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Fetal alcohol spectrum disorders (FASD) – What we know and what we should know – The knowledge of German health professionals and parents

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ABSTRACT

Objective: The objective of our study was to evaluate the knowledge about fetal alcohol spectrum disorders (FASD) and the implementation of the German guideline for FASD among different professionals in the health and social system and among parents with children with FASD.

Methods: A questionnaire about FASD, containing 20 items, was sent by post to all children's hospitals (n = 287), all hospitals for child and adolescent psychiatry (n = 173), all social paediatric centres (n = 162), all neuropaediatricians (n = 129) and all youth welfare offices (n = 672) in Germany. Furthermore a link to the questionnaire as online version was put in the member's newsletter by 14 relevant professional societies. Besides, the questionnaire was distributed personally to the attendees of the annual national FASD conference (n = 363).

Results: Altogether 428 persons took part in the survey. 273 participants were professionals and 155 parents of children with FASD. More than 95% of the professionals and parents knew that alcohol consumption during pregnancy constitutes a risk for the child. The prevalence of maternal alcohol consumption and of FASD was underestimated. Although approx. 70% of the professionals knew which disorders belong to FASD just a few could tell their specific deficits. Questions regarding effective intervention for children with FASD and the long-term outcome were only partially answered correctly.

Discussion: Professionals in the German health and social system are aware of FASD but underestimate the level of damage and the impact on every day functioning of the affected people.

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1. Introduction

According to the study "Gesundheit in Deutschland Aktuell"[1] (translation: "Health in Germany Currently") of the Robert-Koch-Institute 20% of pregnant women in Germany show moderate and 8% risky alcohol consumption (measured by AUDIT[2]). 12% of the interviewed women admit binge drinking (≥5 drinks per occasion) less than once per month, nearly 4% every month and 0.1% at least every week during pregnancy. According to international experts no safe amount of alcohol use during pregnancy can be defined.[3]

Maternal alcohol consumption during pregnancy can lead to brain damage of the unborn child and thereby to fetal alcohol spectrum disorder (FASD) with lifelong deficits in cognition, behaviour and everyday functioning in affected patients.

In Croatia a combined prevalence of fetal alcohol syndrome and partial fetal alcohol syndrome of nearly 6.7% was found in the participating schoolchildren.[4] Studies in Italy describe a prevalence of FASD of more than 2% in 5-year-old children.[5,6] In Germany no prevalence study of the general population exists. As the alcohol use during pregnancy is similar to Italy, but the German diagnostic criteria are stricter, experts estimate the FASD prevalence to be about 1% in Germany. The prevalence of FASD in risk populations is even higher: a study conducted in the Netherlands showed that 31% of the 121 adopted children from Poland had the diagnosis of FASD.[7] In a German survey among foster families, in which a suspected diagnosis was made with help of a FASD screening questionnaire, a prevalence rate of suspected FAS of 22.9% among foster children was estimated.[8] In a Canadian study the risk population of children in child care systems as orphanages or foster care was evaluated and a prevalence of FASD of 16.9% was found.[9]

Therefore intrauterine alcohol exposure seems to be the leading cause of preventable birth defects.

There is no national registry for FASD in Germany. Expert's estimations of the few centres specialized in the diagnosis of FASD in Germany assume that FASD is currently underdiagnosed in Germany.

That was one of the reasons why an evidence- and consensus-based guideline for the diagnosis of FASD in Germany was developed and published recently.[10,11]

Multiple surveys about the knowledge of FASD among professionals in the United States and Canada were performed and showed a good general knowledge about FASD.[11–15] To date studies showing knowledge among professionals in Europe are scarce.[19]

To fill this gap the present study was designed to evaluate the knowledge of different professionals in the health and social system and of parents of children with FASD in Germany about alcohol consumption during pregnancy and about FASD. Furthermore the study was aimed to assess the notice, application and stated feasibility of the S3 German FASD guideline and the pocket guide FASD (ultrashort version of the guideline) among professionals. As an intended side effect of the survey, awareness of FASD might have been raised among relevant professionals by sending the FASD questionnaire.

