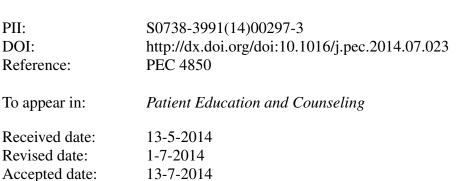
Accepted Manuscript

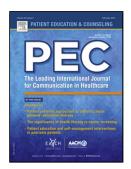
Title: Applying the Verona Coding Definitions of Emotional Sequences (VR-CoDES) in the dental context involving patients with complex communication needs: an exploratory study

Author: Yuefang Zhou Rolf Black Ruth Freeman Daniel Herron Gerry Humphris Rachel Menzies Sandra Quinn Lesley Scott Annalu Waller



Please cite this article as: Zhou Y, Black R, Freeman R, Herron D, Humphris G, Menzies R, Quinn S, Scott L, Waller A, Applying the Verona Coding Definitions of Emotional Sequences (VR-CoDES) in the dental context involving patients with complex communication needs: an exploratory study, *Patient Education and Counseling* (2014), http://dx.doi.org/10.1016/j.pec.2014.07.023

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.



Applying the Verona Coding Definitions of Emotional Sequences (VR-CoDES) in the dental context involving patients with complex communication needs: <u>an exploratory study</u>

Yuefang Zhou¹*, Rolf Black², Ruth Freeman³, Daniel Herron², Gerry Humphris¹, Rachel Menzies², Sandra Quinn³, Lesley Scott² and Annalu Waller² ¹School of Medicine, University of St Andrews, St Andrews, UK ²School of Computing, University of Dundee, Dundee, UK ³School of Dentistry, University of Dundee, Dundee, UK

*Corresponding author at

School of Medicine, University of St Andrews, St Andrews, Fife, KY16 9TF, Scotland, UK Tel: +44 1334 463564; Fax: +44 1334 467470; Email: yz10@st-andrews.ac.uk

Abstract

Objective: The VR-CoDES has been previously applied in the dental context. However, we know little about how dental patients with intellectual disabilities (ID) and complex communication needs express their emotional distress during dental visits. This is the first study explored the applicability of the VR-CoDES to a dental context involving patients with ID.

Methods: Fourteen dental consultations were video recorded and coded using the VR-CoDES, assisted with the additional guidelines for the VR-CoDES in a dental context. Both inter- and intra-coder reliabilities were checked on the seven <u>consultations</u> where cues were observed.

Results: Sixteen cues (eight non-verbal) were identified within seven of the 14 consultations. Twenty responses were observed (12 reducing space) with four multiple responses. *Cohen's Kappa* were 0.76 (inter-coder) and 0.88 (intra-coder).

Conclusion: With the additional guidelines, cues and responses were reliably identified. Cue expression was exhibited by non-verbal expression of emotion with people with ID in the literature. Further guidance is needed to improve the coding accuracy on multiple providers' responses <u>and to investigate potential impacts of conflicting responses on patients.</u> **Practice implications:** The findings provided a useful initial step toward an ongoing exploration of how healthcare providers identify and manage emotional distress of patients with ID.

Key words: the VR-CoDES, dental patients, emotional distress, intellectual disabilities

1. Introduction

For most people, the dental environment is anxiety-provoking. Patients with intellectual disabilities (ID)¹ and complex communication needs² often find their dental visits frightening [1]. This is due largely, to their reduced cognitive ability to fully understand the process and consequences of their dental treatment and/or their impaired communication capacity to express their feelings during dental consultations. Provision of meaningful communication and the quality of patient-centred care, therefore, often depend on the ability of the dental professional team to identify and interpret the verbal and non-verbal cues of emotional distress of this patient group. A reliable and valid behavioural observation scheme becomes a useful tool to measure affective communicative behaviour of this patient group and assist clinicians in effective management of emotional distress of these patients. Although the Verona Coding Definitions of Emotional Sequences (VR-CoDES) has been reliably applied in a dental setting with a standard patient group [2], it is unknown how dental patients with ID express their emotional distress using this scheme. As part of a larger study aiming to improve communication between dental professionals and special-needs patients, this study focuses on investigating the applicability of the VR-CoDES in the dental setting involving patients with complex communication needs.

1.1. Assessing emotional distress in people with ID

People <u>with ID usually have</u> complex communication needs <u>and they often</u> rely on augmentative and alternative communication (AAC) to express thoughts and feelings. The use of facial expression, body language and gestures are the three main unaided, informal communication channels in the AAC system [3]. <u>Therefore, a suitable coding scheme is</u>

required to capture the facial and behavioural expressions of emotion within this population. More importantly, the dental context and the interactive nature of a dental consultation should also be reflected. Although the Emotion Facial Action Coding System (EMFACS [4,5] was appropriate to measure facial expressions of emotion of dental patients, it would fail to capture health providers' interpretation of emotions using this scheme. Similarly, other potentially suitable schemes (e.g. The Disability Distress Assessment Tool :DisDAT [6], and some vocal affect expression assessment tools [7]) all neglected the important interactions between expression and impression (response), an important issue highlighted in both the intellectual disability literature [8] and the emotion research literature [9]. Despite a small sample size (n=13), Wright et al. [2] found that the VR-CoDES could reliably code (with satisfactory inter- and intra-coder scores) dental patients' expressions of emotional distress, as well as dental professionals' responses to patients' cues and concerns. This initial finding has made the VR-CoDES particularly desirable to addressing what has been highlighted in the literature of studying both emotion expression and interpretation (response) of these emotions. Hence, we tentatively applied VR-CoDES with this special patient group in the dental context.

1.2. The VR-CoDES in the dental context

The VR-CoDES is a consensus based system to studying patients' expressions of emotional distress [10] and health providers' responses to patients' expressions emotions [11]. It was developed primarily from medical consultations and <u>only relatively recently has been applied</u> to the dental context [2]. Two dental-specific features were highlighted by Wright et al. [2], which presented challenges in applying the VR-CoDES in the dental context: (1) multiple dental professionals, resulting in multiple responses to patient distress cues and concerns; and

(2) occurrences of non-verbal behaviours, arising from dental treatment conducted in the mouth.

A number of guidelines were, therefore, developed by the research team to tackle these challenges [2], which have relevance when applying the VR-CoDES in communications involving patients with complex communication needs. For patients with ID attending dental treatment, having an additional dental worker at site (e.g. a dental nurse or a dental support worker) is important for successful and efficient delivery of treatment. Patients' expressions of emotional needs are usually recognized and/or responded by either, or both, dental staff. According to the first of Wright et al.'s guidelines which deals with multiple staff members, when the responses follow each other chronologically, the second staff's speech should not be coded as a provider response unless it is directly related to the patient's cue or concern. We were, therefore, interested in exploring, to what extent, this guideline can be applied in patients with ID; particularly when a dental nurse often responds to the dentist, who has initially responded to the patient's cue or concern. In addition, staff non-verbal behaviours are frequently used to assist communication with dental patients with ID (e.g. gesture) and to reduce anxiety (e.g. a reassuring touch). This guideline did not provide additional information on how to code staff non-verbal responses.

The second guideline from Wright et al. was developed to assist coding non-verbal expressions of emotional distress. This guideline was developed due to the impracticality of patient verbal speech during the dental treatment conducted in the mouth. The guideline suggests a careful examination of the 'ah, ooooho' type of verbal expressions and to code as a non-verbal *Cue F* when they carry the function of beyond, merely, describing symptoms. For patients with ID, the 'ah, ooooho' type of verbal expressions might be occurring due to an

extant dental condition and/or their intellectual/communication difficulty. Again, we are interested in investigating how this guideline can be implemented in patients with ID.

1.3. Aim of the study

We attempted to apply the VR-CoDES, assisted with additional guidelines from Wright et al.'s study, in the dental context involving patients with intellectual disabilities and complex communication needs. Specifically, we posed the following research questions:

- Is the VR-CoDES applicable to the dental context where patients with complex communication needs are involved? In other words, we are to explore (a) whether cues, concerns and responses are identifiable using the VR-CoDES – CC and VR-CoDES – P, assisted with the additional guidelines for the VR-CoDES in a dental context; and (b) whether cues, concerns and responses can be reliably coded using the VR-CoDES?
- 2. If the VR-CoDES is applicable in this setting, to what extent do patients with complex communication needs express cues and concerns during a dental consultation?
- 3. How do dental professionals respond to patient cues and concerns?
- 4. Is there a need for modification of both systems of VR-CoDES CC and VR-CoDES P for future application of the VR-CoDES in a similar setting?

2. Methods

2.1. Participants

Fourteen dental consultations from three National Health Service (NHS) special dental care service units in east Scotland were video recorded during a two-month period between April and June 2013. This involved fourteen patients with complex communication needs (six male and eight female) and eight dental staff (four female dentists and four female dental

nurses). All patient participants were seen regularly at the special care dental service due to their varying degree of intellectual disabilities (Down syndrome n=4, Asperger syndrome n=3, attention deficit hyperactivity disorder (ADHD) n=1, non-specific ID n=6). Assessment was made informally by the clinician, based on patient responses to questions relating to their general wellbeing, as well as those related to specific dental issues. Professional experience and intuition were the basis for these decisions rather than any formal assessment. Twelve of them (86%) had a moderate level of ID, only one patient had mild level and one patient had severe and profound ID. All patient participants were, however, considered by the clinical staff to be capable of consenting to participate in the study. Six of the patients had their family members or carers accompany their dental visit when the video recording took place. The majority of the consultation (86%) involved a dental check-up with a varying level of cleaning, polish, oral hygiene and brush advice; only two patients had a more invasive treatment of drilling and/or filling. All staff participants had a minimum of four years of experience of working with patients with special needs.

Recruitment of staff participants were conducted through introductory meetings with eligible dental staff by the research team. Patients were invited to participate by the dental staff who had already consented to the study. The fourteen dental consultations, each lasted from five to 26 minutes, were recorded by two research assistants at the NHS special care service premises. A patient, a dentist, a dental nurse and sometimes a family member (or a carer) and a trainee dental nurse were present at the recording. Family member (or a carer) and trainee nurses were not included in the analysis. Research evidence investigating camera awareness generally supports the use of video recordings as a method to study healthcare communication [12, 13].

