Caries experience and treatment need in adults with intellectual disabilities in two German regions

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Objective: The aim of the study was to determine the caries experience, caries prevalence, dental treatment need and care index of adults with intellectual disabilities living in the German federal states of Baden-Württemberg and Sachsen which differ distinctly with respect to the socio-economic conditions. Research Design: In 2007, legal custodians of all persons working in special day-care institutions (n=2037) were asked to give consent for dental examinations of their custodees. Some 21.9% consented. Thus, 428 persons received a dental examination in the day-care institutions. Results: The mean age of the participants was 35.5 years (range 18–64). Caries prevalence was 93.7% (95% CI 91.3–95.9) in Baden-Württemberg and 97.6% (95% CI 96.2–99.0) in Sachsen. All caries-free persons (n=19) were younger than 35 years. The mean DMFT of the whole sample was 12.3 (95% CI 11.6–12.9). Although DMFT values were the same in both German regions, persons from Baden-Württemberg had more missing teeth than those from Sachsen but untreated carious defects were more common in Sachsen. Conclusions: Dental care for those with intellectual disabilities could be better harmonised within Germany. Furthermore, specific dental care and dental treatment strategies could be introduced in Germany in order to reduce caries prevalence and number of extracted teeth in persons with intellectual disabilities.

Key words: oral health, intellectual disability, dental caries, dental treatment need

Introduction

Before explaining the background of this dental health study, it should be mentioned, that persons with intellectual disabilities may be named in different ways in different countries. In earlier times these people were called mentally retarded or mentally disabled persons. These terms were replaced by "learning disability" or "intellectual disability". In the UK the term "persons with learning disability" is preferred over "persons with intellectual disabilities" (Mansell, 2010). In Germany and elsewhere the term learning disability is used for children with temporary difficulties in learning and in need of special educational support to overcome these. Conversely, in the UK, these children are said to have "learning difficulties". With regard to intellectual disability, the American Association on Intellectual and Developmental Disability (AAIDD) proposes the following definition: "Intellectual disability is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18" (AAIDD, 2012). At present, not only in USA but also in Germany, this definition usually defines those with intellectual disabilities.

Dentists working in practice or in the public health field have reported that the oral health in people with intellectual disabilities is usually poorer than in the general population. Data concerning the oral health of people with disabilities have rarely been published in Germany or elsewhere. Moreover, the results of most

of these studies accomplished in the last 30 years are limited for several reasons. The subjects were patients consulting a university clinic (Gabre et al., 2001), sports persons at one event (Bissar et al., 2010, Leroy et al., 2012; Schulte et al., 2011) or persons from a small specific region (Pieper et al., 1986). A rare example of a national level study is the one concerning the oral health of Belgian 12-year-olds with disabilities (Gizani et al., 1997). More widespread studies concerning the oral health of adults with physical and mental disabilities were conducted in Australia (Pradhan et al., 2009, Scott et al., 1998). Comparisons to reference age groups proposed by the World Health Organization, WHO, like the 35-44-year-olds were seldom carried out (Pieper et al., 1986). Several publications showed that people with intellectual disabilities have on average a higher caries experience and more extracted teeth than the general population. To date, correlation between the oral health of people with disabilities and regional socio-economic factors has not been investigated.

Our working hypothesis was that caries experience in adults with intellectual disabilities living in two German regions with different socio-economic structures does not differ when using caries experience (DMFT-Index) as the measure. Also, the treatment need and the care index were calculated for both regions. Finally, a comparison with national German data was performed.

Method

Before starting this cross sectional study, the approval of the ethics committee of the University of Heidelberg medical faculty was obtained. The examinations were carried out in specific day-care institutions for adults with intellectual disabilities where these persons are cared for and work according to their abilities. Three institutions with a total of 6 affiliations and 1,291 registered persons in the Rhein-Neckar region (federal state of Baden-Württemberg in south-west Germany) and 2 institutions with a total of 4 affiliations and 746 registered persons in the Delitzsch region (Sachsen, south-east Germany) were selected for this study. These institutions gave their consent after being informed about the study. Subsequently, all registered persons with disabilities and their carers (legal custodians) were asked to give informed consent. Each carer was also asked to complete a questionnaire to provide information about the age, the residential situation and the oral hygiene behaviour of their charges. Six weeks after the first information request, a reminder was sent to the carers who had not so far consented.