2. Methods

2.1. *Questionnaire*

A questionnaire about FASD was developed by a German FASD expert (MNL) with the help of a statistician (LA).

The questionnaire contained 20 items with the answer options "yes" and "no" or 1 to 6 or suggested percentages depending on the question (original questionnaire in German and translated in English ePub 1 and 2).

Three questions concerned alcohol use during pregnancy (correct answers in parenthesis):

1. Is there a scientifically defined amount of alcohol during pregnancy which is not dangerous for the unborn child? (no)
2. Is there a time point during pregnancy in which alcohol consumption is not dangerous for the unborn child? (no)
3. How many women (approx.) drink alcohol during pregnancy? (20–40%)

Seven questions were asked about FASD (correct answers in parenthesis):

4. How frequent is fetal alcohol spectrum disorder (FASD) as a consequence of intrauterine alcohol exposure? (1%, more frequent than trisomy 21 and cerebral palsy)
5. Which diseases belong to fetal alcohol spectrum disorder? (FAS, pFAS, ARND, not ARS and ARPD)
6. Which anomalies are *always* present in children with fetal alcohol syndrome? (growth deficits, CNS abnormalities, facial anomalies)
7. Which anomalies are *always* present in children with partial fetal alcohol syndrome? (CNS abnormalities, facial anomalies, probable maternal alcohol consumption)
8. Which anomalies are *always* present in children with alcohol related neurodevelopmental disorder? (CNS abnormalities)
9. Which evidence-based factors lead to a better prognosis of patients with FASD? (stable environment, counselling of parents, training based on everyday life, early diagnosis, no experience of violence)
10. Which statements are correct for adults with FASD? (approx. 1/3 live independently, approx. 1/3 drug/alcohol problems, life expectancy is reduced, >60% victims of abuse, >50% no regular school visit, <20% regular work, higher risk of psychiatric disorders, <40% microsomia)

Nine items regarded the German guideline for FASD:

11. Do you know the S3 German guideline for the diagnosis of FASD?
12. If yes, how did you become aware of the S3 German guideline for the diagnosis of FASD?
13. Do you take care of people with FASD?
14. Do you apply the diagnostic recommendations of the S3 German guideline in your work?

15. How helpful do you find the S3 German guideline for the diagnosis of FASD in children and adolescents (rated as school notes)?
16. How good do you find the practicability and applicability of the S3 German guideline (rated as school notes)?
17. Did you know the pocket guide FAS (precursor of the present pocket guide FASD), which visualizes the diagnostic criteria of the old S3 guideline in an ultrashort version?
18. If yes, did you apply the pocket guide FAS in your work?
19. Do you intend to apply the new pocket guide FASD in your work?

In the last item the participants were asked about their profession or function (parent, nurse, midwife, therapist, doctor, teacher, social worker etc.):

20. Are you a (multiple selections of professions)?

2.2. Procedure

The questionnaire was sent by post to all children's hospitals (n = 287), all hospitals for child and adolescent psychiatry (n = 173), all social paediatric centres (n = 162), all neuropaediatricians (n = 129) and all youth welfare offices (n = 672) in Germany. Furthermore the questionnaire was adapted as online version in Lime Survey and 14 relevant professional societies were asked to send the link and accompanying explanation of purpose in the newsletter to their members. Besides, the questionnaire was distributed personally to the attendees of the annual national FASD conference (n = 363) in September 2016 in Wuerzburg.

2.3. Participants

The filled-in questionnaires of the survey consisted of two samples:

1. Questionnaires sent back by post, fax or E-Mail and the online filled-in questionnaires.
2. Questionnaires collected at the FASD conference.

The first sample included professionals in general whereas the second sample contained only conference attendees, which means that the latter professionals were already interested and attentive regarding FASD otherwise they wouldn't have visited such a special conference. Also as expected, the second sample comprised a lot more parents or guardians of children with FASD than the first group.