2.2. Ethical approval

This study was part of a larger study funded by the Engineering and Physical Sciences Research Council (EPSRC Ref: EP/K012797/1), aiming to develop an interface for supporting dentist – patient interaction. It was independently reviewed and given a favourable opinion by the NHS Tayside Research Ethics Committee, Scotland, UK (approval number: 13/SS/0036). Both patient and staff participants provided written informed consent and were reassured confidentiality prior to their inclusion in the study.

2.3. Coding cues/concerns and response

The Verona Coding Definitions of Emotional Sequence (VR-CoDES-CC and VR-CoDES-P) [10, 11] was used to code patient cues/concerns and staff responses. Additional guidelines [2] for application of the VR-CoDES in the dental context were consulted in coding nonverbal cues and multiple responses from two dental professionals. Staff non-verbal responses to cues and concerns were only coded in the dimensions of *explicit* vs *non-explicit* and *providing space* vs *reducing space*. The coding procedure was implemented through application of the VR-CoDES onto The Observer XT[®] 8.0 [14], a system for collection, analysis and presentation of observational data. The Observer is a trademark of Noldus Information Technology. Two trained researchers (YZ as an overall coder and GH for reliability checks) coded the 14 video tapes over a three-month period between July and September 2013. Cohen's Kappa [15], with 95% confidence interval estimates, was used to check both inter- and intra- coder reliability for cues/concerns and provider responses.

2.4. Data analysis

Analysis of the 14 dental consultations was conducted in the following steps:

- The main coder (YZ), formally trained on the use of the VR-CoDES and The Observer XT system, coded all the 14 clips.
- 2. After coding of the 14 clips was complete, those clips where cues and concerns were present were selected (n = 7) for inter and intra coder reliability checks.
- 3. For the inter-coder reliability check, GH (co-author, professor in health psychology and a member of the Verona network) acted as an external coder. When disagreements arose between coders, discussions were made until agreements were reached and the agreed codes were used for final analysis. Notes for coding were subsequently made to modify the VR-CoDES. On occasions where an agreement was unable to be reached, an external expert coder from the Verona sequence analysis network (LDP) was consulted through an email to resolve text queries without viewing the video clips due to ethical reasons. This expert's coding was used for the final analysis.
- 4. For the intra-coder reliability check, YZ coded the seven selected clips again to ensure the internal coding consistency of the same coder over a period of time.
- 5. Frequencies of cues/concerns and responses were then computed.

In addition, when applying the two guidelines in Wright el al.'s study, the following procedures were adhered to.

In coding multiple responses:

- 1. Establish whether multiple responses occurred through consensus.
- 2. If so, determine whether the second response was directly related to the same cue/concern.
- 3. If directly, code second response as well as the first one.
- 4. <u>Note down challenges, solutions and comments in applying the guideline.</u>

In coding non-verbal cues:

- 1. <u>Search for obvious non-verbal behaviours (e.g. crying, groaning, sighing, silence, gestures).</u>
- 2. Determine *Cue F* through examination of contexts, verbal contents, and checking with clinicians/other coders.
- 3. <u>Examine possible causes (e.g. dental treatment, disability condition or emotional</u> distress) of 'ah, ooooho, groaning' type of non-verbal behaviours to confirm coding.
- 4. Note down challenges and comments.

3. Results

3.1. Applicability of the VR-CoDES to the dental setting involving patients with complex communication needs

[Insert Table 1 here]

Table 1 provides typical examples of cues/concerns identified using the VR-CoDES-CC. As can be seen from Table 1, when cues were identified, they were largely restricted to cue type D (neutral expressions) and F (non-verbal cues). No instances were identified as concerns with this patient group. The overall Cohen's Kappa for both inter and intra coder reliability was considered satisfactory according to Altman' criteria [16] (see Table 2). It is worth noting, however, the large discrepancy between the minimum and maximum agreement values due to low frequency of cues and responses of certain clips.

[Insert Table 2 here]

3.2. Frequency of cues/concerns and responses

Table 3 presents the results on the frequency of cues and response for the 14 clips. A total number of 16 cues were identified from half (n = 7) of the 14 clips. Half of the cues (n = 8)

were non-verbal and the majority of the cues occured in more invasive dental procedures such as drilling or filling. A total of 20 responses were coded, as both the dentist and the dental nurse responded to the same cue on four occasions. *Reducing space* type of response (n = 12) were used more frequently than *providing space* response (n = 8).

[Insert Table 3 here]

[Insert Table 4 here]

Table 4 provides detailed coding of cues and responses for the seven clips where cues were present. <u>Two features emerged regarding the type of cues presented in Table 4: (1) unusual</u> verbal expressions coded as *Cue D*. For example, '*I want Stephanie*.' '*It's a kind of sharp for me*.' '*What's that*?', were determined as *Cue D* after careful examination of the video for communicative intention and intonation inspection. (2) a combination of common non-verbal cues universal to other groups (e.g. crying, sighing and silence) and those that might be unique to this population (e.g. nodding head to consent to being unhappy after carer's prompt, staring at the probe).

