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Parent reported experience of using a Real-time Text Messaging Service for dental appointments for children and young people with autism spectrum conditions: A pilot study

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Abstract

Introduction: Children and young people (CYP) with autism spectrum conditions (ASC) and their parents/carers find dental appointments stressful. Consultation with parents of CYP with ASC identified time spent in dental waiting areas as contributing to dental anxiety. Parents proposed waiting outside the dental practice until the clinician was ready could help mitigate anxiety. **Aims:** To evaluate a Real-time Text Messaging Service (RTMS) to improve dental attendance experience for CYP with ASC. **Methods:** A RTMS was developed for use in the dental clinic. Parents/carers of seventeen CYP with ASC (4 – 20 years) attending a Special Care Dental service were invited to share their dental experience and the impact of using the RTMS. **Results:** Parent experience suggests time in waiting areas can increase anxiety in CYP with ASC. All parents viewed the RTMS as having a positive impact on CYP dental attendance experience. The majority believed it reduced anxiety and enabled CYP to be more accepting of dental treatment. **Discussion:** Many CYP with ASC have dental anxiety exacerbated by use of waiting areas. Findings demonstrate the importance of considering and developing a range of approaches that

respond to the needs of CYP with ASC and their families to improve dental attendance experience.

Keywords: Dental anxiety, Autism spectrum conditions, Real-time text messaging service

Introduction

Children and young people (CYP) with autism spectrum conditions (ASC) can have problems complying with preventive dental care regimes at home and participating in routine dental appointments[1]. Attending dental appointments can be extremely stressful and challenging for a CYP with ASC and their family, with approximately 50 – 72% of children with ASC reported as being anxious and uncooperative.[1-5] Stress can be defined as a "condition in which an individual is aroused and made anxious by an uncontrollable aversive challenge"[6] resulting in fear and anxiety. Anxiety is considered the "anticipation of future threat" whereas fear is the "emotional response" to "imminent threat"[7]. Fear and anxiety are only considered pathological if the emotional and physiological response to a stimulus goes beyond what would be considered normative for the person and situation[7]. Dental anxiety could include worrying about going to the dentist, trying to avoid going and fear may manifest as resisting or refusing treatment.

The first national survey on the oral health of 5 and 12 year old children attending special schools by Public Health England[8] reported that 5-year-olds examined had twice as many teeth extracted compared to their mainstream-educated peers. The survey data highlighted that 24% of 5-year-olds, and 12% of 12-year-olds with ASC were resistant or refused a dental exam. It was therefore not possible to obtain accurate information regarding the oral health of children with ASC from this survey. Children who resist or refuse a basic dental examination may

be more likely to have unaddressed dental needs. Problems coping with sensory input from the dental environment, difficulties adapting to unfamiliar procedures and routines [5,9-11] and family experience relating to difficulty at previous visits have potential to contribute to unmet treatment need for CYP with ASC. It is important to investigate methods to reduce dental anxiety in patients with ASC and their families to encourage dental re-attendance, acceptance of dental preventive regimes and good oral health outcomes. Establishing good oral health will help avoid treatment modalities such as dental general anaesthesia [5,9] with potential health risks for patients and significant healthcare cost.

A consultation with parents of children with ASC revealed a worrying concern from parents that CYP with ASC are required to fit the neurotypical dental appointment system. A major area of concern was using the dental clinic waiting area before their CYP's appointment and having to manage their CYP's increasing anxiety and subsequent challenging behavior. Many families suggested that waiting outside the dental practice until the dentist was ready for them could help mitigate anxiety. It was proposed that a real-time text messaging service (RTMS) to inform parents by text when the clinician is ready to see the patient and thus avoid the waiting area would be of great benefit and potentially improve acceptance of a dental visit for assessment, review or treatment.

This article reports a pilot study evaluating an innovative real-time text messaging service (RTMS) that was offered to parents of CYP with ASC attending a special care dental service (SCDS). The aims were to gather information from parents regarding their experience of using dental clinic waiting areas with their CYP and gain initial understanding of the impact of using a Real-time Text Messaging Service

(RTMS) as an element to improve dental attendance experience for CYP with ASC.