The oral examinations took place between June 2007 and February 2008. Dental mirrors, blunt dental probes and artificial light (portable halogen lamp) were used. Missing teeth, dentine carious lesions, restorations, crowns, bridges, dentures, fissure sealants (even partial) on molars and premolars and the presence of plaque were documented following the WHO recommendations (1997). No auxiliary tools for caries diagnostic (i.e. radiographs, FOTI or Laser) were used for this study.

All examinations were carried out by a dentist (KF) who had been calibrated by another dentist with extensive epidemiological experience (AB). The calibration started with theoretical information illustrated by clinical photos. Then, the two dentists independently examined the same group of 14 patients with intellectual disabilities in a day-care institution. DMFT values were used to calculate inter-examiner agreement yielding a value of 95.4% and the Kappa value was 0.925.

The inclusion criteria for participation in the study were as follows: a person aged 18 years or more with intellectual disabilities attending one of the selected institutions, with their carers giving consent for the examination. Exclusion criteria were: being under 18, absence of consent and the non-feasibility of the dental examination (e.g. because of great fear, aggression, excessive uncontrolled movements).

Caries prevalence and caries experience were then calculated. Wisdom teeth were not considered and were excluded from DMFT index calculations. Teeth having a fissure sealant were considered sound. For the calculation of MT all missing teeth were included except wisdom teeth. It was not distinguished whether the teeth were missing due to caries, periodontitis, orthodontic treatment, etc., because the study participants were usually unable to report the reason for tooth extraction.

Participants with untreated caries (DT>0) were considered to have a treatment need. The tooth-related care index was calculated as $100 \times {}^{\rm FMT}/{}_{\rm DMFT}$

Oral hygiene status was assessed visually with the aid of the PI-Index (Silness and Loe, 1964) using the index teeth 16, 12, 24, 36, 32 and 44. If an index tooth

was missing, an adjacent tooth from the same group was substituted. However, when all teeth were missing, the index was not rated. Code 0 denotes no plaque; code 1, very thin plaque line on the gingival margin; code 2, moderate plaque deposition on the gingival margin, and code 3, massive plaque deposition on the gingival margin and filling the interproximal spaces.

Furthermore, correlations between caries experience and various socio-economic factors (e.g. region, age, gender and residential place) were investigated by using the information from the questionnaires.

The socio-economic structure of the two federal states involved differs markedly. In 2009, the gross domestic product was 31,982 € per capita in Baden-Württemberg and 22,228 € per capita in Sachsen with the respective unemployment rates being 5.1% and 12.9% (Bundesagentur für Arbeit, 2008; Statistisches Landesamt Baden-Württemberg, 2011).

Statistical analyses were performed using SPSS v15.0 to compare the two independent groups and test for statistical significance with p values under 0.05 taken as significant. Because of the non-normal distribution, the Mann-Whitney test was used. Data on caries prevalence in the groups were tested for significance using the chi-square test. The Significant Caries Index (SiC) was calculated according to the recommendation of Bratthall (2000).

Results

In total, the legal carers of 2037 persons with intellectual disabilities were contacted. The overall approval rate was 21.9%. This rate was much lower in Baden-Württemberg (18.0%) than in Sachsen (28.6%). As a result 445 persons consented to this study. However, it was not possible to examine 17 persons. These were excluded from this survey leaving the 428 participants on which the following data are based.

The number of participants in the regions was almost identical (Table 1). The mean age of the subjects was

Table 1. Description of the study group. In three categories (region, gender and residential situation) it was checked whether the subgroups differed statistically concerning age.

	Number of participants	Mean age (sd), yr	Age range, yr
Baden-Württemberg	221	36.7 (10.9)	18 - 60
Sachsen	207	34.3 (11.1)	18 - 64
p-value		0.021	
Men	220	34.3 (10.7)	18 - 60
Women	208	36.8 (11.3)	18 - 64
p-value		0.019	
Living with family ^a	255	33.5 (10.8)	18 - 64
Living in institutions ^b	163	39.9 (10.6)	19 - 58
p-value		<0.001	
All	428	35.5 (11.0)	18 - 64

^a Either living with the parents (n=224) or with other family members (n=31)

b Ten persons living in their own apartments were not taken in consideration.

