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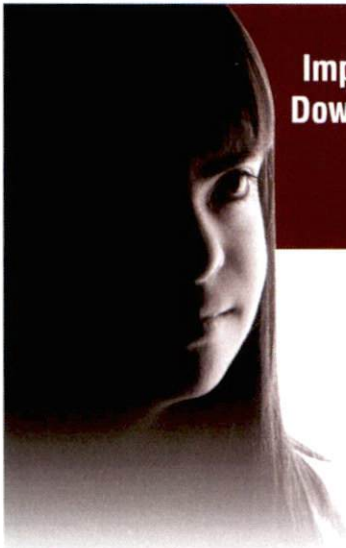
**On:** 23<sup>rd</sup> April 2015 10.30am – 4.45pm  
24<sup>th</sup> April 2015 9.15am – 3.15pm

**Venue:** The Royal Armouries, Leeds

Professor Elizabeth Treasure  
President, BASCD

# Impact of Oral Health on the Quality of Life of Adolescents with Down syndrome: Qualitative Exploration of Mothers' Perceptions

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## Introduction

Down syndrome is the most common genetic cause of intellectual disabilities (van Trotsenburg et al., 2006). In addition, it is the most common chromosomal anomaly among live-born infants with an incidence of 1:600 to 1:900 (Yang et al., 2002; Canfield et al., 2006). Individuals with this condition exhibit special oro-facial characteristics that increase their risk of oral conditions (Fiske & Shafik, 2001; Hennequin et al., 1999). The impact of oro-facial conditions on individuals may be related closely to their oral health (such as pain, discomfort, and in severe cases tooth loss), but can also extend to broader effects on personal relationship, emotional status and quality of life. However, there is very little research on the way oral health affects the quality of life of people with Down syndrome. Such information is very important to guide the service provision and evaluation of oral health promotion programs and services initiatives for this segment of population. For example, it could be used in clinical decision making to assess the effectiveness of dental treatment and/or early intervention such as physiotherapy targeting drooling or tongue hypo-tonicity of children with Down syndrome; thereby advancing the outcomes research agenda.

## Aim

This study aimed to explore mothers' perceptions of oral health conditions of their children with Down syndrome; and also to explore how the oral problems impacted different aspects of the life of child with Down syndrome and his/her family.

## Methods

Semi-structured, in-depth interviews with 20 mothers of 12-18 years old children with Down syndrome were conducted in special care centres in Riyadh city of Saudi Arabia. A topic guide was used to insure uniformity across all interviews, and that all areas of the research are covered, Figure 1 shows the sequences of the interview process.

Interviews were recorded using a digital recorder, and field notes were also collected. To aid data analysis, all recorded interviews were transcribed verbatim. NVivo software was used for data management. The data was analysed using thematic analysis.



Figure 1. Structure and flow of the topic guide

## Results

Findings revealed that:

- From the mothers' perceptions lower priority was given to oral health compared to child's general health.
- The predominant oral-health related problem was 'difficulty speaking', here is one of mothers' quotes

*'The source of her suffering is that she wants to speak fluently'..... 'She is shy because she is unable to speak well' (DG2)*

- Mothers also reported that 'dental caries' and 'toothache' are important problems that also have an undesirable effect on different aspects of child's life including daily activities, emotional wellbeing, and social relationships.
- Results also showed that the child's oral health have negative impacts of aspects of family's life, Figure 2.

A mother of a girl/boy reported that her child's speaking ability affects family as she reported

*'Yes,,, I'm I'm worried about the future, if I'm gone who will help him, how will he communicate (clarity of speech)' (SB5)*

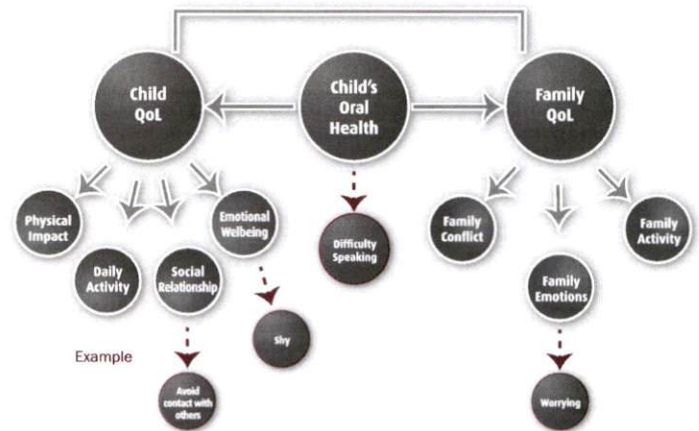


Figure 2. Impacts of child's oral health on his/her quality of life and that of the family as a whole.

## Conclusion

This study revealed an array of undesirable impacts of oral conditions on different aspects of children with Down syndrome quality of life. Finding also revealed impacts on families' lives as well. Further studies would be of value to expand on these findings, and to assess such impacts on different family members such as siblings.

As it is clear in the literature, individuals with disabilities especially those with intellectual disabilities experience worse oral health condition and poorer provision of oral health care services, and knowing that oral health does have an impact on them and their families, policy initiatives along with professionals (including dentists, physicians and other health and social care providers) should collaborate and work actively to improve the status and provision of services for people with disabilities.

## References

- Canfield, MA., Honein, MA., Yuskiv, N., Xing, J., Mai, CT., and Collins, JS. (2006). National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1990-2001. *Birth Defects Res A Clin Mol Teratol.* 76: 747-56
- Fiske, J., and Shafik, H. (2001). Down's syndrome and oral care. *Dental update.* 28: 148.
- Hennequin, M., Faulks, D., Veyrune, JL., and Bourdiol, P. (1999). Significance of oral health in persons with Down syndrome: a literature review. *Developmental Medicine & Child Neurology.* 41: 275-283
- Van-Trotsenburg, AS., Heymans, HS., Tijssen, JG., de Vijlder, JJ., and Vulsma, T. (2006). