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Differences between caregiver-perceived and dentist-assessed oral health status of patients among intellectual disabilities

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Objective: This study compared the caregiver-perceived and dentist-determined oral health status of patients with intellectual disabilities to determine factors that affect caregiver-perception of patients' oral health. ***Materials and Methods:*** 297 patients [mean (SD) age = 51.9 (12.5) years] and 56 professional caregivers [42.1 (8.2) years] from three institutional facilities took part. Data were acquired via self-administered questionnaires by caregivers and oral examination by dentists. Oral hygiene condition, numbers of decayed and missing teeth, and periodontal disease reported by caregivers and dentists were compared using paired t-test and Pearson correlation. Demographic and dental factors of the patients and caregivers were analyzed using chi square and Fisher's exact tests. ***Results:*** Caregivers underestimated decayed and missing teeth compared to dentists ($p<0.05$). Oral hygiene condition and periodontal disease were similarly rated by the two groups. Tooth brushing, diet type, sex, and overall oral health status of the patients were associated with caregiver perception ($p<0.05$). Career length and time since caregivers last received dental care were also related factors ($p<0.05$). ***Conclusion:*** Professional caregivers of adult patients with intellectual disabilities had different perceptions of oral health status based on patient and caregiver circumstances.

Keywords: *Caregiver, Dentist, Intellectual disability, Oral health, Special care*

Introduction

Special care dentistry is concerned with the oral care in patients with physical, sensory, intellectual, mental, medical, emotional or social impairments or disabilities (Gallagher and Fiske, 2007), representing a diverse range of disabilities and complex additional needs for dental care services. They often face barriers to dental visits, resulting in poorer oral health conditions and higher treatment needs compared to the general population (Barry *et al.*, 2014). In particular, patients with severe intellectual and cognitive disabilities have difficulties maintaining oral hygiene and receiving treatment (Anders and Davis, 2010). In addition, communication challenges make it difficult for caregivers and dental professionals to recognise their symptoms when they have dental problems (Espinoza and Heaton, 2016). Consequently, clinical problems may be neglected, further exacerbating related diseases. Therefore, the main caregivers that assist with patients' daily activities such as eating and tooth brushing are critical in the detection and interpretation of the oral symptoms in this vulnerable population.

In South Korea, among a total of 196,000 persons with intellectual disabilities (7.8% of a total 2,500,000 of population with disabilities), 30.5% were ≥40 years old (Korea Employment Agency for the Disabled, 2018). People with intellectual and mental disabilities account for 39.1% of all people with disabilities cared for in institutional facilities (12,008 out of 30,693) (Korea Ministry of Health and Welfare, 2018). This implies a high need for assistance with the daily care of this population.

Adults with intellectual disabilities who require daily assistance with self-care are more likely to receive professional care in institutional facilities than children, as their parents and family members age and become less able to care for them. Caregivers' perceptions of the dental status of the adults for whom they care are strongly associated with individual backgrounds, resulting in dissimilar decision-making and access to dental health care services (Heft *et al.*, 2003; Finlayson *et al.*, 2007; Firmino *et al.*, 2018). Considering the diversity of caregiving circumstances, professional caregivers have a broader spectrum of awareness and attitudes toward oral health compared with parental caregivers. It is important to investigate caregiver responses to patient symptoms and to compare those to dentists' judgements. Caregiver perceptions can yield timely and optimized intervention, improving the oral health of this vulnerable patient group.

Previous studies have compared self-reported oral health and professionally-determined oral health status (Heft *et al.*, 2003; Liu *et al.*, 2010; Weintraub *et al.*, 2013). In other studies, proxy-ratings were provided by parents, particularly for very young children with limited communication. Many studies of proxy-reports have focused on oral health-related quality of life or have explored the impact of parents' oral health behavior on children's dental problems (Finlayson *et al.*, 2007; Naidu *et al.*, 2013; Folayan *et al.*, 2014). However, investigations of proxy-ratings of the oral condition for adults with intellectual and cognitive impairments are rare. Reports of professional caregivers acting as proxies have typically focused only on severe or complex issues.

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This study aimed to identify how caregiver-perceived oral health conditions in patients with intellectual disabilities vary from dentist-determined outcome measures, and, second, whether caregivers' perceptions of their patients' oral health status were related to demographic and dental factors among patients and caregivers.