2.4. Statistical analysis

The answers of all questions were analysed separately for professionals and for parents using descriptive statistics by the statistical software R version 3.1.0 (https://www.R-project.org). Furthermore the answers of the professions social workers/social pedagogues, paediatricians, child and adolescent psychiatrists and psychologists were compared and proportions and 95% confidence intervals were calculated.

3. Results

The percentage of target persons participating in the survey was different according to the mode of distribution of the questionnaire: 176 participants were conference attendees (176 out of 363 conference attendees in total, response rate 48.48%), 140 professionals sent back the questionnaire by post, fax or E-mail (140 out of 1423 target persons who received the questionnaire by post, response rate 9.84%) and 112 persons filled in the online survey (target population not definable as the questionnaire was spread via homepages of professional societies but the visit of the homepages is not registered). Overall 428 persons participated in the survey whereof 273 were professionals and 155 parents.

3.1. Participants' characteristics

The profession or function of the participants of the post/online and of the conference groups is shown in Table 1. In the post/online group nearly half of the respondents were paediatricians (46.4%, n = 117), about a quarter social workers or social pedagogues (24.6%, n = 62) and 11.51% psychologists. The participants of the survey attending the national FASD conference (group 2), were 63.07% (n = 111) foster parents, 17.16% (n = 31) adoptive parents and 21.59% (n = 38) social workers or social pedagogues. Only 5.68% (n = 10) were medical doctors.

For better readability and comprehensibility the following results regarding the knowledge of the participants are described separately for professionals and for parents in each chapter.

Table 1 – Professions/functions of the participants of the survey (post/online and conference sample).

Participants of the survey	% (n) = post/online survey	% (n) = conference survey
biological parent	3.57 (9)	2.84 (5)
adoptive parent	1.59 (4)	17.61 (31)
foster parent	3.57 (9)	63.07 (111)
social worker/social pedagogue	24.6 (62)	21.59 (38)
patient with FASD	0 (0)	1.14 (2)
paediatrician	46.43 (117)	3.41 (6)
child and adolescent psychiatrist	5.56 (14)	1.70 (3)
psychiatrist	0 (0)	0 (0)
gynaecologist	0 (0)	0.57 (1)
psychologist	11.51 (29)	4.55 (8)
remedial teacher	2.78 (7)	3.98 (7)
midwife	0 (0)	0.57 (1)
nurse	0.79 (2)	6.25 (11)
teacher	2.38 (6)	6.82 (12)
speech therapist	0.79 (2)	0 (0)
behavioural therapist	1.19 (3)	1.7 (3)
physiotherapist	1.19 (3)	0.57 (1)
other:	9.26 (24)	15.51 (29)

3.2. Alcohol use during pregnancy

In large part the participating professionals correctly stated that there is no, scientifically based, safe amount of alcohol during pregnancy for the unborn child (96.3%, n = 262).[3] They also knew that there is no safe time point during pregnancy at which maternal alcohol consumption is harmless to the child (99.26, n = 269). The prevalence of alcohol consumption during pregnancy (20%–40%[1]) was estimated properly by 63.6% (n = 167) of the professionals.

About 99% of the participating parents stated correctly that there is, scientifically based, no safe amount of alcohol (98.69%, n = 151) and no safe time point during pregnancy (99.35%, n = 154) for the unborn child. The frequency of alcohol consumption during pregnancy was estimated properly by 76.19% (n = 112) of the parents.

3.3. Fetal alcohol spectrum disorders

The prevalence of FASD as consequence of intrauterine alcohol exposure was mainly underestimated by professionals: only 25.38% (n = 66) of the respondents knew that the prevalence in Germany is estimated to be at least 1%.[11] That FASD is more frequent than trisomy 21 or cerebral palsy was ticked rightly by 91.57% (n = 239) and by 72.62% (n = 183) respectively.

Parents, similar to professionals, underestimated the prevalence of FASD, (correct answer 34.81%, n = 47) whereas most parents knew that FASD was more often than trisomy 21 and cerebral palsy (96.15%, n = 125 and 75.23%, n = 82 respectively).

