out of 6 (SD 1.10; Median 5; variance 1.22; n = 100). A clear trend towards a lower life satisfaction was observed among caregivers of children in the Psy-group: 27.2% (6/22) rated their "life overall" as "very unsatisfied" to "rather unsatisfied" compared to only 9% (2/22) of the DD-group, 7% (2/28) of the Neuro-group, and 7% (2/28) of the Non-DNP.

DISCUSSION

Paediatric feeding and eating disorders have already been analysed with respect to comorbidities about 20 years ago [10,11]. This is the first study to examine the differences of long-term outcomes of severe paediatric feeding and eating disorders with regard to subgroups of predominant neurological, developmental and behavioural comorbidities. The caregivers' perspective with respect to these subgroups has been examined and related to the outcome.

Intellectual and neurological disabilities as well as neurobehavioral problems were found to be relevant for long-term outcome with regard to aspects like age-appropriate eating or burden of disease perceived by the parents. Positive predictors seem to be age-appropriate development, absence of severe neurological and behavioural conditions and early age at treatment. Prematurity and low birth weight may contribute to the development of early eating disorder, [17] but seem to have no negative impact on the long-term outcome when complex neurological or behavioural conditions are absent.

Comparison of outcomes with the existing literature is limited because insufficient details on patient characteristics and symptom severity (e.g. developmental delay) are provided as noted in a recent meta-analysis [13]. The heterogeneity of outcome measurements poses additional challenges [13].

Schadler G, et al. [5] analysed a population of preterm born children presenting similar comorbidities as in the present study (neurological impairment, developmental delays and interaction problems) who achieved in 61.6% (52 of 83 patients) an overall long-term obtainment of the initial treatment success after a median follow-up of 3 years. However, subgroups have not been analysed.

With respect to the complex and severe comorbidities in this study, it seems reasonable that the frequency of successful tube weaning is relatively low (57.8%) compared to the literature, e.g. with 80% of 414 patients by follow-up (95% CI, 66%-89%) [13]. This stays in line with literature describing a worse outcome in children with neurodevelopmental issues or other comorbidities like metabolic diseases [18,12] which is, however, not stated in all studies [4]. Marinschek S, at al. [4] described a tube weaning rate of 92.3%, independent of comorbidities like genetic syndromes (26%), prematurity (23%), CP (7%) and ASD (6%), after a follow-up period of 1 to 6 years in a sample of 266 participants. At the same time, 68% ate an age-appropriate diet at follow-up and only few ate selectively (12.5%). However, the numbers of children with neurodevelopmental and neurobehavioral issues were possibly too small to detect significant differences. Further, no information was provided on severity.

There are two studies consisting of populations with prevailing gastrointestinal comorbidities using a similar outcome measurement [19,20]. A trial with a follow-up period of approximately one year examined the outcome of 67 patients with a similar 5-point Likert scale reaching a good improvement in 97% (Likert scale 4-5 of 5) hereafter [20]. A randomized-controlled trial conducted in the same clinic regarding a five day long intervention, reported after a short follow-up (mean 36 days, 3 Missing Data) a mean result of 3.6 on a 5 point Likert scale for age-appropriate "normal" eating in the intervention group (n = 10) [19]. The mean of 4.04 on a 10 point Likert scale and a much longer follow-up period in the present study, raises the question whether the study samples are comparable. This supports the hypothesis that eating disorders in children with medical problems like congenital heart diseases, GERD and other gastrointestinal comorbidities have better outcomes than those with neurodevelopmental and behavioural comorbidities.

There are indications that general life satisfaction is lower among caregivers of children with major behavioural comorbidities who, at the same time, show the poorest long-term outcome. In contrast, it is surprising that parents of children with multiple severe disabilities (CP, mean GMFCS 4.5) perceive such a positive outcome and high satisfaction with previous inpatient treatment, despite the poor long-term outcome with respect to age-appropriate eating behaviour. Moreover, parents of children with severe CP described normal life satisfaction. This may be interpreted that these parents have developed good coping strategies and appropriate long-term expectations with respect to the limited ability of improvement in their severely handicapped children. On the other hand, we suggest that the caregivers of children with behavioural comorbidities and to some extent also parents of children with developmental disabilities, mainly caused by genetic syndromes may need more coaching in order to work on realistic goals and coping with the eating problems of their children.

LIMITATIONS

The strength of this study is the large sample size with a wide range of comorbidities and the long follow-up period. Certainly, the sample shows a bias towards neurodevelopmental disorders and disabilities with a fairly low prevalence of gastroenterological and surgical cases. These comorbidities have usually been excluded or been treated in regional paediatric hospitals before admission to the special centre of developmental paediatrics. Based on these findings, a prospective longitudinal study would be useful to examine more precisely the influence of comorbidities on the prognosis of eating disorders in childhood.

CONCLUSION

Comorbidities are crucial parameters for the long-term outcome of early eating and feeding disorders as perceived by parents and should be taken into account in the treatment. A multidimensional ICF-based description of eating disorders in childhood could be useful both in clinical practice and in further studies. A training and coaching of caregivers concerning problem perception and coping strategies together with realistic long-term expectations seems to be necessary. Especially, high burden and stress in parents of children with behavioural comorbidities may need more attention than expected over a longer period of time.

HIGHLIGHTS

- Normal development and absence of neurological and behavioural disorders predict good outcome in infant eating disorders

- Prematurity alone shows no negative impact on the long-term outcome
- Severe feeding and eating disorders in children with neurodevelopmental and behavioural disorders persist over several years
- In spite of low long term improvements of the eating disorders, caregivers of children with neurological impairments are much more satisfied with the previous treatment
- Caregivers of children with behavioural comorbidities are in need of realistic long-term expectations, ie. achievable goals and coping strategies.

CONFLICTS OF INTEREST

The authors declare that they have no relevant or material financial interests that relate to the research described in this paper.

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