35.5 years (sd 11.0, range 18-64). The average age of those from Baden-Württemberg was a little higher than for of those from Sachsen (Table 1). Regarding gender, 51.4% of all participants were men. Further information about the participants can be found in Table 1.

The proportion of subjects with caries experience was 93.7% (95% CI 91.3–95.9) in Baden-Württemberg and 97.6% (95% CI 96.2–99.0) in Sachsen with an overall value of 95.6% (95% CI 93.2–97.5) for all participants. The respective proportions were similar for men (95.7%; 95% CI 93.8–97.6) and women (95.4%; 95% CI 93.5–97.5). Only 19 (4.4%) of the participants were caries-free (DMFT=0), all younger than 35 years (Table 2).

The overall proportion of participants without need of treatment (but with caries experience) was 36.9%: a higher proportion being from Baden-Württemberg.

Concerning treatment need (the 58.6% with active caries lesions), the proportion was lower in Baden-Württemberg than in Sachsen (Table 2).

The tooth-related care index was higher in Baden-Württemberg (83.3%) than in Sachsen (77.9%). Note that caries-free persons were not taken into account for this calculation.

The mean DMFT of the study participants was 12.25 (sd 6.95, 95% CI 11.6-12.9) with no difference between regions (Table 3). Nevertheless, more decayed teeth (DT) and filled teeth (FT) were found in Sachsen compared to Baden-Württemberg (Table 3). On the other hand, the subjects from Sachsen had fewer missing teeth than those from Baden-Württemberg (Table 3). No gender differences were observed with regard to caries experience and care index (Table 3). Persons living with their parents

Table 2. Prevalence of persons with intellectual disabilities without caries experience or without treatment need or with treatment need in two German regions and in different age groups

Groups	Number of persons	Caries free, % (DMFT=0)	Without treatment need, % $(D=0 \text{ and } MFT>0)$	With treatment need, % (DT>0)
Baden- Württemberg	221	6.7	42.5	51.2
Sachsen	207	2.4	30.9	66.7
p-valu	e	n.a.	0.357	0.001
All	428	4.5	36.9	58.6
18-24-year olds	95	17.0	26.6	56.4
25-34-year olds	105	2.8	34.0	63.2
35-44-year olds	127	0.0	39.4	60.6
45-54-year olds	79	0.0	49.4	50.6
55-65-year olds	22	0.0	36.4	63.6

Table 3. Mean DT, MT, FT and DMFT and standard deviation (sd) accordingly to region, gender and residential situation

Groups	DT (sd)	MT (sd)	FT (sd)	DMFT (sd)
Baden-Württemberg	1.64 (2.15)	6.12 (7.40)	4.21 (3.77)	11.97 (7.01)
Sachsen	2.34 (2.48)	5.19 (7.21)	5.02 (3.96)	12.55 (6.88)
p-value	0.001	0.043	0.025	0.532
Men	2.14 (2.49)	5.72 (7.14)	4.56 (3.76)	12.42 (6.68)
Women	1.83 (2.17)	5.63 (7.49)	4.63 (4.00)	12.09 (7.20)
p-value	0.193	0.569	0.921	0.505
Living with family	2.03 (2.25)	4.10 (6.02)	4.77 (3.90)	10.90 (6.19)
Living in institutions ^a	1.89 (2.09)	8.52 (8.65)	4.51 (3.96)	14.98 (7.29)
p-value	0.760	< 0.001	0.510	< 0.001

^a Ten persons living in their own apartments were not taken into account.

