Parental perceptions of oral health and access to oral health care services for children with special educational needs in South Bedfordshire

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Abstract

Aim: To investigate the perceptions of oral health and barriers to care of parents of children with special educational needs in South Bedfordshire.

Objectives: To undertake a questionnaire study of parents of children in primary and secondary schools in South Bedfordshire in order to investigate parental perception of oral health of their children; analyse the key factors that act as barriers to care and relate the parental oral health perceptions to their views on access to care.

Design: A qualitative, semi-structured questionnaire was devised with the main themes related to perceived oral health and access to oral health care services. There were 21 closed and open-ended questions with the opportunity for additional comments. The questionnaire was answered anonymously.

Results: 451 questionnaires were distributed with 212 returned (47%). Parental perception underestimated the level of oral health and there was a reported lack of oral health education provided by the dental profession. Although the majority of children with special educational needs attended a dentist, parents were more likely to experience difficulties accessing oral health care services.

Conclusions: The level of oral health of children with special educational needs in South Bedfordshire is underestimated by parents. The Disability Discrimination Act (2005) aims to reduce inequalities but parents still experience barriers when accessing oral health care services.

Key words: Perceptions of oral health, special education needs, access to dental care

Introduction

Oral health is an integral part of general health and well-being of disabled children and adults. ‘Valuing People’s Oral Health: A good practice guide for improving the oral health of disabled children and adults’ was published by the Department of Health in November 2007. This document builds upon the principles and evidence-based approach in previous Department of Health publications. It aims to prevent oral disease and protect and secure oral health for this vulnerable group.

The Department for Work and Pensions (2006) estimates that there are over 10 million people with disabilities in Britain, including people with limiting, long-standing illnesses. Of this number, 1.2 million adults have learning difficulties, ranging from mild intellectual impairments to approximately 200,000 individuals who are profoundly disabled with additional physical or intel-
lectual disabilities. Children make up a fifth of this figure, with twice as many males than females reported to have a severe disability (Meltzer et al., 2000). A person with a learning disability has a significant impairment of intelligence and social function that is acquired before adulthood. Some have specific single or multiple learning disabilities. Other individuals may have combinations of learning, sensory and physical disabilities.

Oral health in the UK has improved dramatically over the last 25 years. However, inequalities still exist. Evidence shows that people with disabilities experience poorer general and oral health, have greater unmet health needs than the general population and have a lower uptake of services (Rosenheck et al., 1997). People with learning disabilities have the same right to good oral health as the general population (The United Nations Universal Declaration of Human Rights 1948, Article 25; Department Of Health 2001; Disability Discrimination Act 2005). This right is realised in part through access to good quality oral health care services. Problems of access to local healthcare services are issues that people with disabilities often share with mainstream groups. However, they may have additional barriers as a direct or indirect consequence of their particular disability.

The impact of poor oral health on an individual’s quality of life can be profound (Locker 1992). Good oral health can promote good communication, good nutrition, positive self-esteem and improve overall quality of life. Poor oral health, by contrast, can cause significant pain and infection, which may affect communication, behavioural or medical conditions and their treatments (Griffiths and Boyle, 1993; Fiske et al., 2000; Fenton, et al., 2003; Elliot et al 2005). This in turn can lead to further frustration or even damage such as self-harm. The benefits arising from good oral health care cannot be underestimated. It empowers disabled children and adults, giving confidence and enabling them to participate fully at their respective level in society (Department of Health 2007).

The aim of this study therefore, was to investigate the perceptions of oral health and barriers to care of parents with children with special educational needs attending special needs schools in South Bedfordshire.

**Method**

There are six, dedicated special needs schools in South Bedfordshire responsible for providing education for children with special educational needs. These schools have a diverse student population, catering for children from all backgrounds and ethnicity. Currently, there are over 450 students registered, all with different levels of learning disability, physical impairments, complex medical histories, emotional and behavioural problems (Figure 1).

Ethical approval for the study was obtained from the King’s College London College Research Ethics Committee; all six schools were happy to participate in the anonymised, questionnaire study.

**Questionnaire**

A confidential, semi-structured questionnaire was the basis of the investigation. The main themes of the questionnaire related to perceived oral health needs and access to oral health services.

An initial questionnaire was piloted on five individuals who satisfied the criteria for the target population. A feedback session was carried out and the final revised version of the Parental-Child Perception Questionnaire was distributed to each student to take home to their parents, carers or legal guardians for voluntary participation.

A total of 451 Parental-Perception Questionnaire were distributed to parents, carers or legal guardians (Figure 2). This questionnaire comprised of 21 open and closed-ended questions and opportunity for participants to add any further comments. Data were converted into numerical values and statistical analysis was carried out using a standard statistical tool (STATA 3.0). Closed questions that were incomplete were not considered in the data analysis. However, when this type of questionnaire is used, some loss of control must be accepted since the validity of the results is based on honesty of the parent. Qualitative information was taken into consideration in conjunction with the statistical findings.

![Figure 1 Student Demography](image1)

![Figure 2 Flowchart depicting questionnaire distribution cycle](image2)
Results

Questionnaires were returned and collected by the school: 212 were returned completed; 137 were returned after the first wave of distribution and an additional 75 were returned in the second wave. This represented an overall 47% response rate.

Perception of oral health and symptoms

Generally, parents thought that their child was in good general health (96%). However, 17% of respondents perceived their child’s dental health as poor and 18% of respondents believed their child to have dental cavities.

Data showed that 19% of children were reported to have had experience of toothache, with 17% requiring analgesics for the pain and 3% having to take time off school as a result. Other oral symptoms included gingival bleeding (16%); halitosis was reported by 20% of respondents (Figure 3).

Oral hygiene instructions and preventive advice

Less than half of all respondents (44%) in this study felt they had received information on oral hygiene and tooth brushing instruction. Only 7% of parents believed they were ever given information on the benefits of fluoride use, while the majority of respondents (56%) who had received dietary advice, cited that it had been their dietitian or health visitor who had provided this.

Dental service use

Some experience of seeing a dentist was reported by 90% of the children in this study and parents most commonly found their child’s dentist though their school; some children saw the same dentist as their parents, yet a significant number gained information about oral health care via other medical services (Table 1).

Of the 90% of parents who reported taking their child to see a dentist, the majority of these (39%) accessed oral health care via a general dental practitioner. The remainder of children either received oral health care at a hospital (8%); 21% attended the salaried primary dental care service based a health centre while 21% of parents reported their child was seen by a dentist who visited their school on a regular basis (Figure 4).

Table 1 How parents found dentist for their child

<table>
<thead>
<tr>
<th>How did you find dentist?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Through own GP</td>
<td>15%</td>
</tr>
<tr>
<td>Through child’s school</td>
<td>31%</td>
</tr>
<tr>
<td>Through own dentist</td>
<td>31%</td>
</tr>
<tr>
<td>Via NHS Direct</td>
<td>6%</td>
</tr>
<tr>
<td>Through a friend or colleague</td>
<td>4%</td>
</tr>
</tbody>
</table>

Access to oral health care services

More than a quarter of parents reported they had experienced difficulty accessing oral health services; 16% reported dental services were located too far away; 18% that appointment times were unsuitable for them while 40% complained they were unable to get an appointment for their child as the waiting lists were full. The main form of transport to the dental service was by private car (67%). However, 1 in 10 respondents found parking or transport to the dental service a barrier to accessing oral health care services.

Discussion

Questionnaires are an effective way to gather information from a potentially large and disparate target group and also useful for protecting the privacy of participants. They are also extremely versatile in what they can collect such as subjective and qualitative data, as well as objective and quantitative data.
When this type of questionnaire is used, some loss of control must be accepted since the validity of the results is based on the honesty and opinion of the individual respondent. Qualitative information was taken into consideration in conjunction with the statistical findings. Less than half of all parents (47%) returned the questionnaire despite a two-wave distribution cycle. There are many reasons why an individual may decide not to partake in a questionnaire-based study; and similarly a multitude of reasons why they do not complete but fail to complete all parts of the exercise. A dropout analysis looks at those who have not completed the questionnaire and provides a ‘snapshot’ of where they ‘dropped out’, so further analysis may be possible.

Research into the nature of questionnaires reveals that respondents are more likely to commit to answering a questionnaire when they see it as interesting, of value, short, clearly thought through, and well presented. A dropout analysis was not performed in this study but would be included in further work to help validate results.

Parents thought their child was in good general health (96%) but 17% of respondents perceived their child’s oral health as poor. In annual school dental screening figures, 42% of children were deemed to require dental treatment. This compares with only 18% of parents believing their child had dental cavities. Discrepancies between parental perception and dental professional assessment of oral health status may indicate a lack of insight into their child’s oral condition or reflect real-life differences in outlook, understanding and priorities. It also highlights the nature of dental disease, which is frequently devoid of any obvious signs or symptoms that could be easily noticed by parents or family. This increases the value of dental examination in this group.

Some parents explained the reason they did not know whether their child had dental cavities was not due to unawareness or lack of importance, but in some cases they found it impossible to look inside their child’s mouth or to even carry out basic oral hygiene procedures. Parents’ comments included:

“Unable to brush his teeth and does not allow [sic] to help him”

“Refused to open his mouth”

These statements underline the importance of free and easy access to oral health screening and treatment services for this group by experienced, trained staff.