Materials and methods

Study design

The study population comprised of patients and professional caregivers in three institutional facilities for persons with intellectual disabilities in cities I, J, and A in South Korea. The Seoul National University Dental Hospital Institutional Review board approved the study (CRI18006). A total of 297 patients [90 females and 207 males, mean (SD) age = 51.9 (12.5) years] and 56 professional caregivers [30 females and 26 males, 42.1 (8.2) years] were included in the study. The inclusion criteria for the patients were as follows: (1) older than 12 years, (2) intellectual and cognitive disabilities, (3) received care from full-time employees at one of the institutions, and (4) co-operated with oral examinations. The inclusion criteria for the caregivers were as follows: (1) full-time employed at the facility (not less than 40 working hours per week) and (2) they were main caregivers that assisted with daily activities of the patients. Based on an assessments of their cognitive capacity, we considered that the patients lacked the capacity to understand information relevant to the decision to participate (Dougall and Fiske, 2008). The study design was thoroughly explained to the participating caregivers and the patients' legal guardians who gave written consent. Data were obtained from (1) an oral examination performed by dentists, and (2) a questionnaire completed by the professional caregivers.

Oral examination

The patients were seated on a chair in the institution. Examination was performed using a lightweight portable light and a dental mirror, by one of six calibrated dentists. All of the dentists had 15 years experience in care for patients with special needs and were not the authors of this study. The examination yielded clinical data such as oral hygiene condition, the numbers of decayed and missing teeth, and periodontal status. Oral hygiene condition was assessed based on the modified plaque scores of Mombelli et al. (Hoeksema *et al.*, 2017) (score 1=absence or some plaque was detected, score 2=thin layers of plaque were seen on all surfaces, and score 3=layers of plaque were present in the whole dentition). The numbers of decayed or missing teeth were determined based using the World Health Organization criteria (2013). Periodontal disease was recorded as absent or present using the Community Periodontal Index (CPI) (Score 0 vs. CPI≥1 if there was any sign of gingival bleeding, calculus or pockets).

Questionnaires

The self-administered questionnaires enquired about the sociodemographic characteristics, oral health conditions and behaviors of both patients and caregivers. Four sets of independent variables were included: (1) patient demographics, (2) patient dental condition, (3) caregiver demographics, and (4) caregiver dental condition. Demographic factors for patients were sex, age, daily activity, types and severity of disabilities, medication, consistency of meals, cooperation with daily care, communication skills, and economic status. Dental factors for patients were pain in the teeth, oral hygiene condition, tooth brushing pattern, untreated cavity, gum bleeding on tooth brushing, missing teeth, cooperation with dental care, last dental visit, last dental treatment, amount of saliva, chewing and swallowing difficulty and overall oral health status. Demographic factors for caregivers were sex, age, marital status, education, career length, employment type, number of patients in their care, and work satisfaction. Dental factors for caregivers comprised the presence of dental pain, gums bleeding on tooth brushing, untreated cavity, missing teeth. The questionnaire also enquired about caregivers' frequency of dental flossing, last dental visit, last dental treatment, amount of saliva, chewing and swallowing difficulty, and overall oral health status.

Statistical analysis

Four dependent variables were measured in oral examination by dentists and in subjective assessment by caregivers: (1) oral hygiene condition, (2) number of decayed teeth, (3) number of missing teeth, and (4) periodontal disease. The paired t-test and Pearson correlation were used to compare the differences between scores rated by caregivers and dentists in the previously listed four variables [(1) n=225, (2) n=174, (3) n=217, (4) n=199]. Each dependent variable was categorised in relation to three categories: (1) caregiver evaluated patient status worse than the dentists, (2) caregiver evaluated patient status equal to the dentists, and (3) caregiver evaluated patient status better than the dentists. Pearson chi square test and Fisher's exact test were used to compare proportions among the three categories for the caregiver-to-dentist evaluation [(1) n=175, (2) n=137, (3) n=171, (4) n=152]. For this analysis, samples that contained any missing or unknown values (unmarked or answered with "I don't know") were excluded. We used Stata/MP version 13.0 for analysis with the alpha level set at 0.05.

Results

Table 1 summarizes the demographic characteristics and oral health status of the patients. Approximately 99% had a severe disability with subsequent difficulty in recognizing, expressing, and communicating oral signs without involvement of caregivers.