Table 4. Mean DT, MT, FT and DMFT with standard deviations (sd) as well as Significant Caries Index (SiC) in different age categories

Age range (yrs)	DT (sd)	MT (sd)	FT (sd)	DMF-T (sd)	SiC-Index
18-24	1.69 (1.91)	1.44 (3.58)	3.65 (3.53)	6.78 (5.45)	12.6
25-34	2.15 (2.14)	3.00 (4.61)	4.94 (4.05)	10.09 (5.16)	14.8
35-44	1.82 (2.01)	6.11 (6.59)	5.73 (3.88)	13.66 (5.57)	18.5
45-54	2.24 (3.31)	11.51 (8.88)	4.02 (3.67)	17.77 (6.49)	25.4
55-64	2.45 (2.46)	13.32 (7.95)	2.68 (3.44)	18.45 (6.79)	26.0
All	1.98 (2.33)	5.67 (7.32)	4.58 (3.88)	12.25 (6.95)	19.5

or with other family members had a lower mean DMFT than those living in institutions (Table 3).

With rising age the mean DMFT increased (Table 4). In the 35-64-year-olds, the average number of extracted teeth (mean MT) was higher than the average number of restored teeth (mean FT). In each age group the SiC-Index was distinctly higher than the mean DMFT (Table 4).

Removable dentures were found in 13.6% of those examined (Table 5). About a quarter had received fixed prosthodontic treatments (crowns and bridges). However, 55.1% needed prosthodontic treatment because tooth spaces were present. The proportion of subjects without tooth loss was higher and the proportion of the untreated tooth spaces lower in Sachsen compared to Baden-Württemberg (Table 5). But the proportion of people with at least one crown was twice as high in Baden-Württemberg as in Sachsen (Table 5). Those from Baden-Württemberg had on average more (untreated) tooth spaces than to those from Sachsen (Table 5).

The PI index (Silness and Loe, 1964) was on average 1.77 with no significant differences by gender (p=0.519) or by federal state (p=0.839). Nevertheless, with rising age, an increase in the mean PI index was observed: 1.33 (sd 0.70) in 18-24-year-olds, 2.18 (sd 0.77) in 55-65-year-olds.

Discussion

This survey details the current oral health status of German adults with intellectual disabilities because different age groups and two regions with different socio-economic status were examined. We know from an organisation working for the wellbeing of people with intellectual disabilities that about 90% of German adults with intellectual disabilities are cared for in such specialised institutions as those surveyed. Participants comprise both persons with mild disabilities and those with severe or multiple disabilities. However, when considering the findings it has to be taken into account that only 21.9% of the carers consented to participation. The authors' long experience with patients with intellectual disabilities leads them to believe that many carers did not consent for fear this reveals the poor oral health status and the dental care deficit of their charges. Therefore, the oral health of adults with intellectual disabilities is probably poorer than shown by this study. Nevertheless, most of the persons with intellectual disabilities in the institutions wanted to be examined and were disappointed to hear that this was not possible because the carer had not consented.

Our hypothesis that there is no difference between the two regions in caries experience of persons with intellectual disabilities despite contrasting socioeconomic conditions was proved. A difference could have been expected because results from previous surveys on 12-year-old children showed that the mean DMFT in Baden-Württemberg was much lower than in Sachsen (Schulte *et al.*, 2006).

However, the analysis of other results in this survey, such as treatment need, showed that important differences between the regions do exist. The proportion of study participants needing treatment due to caries (DT>0) in Baden-Württemberg was lower than in Sachsen. On the other hand, more extracted teeth (MT) were found in Baden-Württemberg and the proportion of participants with teeth replaced by bridges or dentures was much higher there than in Sachsen (Table 5). A possible explanation for these differences is that the proportion with severe disabilities was higher in Baden-Württemberg. Due to the limited cooperation, it is more difficult to place large restorations in these persons than in those with mild disabilities. Thus teeth with big defects are more likely to be extracted than restored. However, as the examiner did not have more difficulties in examining the teeth of the participants in Baden-Württemberg than in Sachsen, this argument is countered. More probably, financial factors have contributed to the different dental care in the regions. In Germany, the costs for prosthodontic therapy are reimbursed only in part by the social security system which means that the patients/carers have to pay about 40-70% of costs. In addition, the social security system does not pay for preventive dental care comprising professional tooth cleaning, instructions about oral hygiene and balanced nourishment and application of fluorides. This is only paid for patients under 17 years with adults paying the full costs for these measures. It seems that the legal carers can afford to pay for dental care measures more easily in Baden-Württemberg, where the average income is much higher and the unemployment rate much lower than in Sachsen. One should also keep in mind that until the German reunification in the year 1990, Sachsen was part of the socialist German Democratic Republic. In West Germany education in prosthodontics played a more important role than in East Germany. Conversely, education in pediatric dentistry (including treatment and care for those with disabilities) was much more advanced in East Germany than in West Germany. The authors assume that the treatment difference which became apparent in both regions is due to the present

