Original Article

A Comparative Analysis of Quality of Life in Children Managed for Omphalocele and Gastroschisis

Melanie Kapapa, Teresa Rieg[1], Alexandre Serra

Department of Surgery, Division of Pediatric Surgery, University Medical Centre Ulm, Ulm, [1]Department of Gynaecology and Obstetrics, Hospital Heidenheim, Heidenheim an der Brenz, Germany

Abstract

Background: Evaluation of quality of life (QoL) in paediatric surgical patients has not always received enough attention in the past. Our aim was to follow up patients with abdominal wall defects for a decade and (1) to analyse children's view on QoL and to analyse parent's view on QoL, (2) to evaluate satisfaction and psychological problems, (3) to assess present complaints including subjective aspects such as food intake, reduced appetite, pain in scar area and general abdominal pain and (4) verifiable clinical symptoms assessed through a physical examination and ultrasound. It was hypothesised that QoL would differ from gastroschisis (GS) and omphalocele (OC) children depending on the type of abdominal wall defect. **Materials and Methods:** A retrospective case–control design was used to compare children with GS (n = 36) and OC (n = 18). A clinical examination, including abdominal inspection, palpation and auscultation of bowel sounds with abdominal ultrasound, was offered, combined with a structured interview and specific QoL questionnaire (KINDL®). The focus was on QoL, child development, present complaints and satisfaction with the cosmetic outcome. **Results:** During clinical examinations with ultrasound, GS children were significantly more likely to have bowel loops stuck at the scar area (P = 0.008) with bowel malrotation and abnormal appendix position, compared to OC children (P = 0.037). They were significantly more likely to report irregular stools (P = 0.02) but were satisfied with the cosmetic outcome of the abdominal skin scar in 81% of cases. The KINDL® evaluation showed in the dimensions of QoL, namely 'body awareness', 'mental health', 'self-esteem', 'family', 'friends' and 'school', that there were no significant differences to healthy children. OC/GS parents were satisfied with their children's physical development and QoL, noting no limitations in normal daily activities. Parents of OC children reported suffering from OC/GS-associated problems (P = 0.028) at the time point of interview. **Conclusion:** Subjective QoL did not differ significantly between OC and GS children. The satisfaction with the cosmetic outcome of the abdominal skin scar was good. On ultrasound examination, adherent bowel loops and bowel malrotation with resulting stool irregularities affect GS children. OC children's parents reported suffering from OC/OS-associated problems, and all parents need to be educated about the symptoms of recurrent sub-ileus events or atypical appendicitis.

Keywords: Abdominal wall defect, children, gastroschisis, omphalocele, outcome, parents, quality of life

Introduction

In recent decades, health-related quality of life (QoL) has become increasingly important in medicine.[1] In paediatrics, it is considered an important and sensitive outcome measure for the evaluation of medical interventions.[2,3] The birth of an omphalocele (OC)/gastroschisis (GS) child poses significant challenges to parents because multiple surgeries may often be required until the abdominal wall defect is closed.[4] Since a wide range of health problems exists, ranging from mild recurrent abdominal pain to significant limitations due to sub-ileus events, and we wanted to capture not only the physical symptoms but also individual psychological components such as 'teasing at school' and the fact of living without a 'real' belly button, we conducted a comprehensive data acquisition. There are a variety of different measurement tools to assess QoL in children and adolescents because QoL is considered an important and sensitive outcome measure for the evaluation of medical interventions, especially in paediatrics.[5] Therefore, it was important to map the assessment of QoL

Address for correspondence: Dr. Melanie Kapapa, Department of Surgery, Division of Pediatric Surgery, University Medical Centre Ulm, Eythstrasse 24, 89075 Ulm, Germany.
E-mail: melanie.kapapa@uniklinik-ulm.de

Received: 20-10-2022 **Revised:** 12-04-2023 **Accepted:** 24-07-2023 **Available Online:** 16-05-2024

Access this article online

Quick Response Code:

Website: https://journals.lww.com/AJPS

DOI: 10.4103/ajps.ajps_140_22

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

How to cite this article: Kapapa M, Rieg T, Serra A. A comparative analysis of quality of life in children managed for omphalocele and gastroschisis. Afr J Paediatr Surg 2024;21:178-83.

from the parents' perspective as well.[6,7] To address all these approaches, we decided to use a combination of revised KINDL® questionnaires,[8] physical follow-up in combination with abdominal ultrasound and a survey on current satisfaction and complaints, which had never been collected in this setting in such a cohort. We hypothesise that results would differ depending on the type of abdominal wall defect.