In response to the question, "How is the overall oral hygiene status of your patient?", caregivers responded for 289 of the 297 patients (8 responded "I don't know" or did not respond). In total, 82.0% of patients were thought to have 'poor' (36.7%)' or 'very poor' (45.3%) oral health (Table 1). These values corresponded to the dentists' assessments of carious (56.0%) and missing teeth (80.8%).

Table 2 shows the caregivers' and dentists' assessments of patients' oral health status. The higher scores indicate a worse status of patient oral health. Similar caregivers' and dentists' scores indicate greater agreement. Caregivers' scores that are higher than the dentists indicate an overestimation of patients' health status. Lower scores represent an underestimation.

Table 1. Demographic characteristics and oral health conditions of 297 patients

Variables		*Number (%)*	*Total number*
Demographic characteristics answered by caregivers			
Oral hygiene condition	Reasonable	52 (18.0)	289
	Poor	106 (36.7)	
	Very poor	131 (45.3)	
Gender	Female	90 (30.3)	297
	Male	207 (69.7)	
Age (years)	<20	7 (2.4)	293
	20-29	10 (3.4)	
	30-39	25 (8.5)	
	40-49	57 (19.5)	
	50-59	113 (38.6)	
	≥60	81 (27.6)	
Onset of disability	Acquired	166 (83.0)	200
	Congenital	34 (17.0)	
Level of disability§	Level 1	49 (16.9)	290
	Level 2	160 (55.2)	
	Level 3	78 (26.9)	
	Level 4	3 (1.0)	
	Level 5 and 6	0 (0.0)	
Legal guardian	Nonfamily members	62 (21.1)	294
	Family members	232 (78.9)	
Medication	No	29 (10.3)	282
	Yes	253 (89.7)	
Drinking history	Never have drunk alcohol	131 (45.8)	286
	Not drunk for the last year	151 (52.8)	
	Have drunk for the last year	4 (1.4)	
Smoking history	Never have smoked	146 (50.2)	291
	Have quit smoking	21 (7.2)	
	Currently smoking	124 (42.6)	
Oral health conditions assessed by dentists			
Oral hygiene condition	Reasonable	34 (14.7)	231
	Poor	112 (48.5)	
	Very Poor	85 (36.8)	
Carious teeth	No	113 (44.0)	257
	Yes	144 (56.0)	
Missing teeth	No	57 (19.2)	297
	Yes	240 (80.8)	
Periodontal disease	No	143 (51.2)	279
	Yes	136 (48.8)	
Malocclusion	No	214 (77.0)	278
	Yes	64 (23.0)	
Temporomandibular disorders	No	254 (91.4)	278
	Yes	24 (8.6)	
Tooth defects (attrition, erosion)	No	180 (65.7)	274
	Yes	94 (34.3)	

§The disability levels were rated from level 1 (very severe) to level 6 (very mild) using Enforcement Rule of the Act on Welfare of Persons with Disabilities (Ordinance Of the Health and Welfare No. 527, Oct. 13, 2017) in South Korea

Table 2 showed that caregivers and dentists scored the numbers of decayed and missing teeth differently (mean scores of decayed teeth = 0.53 and 0.89 and mean scores of missing teeth = 1.00 and 1.62, respectively; $p<0.05$). Scoring of oral hygiene condition and periodontal disease were similar across both groups.

Table 3 shows patient-related factors related to caregivers' and dentists' judgements of patients' oral hygiene condition. Patients who brushed their teeth less frequently or required assistance for brushing received poorer oral hygiene condition ratings by caregivers than dentists ($p<0.05$). Conversely, patients who brushed more frequently or independently received better assessment scores by caregivers than by dentists. When the overall oral health status of the patients was perceived by caregivers as worse, the oral hygiene condition of the patients was also estimated more negatively than by dentists ($p<0.05$).

Table 4 shows patient- and caregiver-related factors associated with differences in numbering decayed teeth by the two observer groups. The caregivers identified more decayed teeth than dentists if patients were female, consumed a diet with less than normal consistency, or brushed teeth their less frequently ($p<0.05$). For caregiver-related factors, caregivers identified more decayed teeth than dentists if the caregiver had had a longer career, had more patients to care for, and had not visited a dentist for more than 24 months ($p<0.05$).