70.26% of the professionals correctly stated that fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS) and alcohol related neurodevelopmental disorder (ARND), but not alcohol related schizophrenia (ARS) and alcohol related personality disorder (ARPD) belong to FASD.[11]

Regarding the symptoms of the different FASD which have to be present for diagnosis (according to the German guideline[11]), the proportion of right answers was much lower. The participants had the following 6 possible anomalies as answer options: 1) growth abnormalities, 2) functional deficits of the central nervous system (CNS), 3) malformations of inner organs, 4) hearing loss or impaired vision, 5) facial anomalies (short palpebral fissure length, smooth philtrum, thin upper lip), and 6) probable or confirmed maternal alcohol consumption during pregnancy. For FAS only 10.59% (n = 25) of the professionals gave the right answers including growth abnormalities, functional deficits of the central nervous system and facial anomalies. The anomalies of pFAS were stated correctly by 28.07% (n = 64) whereas the deficits of children with ARND were ticked rightly by only 8.48% (n = 19) of the interrogated professionals.

The interviewed parents of children with FASD surprisingly ticked the disorders which belong to FASD (FAS, pFAS, ARND) rightly in only 57.84% (n = 59).

Regarding the symptoms of the different spectrum disorders parents were also very unsure: 6.96% (n = 8) ticked the anomalies of FAS, 30.3% (n = 30) the deficits of pFAS and only 4% (n = 4) the criteria of ARND correctly. Interestingly the false answers contained mostly additional anomalies which are not specific symptoms relevant for the diagnosis of FASD.

Factors which contribute to an effective training and a better prognosis for people with FASD are an early diagnosis, a stable environment, counselling of the parents/guardians, everyday-life like training and no experience of violence.[16–18] Most of the professionals and parents knew these factors (Table 2). Medications and visiting a secondary school doesn't always and generally contribute to a better long-term outcome in children with FASD, which knew 76.25% and 82.99% of the professionals respectively.

Regarding medication 57.89% of the parents and regarding secondary school 94.12% of the parents did correct statements.

A very high amount of different trainings is not helpful for children with FASD. Only 28.24% of the professionals and 42.86% of the parents agreed with this.

Only 10.76% (n = 24) of the participating professionals and 23.16% (n = 22) of the parents answered the whole question regarding factors which ameliorate the prognosis in a correct way.

The part of the questionnaire which concerned prognosis and impairments of adults with FASD was answered correctly in total by only 4.59% (n = 10) of the professionals and 7.53% (n = 7) of the parents.

Especially the fact that microsomia is often not seen in adults with FASD anymore[19] was not known by the majority of respondents (professionals and parents). The proportion of adults with FASD not having a regular school graduation was rated correctly by nearly 89% of the professionals and 90% of the parents. The percentage of adults having been victim of physical or sexual abuse[16] was underestimated. The answers of the professionals and parents concerning adults with FASD are shown in Table 3.

3.4. S3 German guideline for FASD

55.89% of the professionals and 84.67% of the parents know the S3 German guideline for the diagnosis of FASD.

In the group of professionals 37.5% (n = 69) became aware of the guideline by their professional/scientific organization, 32.61% (n = 60) by congresses or trainings, 15.22% (n = 28) by colleagues, 6.52% (n = 12) by the homepage of the Consortium of the scientific societies (AWMF: Arbeitsgemeinschaft wissenschaftlicher medizinischer Fachgesellschaften) and 4.35% (n = 8) by the German Ministry of Health. Less than 5% got informed about the guideline by affected individuals and their parents, by newspaper or by the homepage of the Dr. von Hauner Children's' hospital of the university of Munich.

In the group of the parents 59.71% (n = 83) became aware of the guideline by congresses or trainings, 17.99% (n = 25) by professional/scientific organization, 15.83% (n = 22) by affected patients and their parents, 3.6% (n = 5) by the German Ministry of Health, 1.44% (n = 2) by colleagues and 1.44% (n = 2) by the homepage of AWMF.

About two thirds of the participating professionals (68.77%, n = 185) take care of children with FASD, but only 49.43% use the diagnostic criteria of the German FASD guideline (for differentiation of professional groups see chapter 3.5.).