Materials and Methods

Design

Our study was designed as an observational study, and because of the small number of cases, an age-matched case–control design was used. Children with OC or GS and their parents during the study period 01/01/2000–07/30/2011 were included. The local Ethics Committee (No. 29/11) approved this study.

Inclusion criteria

Patients who during their newborn period were treated surgically for OC/GS during the study period at the University Hospital, Division of Pediatric Surgery, were included.

Exclusion criteria

We excluded newborns with syndromic anomalies such as multiple midline anomalies (e.g. Cantrell's pentalogy), body wall–limp defect complexes and those who died (n = 4; OC patients).

Patients and surveyed subjects

The diagnostic code Q79.3 for GS and Q79.2 for OC of the International Classification of Diseases (ICD-9 and ICD-10) was used to identify the newborns. During the study period, 27.438 deliveries occurred, therefrom 36 GS and OC newborns. Forty-one families of 50 survivors joined, 72% of GS (n = 28) and 79% of OC (n = 13) children.

Data collection

All families were first contacted by telephone and informed about the study. After receiving written informed consent, quality of life data were collected using the KINDLR questionnaires ("Kiddy" version for children aged 4-7 years, "Kid" version for 8-11 year old patients, "Parents" version; Supplementary files 1-3). The 'Kiddy' version is suitably age adjusted, including only 12 items in six aspects of QoL. There are only three possible answers: 'never', 'sometimes' and 'very often'. The KINDL® questionnaires for parents and the 'Kid' version consist of 24 items, recorded in the six aspects assessing the QoL: 'body awareness', 'mental health', 'self-esteem', 'family', 'friends' and 'school'. In each question, the possible answers were 'never', 'rarely', 'sometimes', 'often' and 'always'. This project has been registered under the ID number 1031 for the standardised Kiddy-KINDL® questionnaire within the KIDSCREEN Group Europe.[8,9] The results of our survey accepted a significance level of 95%. The families were invited for a structured interview, which questions included the field of satisfaction and present complaints. The structured interview comprised a total of 21 different sections with questions or data entries, most of which had to be answered with yes or no, or age appropriate or not age appropriate. The subjective impression was recorded by means of grades (1 – very good to 6 – insufficient), e.g. for the cosmetic result of the scar.

OC/GS children were additionally offered a clinical follow-up with assessing bowel motility, adherent bowel loops, non- or malrotation and location of the appendix via an abdominal ultrasound examination done by a senior paediatric surgeon with trained skills in ultrasound [Figure 1].

Statistics

The recorded data were initially analysed with descriptive methods and clearly outlined. The mean and standard deviation were reported for quantitative parameters. Exploratory tests between interesting subsets were selected based on the underlying parameters. Given the size of the subsets, the t-test and non-parametric tests, such as Wilcoxon, were performed in addition to ANOVA. Significance was established as $P \leq 0.05$. All statistical tests were analysed using the IBM SPSS software, version 26 (IBM, Chicago, IL, USA).

Results

Sex ratio

During the study period, newborns with a GS were in 64% of males and 36% of females, whereas with an OC, 56% were males and 44% females.

KINDL® questionnaires

Forty-two per cent of GS (42%) and 50% of OC children and parents completed the KINDL® questionnaires so that they could be evaluated in the six aspects assessing QoL, such as 'body awareness', 'mental health', 'self-esteem', 'family', 'friends' and 'school'. The apparent number of participants is explained by the average age of the patients, which was 5.6 years for OC and 4.5 years for GS. The KINDL® questionnaires are suitable for the age of 4 years, and in our cohort, the overall age was still low. The overall result was 'good', especially for body perception and emotional well-being. The assessment by parents in the 8–11-year group showed in all six dimensions no significant differences between OC and GS children. The aspect 'school' scored worse in GS parents and children but without significance. In the self-assessment 'Kid' questionnaire (8–11 years), it was notable that the GS scored worse compared to