Table 5 shows the factors that contributed to over- or under- estimation of missing teeth by caregivers. Caregivers overestimated the number of missing teeth for patients with poorer oral health status ($p<0.05$). In addition, caregivers with a longer career identified more missing teeth than dentists ($p<0.05$). Finally, caregivers with more recent dental visits estimated the periodontal condition more positively than the dentists (Table 6, $p<0.05$).

Table 2. Relationships between caregiver- and dentist-assessed oral health status of patients with intellectual disabilities

Oral Examination (Dentist)	*Questionnaire (Caregiver)*	*Scores*	*Observer*	*Mean (SD)*	*Paired T-test*	*Correlation coefficient*
Oral hygiene condition	How is the overall oral hygiene status of your patient?	1=reasonable 2=poor 3=very poor	Caregiver Dentist	2.30 (0.73) 2.22 (0.69)	1.36 (p=0.18)	0.13 (p=0.04)
Number of carious teeth	Does your patient have untreated cavities?	0= none 1= 1-2 teeth 2= 3-4 teeth	Caregiver Dentist	0.53 (0.73) 0.89 (1.01)	-4.06 (p=0.00)	0.14 (p=0.07)
Number of missing teeth	Does your patient have missing teeth (except 3rd molars)	3= more than 5 teeth	Caregiver Dentist	1.00 (1.17) 1.62 (1.14)	-7.27 (p=0.00)	0.40 (p=0.00)
Periodontal disease	Does your patient show gum bleeding during tooth brushing?	0=absence 1=presence	Caregiver§ Dentist	0.45 (0.50) 0.48 (0.50)	-0.53 (p=0.60)	0.10 (p=0.15)

§Caregiver-reported periodontal disease was defined by "bleeding on tooth brushing"

Table 3. Factors associated with caregiver- and dentist-assessed oral hygiene conditions of patients with intellectual disabilities

Factors		*Assessment of oral hygiene condition, n (%)*				*p-value*
		Caregiver scored worse than dentist	*Caregiver scored equal to dentist*	*Caregiver scored better than dentist*	*Total*	
Patient-related						
Frequency of tooth brushing	>2 times a day	17 (28.8)	28 (40.0)	28 (60.9)	73 (41.7)	0.01
	2 times a day	25 (42.4)	22 (31.4)	15 (32.6)	62 (35.4)	
	1 time a day	10 (17.0)	16 (22.9)	3 (6.5)	29 (16.6)	
	<1 time a day	7 (11.9)	4 (5.7)	0 (0.0)	11 (6.3)	
Tooth brushing method	Without assistance	42 (71.2)	62 (88.6)	40 (87.0)	144 (82.3)	0.03
	With assistance	17 (28.8)	8 (11.4)	6 (13.0)	31 (17.7)	
Overall oral health status	Very good or good	2 (3.4)	13 (18.6)	19 (41.3)	34 (19.4)	0.00
	Average	23 (39.0)	24 (34.3)	21 (45.7)	68 (38.9)	
	Poor or very poor	34 (57.6)	33 (47.1)	6 (13.0)	73 (41.7)	
Total		59 (33.7)	70 (40.0)	46 (26.3)	175 (100.0)	

Table 4. Factors related to caregiver- and dentist-assessed numbers of decayed teeth of patients with intellectual disabilities