3.3. Challenges of applying the VR-CoDES - P

When both dentist and nurse responded to a same cue, according to Wright et al.'s guildelines, the second dental professional's speech should be only coded when the speech is directly related to the cue. This rule was not straightforward in coding nurse's remarks on the dentist's response to a cue. Here we present an example from P14 in Table 4. When dentist responded to patient's *Cue D* ('*I want Stephanie*.') as 'you want Stephanie? Right, can we go and get Spephanie, please (to the nurse)', nurse's response '*I'll get her*.' was arguably coded as *ERIa* as it can be considered as directly responding to either the cue or dentist's request.

Another challenge concerns how to code non-verbal responses. It is common to see a dental staff member providing a reassuring touch to a patient with or without verbal expressions (see P14 in Table 4 for considering *EPCAc* code). Coding the non-verbal response beyond the dimension of *providing* vs *reducing* space is challenging. In our example when the dental nurse held the patient's hand and stroked gently, it was tentatively coded as *EPCAc*.

4. Discussion and conclusion

- 4.1. Discussion
- 4.1.1. Application of the VR-CoDES in a dental setting involving patients with complex communication needs

This study investigated the application of the VR-CoDES in a dental setting involving patients with complex communication needs. Our results show that both cues and responses were identifiable using the VR-CoDES – CC and the VR-CoDES – P, when assisted with the additional guidelines for the application of the VR-CoDES in a dental context. Satisfactory inter and intra coder reliability were achieved for both cues and responses.

4.1.2. Patient's expression of emotional distress

Sixteen cues were identified within 14 consultations, resulting in about one cue in each dental-patient interaction. Furthermore, no cues or concerns were observed in half of the consultations. Compared to the 7.3 mean cue <u>expression</u> rate per dental appointment in the first study where the VR-CoDES was applied in a dental context [2], this patient group demonstrated a far lower frequency of cues. It would be premature to conclude that this patient group do not have many emotional cues/concerns during their dental visit, compared

to those dental patients whose intellectual and/or communication abilities are not impaired. We suspect that this low frequency of observed cues might be due to a limited understanding, from both researcher and dental staff points of view, of how dental patients with ID express their emotions in general [17]. It was also possible that researchers and dental workers unfamiliar with that individual are disadvantaged in identifying and responding to emotional cues compared to carers who have greater knowledge and familiarity with those individuals as indicated in Regnard et al's study [6]. Unlike the DisDAT [6], no baseline behaviour in a non-clinical setting was obtained in the VR-CoDES to help detect behavioural changes as indicators for emotional distress. This lack of an additional video recording of the patient in the company of another adult (e.g. teacher, trainer) might also have contributed to a relatively low cue <u>expression</u> frequency.

The absence of both explicit verbalization of emotional distress (*concern*) and verbal use of metaphors or unusual words to hidden emotions (*Cue B*), which were observed in the Wright et al.'s study [2], did seem to suggest a different channel of emotional expressions for patients challenged with intellectual and/or communication difficulties. Cue <u>expression</u> with this patient group was also limited to certain types (*Cue D* and *Cue F*), with a higher frequency in phases of interactions with more invasive dental procedures, such as drilling. Dental treatments with more invasive elements are likely to be linked with higher level of dental anxiety [18] and it seemed to be no exception for patients with complex communication needs. Non-verbal cues (e.g. *stretching out hands for help, crying* and *groaning*) were commonly observed as expressions of emotional distress for this patient group. Absence of explicit verbal cues and high frequency of non-verbal expressions of emotional distress are consistent with the literature evidence that facial and behavioural expressions are the primary source of emotional expression within people with ID [8].

While it proved challenging in our study to distinguish between cues arising from patient intellectual/communication difficulties, and from the nature of the treatment or from the combination, it will be useful for future researchers to explore further this area and gain additional evidence to assist the dental clinicians in improving attendance to patients' emotional needs through understanding causes of emotional distress.

Close inspection of cue <u>expression</u>, 75% of cues (12 out of 16) were elicited by the patient him/herself. Apart from many non-verbal cues being elicited by patients, other verbal expressions (e.g. *I want Stephanie. It's (the top of a probe) a kind of sharp for me.*), which might be perceived uncommon in other patient groups, were relatively easy to be identified as cues (standing out from narrative backgrounds coded as *Cue D*). This finding suggested that, on one hand, dentists might be busy engaging in the procedures resulting in less elicitation to patients' emotions; on the other hand, these patients were less inhibited to speak out their concerns when needed. Our coding experience called for special attention to be paid to these <u>unusual</u> verbal expressions, which might be a unique feature for people with moderate level of intellectual disabilities. Additional measures might be also needed to help identify whether this type of neutral expressions (*Cue D*) are indeed expressions of emotional distress, for example, by talking to the carer and/or a family member.

4.1.3. Multiple responses to cues and non-verbal responses

Out of 20 responses provided by the dental team, 12 were *reducing-space*, which was 20% more than *providing-space* type of response. In Wright et al.'s study [2], where dental patients were involved, the frequency of *reducing-space* type response was 50% more than *providing-space* type response. Due to the small sample size in our study, it is difficult to

conclude that this finding was consistent with that found in the literature. A larger study is required to obtain further evidence regarding how dental professionals manage emotional distress expressed by this special group of patients.