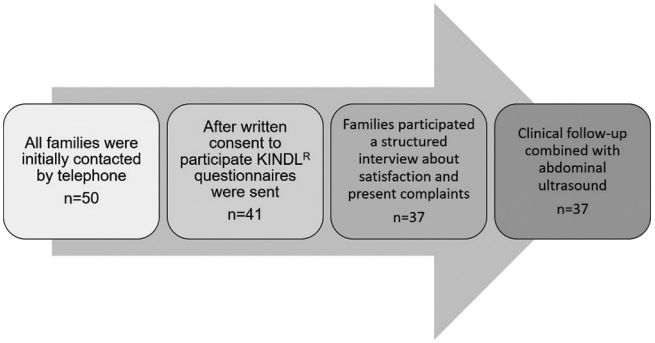


Figure 1: Type of information acquisition of omphalocele/gastroschisis patients

Table 1: KINDL® questionnaires: Parent's and children's view

KINDL® questionnaires	Parent's view (8–11 years)			Children's view (8–11 years)		
	GS (%; mean; SD) (*n*=6)	OC (%; mean; SD) (*n*=4)	*P* (GS versus OC)	GS (%; mean; SD) (*n*=6)	OC (%; mean; SD) (*n*=4)	*P* (GS versus OC)
Overall QoL	74; 74.3; 11.33	78; 78.9; 1.78	0.364	75; 75.3; 9.76	81; 80.5; 7.72	0.399
Body perception	76; 77.1; 13.5	86; 85.9; 9.38	0.293	78; 78.1; 16.18	91; 90.6; 11.97	0.225
Emotional well-being	82; 82.3; 12.13	83; 82.8; 7.86	0.944	79; 79.2; 15.14	83; 82.8; 9.38	0.685
Self-esteem	66; 65.6; 14.11	70; 70.3; 7.86	0.566	69; 68.8; 19.76	64; 64.1; 10.67	0.679
Family	78; 79.2; 19.23	76; 76.6; 11.83	0.817	76; 77.1; 8.54	86; 85.9; 10.67	0.185
Friends	77; 77.1; 15.14	75; 75.0; 10.21	0.816	83; 83.3; 10.21	78; 78.1; 11.97	0.481
School	64; 64.6; 18.82	83; 82.8; 10.67	0.121	66; 65.6; 11.69	81; 81.2; 19.76	0.151

QoL: Quality of life, GS: Gastroschisis, OC: Omphalocele

Table 2: Individual interview, examination and abdominal ultrasound

Type of information acquisition	Patients (*n*=37)		*P* (GS versus OC)
	GS	OC	
Satisfaction and daily life problems	*n*=26	*n*=11	
Physical development satisfaction	96	100	0.515
Cosmetic scar result satisfaction	81	91	0.451
No existing navel	23	36	0.138
Suffering of disease	42	82	0.028
Psychological problems	4	9	0.884
Teased in school	11	18	0.594
Present complaints	*n*=11	*n*=9	
Reduced appetite	18	0	0.189
Vomiting	9	33	0.189
Food intake problems	18	11	0.668
Toleration of only small portions	18	22	0.827
Diarrhoea	18	11	0.668
Abdominal pain	54	33	0.355
Pain scar area	18	0	0.189
Irregular stool (diarrhoea and constipation)	63	11	0.020
Headache	0	22	0.108
Clinical examination			
Weight/height			
Hypotrophy	15	9	0.594
Eutrophic	77	82	0.614
Hypertrophy	8	9	0.710
Scar hernia	19	27	0.557
Navel hernia	15	9	0.710
Ultrasound results	*n*=26	*n*=11	
Mal- or non-rotation of bowels	58	54	0.626
Normal bowel movement	81	64	0.223
Adherent bowel loop in scar area	77	27	0.008
Appendix in malposition	50	18	0.037
Diastasis of the rectus muscle	73	82	0.576

GS: Gastroschisis, OC: Omphalocele

OC in almost all areas, especially in 'school', yet the difference was not significant [Table 1].

Personal interview followed by physical examination and ultrasound

Satisfaction and problems

Almost all OC/GS parents were very satisfied with their children's physical development, with 96% of GS parents and 100% of OC parents reporting subjective satisfaction with it. The length of the initial hospital stays or the number of operations until final abdominal closure was irrelevant. However, at the same time, almost twice as many OC parents (82%) than GS parents (42%) reported that their children were still suffering from the consequences of their disease with a negative influence on everyday life ($P = 0.028$). With the cosmetic outcome of the abdominal scar, 81% of GS

and 91% of OC parents were satisfied. Psychological problems were reported by 4% of GS and 9% of OC parents, with 11% of GS and 18% of OC children being teased at school. A reconstructed belly button was missing in 23% of GS and 36% of OC children [Table 2].