Methods

Thirty-seven parents/carers of CYP with an ASC diagnosis due to attend a SCDS in the UK over a period of four weeks were identified. Parents/carers were sent information about the RTMS evaluation by post (including a consent letter and pre-appointment questionnaires) and invited to use the service for their CYP's next dental appointment. Twenty-three parents/carers agreed to take part in the service evaluation and registered to use the RTMS for appointments scheduled during thirteen clinic sessions at three different dental care centres. The waiting areas of the SCDS consist of a reception desk where patients or their parents/carers approach the receptionist to confirm their arrival and chairs to sit on while waiting. Two of the three dental care centres did not have any toys or magazines for children and one of the centres had one table-based bead maze toy.

RTMS outline

- Parent/carer texts RTMS service to register
- RTMS replies to text to confirm registration
- Parent/carer texts RTMS to confirm arrival at clinic site
- RTMS confirms receipt of text: 'Thank you, please wait to be called'
- When dentist is ready the RTMS texts parent/carer: 'Please come for your dental appointment'
- Parent/carer and patient arrive and walk straight in to see the dentist/dental therapist for their dental appointment

Participants

As the majority of participants were parents (16/17) we will use the term parent/s to represent both groups. However, it should be noted that more than one carer from respite/residential homes for young people with special needs were involved in supporting parents and their children with ASC to access the SCDS and the RTMS.

Measures

1. *A Parental-report child anxiety scale*[12]

   Parents report on a scale of 1-10 how anxious they feel their child is at the dentist including an option for 'my child never goes to the dentist'.

2. *Real-time Text Messaging Service Evaluation Questionnaires* (RTMS-Q. A, RTMS-Q. B) designed specifically to evaluate the experience of parents and carers of CYP with ASC using the dental clinic waiting room and evaluation of the RTMS. Some questions were followed by 'Please can you say how' or 'Please can you say why' and parents/carers were given space to provide more detail of their experiences.

Results

Parents rated 69% of CYP with ASC that took part in this evaluation as having moderate to extreme anxiety (Table 1) with over half rated from 8 to 10 (Table 2).

Table 1. Parental dental anxiety ratings of CYP with ASC attending the SCDS.

How anxious does your child get when they visit the dentist?	Children and young people with ASC (*N* = 16)
1 – not anxious	0%

2-4 low anxiety	31%
5-10 moderate to extreme anxiety	69%
Never goes to the dentist	0%

Table 2. Total frequency of parental-report dental anxiety ratings of CYP with ASC (*N* = 16)

Anxiety Rating	**1 Not anxious**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10 Extremely anxious**
Rating Frequency	0	0	4	1	0	1	1	2	5	2

Real-time Text Messaging Service (RTMS) Questionnaire

All parents expressed concern over using the dental clinic waiting area with the majority (11/16) agreeing that the statement *'I worry about how long I might have to wait in the dentist's waiting room before my child/young person's appointment'* was 'very true' and five out of 16 agreeing that the statement was 'somewhat true'. Whether concerns over waiting might affect parents' attitudes to taking their CYP with ASC to the dentist was explored in the statement '*Waiting too long with my child/young person before their dental checkup puts me off going to future appointments',* in which over half of parents disclosed that waiting too long was 'likely' (4/16) or 'extremely likely' (5/16) to put them off going to a future dental checkup. Whereas, only a minority of parents asserted that concerns over waiting were 'unlikely' (1/16) or 'extremely unlikely' (2/16) to affect their future attendance with the remaining parents (4/16) feeling 'neutral' toward the statement.

Nearly all parents completed the statement '*My child/young person finds waiting in the dentist's waiting room before their appointment',*

‘difficult’ (9/16) or ‘very difficult’ (5/16) with only a minority (2/16) feeling neutral toward the statement and no parents reporting that their CYP found waiting ‘easy’ or ‘very easy’. Parents’ comments below reveal some of the reasons CYP with ASC find the waiting room difficult:

“He constantly asks me “how long now?” and gets anxious when it’s past his appointment time”

“Anxiety levels increase dramatically. Sensory overload from lights, sounds, other people, strange environment and the unexpected”

“he can become very agitated, hitting out, hitting himself or damaging property”

“he struggles with transitioning from one situation to another”

The majority of parents (87.5%) considered that ‘*Waiting too long in the waiting room has an effect on my child/young person’s behaviour when they see the dentist’* with seven out of 16 believing it had a ‘major effect’, seven out of 16 considering it had a ‘moderate effect’ and a small group (2/16) feeling waiting only had a ‘minor effect’. However, no parents responded that it had ‘no effect’ on their CYP’s subsequent behaviour. Parents describe in comments below how waiting too long can result in CYP with ASC entering the dentist’s room in a heightened state of anxiety from the dental waiting room, making them less able to cope with the appointment and sometimes causing them to have to leave the clinic and miss the appointment.