Both dentist and nurse responded to the same cue on four occasions, and the guidelines in coding multiple dental professionals' response provided by Wright et al. were applicable for three occasions. On one occasion, however, when the second response provided by the nurse (I will get her) could be considered as a response directly related to the patient cue (I want Stephanie) or the first response offered by the dentist (Can we go and get Stephanie, please?), clearer instructions are needed to improve the guidelines to deal with complex situations. Furthermore, for each of the four multiple responses, the dentist and the nurse offered <u>opposite</u> response to the same cue in terms of *reducing space* versus providing space. Considering patient subsequent behaviour, following provider response(s), we were not able to ascertain which provider response (first, second or combined) had a profound impact on patient behaviour. Further investigation is needed to explore potential impacts of *conflicting* responses provided by multiple health professionals, for example, how patients react to treatment instructions. Staff non-verbal responses to cues were also observed in this context. Although the non-verbal responses were reliably coded in the *providing* versus *reducing space* dimension, we feel that, with a patient group with complex communication needs, it would be beneficial to develop additional guidelines to assist coding further dimensions of non-verbal responses.

4.1.4. Modification of VR-CoDES for the dental setting involving patients with complex communication needs

Our findings have highlighted a need and suggested directions to further improve the guidelines in the areas that have been discussed earlier in this section, in particular, multiple health professionals' responses to the same cue and their impact on patient response.

4.1.5. Study limitations and strengths

This is the first time that authors are aware that the VR-CoDES has been applied to the dental context involving patients with complex communication needs. We appreciate the small sample size and how this feature may detrimentally influence the internal and external validity of the findings. We believe, however, our coding experience and reported cues and responses with this special patient group have provided a useful initial step towards an ongoing exploration of how health providers in general identify and manage emotional distress of patients with intellectual and/or communication difficulties. <u>Due to a limited sample size</u>, we were unable to make comparisons in emotional expressions among patients with different types of ID. In future studies, it will be beneficial, with a larger sample size, to explore possible differences in emotional expressions between, for example, patients with <u>Down syndrome and those with ADHD</u>. The important strength of adopting the VR-CoDES with this patient group is that the researcher is able to study the close correspondence between emotional experiences of the patient and, importantly, the clinician response. Other systems of detecting observational emotional content in interactions tend to ignore clinician's responses.

4.2. Conclusion

Supplemented by the guidelines of the VR-CoDES in a dental setting by Wright et al., the current version of the VR-CoDES is a <u>potentially</u> reliable tool for coding emotional cues of dental patients with intellectual and communication difficulties, as well as dental

professional's response to cues. Cues were found to be present in half of the dental treatment sessions and the majority were non-verbal cues. No instances of concerns were identified with this patient group. Identification of non-verbal cues is generally consistent with the facial and behavioural expression of emotion within people with intellectual disabilities discussed in the literature. Additional guidance is needed to improve the coding accuracy on multiple dental professionals' response to cues and its impact on <u>patient subsequent</u> <u>behaviour.</u>

4.3. Practice implications

The current version of the VR-CoDES, with further guidelines for application in the dental context, provides a potentially useful tool not only for understanding emotional distress of dental patients with complex communication needs and but also, and crucially, how dental professionals manage these emotional cues. The authors encourage future researchers to explore further the application of the VR-CoDES with this patient group and modify the coding scheme through continuing discussion.

Conflict of interest

The authors have no conflict of interest that could inappropriately influence or be perceived to influence this manuscript.

Acknowledgements

This study was conducted as part of a larger collaborative study funded by the EPSRC, between the University of St Andrews and the University of Dundee. We wish to thank all dental staff and patients who participated in the study. We acknowledge the assistance of LDP in assisting interpretation of the VR-CoDES system.

Authors' statement

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Role of funding

The funder of the study (the Engineering and Physical Sciences Research Council) has no role in any of the following: study design; collection, analysis and interpretation of data; writing of the report; and in the decision to submit the article for publication.

Footnote

¹The term 'intellectual disability' will be used throughout this article in preference to a number of other terms (such as learning disability, mental retardation, mental handicap and

mental deficiency) in line with current usage of terminology in recent UK Department of Health publications since 2011.

²Many intellectual disabilities are often associated with communication impairments. People who sit at the more severe end of the communication impairment severity spectrum are usually considered as having complex communication needs. As a significant number of participants in our study have a moderate level of intellectual disabilities, we use the term 'complex communication needs' in a broader sense to include anyone having communication difficulties caused by their intellectual disabilities.