Factors		*Assessment of decayed teeth, n (%)*				*p-value*
		Caregiver scored higher than dentist	*Caregiver scored equal to dentist*	*Caregiver scored lower than dentist*	*Total*	
Patient-related						
Sex	Male	14 (66.7)	31 (50.8)	43 (78.2)	88 (64.2)	0.01
	Female	7 (33.3)	30 (49.2)	12 (21.8)	49 (35.8)	
Diet type	Normal consistency	9 (42.9)	44 (72.1)	41 (74.6)	94 (68.6)	0.03
	Soft or liquid	12 (57.1)	17 (27.9)	14 (25.5)	43 (31.4)	
Frequency of tooth brushing	>2 times a day	7 (33.3)	40 (65.6)	22 (40.0)	69 (50.4)	0.04
	2 times a day	10 (47.6)	14 (23.0)	24 (43.6)	48 (35.0)	
	1 time a day	3 (14.3)	5 (8.2)	8 (14.6)	16 (11.7)	
	<1 time a day	1 (4.8)	2 (3.3)	1 (1.8)	4 (2.9)	
Caregiver-related						
Career length (years)	<10	2 (9.5)	21 (34.4)	9 (16.4)	32 (23.4)	0.03
	10-14	5 (23.8)	17 (27.9)	22 (40.0)	44 (32.1)	
	15-19	14 (66.7)	20 (32.8)	19 (34.6)	53 (38.7)	
	≥20	0 (0.0)	3 (4.9)	5 (9.1)	8 (5.8)	
Number of patients per caregiver	<10	1 (4.8)	14 (23.0)	5 (9.1)	20 (14.6)	0.02
	10-19	10 (47.6)	32 (52.5)	24 (43.6)	66 (48.2)	
	20-29	0 (0.0)	3 (4.9)	8 (14.6)	11 (8.0)	
	>30	10 (47.6)	12 (19.7)	18 (32.7)	40 (29.2)	
Last dental visit (months)	<6	7 (33.3)	9 (14.8)	18 (32.7)	34 (24.8)	0.01
	6 to 12	5 (23.8)	25 (41.0)	13 (23.6)	43 (31.4)	
	12 to 24	7 (33.3)	19 (31.2)	24 (43.6)	50 (36.5)	
	>24	2 (9.5)	8 (13.1)	0 (0.0)	10 (7.3)	
Total		21 (15.3)	61 (44.5)	55 (40.2)	137 (100.0)	

Table 5. Factors related to caregiver- and dentist-assessed numbers of missing teeth of patients with intellectual disabilities

Factors		*Assessment of missing tooth*				*p-value*
		Caregiver scored higher than dentist	*Caregiver scored equal to dentist*	*Caregiver scored lower than dentist*	*Total*	
Patient-related						
Overall oral health status	Very good or good	2 (10.0)	14 (21.2)	24 (28.2)	40 (23.4)	0.02
	Average	7 (35.0)	17 (25.8)	36 (42.4)	60 (35.1)	
	Poor or very poor	11 (55.0)	35 (53.0)	25 (29.4)	71 (41.5)	
Caregiver-related						
Career length (years)	<10	4 (20.0)	21 (31.8)	19 (22.4)	44 (25.7)	0.01
	10-14	3 (15.0)	20 (30.3)	32 (37.7)	55 (32.2)	
	15-19	10 (50.0)	18 (27.3)	33 (38.8)	61 (35.7)	
	≥20	3 (15.0)	7 (10.6)	1 (1.2)	11 (6.4)	
Total		20 (11.7)	66 (38.6)	85 (49.7)	171 (100.0)	

Table 6. Caregiver- and dentist-assessed periodontal condition of patients with intellectual disabilities

Factors		*Assessment of periodontal condition*				*p-value*
		Caregiver scored worse than dentist	*Caregiver scored equal to dentist*	*Caregiver scored better than dentist*	*Total*	
Caregiver-related						
Last dental visit (months)	< 6	4 (10.8)	21 (25.3)	16 (50.0)	41 (27.0)	0.01
	6 to 12	16 (43.2)	24 (28.9)	3 (9.4)	43 (28.3)	
	12 to 24	12 (32.4)	31 (37.4)	10 (31.3)	53 (34.9)	
	>24	5 (13.5)	7 (8.4)	3 (9.4)	15 (9.9)	
Total		37 (24.3)	83 (54.6)	32 (21.1)	152 (100.0)	

Discussion

This study investigated how non-parental caregivers perceived the oral health status of their patients with intellectual disabilities and identified factors related their different estimations compared with those of the dentist. Patients' oral hygiene behaviors and carers' career patterns and dental care habits were associated with caregiver-perceived oral health status.

Divaris and colleagues (2012) reported that parental caregivers' assessments of their children's oral health status and their clinically determined restorative treatment needs were closely associated. The accuracy of caregiver assessments was influenced by caregiver socio-economic backgrounds such as age, oral health literacy, dental visits, and education level. However, non-parent caregivers' proxy-reports of the oral health of middle-aged, intellectually impaired patients has received less attention. We developed self-administered questionnaires enquiring about dental behaviors and clinical signs observed by caregivers. For non-parental caregivers caring for many patients, it can be challenging to respond to a large number of questions for each patient. We eliminated all data with missing or invalid answers, which decreased the sample size available for analysis. Four clinical variables were compared between caregiver and dentist reports. The variables were relatively intuitive so that they could be recognized by non-dental staff: oral hygiene condition, numbers of decayed and missing teeth, and gums bleeding on tooth brushing.