Table 2 – Factors which, scientifically confirmed, contribute to a better prognosis of people with FASD (CI = confidence interval).

Positive prognostic factors (right answer)	% rightlyanswered (n) [95% CI]: professionals	% rightly answered (n) [95% CI]: parents
Medications (no)	76.25 (183) [70.26–81.38]	57.89 (66) [48.28–66.97]
Stable environment (yes)	99.25 (263) [97–99.87]	100 (149) [96.87–100]
Counselling and training of the parents (yes)	91.6 (240) [87.39–94.54]	87.4 (111) [80.06–92.4]
Everyday life like training (yes)	93.05 (241) [89.05–95.71]	90.77 (118) [84.1–94.93]
Early diagnosis (yes)	94.4 (253) [90.75–96.72]	100 (148) [96.85–100]
High amount of different trainings (no)	28.24 (72) [22.88–34.26]	42.86 (51) [33.93–52.25]
No experience of violence (yes)	89.11 (229) [84.48–92.52]	96.53 (139) [91.67–98.71]
Visit of a secondary school (no)	82.99 (200) [77.51–87.39]	94.12 (96) [87.13–97.59]

Table 3 – Adults with FASD (CI = confidence interval).

Statement regarding adults with FASD (right answer)	% rightly answered (n) [95% CI]: professionals	% rightly answered (n) [95% CI]: parents
approx. 1/3 independent living (yes)	81.89 (199) [76.34–86.41]	71.54 (88) [62.59–79.13]
approx. 1/3 drug or alcohol problems (yes)	89.52 (222) [84.85–92.91]	92.74 (115) [86.28–96.42]
life expectancy not reduced (no)	68.33 (164) [61.98–74.09]	54.39 (62) [44.82–63.65]
>60% victim of abuse (yes)	53.02 (123) [46.38–59.55]	69.72 (76) [60.07–77.96]
>50% no regular school graduation (yes)	88.66 (219) [83.88–92.21]	90.55 (115) [83.74–94.8]
>20% job at the regular labour market (no)	51.24 (124) [44.77–57.67]	43.7 (52) [34.72–53.08]
higher risk of psychiatric diseases (yes)	98.02 (247) [95.17–99.27]	92.91 (118) [86.59–96.5]
>40% microsomia (no)	35.1 (86) [29.2–41.48]	35.83 (43) [27.43–45.15]

Table 4 – Helpfulness of the S3 German guideline for the diagnosis of FASD in children and adolescents according to the interviewed professionals.

Rating (as school notes: 1 = best, 6 = worst)	% (n)
1	33.91 (59)
2	47.13 (82)
3	13.22 (23)
4	5.17 (9)
5	0.00 (0)
6	0.57 (1)

Table 5 – Practicability and applicability of the S3 German guideline according to the interviewed professionals.

Rating (as school notes: 1 = best, 6 = worst)	% (n): group 1
1	19.28 (32)
2	53.01 (88)
3	19.28 (32)
4	7.23 (12)
5	0.60 (1)
6	0.60 (1)

About 81% of the interviewed professionals rate the guideline as very helpful or helpful (note 1 or 2) (Table 4).

The practicability and applicability of the German guideline was rated mostly as good (note 2) by the professionals (Table 5).

The pocket guide FAS (precursor of the current pocket guide FASD), which summarizes the diagnostic criteria of the S3 guideline in an ultrashort version, was known by 27.99% (n = 75) of the professionals, whereof 32.45% (n = 49) used it at their work. 72.17% of the professionals plan to implement the new pocket guide FASD in their future work.

3.5. *Comparison of different professions*

To compare the knowledge of different, for FASD relevant, professions the questionnaire was also analysed stratified by selected professionals (social workers/social pedagogues, paediatricians, child and adolescents psychiatrists and psychologists) (Table 6).

The proportion of correct answers varies between the professional groups, but there are no statistically significant differences as confidence intervals overlap.

Whether the professionals know the guideline, take care of people with FASD and apply the guideline recommendations was also evaluated separately for the different professions (Table 7).