Table 5. Prevalence of persons without dental spaces, with untreated dental spaces and with different prosthodontic restorations

Groups	Neither spaces nor restorations	Untreated spaces	Crowns	Bridges	Dentures	Total dentures
Baden-Württemberg	25.8 %	60.6%	29.4%	15.4%	14.5%	3.2%
Sachsen	34.8 %	49.3%	14.0%	10.6%	12.6%	4.3%
Men	27.3%	52.3%	25.0%	15.0%	11.4%	4.1%
Women	33.2%	58.2%	18.7%	11.1%	15.9%	3.4%
All a	129	236	94	56	58	16

^aAs individuals may receive different types of prosthodontic treatments, the sum in the final row exceeds 428

Table 6. Mean DT, MT, FT and DMFT in 35-44-year-olds from different surveys

	DMFT	DT	MT	FT	Survey participants
Present survey	13.6	1.8	6.1	5.7	
Schulte et al., 2011	13.5	0.9	4.2	8.4	Persons with intellectual disabilities participating in the German Special Olympics
Micheelis and Schiffner, 2006	14.5	0.6	2.4	11.5	German national representative random sample
Pieper et al., 1986	19.7	8.2	8.0	3.5	Persons with intellectual disabilities from an institution for persons with special needs
Pradhan et al., 2009	8.3	n.a.	n.a.	n.a.	Australian persons with intellectual disabilities

socio-economic differences and the different dental education in the past. Nevertheless, these differences make clear that it is necessary to improve and harmonise dental therapy for German people with intellectual disabilities.

Compared with representative data on oral health of German adults without disabilities (Micheelis and Schiffner 2006, Schiffner et al. 2009), people with intellectual disabilities have more extracted teeth, more untreated decayed teeth and fewer restored teeth (Table 6). This clearly shows a need to improve not only the preventive care for these persons, but also their access to dental therapy. In persons with intellectual disabilities who took part as athletes in the German Special Olympics (Schulte et al., 2011) the number of missing teeth was also higher than in the general population but lower than in the present study (Table 6). An explanation for this might be that, on average, Special Olympics athletes have less severe disabilities than those attending special day-cares and thus are better able to cooperate with dental treatment. Furthermore, in our study persons living in an institution had more missing teeth than those living with their families (Table 3). This result must be interpreted with caution because in the Special Olympics athletes study we found that 35-44-yearolds living in an institution on average had fewer missing teeth than persons living with their families (Schulte et al., 2011). Unfortunately, we do not have information for how many years the persons examined in either study had been living in an institution. This should be explored more extensively in further studies.

In other countries it was also observed that, due to the reduced cooperation, the dental treatment in persons with intellectual disabilities consisted mostly of extractions; consequently more teeth are missing and fewer are restored (Gabre et al., 1999; Kendall, 1991). Nevertheless, it is encouraging to see that dental health and the dental treatment degree in people with intellectual disabilities in Germany have improved during the last three decades. In 1983, the mean DMFT in the 35-44-year-old persons with intellectual disabilities was about 50% higher than in the present survey (Table 6) and a distinctly higher number of untreated decayed teeth had been found (Pieper et al., 1986). In addition, an Australian survey shows that people with intellectual disabilities can have a better oral health than the general population if adequate programmes or facilities like public dental services are offered (Scott et al., 1998).

It is concluded, that in Germany dental treatment for persons with intellectual disabilities differs in regions with different socio-economic backgrounds. Nevertheless, in both regions these persons have worse oral health than the general population with many more teeth being extracted. Therefore, in accordance with the goals of the German Dental Association for the year 2020 (Ziller *et al.*, 2006), special arrangements for dental care must be offered for persons with intellectual disabilities. The goals should be to reduce caries prevalence, to promote early diagnosis and early treatment of decayed teeth and periodontal diseases and to reduce treatment disparities within Germany.

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