Present complaints

GS children reported more problems than OC children with food intake, reduced appetite, pain in scar area and general abdominal pain, but just the sub-aspect about irregular stool (constipation or diarrhoea) showed significance [$P = 0.020$, Table 2].

Clinical examination

Physical development measured by weight and height yielded hypotrophy in 15% of GS and 9% of OC children; overall, 77% of GS and 82% of OC children were eutrophic. On physical examination, 19% of the GS group had a scar hernia located in the abdominal incision line, but not in the umbilicus area, compared with 27% of the OC group. Umbilical hernia, located only directly in the umbilicus area, was present in 15% of GS children and 9% of OC children [Table 2].

Ultrasound results

Ultrasound examinations were offered to children with GS and OC. Through ultrasound examination, an intestine mal- or non-rotation was present in more than half of OC/GS children (58% GS vs. 54% OC). In 50% of GS children, the appendix could not be detected in the 'loco typico' position but elsewhere ($P = 0.037$). Normal bowel movements were detected in 81% of GS and 64% of OC children and adherent bowel loops at scar area were observed significantly more often in GS (77%) than in OC children (27%; $P = 0.008$). A diastasis of the rectus muscle was found in 73% of GS and 82% of OC children [Table 2].

Discussion

Our findings were different from Koivusalo *et al*., which conducted a survey amongst OC/GS adults (18–48 years) and found no difference in the QoL in comparison to the general population[10] like Kaiser *et al*.,[11] who found comparable results with parents' evaluation or Halsband and von Schwabe,[12] who studied OC/GS children with an average follow-up of 7.4 years and found no physical and psychological impairments or restrictions in daily life.[11,12] However, with a closer look at our results, it was clear that the individual pillars of the QoL were rated differently, either well or poorly. Thus, GS parents rated them lower in 'overall QoL', 'body perception', 'self-esteem' and 'school' (19% worse) than OC parents for their children did. While, on the positive side, OC parents rated their children in 'body perception' with 86% of 100%, which was a very good result. These results suggest that the specificity of the questionnaire is crucial for the quality of the statements made. In other words, if you do not ask the right questions, you cannot expect the answers to be sufficient and comprehensive with respect to the problem you are trying to address. With a questionnaire that is too superficial, the subtleties of the different pillars cannot be captured and in the worst case lead to misjudgements or interpretations of the QoL.[13]

Seventy-four per cent of OC/GS children under care participated in clinical follow-up, including a personal interview and ultrasound. This was a representative sample including children with a mean age of 4.5 years (GS) and 5.6 years (OC), indicating a balance in both age and frequency of participation.[2,8]

The fact that the OC/GS parents reported both physical development and cosmetic outcome of abdominal skin scar between 81% and 100% (range: 0%–100%) shows that they are aware of the severity of the disease and potential complications and can reflect on the situation appropriately.[14] This does not contradict the finding that almost twice as many OC parents (82%) than GS parents (42%) reported that their children were still suffering from the consequences of disease. Since the physical complaints of the OC children were significantly lower than those of the GS children, we were able to find out on inquiry that in the overwhelming majority of cases, this meant the consequences of the accompanying medical conditions like congenital heart defects.[15] Sometimes, it is surgically not possible to reconstruct an umbilicus due to skin tension, and then, it is not done because the threat of wound healing disorder outweighs the cosmetic reconstruction of the navel. Therefore, a reconstructed belly button was missing in 23% (GS) and 36% (OC) and those children reported teasing and bullying from other children, often because of the abdominal scar. In our cohort, parents reported psychological problems in 4% of GS and 9% of OC children, but none of them received psychological support. The most important recommendation for parents in these situations is that they raise their children to be self-confident people who accept their bodies and know that they do not have to hide their scars or be ashamed of them. Then, they can better cope with psychologically hurtful situations and conflicts at school amongst their peers.[16,17] However, if parents have the impression that their children are suffering from their outward appearance and are becoming increasingly withdrawn, these warning signals should be taken seriously and they should be made an offer of individual psychological support for their children[18] or themselves.[13,19,20]