Caregivers' and dentists' judgements about patients' oral hygiene condition and bleeding gums were similar. We asked caregivers to score the patients' decayed and missing teeth rather than use exact numbers, to allow for some error by non-professionals. Even so, the numbers of decayed and missing teeth were underestimated by caregivers compared to dentists.

Caregivers were sensitive to patients' oral hygiene behaviors. Patients' tooth brushing pattern was the most prominent factor related to caregivers' perceptions of patients' oral health status. If the caregivers believed that their patients did not brush adequately, they were more likely to have an unfavorable impression of their patient's oral health status. Consequently, caregivers reported their patients' oral hygiene conditions as more negative or estimated their numbers of cavities at higher values than determined by the dentist. Caregivers tended to indicate that patients consuming meals of less than normal consistency were likely to have more untreated cavities and more cavities for female than male patients. The overall oral health status of patients reported by caregivers was related to other caregiver perceptions. When caregivers believed that the patients' oral health status was poor, then, they were more likely to indicate that the patients had poorer oral hygiene and more missing teeth compared to dentist assessments.

Distinct from patient-related circumstances, caregiver working environment was also associated with their perspectives. When patients require considerable assistance in daily care, such as patients with dementia in nursing homes, there are barriers to maintaining oral healthcare not only from patient factors but also caregiver circumstances (Willumsen *et al.*, 2012). As in this study, institutional caregivers are often responsible for multiple patients and face time constraints when assisting with oral hygiene. In our study, caregivers with longer working experience or who were responsible for more patients were more sensitive to their patients' oral health problems, resulting in an overestimation of untreated cavities.

We investigated whether the dental behaviors' of institutional caregivers were related to their perceptions of their patients' oral health. Liu et al. (2010) compared self-reported and clinical assessment models, showing that fewer dental visits among respondents were associated with a larger difference between the two assessments. Similarly, professional caregivers who attended the dentist regularly had better oral health care knowledge and attitudes (Frenkel *et al.*, 2002). In our data, caregivers' last dental visit showed a relationship to their awareness of patients' decayed teeth and gum bleeding. Implementation of training programs for caregivers led to improvements in the oral hygiene status of dependent elderly people with cognitive impairments in their care (Samson *et al.*, 2009; Portella *et al.,* 2015), enhancement of periodontal health and denture hygiene (Zenthofer *et al.*, 2016), and a decrease in oral candidiasis (Grimoud *et al.*, 2005). Therefore, good awareness of dental behaviours by caregivers may help patients maintain their oral health.

We investigated professional caregivers' proxy-reports of middle-aged patients with special needs. Research in this population has been limited, and previous studies have primarily focused on reports from dyads of children and parents. Only a few studies have reported on dental problems and treatment needs of patients at institutional care centers. In a study by Gurbuz et al. (2010), a group of middle-aged patients hospitalized with mental illness had very high DMFT scores (19.3±7.9), of which missing teeth comprised more than 80%. Many of the institutionalized elderly people examined by Hoeksema et al. (2017) had poor oral hygiene and multiple caries and broken teeth, resulting in a need to remove of all teeth, and many were already edentulous. Often, patients' unmet needs for extensive treatment are caused not only by their unwillingness to allow daily oral hygiene, but also from their inability to inform staff about their dental problems (Vigild *et al.*, 1993). Therefore, identifying and being proactive to address dental problems in adult patients with special needs should be emphasized.

There is only limited information for dental professionals to use to care for patients with intellectual disabilities. This hurdle for practitioners with patients with special needs supplements patients' inability to seek care. Early detection of dental problems by caregivers will aid dental practitioners in making accurate diagnoses and prioritizing treatment needs. Additional studies should further assess this susceptible group of patients and to establish clinical evidence applicable to their treatment.

Conclusions

Professional caregivers of patients with intellectual disabilities showed their perceptions of oral health problems differed to those of dentists. Both patient and caregiver circumstances affected the caregiver-perceived oral health status of their patients.

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