4. Discussion

This study is the first in Germany evaluating the knowledge about FASD among different relevant professionals and parents.

In summary the following results of the survey are important and should be discussed regarding further efforts towards prevention and education about FASD of the professional and the general society in Germany.

4.1. *Knowledge among professionals—what we know*

Alcohol consumption during pregnancy is, regardless of the amount and time point, a risk for the unborn child. This was known by 90–100% of the different professionals (questions 1 + 2, Table 6). This rate is even better than in another European survey wherein 60% of Italian and 80% of Spanish paediatricians responded that ethanol use in pregnancy is dangerous.[20]

Table 6 – Comparison of the knowledge of different professional groups.

Question (right answer)	Social workers/ social pedagogues N = 100	Paediatricians N = 123	Child and adolescent psychiatrists N = 17	Psychologists N = 37
	% right answer [95%–CI]			
1. Is there a scientifically defined amount of alcohol during pregnancy which is not dangerous for the unborn child?(no)	95 [88.17–98.14]	98.36 [93.61–99.72]	94.12 [69.24–99.69]	97.3 [84.19–99.86]
2. Is there a time point during pregnancy in which alcohol consumption is not dangerous for the unborn child? (no)	99 [93.76–99.95]	100 [96.23–100]	100 [77.08–100]	97.22 [83.8–99.85]
3. How many women (approx.) drink alcohol during pregnancy? (20–40%)	65.31 [54.95–74.45]	66.38 [56.94–74.72]	76.47 [49.76–92.18]	63.89 [46.21–78.66]
4. How prevalent is fetal alcohol spectrum disorder (FASD) as a consequence of intrauterine alcohol exposure? (1:100)	19.78 [12.45–29.72]	30.83 [22.9–40.02]	28.57 [9.58–58]	22.22 [10.73–39.59]
5. Is FASD less frequent than Down syndrome/Trisomy 21? (no)	88.89 [80.08–94.25]	93.44 [87.08–96.92]	100 [75.93–100]	94.44 [79.99–99.03]
6. Is FASD more frequent than cerebral palsy? (yes)	67.47 [56.19–77.11]	78.15 [69.46–84.99]	66.67 [38.69–87.01]	69.44 [51.73–83.08]
7. Which diseases belong to fetal alcohol spectrum disorder?	58.33 [46.12–69.65]	72.48 [62.95–80.39]	92.31 [62.09–99.6]	79.41 [61.59–90.66]
8. Which anomalies are *always* present in children with fetal alcohol syndrome?	7.04 [2.62–16.35]	12.61 [7.32–20.58]	13.33 [2.34–41.61]	14.29 [5.38–31.04]
9. Which anomalies are *always* present in children with partial fetal alcohol syndrome?	23.44 [14.12–35.98]	30.36 [22.21–39.87]	46.15 [20.4–73.88]	24.24 [11.74–42.63]
10. Which anomalies are *always* present in children with alcohol related neurodevelopmental disorder?	5.88 [1.9–15.14]	12.15 [6.88–20.23]	16.67 [2.94–49.12]	0 [0–12.98]
11. Which evidence-based factors lead to a better prognosis of patients with FASD?	8.7 [3.58–18.6]	10.58 [5.66–18.52]	0 [0–28.34]	18.75 [7.86–37.04]
12. Which statements are correct for adults with FASD?	1.52 [0.08–9.27]	8.57 [4.24–16.07]	7.14 [0.37–35.83]	5.88 [1.03–21.06]

Table 7 – Comparison of the application of the guideline recommendations by different professional groups.

Question	Social workers/social pedagogues N = 100	Paediatricians N = 123	Child and adolescent psychiatrists N = 17	Psychologists N = 37
	% positive answer [95%–CI]			
Do you know the S3 German guideline for the diagnosis of FASD?	49.45 [38.89–60.06]	73.95 [64.96–81.37]	76.47 [49.76–92.18]	48.65 [32.24–65.33]
Do you take care of people with FASD?	73.47 [63.42–81.64]	72.95 [64.02–80.4]	88.24 [62.25–97.94]	56.76 [39.64–72.5]
Do you apply the diagnostic recommendations of the S3 German guideline in your work?	24.44 [16.26–34.84]	73.11 [64.07–80.63]	82.35 [55.8–95.33]	45.95 [29.85–62.87]

The prevalence of maternal alcohol use during pregnancy was rated correctly by approx. two third of the paediatricians, child and adolescent psychiatrists and psychologists but only by half of the social pedagogues in Germany (question 3, Table 6). As the social pedagogues in Germany are often responsible for high-risk families and therefore would have a good possibility for prevention this result is alarming.