19

References

- [1] Peltier B. Psychological treatment of fearful and phobic special needs patients. Spec Care Dentist 2009; 29: 51-7.
- [2] Wright A, Humphris G, Wanyonyi KL, Freeman R. Using the Verona coding definitions of emotional sequences (VR-CoDES) and health provider responses (VR-CoDES-P) in the dental context. Patient Educ Couns 2012; 89: 205-8.
- [3] Iacono T, Johnson H. Patients with disabilities and complex communication needs: The GP consultation. Aust Fam Physician 2004;33:585-9.
- [4] Ekman P, Friesen WV. The Facial Action Coding System: A technique for the measurement of facial movement. Palo Alto, CA: Consulting Psychologists Press; 1978.
- [5] Friesen WV, Ekman P. The emotion facial action coding system (EMFACS). Unpublished document; 1986.
- [6] Regnard C, Reynolds J, Watson B, Mattews D, Gibson L, Clark C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). J Intell Disabil Res 2007;51:277-92.
- [7] Scherer KR. What are emotions? And how can they be measured? Soc Sci Info 2005;44: 695-729. DOI: 10.1177/0539018405058216.
- [8] Adams D, Oliver C. The expression and assessment of emotions and internal states in individuals with severe or profound intellectual disabilities. Clin Psychol Rev 2011;31:293-306.
- [9] Scherer KR, Johnstone T, Klasmeyer G. Vocal expression of emotion. In: Davidson, RJ, Scherer KR, Goldsmith H. Handbook of affective sciences. Oxford University Press; 2003. p. 433-56.
- [10] Zimmermann C, Del Piccolo L, Bensing J, Bergvik S, De Haes H, Eide H, et al. Coding patient cues and concerns in medical consultations, the Verona coding definitions of emotional sequences (VR-CoDES). Patient Educ Couns 2011;82:141-8.
- [11] Del Piccolo L, de Haes H, Heaven C, Jansen J, Verheul W, Bensing J, et al. Development of the Verona coding definitions of emotional sequences to code health providers' responses (VR-CoDES-P) to patient cues and concerns. Patient Educ Couns 2011;82:149-55.
- [12] Penner L A, Orom H, Albrecht T L, Franks M M, Foster T S, Ruckdeschel J C. Camera-related behaviours during video recorded medical interactions. J Nonverbal Behav 2007; 3:99-117.

- [13] Zhou Y, Forbes G M, Humphris G. Camera-related behaviours of female dental nurses and nursery school children during fluoride application interactions in nursery school settings. Int J Paediatr Den 2010;20:374-81.
- [14] Noldus Information Technology. Available from <u>http://www.noldus.com/human-behavior-research/products/the-observer-xt</u> [accessed 08.05.14].
- [15] Cohen J. A coefficient of agreement for nominal scale. Educ Psychol Meas 1960; 20: 37-46.
- [16] Altman DG. Practical statistics for medical research. London, NY: Chapman & Hall; 1991.
- [17] McGuire D, Chicoine B. Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges. Woodbine House Inc, USA, 2006.
- [18] Humphris G, Crawford JR, Hill K, Gilbert A, Freeman R. UK population norms for the modified dental anxiety scale with percentile calculator: Adult dental health survey 2009 results. BMC Oral Health 2013;13:29, <u>http://www.biomedcentral.com/1472-6831/13/29</u>.

Key findings

- We applied the VR-CoDES to a dental context involving patients with complex communication needs.
- Sixteen cues were reliably identified within seven of the 14 consultations.
- Cue expression was exhibited by non-verbal expression of emotion with people with intellectual disabilities.
- Further guidance is needed to improve the coding accuracy on multiple dental professionals' responses.

31

Table 1 Definitions of cues and concerns and examples from the dental consultations involving patients with complex communication needs

Definitions	Typical examples from the dental consultations
CONCERN: a clear and unambiguous expression of an unpleasant current or recent emotion where the emotion is explicitly verbalized with or without a stated issue of importance.	None.
CUE: a verbal or non-verbal hint suggests an underlying unpleasant emotion and would need a clarification from the health provider. Instances included:	
Cue A: vague or unspecified words or phrases in which the patient uses to describe his/her emotions.	'I don't like drills.'
Cue B: verbal hints to hidden concerns (emphasizing, unusual words, unusual description of symptoms, profanities, exclamations, metaphors, ambiguous words, double negations, expressions of uncertainties and hope).	'I hate that pointy thing.'
Cue C: words or phrases that emphasizes (verbally or non-verbally) physiological or cognitive correlates (regarding sleep, appetite, physical energy, excitement or motor slowing down, sexual desire, concentration) of unpleasant emotional states.	None.
Cue D: neutral expressions that mention issues of potential emotional importance which stand out from the narrative background and refer to stressful life events and conditions.	'I want Stephanie (a disguised name for the carer).' 'It's (the top of a probe) a kind of sharp for me.' 'What's that?'
Cue E: a patient elicited repetition of a previous neutral expression (repetitions, reverberations or echo of neutral expression within a same turn are not included).	None.
Cue F: non-verbal cues including clear expressions of negative or unpleasant emotions (crying) or hint to hidden emotions (sighing, silence after provider question, frowning etc.).	Crying, sighing, groaning, moving hands indicating anxiety, silence, staring at the probe with anxiety.
Cue G: a clear and unambiguous expression of an unpleasant emotion which occurred in the past (more than one month ago) or is without time frame.	None.