In our cohort, GS children reported more problems than OC children amongst others with food intake, reduced appetite, pain in scar area and general abdominal pain, but just the sub-aspect about irregular stool (constipation or diarrhoea) showed significance. These findings were only partially confirmed by Fasching *et al*., who found more abdominal pain and gastro-oesophageal reflux, yet no constipation or diarrhoea in GS children, like we do.[21] The more frequent occurrence of the described complaints in GS can be well reconciled with the sonographic results and those of the physical examination. However, manifest ileus, which again required surgery, did not yet occur in our cohort, but early laxative measures were able to control all episodes of faecal irregularity. Possible

explanations include an excessive awareness of children and parents in regard to symptoms affecting the gastrointestinal tract.[14] GS children are more prone to long-term intestinal problems than OC children, which may be a direct result of the pre-natal thickening of the intestinal walls with oedema and fibrin deposition on the intestinal wall.[22-25]

During clinical follow-up, we were able to confirm the results of Guida *et al*., who showed that the physical development of most children with OC/GS is the same as compared to healthy children, despite pre-maturity, low birth weight and post-natal problems.[14] The presence of a scar hernia was higher in OC children, while a navel hernia could be found more often in GS children; both findings had no immediate surgical consequence.

Diastasis of the rectus muscle was found in 73% of GS and 82% of OC children. In the scar area, 81% of the GS and 64% of the OC children had normal bowel movements, so that it is not necessarily possible to draw a conclusion about problems due to the surgery that took place. The abdominal pain and stool irregularity more frequently described by GS children can be well explained by our findings of adherent bowel loops at the scar area.[25] In addition, the evidence of intestinal mal- or non-rotation, often with accompanying 'non-loco-typico' location of the appendix, should be explained in detail to the parents so that they can react appropriately in case of appendicitis with atypical pain localisation.[26] Otherwise, a delayed diagnosis with severe consequences could occur.

The major strength of our study was the high participation rate of OC/GS children and their parents and the long-time observation period. However, our study is not without limitations, such as the small sample size of a single-centre study. Another limitation is the age of the children, and further examinations and additional questionnaires in a few years would help to complete the subjective QoL. Nonetheless, we believe that these limitations do not interfere with the overall conclusions, as mentioned above.

Conclusion

We conclude that the KINDL® questionnaire is suitable for assessing the QoL of children with GS or OC. Contrary to expectations, no differences were found depending on the type of abdominal wall defect. A combination of the KINDL® with physical examination, including abdominal ultrasound, optimises the follow-up of GS and OC children, as current problems can be discussed directly with the parents. In cases where a reconstructed belly button was missing, children reported being teased and bullied by other children, often because of the belly scar. As this can lead to psychological problems or have a lasting impact on self-esteem, early psychological care must be considered. Our recommendation is that serious abdominal problems in OC/GS children should be treated in centres with appropriate experience and that the recording of QoL should be firmly established in the follow-up of children with congenital malformation.