The prevalence of FASD was underestimated by 78% of the German professionals in our study (question 4, Table 6). This is also reflected in an American survey among rehabilitation professionals in which nearly 75% underestimated current prevalence rates of FASD.[21] Another American study examining American paediatricians showed that only half of them correctly estimated the prevalence of FAS.[13]

The participating German professionals knew which disorders belong to FASD but most of them couldn't specify the symptoms of the different FASD (question 7 to 10, Table 6). The lack of concrete knowledge about the symptoms of FASD is one of the causes which inhibit an early and correct diagnosis of children with FASD in Germany. Birch et al. showed that professionals receiving trainings feel more prepared to correctly identify children with FASD.[21] This emphasizes the necessity to implicate educational modules about the specific symptoms of FASD in the professional education curricula.

Questions about effective interventions and support for children with FASD were only partly answered rightly in our survey (question 11, Table 6). The uncertainty regarding the management of children with FASD was also shown in an older study of Gahagan et al. in the United States.[13] Even if this publication is not very recent it reflects the, even now, insufficient number and quality of scientific publications about reasonable training for children with FASD and about useful counselling strategies for their families. Many professionals therefore ticked "high amount of different trainings" as useful

for the long-term outcome of children with FASD in our survey even if these therapeutical strategies are not confirmed in studies and sometimes an overload of (medical) therapies is even disadvantageous according to the experience of many FASD experts. Most participating professionals have the experience that medication is often not effective for the long-term outcome of children with FASD which is in accordance to our clinical experience. But we have to acknowledge that some participants might have misunderstood the questions as "what generally helps children with FASD?" and ticked medication and high amount of therapies as correct as a lot of children with FASD benefit of drugs and accompanying therapies. The questions about the effectiveness of different medication and of different amounts and types of training have still to be discussed. Birch et al.[21] demonstrated in their study that rehabilitation professionals were able to identify basic concepts related to FASD but lacked confidence in working with patients with FASD. Professionals who participated in a formal training of FASD felt better prepared to manage intervention plans for children with FASD.[22,25] Zoorob et al.[23] similarly found out that physicians felt better prepared to treat individuals with FASD after a training. This again underlines the importance of the implementation of FASD trainings in the professional education.

The long-term outcome of individuals with FASD is rated too positively and the severity of the alcohol-toxic brain damage and its impact on everyday life, persisting into adulthood, is therefore underestimated (question 12, Table 6). But, approximately 94% of the professionals in our study knew that an early diagnosis is a positive factor for prognosis. This was also shown in an American study that indicated that rehabilitation professionals (behavioural, physio and speech therapists) knew in a percentage of 91.8% that an early diagnosis may lead to secondary prevention of disabilities.[21] However, a European survey indicated that only 52% of the Italian neonatologists, 78% of the Italian paediatricians and only 4% of the Spanish paediatricians identified the early diagnosis of FASD as a positive outcome factor.[20]

Regarding the higher risk for addiction of individuals with FASD nearly 90% of the professionals of our survey gave a correct answer. This knowledge was higher than in the group of rehabilitation professionals in the previously cited US-study.[21]