Table 2 Results of inter- and intra-coder reliability (n = 7)

Туре	Occasion of check	Cohen's <i>K</i> (95% CI)	Agreement (%) (min-max)
Inter-coder	Average of 7 clips	0.76 (0.57, 0.94)	78.8 (50 – 100)
Intra-coder (main coder)	Average of 7 clips	0.88 (0.86, 0.95)	91.4 (50 – 100)

Accepted Manus

Table 3 Frequency of cues and reponses (n = 14)

Clip		*P1	P2	P4	P5	P8	P11	P13	P3	P6	P7	P9	P10	P12	P14	Total
Cue	А	0	0	0	0	0	0	0	0	0	0	0	0	3	0	3
	В	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
	D	0	0	0	0	0	0	0	0	2	1	0	0	0	1	4
	F	0	0	0	0	0	0	0	2	0	0	2	1	0	3	8
Total cues		0	0	0	0	0	0	0	2	3	1	2	1	3	4	16
Response	Providing space	0	0	0	0	0	0	0	1	1	1	1	0	1	3	8
	Reducing	0	0	0	0	0	0	0	1	3	0	1	1	2	4	12
Total responses	space	0	0	0	0	0	0	0	2	4†	1	2	1	3	7 †	20

*P1= dental patient number 1 †= responses from both dentist and dental nurse

Table 4 Results of coding cues/concerns and responses (n = 7)

Clip (patient gender, treatment, analyzed duration at min:sec, learning difficulty)	Conversation in turns containing cues/concerns and responses (underline = cues; italics = responses)	Coding cues/concerns and responses
P3 (male, cleaning, 5:17, SID*)	 Carer: 'The only thing is that he is not happy with the glasses.' Patient: Bending head down nodding slightly, indicating that he agrees with what the carer said about the glasses. Dentist: 'What would you reckon, XX (patient's name)?' 'Would you like to put on some glasses?' (Showing the patient a pair of glasses). 	 Cue F (Carer-E): Non-verbal cue elicited by the carer indicating hidden emotions (i.e. unhappy about the possibility of having to put on a pair of glasses as part of the procedure.) NPAi: Dentist seeks further disclosure from the patient about the nonverbal cue without making an explicit reference to either the content (i.e. the glasses) or the emotion (i.e. unhappy) in the cue.
	 Dentist: Turned attention away from the patient to pick up another instrument (i.e. 3-in-1) in her hands. Patient: Lifting his head away from the normal lying position to look at the instrument anxiously for more than three seconds. Dentist: (While demonstrating air blow on her own hand) 'XX (patient name), this is just a bit of air to help dry your teeth.' 	 Cue F (PE): Non-verbal cue elicited by patient himself, indicating his anxiety of being uncertain of what the new instrument is going to do with him. NRIa: Dentist offers verbal reassurance without explicitly referring to the cue in a general way with the function of non-inviting further disclosure.

P6 (male, check up,

cleaning, 7:14, MID)

Dentist: 'What we're going to do here, I think you've probably had this before, haven't you? That's the wee probe and I just touch on the surface of your teeth with that.'

Patient: 'Oh I hate that pointy thing.'

Dentist: '*You do. Is it alright if I run it round the front teeth there, is that alright?*'

Dental nurse: *'This one isn't sharp*. Do you want to feel it on your finger first?

Patient: Moves to touch the instrument.

\triangleright

Dentist: 'See it's got a little ball on the end.'

Patient: Sits up in chair and looks at the probe, saying: '<u>It's kind of sharp for me</u>.'

Dentist: '*But we don't stick it in, we just touch your teeth with it.* Is that alright?'

Patient: 'Are you like scraping it?

Dentist: 'Like I do in my finger. Shall I do it on your finger, exactly the same way as I do it on your teeth?'

Cue B (HPE): Using emphasis (hate) to express hidden emotions.

EPCEx: Dentist makes an explicit response to the factual component of the cue by actively exploring more information on the topic area without acknowledging the affective component (i.e. 'hate').

NRIa: Dental nurse offers further information as reassurance without explicitly referring to the cue.

\triangleright

Cue D (**HPE**): neutral expression that stands out from the narrative background which relates to a stressful condition.

NRIa: Dentist offers verbal reassurance without explicitly referring to the cue in a general way without inviting further disclosure of the cue.

	 Patient: Moves hand to instrument. Dentist: 'You fingernail's hard, like your tooth. It's like that.' Patient: 'It's just a don't like it scraping around.' Dentist: 'Yeah, I won't scrape it around. Is that ok?' Patient: Nods. 	 Cue D (PE): Neutral expression that stands out from narrative background that refers to a stressful condition ERIa: Dentist makes an explicit response to the cue content. The affect (i.e. 'don't like) is dismissed without being devaluated by offering verbal reassurance.
P7 (male, check up, cleaning, 6:25, MID)	 Dentist: (speaking to the dental assistant) 'I could do with a probe actually. There is one area I want to check.' (then to the patient) 'XX (patient name), I'll show you what this is.' Patient: '<u>What's that</u>? (Staring at the probe anxiously). Dentist: 'It's a wee probe and that's just to touch on the surfaces of the teeth.' Patient: Keeps looking at the probe. Dentist: 'Shall I do it on your finger first, with your nail so you know what it's like, yeah?' (Showing the patient the probe) 	 Cue D (PE): Neutral expression that stands out from narrative background that refers to stressful condition, which is confirmed by non-verbal behaviour 'staring'. ERIa: Dentist makes an explicit response to the cue content; however the affective component of the cue (worry, anxiety) is dismissed without being devaluated by providing verbal reassurance.

P9 (female, check up, cleaning, 21:56, MID)

Dentist: Using the 3-in-1 instrument to break the calculus during the cleaning process.

Patient: <u>Crying and choking (using right hand to dry tears)</u>.

Dentist: '*Are you OK*?'

Patient: 'Fine.'