Acknowledgements

We would like to thank the Collaboration Centre of Prof. Dr. Ulrike Ravens-Sieberer, Research Unit Child Public Health and Centre for Obstetrics and Pediatrics, Department of Psychosomatics in Children and Adolescents, University Medical Centre Hamburg-Eppendorf, Germany.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Ravens-Sieberer U, Bullinger M. Assessing health-related quality of life in chronically ill children with the German KINDL: First psychometric and content analytical results. Qual Life Res 1998;7:399-407.
2. Limbers CA, Skipper S. Health-related quality of life measurement in siblings of children with physical chronic illness: A systematic review. Fam Syst Health 2014;32:408-15.
3. Equit M, Hill J, Hübner A, von Gontard A. Health-related quality of life and treatment effects on children with functional incontinence, and their parents. J Pediatr Urol 2014;10:922-8.
4. Lepigeon K, Van Mieghem T, Vasseur Maurer S, Giannoni E, Baud D. Gastroschisis – What should be told to parents? Prenat Diagn 2014;34:316-26.
5. Jürgensen M, Lux A, Wien SB, Kleinemeier E, Hiort O, Thyen U. Health-related quality of life in children with disorders of sex development (DSD). Eur J Pediatr 2014;173:893-903.
6. Klassen AF, Stotland MA, Skarsgard ED, Pusic AL. Clinical research in pediatric plastic surgery and systematic review of quality-of-life questionnaires. Clin Plast Surg 2008;35:251-67.
7. Seid M, Huang B, Niehaus S, Brunner HI, Lovell DJ. Determinants of health-related quality of life in children newly diagnosed with juvenile idiopathic arthritis. Arthritis Care Res (Hoboken) 2014;66:263-9.
8. Ravens-Sieberer U, Ellert U, Erhart M. Health-related quality of life of children and adolescents in Germany. Norm data from the German health interview and examination survey (KiGGS). Federal Health Gazette, Health Research, Health Protection 2007;50:810-8.
9. The-Kidscreen-Group-Europe. The KIDSCREEN Questionnaires. Quality of Life Questionnaires for Children and Adolescents. Lengerich: Pabst Science Publishers; 2006.
10. Koivusalo A, Lindahl H, Rintala RJ. Morbidity and quality of life in adult patients with a congenital abdominal wall defect: A questionnaire survey. J Pediatr Surg 2002;37:1594-601.
11. Kaiser MM, Kahl F, von Schwabe C, Halsband H. Omphalocele and gastroschisis. Outcome – Complications – Follow-up – Quality of life. Chirurg 2000;71:1256-62.
12. Halsband H, von Schwabe C. Long term results and quality of life of children with omphalocele and gastroschisis. Langenbecks Arch Chir Suppl II Verh Dtsch Ges Chir 1989. p. 951-5.
13. Rankin J, Glinianaia SV, Jardine J, McConachie H, Borrill H, Embleton ND. Measuring self-reported quality of life in 8- to 11-year-old children born with gastroschisis: Is the KIDSCREEN questionnaire acceptable? Birth Defects Res A Clin Mol Teratol 2016;106:250-6.
14. Guida E, Pini-Prato A, Mattioli G, Carlucci M, Avanzini S, Buffa P, *et al.* Abdominal wall defects: A 33-year unicentric experience. Minerva Pediatr 2013;65:179-85.
15. Mueller GC, Sarikouch S, Beerbaum P, Hager A, Dubowy KO, Peters B, *et al.* Health-related quality of life compared with cardiopulmonary exercise testing at the midterm follow-up visit after tetralogy of fallot repair: A study of the German competence network for congenital heart defects. Pediatr Cardiol 2013;34:1081-7.
16. Glinianaia SV, Embleton ND, Rankin J. A systematic review of studies of quality of life in children and adults with selected congenital anomalies. Birth Defects Res A Clin Mol Teratol 2012;94:511-20.
17. Tunell WP, Puffinbarger NK, Tuggle DW, Taylor DV, Mantor PC.

Abdominal wall defects in infants. Survival and implications for adult life. Ann Surg 1995;221:525-8.
18. Oris L, Seiffge-Krenke I, Moons P, Goubert L, Rassart J, Goossens E, *et al.* Parental and peer support in adolescents with a chronic condition: A typological approach and developmental implications. J Behav Med 2016;39:107-19.
19. Kim AJ, Servino L, Bircher S, Feist C, Rdesinski RE, Dukhovny S, *et al.* Depression and socioeconomic stressors in expectant parents with fetal congenital anomalies. J Matern Fetal Neonatal Med 2022;35:8645-51.
20. Li J, Gao W, Zuo W, Liu X. Relationship between quality of life and social support in parents of children with congenital anorectal malformations in China. J Pediatr Nurs 2020;53:e87-92.
21. Fasching G, Huber A, Uray E, Sorantin E, Mayr J. Late follow-up in patients with gastroschisis: Gastroesophageal reflux is common. Pediatr Surg Int 1996;11:103-6.
22. David AL, Tan A, Curry J. Gastroschisis: Sonographic diagnosis, associations, management and outcome. Prenat Diagn 2008;28:633-44.
23. van Eijck FC, Wijnen RM, van Goor H. The incidence and morbidity of adhesions after treatment of neonates with gastroschisis and omphalocele: A 30-year review. J Pediatr Surg 2008;43:479-83.
24. Kapapa M, Rieg T, Serra A. Does meconium contaminated amniotic fluid affect intestinal wall thickness and functional outcome in patients with anterior abdominal wall defects? Afr J Paediatr Surg 2022;19:46-51.
25. Snoep MC, de Heus R, Manten GT, Lap CC, Snoeker BA, Lindeboom MY. Gastro-intestinal function and quality of life are favorable in adolescent and adult gastroschisis patients. Early Hum Dev 2020;141:104936.
26. Feitz R, Vos A. Malrotation: The postoperative period. J Pediatr Surg 1997;32:1322-4.