The newsletters or homepage announcements of professional and scientific societies as well as congresses and trainings seems to be the best German platforms for disseminating information about guideline recommendations. The German S3 guideline for FASD includes diagnostic criteria, recommendations for the diagnostic process and suggestions for neuropsychological testing as well as percentiles and the lip-philtrum-guide. The German guideline was developed to be used for the clinical diagnosis of FASD by paediatricians and child psychiatrists as well as by psychologists. About 70% of the paediatricians and over 80% of the child and adolescent psychiatrists use the guideline criteria for their work (see also Table 7). Although the psychologists are also a target professional group of the guideline as they assess the neuropsychological abilities and deficits in children only 46% apply the guideline recommendations. As social pedagogues in Germany usually don't diagnose children with FASD themselves but take care of already diagnosed children it is not surprising that only 24% ticked that they use the diagnostic guideline criteria at work. The ones who apply the guideline at work mostly rated it as "good" regarding helpfulness, practicability and applicability. A lot of participants didn't know the ultrashort version of the guideline, the pocket guide FASD, but were interested to apply it at future work.

To summarize, the first steps of implementation of the S3 German guideline FASD are done but the recommendations of the guideline should be spread even wider in the professional field especially among psychologists.

4.2. *Knowledge of parents of children with FASD*

In the last years only few publications concentrated on the knowledge about FASD among parents or guardians. In Germany our study is the first to assess the FASD knowledge of biological, foster and adoptive parents of children/adolescents/adults with FASD.

The results of our survey among parents are reflected in a focus group study by Crawford–Williams et al. in which the majority of participants (n = 21) knew that alcohol was harmful but had limited information about the actual effects to the child.[24]

As the parents only need to know what is relevant for their child and are not expected to know all details of the diagnostic and prognostic criteria of FASD and as they are not the target population of the German guideline their questionnaire results are not further discussed in this article.

4.3. *Strengths and limits of the study*

A strength of the study is that it is the first in Germany which evaluates the knowledge about alcohol consumption during pregnancy and about FASD not only among professionals in the health and social system but also among concerned parents.

As many professionals don't take the initiative to inform themselves deliberately about FASD, another strength of the survey is that it might have raised the awareness of professionals. As every hospital for paediatrics and for child/adolescent psychiatry, every child neurologist and every youth welfare office in Germany received the questionnaire by post, the professionals had at least to open the letter and read the topic. Also the launch of the questionnaire via homepages and newsletters of the professional societies might have reached some professionals. Unfortunately we cannot estimate the interest of the professionals who didn't fill in the questionnaire.

A limit of the study is the small response rate (approx. 10% of the professionals invited by post and 48% of the conference attendees). A bias cannot be excluded as it might be suspected that the non-responders may have less knowledge about FASD and thus may have been deterred from filling in the questionnaire. Because a small response rate was already suspected before the start of the study, the sighted out, for the diagnosis and care of children with FASD relevant, professional groups were contacted per post by the study leaders as well as per member's newsletter by their professional

organizations for the online survey. Furthermore all attendees of the national FASD conference had the questionnaire in their conference folder. An explanation about the background of the survey and the request for participation was formulated twice in front of the whole congress plenum and the filled-in questionnaires were selected at the only exit of the conference room by two persons at two breaks. The most probable explanations for the small response rates especially among professionals are that the professionals didn't find the time to answer the questions, weren't interested in the topic FASD or were afraid to give false answers.

As the sample of the child and adolescent psychiatrist was small (n = 14) no generalized conclusions can be drawn. Another limit of the study is that it didn't control for collective filling-in of the questionnaires.

4.4. *What we should know—conclusions*

This study shows that a basic knowledge about FASD is present among professionals in the health and social system in Germany, at least among the ones who participated in this survey. The first steps of implementation of the German guideline for the diagnosis of FASD were effective but have to be completed by further personal engagement of German FASD experts and politicians. A detailed education of professionals about the different symptoms and deficits of children with FASD and their impact on everyday life is necessary. To realize this not only the pocket guide FASD should again be advertised for download but also educational modules of FASD should be systematically developed and distributed via the professional societies and via congresses.

Education on FASD in conferences and trainings as well as information spread in professional networks are the prerequisites for primary prevention, for an early and correct diagnosis of children with FASD and thus for the support of concerned families. Further comprehensive research about effective training, support and counselling of children with FASD and their guardians is needed.

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Conflicts of interests

All authors declare no conflict of interest.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.ejpn.2018.02.010.

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