“he may get so upset that he has to leave and not see the dentist”

“more restless, less flexible, more anxious and hypersensitive to touch, pain. Overall he has less tolerance and doesn’t cope so well”

"his mood gets more aggressive and harder to control, this makes it harder to get him to cooperate in the dentist's room"

After using the RTMS nearly all parents (93%) agreed or strongly agreed that they found the service helpful (Table 3, Statement 1), 87% of parents agreed or strongly agreed that the service reduced the amount of time they had to wait compared to previous appointments (Table 3, Statement 2) and 87% also agreed or strongly agreed that using the service helped their child (Table 3, Statement 3).

Table 3. Frequency of response options to statements 1, 2 and 3 of the RTMSQ-B

	Frequency of response options to statements 1 – 3 (RTMSQ-B)		
Response Option	Statement 1	Statement 2	Statement 3
Strongly disagree	0	0	0
Disagree	0	0	0
Neutral	1	2	2
Agree	4	5	5
Strongly Agree	10	8	8

Statement 1. I found using the real-time text messaging service helpful.
Statement 2. Using the text messaging service reduced the amount of time I had to wait in the waiting room compared to previous dental appointments.
Statement 3. Using the service helped my child/young person.

Parents' comments below demonstrate that being able to choose where to wait, such as in the car and knowing that they had this option reduced stress and anxiety in both the parents and CYP with ASC.

"[his] appointment was running late, I was able to keep him happy in the car"

"We arrived early for our appointment we were able to wait in the car"

"Knowing we could wait where we liked was a major de-stressor"

"no waiting around reduced his stress and his worries".

"Being free to wait anywhere and even when my son tried to leave I was able to get him and…. [we] didn't miss our appointment"

" My son walked straight into his appointment completely stress free for the both of us"

Parents responded that they found the text alerts helpful (6/16) or extremely helpful (10/16) and 100% affirmed, "I would like to use this service for future dental appointments".

Discussion

A key finding of this service evaluation is that using the dental waiting area is a worry for parents' of CYP with ASC, and managing anxiety and behaviour in the waiting area can put parents off from going to future dental appointments. This is crucial as without parents bringing this group of patients to the dentist their oral health needs may be neglected. The RTMS allowed parents and CYP with ASC to choose where to wait and facilitated a less stressful dental visit. Notably, all parents that used the RTMS wanted to use the service for future appointments.

Parents believe waiting too long in the waiting room before their CYP sees the dentist adds to their child's dental anxiety. Parents refer to the unpredictable nature of waiting, transitioning from one environment to another, sensory issues and unfamiliar people and places, experiences that can accumulate to intensify anxiety and lead to potential behavioural difficulties. Significantly, parents

suggested that using the RTMS reduced their child's dental anxiety. Parents proposed that avoiding the waiting room meant CYP with ASC were less anxious when they entered the dentist's room, which enabled them to be more cooperative when seeing the dentist. Using a RTMS means that CYP with ASC can potentially wait in a more familiar and comfortable environment, such as their car before they have treatment. The RTMS reduces the amount of transitions the CYP with ASC experience, and also the amount of unfamiliar people they meet. Therefore, the RTMS could be a very effective tool to reduce dental anxiety in CYP with ASC and potentially increase acceptance of dental visit procedures.

Further research should increase the sample size and utilise a randomised control trial to establish the benefit of using a RTMS compared to patients and parents using the dental waiting room as usual. Modifications to the study design should also be considered to examine past dental clinic experience for patients as well as parents in order to assess dental anxiety in CYP with ASC and to control for any potential bias in the parents' perceptions of the dental experience. It would also be beneficial to assess whether improving the waiting room experience for CYP with ASC could reduce dental anxiety and evaluate any effects on dental anxiety of the cognitive and communicative functioning of CYP with ASC.

This service evaluation identified that CYP with ASC attending a SCDS have dental anxiety that puts them at risk of not being able to receive routine dental care and prevention. Significantly, parents and carers tell us that using clinic waiting areas increases anxiety and challenging behaviour in CYP with ASC before they see the dentist and that this is a worry that can deter parents from going to future appointments. The RTMS was a result of a consultation with parents to

identify ways to improve access to dental care for CYP with ASC. The findings of the RTMS evaluation demonstrate the importance of developing services that respond to the needs of CYP with ASC and their families in order to improve access to oral health.

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