ID: _ _ _ _ _ _

Quality of Life Questionnaire for Children

Kid- & Kiddo-KINDL
Parents' Questionnaire KINDL^R

Dear Parent,

We really appreciate your taking the time to complete this questionnaire about your child's well-being and health-related quality of life.
Since it is a matter of **your** own assessment of your child's well-being, please complete the questionnaire yourself according to the instructions, i.e. without asking your child.

- ⇨ Read each question carefully.
- ⇨ Think about how your child has been feeling during the past week.
- ⇨ Put a cross in the box corresponding to the answer **in each line** that fits your child best.

For example:

During the past week ...	never	seldom	some-times	often	all the time
. ...my child has slept well	☐	☐	☐	☒	☐

My Child is a: ☐ Girl ☐ Boy
Age: ____ Years
You are: ☐ Mother ☐ Father ☐ Other _____?
Date of fill out: __ / __ / __ (day / month / year)

1. Physical Well-being

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child felt ill	☐	☐	☐	☐	☐
2. ... my child had a headache or tummy-ache	☐	☐	☐	☐	☐
3. ... my child was tired and worn-out	☐	☐	☐	☐	☐
4. ... my child felt strong and full of energy	☐	☐	☐	☐	☐

2. Emotional Well-being

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child had fun and laughed a lot	☐	☐	☐	☐	☐
2. ... my child didn't feel much like doing anything	☐	☐	☐	☐	☐
3. ... my child felt alone	☐	☐	☐	☐	☐
4. ... my child felt scared or unsure of him-/ herself	☐	☐	☐	☐	☐

3. Self-esteem

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child was proud of him-/herself	☐	☐	☐	☐	☐
2. ... my child felt on top of the world	☐	☐	☐	☐	☐
3. ... my child felt pleased with him-/ herself	☐	☐	☐	☐	☐
4. ... my child had lots of good ideas	☐	☐	☐	☐	☐

4. Family

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child got on well with us as parents	☐	☐	☐	☐	☐
2. ... my child felt fine at home	☐	☐	☐	☐	☐
3. ... we quarrelled at home	☐	☐	☐	☐	☐
4. ... my child felt that I was bossing him/ her around	☐	☐	☐	☐	☐

5. Social Contacts

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child did things together with friends	☐	☐	☐	☐	☐
2. ... my child was liked by other kids	☐	☐	☐	☐	☐
3. ... my child got along well with his/ her friends	☐	☐	☐	☐	☐
4. ... my child felt different from other children	☐	☐	☐	☐	☐

6. School

During the last week in which my child was at school ...	never	seldom	some-times	often	all the time
1. ... my child easily coped with schoolwork	☐	☐	☐	☐	☐
2. ... my child enjoyed the school lessons	☐	☐	☐	☐	☐
3. ... my child worried about his/her future	☐	☐	☐	☐	☐
4. ... my child was afraid of bad marks or grades	☐	☐	☐	☐	☐

Thank you for your co-operation!

Supplementary File 1: Parents' questionnaire

ID: _ _ _ _ _ _

Children's Questionnaire

Kid-KINDL^R



Hello there!
we would like to know how you have been feeling during the past week, so we have worked out a few questions which we would like you to answer.

- ⇨ Please read each question carefully.
- ⇨ Think about how things have been for you over the past week.
- ⇨ Choose the answer that fits you best in each line and put a cross in the box.

There are no right or wrong answers. It's what you think that matters.

For example:	never	seldom	some-times	often	all the time
During the past week, I liked to listen to music.	☐	☐	☐	☒	☐

Date of fill out:

_____

(day / month / year)

Please tell us something about you. Please put a cross or fill in!