The Children’s Dental Health Survey, last carried out in 2003 measured normative oral health need rather than perceived need, so it has not been possible to make direct comparisons between these two groups.

Oral hygiene practices and dietary habits can have a significant bearing on a child’s oral health (Locker, 1992). A basic understanding of the principles and practices of good oral hygiene, combined with a reduction in the frequency of sugar exposure, can help reduce dental disease in this vulnerable group of children. Less than half of all respondents in this study felt they had received information on oral hygiene and tooth brushing instruction; and only one in fourteen believed they were ever given information on the benefits of fluoride use. However, in some situations, even when oral health education has been provided, some children with learning difficulties may not cooperate with basic oral hygiene practices.

“I have trouble brushing his teeth as he does not like it and I cannot keep him still for two minutes”

In these circumstances it is important that dental professionals recognise the limitations and difficulties faced by parents and carers and attempt to develop strategies to cope with or work around these problems.

Parents most commonly found their child’s dentist though their school; some children saw the same dentist as their parents; yet a significant number gained information about oral health care via other medical services (Table 1). Promotion of dentistry in these settings and encouraging uptake of services, could increase active attendance, promote preventive oral health advice and potentially reduce the need for dental intervention. Adjunct oral health education could also be provided by other health care workers, such as midwives and health visitors, in order to encourage good oral health behaviours and attitudes from an early age. It is important that oral health messages given are constant and evidence-based to avoid confusion.

More than a quarter of respondents reported that they had experienced difficulty accessing oral health services. This is over two-and-a-half times the reported national average (The Children’s Dental Health Survey, 2003). The National Health Service was founded on the principle of equal access to all, on the basis of need rather than the ability to pay. Since its creation, however, the NHS has been plagued by problems of access. Research has shown that the ‘Inverse Care Law’ often exists (Hart 1971, Smith 1999) whereby availability and utilisation of services is lowest among those with the greatest need. Only 5% of respondents were unaware of any dental services close to them; this small number is encouraging since the centralisation of services into larger health care premises can sometimes take providers further away from their client groups. This especially affects groups with disabilities where mobility and transport can be a major factor. This issue is reflected by the number of respondents in the questionnaire who reported dental services were located too far away.

There were expressed concerns over the building design where some dental surgeries were based. These included access difficulties for pushchairs or wheelchairs and there were safety issues too:

“Dentist [sic] upstairs surgery and no lift, okay when my son was small, no good now [sic] he is too heavy to carry upstairs, he is in a wheelchair.”
A small number of respondents expressed their frustration over perceived limitation of facilities and treatment options available in the National Health Services. This was not isolated to the dental services. Among the comments were:

“My son never gets to see a special needs dentist as the waiting list is too long. When he needs a general [anaesthetic] at the hospital it took ages to see him. He had to see two people before the referral so he had toothache for three months.”

“The NHS had no services to serve the needs of autistic children, be it dental or otherwise.”

Good access is achieved when there is a high degree of fit between the health service providers and its user (Penchansky and Thomas, 1981).

Whilst there has been much interest and research into access and barriers to health care services within the UK, there has been little research focusing on oral health care issues faced directly or indirectly by children with learning disabilities. This study highlights that barriers still exist when children with special educational needs and their families try to access oral health care services. The oral health of a child may also be significantly underestimated by parents or those with parental responsibility. Nevertheless, the perspective of the parent has an important bearing on health care decisions; if parents are to be considered important participants and the decision-makers in the health care of their children, then their perceptions should be considered, respected and understood by clinicians.

Oral health care needs to be integrated into holistic healthy policy at all levels and should be included in every individual care plan in these groups. Oral health issues can easily be overlooked. Effective integration of oral health into the mainstream health agenda is required to ensure that oral health issues are not omitted or dealt with separately and seen as ‘the dentist’s problem’.

Barriers to service access, whether perceived or actual, can only be removed through continual and constant review with analysis by service providers and users alike. Access is a complex and multi-faceted concept; it is not simply about supply and demand, but more importantly the dynamic relationship between the two. Optimal access to health care has been defined as ‘providing the right service at the right time in the right place’ (Rogers et al., 1999).

Conclusions

The level of oral health of children with special educational needs may be significantly underestimated by parents. However, the perspective of the parent has an important bearing on health care decisions; if parents are to be considered important participants and the decision-makers in the health care of their children, then their perceptions should be considered, respected and understood by clinicians.

Children with special education needs still experience barriers when accessing oral health care services. The Disability Discrimination Act (2005) aims to reduce inequalities but further development is needed to improve access to oral health care services for this group.

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