Dentist: 'Are you sure?'

Patient: 'I want to get it done.'

 \triangleright

 \geq

Dentist: 'Excellent, you did really well (during a break through the treatment process).'

Patient: <u>A big sigh</u>.

Dentist: 'What a big sigh there (pause).'

P10 (male, check up, cleaning, 24:12, MID)

Dentist: 'Right I'll take your sunglasses for you. Stephanie's got your own glasses.'

Patient: 'Am I getting the thing?'

Cue F (PE): Crying indicating emotional distress.

NPAc: Dentist non-specifically acknowledges the fact that the patient is upset (i.e. crying), which provides space for the patient to say more about the cue.

 \triangleright

Cue F (PE): Sighing indicating a hidden emotional distress.

EPAAc: Dentist explicitly acknowledges affective aspect of the cue (i.e. a big sigh), which provides space for the patient to say more about the cue without specifically seeking it.

Dentist: 'The thing?'

Patient: 'I thought you were going to fill me.'

Dentist: 'Do you want me to clean them today? You don't mean a filling, do you?'

Patient: 'No, I mean..... (Silence), I want the cameras (pointing to his teeth).'

Dentist: '*To do your teeth. Get them cleaned. No problem. We'll do that.*'

\triangleright

Cue F (HPE): Noticeable silence following a dentist question indicating hidden emotional distress.

NRIa: Dentist offers verbal reassurance without explicitly referring to the cue in a general way with the function of not-inviting further disclosure.

P12 (female, drilling, filling, 20:00, MID)

Patient: 'I don't like drills.'

 \geq

Dentist: '*I know you don't like drills*. Well, this is more just to give your teeth a very quick clean, about five seconds.'

Patient: 'I don't like drills.'

Dentist: '*I know (pause)*. But you managed very well today.'

\triangleright

Cue A (PE): A clear expression of an unpleasant emotion (don't like).

ERIa: Dentist makes an explicit response to the cue. The affect (i.e. 'don't like) is dismissed without being devaluated by offering information and reassurance.

\triangleright

Cue A (PE): Same as above (Cue E is not considered unless previous cue was a neutral expression as Cue D) **NPAc**: Dentist non-specifically acknowledges what has been said by the patient, which provides space for the patient to say more about the cue.

5

	 Patient: <u>'I don't like drills.'</u> Dentist: 'I know you don't like drills; but you did today was fine.' 	 Cue A (PE): Same as above. ERIa: Dentist makes an explicit response to the cue. The affect (i.e. 'don't like) is dismissed without being devaluated by offering praise as a form of reassurance.
P14 (female, injection, drilling, filling, 26:09, MID)	Dental nurse: 'That's the little elastic bits that just go between your teeth (shows the patient the elastics). It's like floss, but it's elastic!'	
	Dentist : 'Okay. Right, xx (patient name).' Patient : 'Could you take (Holding out hand).	Cue F (PE): Nonverbal 'holding out hand' indicating anxiety about the on-coming procedure.
	 Dental Nurse: 'Yes. (Taking patient's hand).' Dentist: 'Turn to me a wee bit; let me just pop this wee bit of cotton wool under your lip, okay? Just lifting this out of the way, okay? I'll pop this wee sheet of rubber.' Dental nurse: 'Just like flossing your teeth, xx (patient name).' 	 NPBc: Dental nurse's attention is directed to the patient and encourages further disclosure of the cue. This is consistent with the non-verbal behaviour of taking the patient's hand. NRIg: Dentist ignores the cue and concentrates on the procedure.
	Patient: 'Mhm (groaning loudly). What's that?'	➤ Cue F (PE): Groaning.
	Dentist : ' <i>It</i> 's just the wee sheet of rubber. I need you to open wide for me DD, okay? Well done.'	NRIa : Dentist offers verbal reassurance without explicitly referring to the cue in a general way with the function of non-inviting further disclosure.
	Dental nurse: 'Well done, xx (patient name).'	renetion of non-inviting further disclosure.

6

 Patient: 'Stephanie, I want Stephanie (disguised name for the carer).' Dentist: 'You want Stephanie? Right, can we go and get Stephanie, please (talking to the dental nurse).' Dental nurse: 'I'll get her (the carer).' 	 Cue D (PE): The verbal content is neutral and stands out from the narrative background and refers to stressful conditions. EPCEx: Dentist refers to the factual content of the cue by affirming what has been said by the patient, which allows the patient to take things further without explicitly asking for further information. ERIa: Dental nurse explicitly refers to the content of the cue without acknowledging the affective aspect.
Patient: During treatment, <u>lifts one of her hands up slightly</u> indicating anxiety.	Cue F (PE): Non-verbal shaking hand indicating anxiety.
Dental nurse : <i>Holds the hand and strokes it gently</i> (to provide reassurance and comfort).	EP: Dental nurse provides space for the cue by offering a reassuring touch (EPCAc is considered).
Dentist : Concentrates on the treatment without noticing the nervous hand for a while and then says: ' <i>Can I just turn you a bit</i> ?'	NRIg : Dentist misses the signs of the hand interpreted as inattentive silence and asks a question that is not relevant to the cue.

SID: severe intellectual disability

MID: moderate intellectual disability

Note: All patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.