I am a ☐ girl ☐ boy

Age: _____ years old

How many siblings do you have? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ more than 5

Which type of school do you go to? _____

1. First of all, we would like to know something about your physical health...

During the past week...	never	seldom	some-times	often	all the time
1. ... I felt ill	☐	☐	☐	☐	☐
2. ... I had a headache or tummy-ache	☐	☐	☐	☐	☐
3. ... I was tired and worn-out	☐	☐	☐	☐	☐
4. ... I felt strong and full of energy	☐	☐	☐	☐	☐

2. ... then something about how you've been feeling in general...

During the past week...	never	seldom	some-times	often	all the time
1. ... I had fun and laughed a lot	☐	☐	☐	☐	☐
2. ... I was bored	☐	☐	☐	☐	☐
3. ... I felt alone	☐	☐	☐	☐	☐
4. ... I was scared	☐	☐	☐	☐	☐

3. ... and how you have been feeling about yourself.

During the past week...	never	seldom	some-times	often	all the time
1. ... I was proud of myself	☐	☐	☐	☐	☐
2. ... I felt on top of the world	☐	☐	☐	☐	☐
3. ... I felt pleased with myself	☐	☐	☐	☐	☐
4. ... I had lots of good ideas	☐	☐	☐	☐	☐

4. The next questions are about your family ...

During the past week...	never	seldom	some-times	often	all the time
1. ... I got on well with my parents	☐	☐	☐	☐	☐
2. ... I felt fine at home	☐	☐	☐	☐	☐
3. ... We quarrelled at home	☐	☐	☐	☐	☐
4. ... My parents stopped me from doing certain things	☐	☐	☐	☐	☐

5. ... and then about friends.

During the past week...	never	seldom	some-times	often	all the time
1. ... I played with friends	☐	☐	☐	☐	☐
2. ... Other kids liked me	☐	☐	☐	☐	☐
3. ... I got along well with my friends	☐	☐	☐	☐	☐
4. ... I felt different from other children	☐	☐	☐	☐	☐

6. Last of all, we would like to know something about school.

During the last week in which I was at school...	never	seldom	some-times	often	all the time
1. ... doing my schoolwork was easy	☐	☐	☐	☐	☐
2. ... I enjoyed my lessons	☐	☐	☐	☐	☐
3. ... I worried about my future	☐	☐	☐	☐	☐
4. ... I worried about bad marks or grades	☐	☐	☐	☐	☐

Thank you for helping us!



Supplementary File 2: Children's questionnaire

STANDARDISED FOLLOW-UP QUESTIONNAIRES

Outcome after gastroschisis or omphalocele- quality of life
Examination and questionnaire for the follow-up examination

Questionnaire- No.:.....
Date of examination: _____

Name, Vorname: _____

Birthday: ___/____/____Weight at birth: _____g Height at birth:_____cm

Sex:. □ male □ female

Disease: □ Gastroschisis □Omphalocele

General questions about your child's development

Current data of your child:
- Current age: _____ year/ month
- Current weight: _____kg (percentile _____)
- current height: _____cm (percentile _____)

Physical development from birth to present:
□ age-appropriate □ not age-appropriate

Course of growth:
□ age-appropriate □ not age-appropriate

Any abnormalities in the pediatric-examinations (yellow booklet)? Yes □ No
If yes, which examination was conspicuous?
Exact description of the problems
1. _____

_____

2. _____

_____

3. _____

_____

1

Name, Vorname: _____

Birthday: ___/____/____

Physical performance (participation in sports activities):
□ limited □ not limited

Attendance at day care / school (also expected or in the past):
□ age-appropriate □ not age-appropriate □ child in home care.

Which type of school?
Primary school □ Special school □ Secondary school □ Real school □ Grammar school

Are you satisfied with the general development of your child? :
□ yes □ no

Are you/is your child satisfied with the cosmetic surgery result?
□ yes □ no expressed in school grades.

Are corrective operations planned in the future?
□ yes □ no

Has your child ever been teased by others because of the scar?
□ yes □ no

Does your child still suffer from the consequences of the disease today?
□ yes □ no

Follow-up operations When: _____

What was operated on? _____

□ Abdominal pain
□ Pain of the scar (e.g. when growing/lengthening)
□ Problems with food intake
□ Lack of appetite
□ Diarrhoea
□ Vomiting
□ Stool irregularities
□ Irritable bowel syndrome
□ Wound healing disorder / reinfection of scar tissue
□ Severe weight fluctuations
□ General malaise
□ Weakened immune system

2

Supplementary File 3: Follow-up questionnaire: Personal interview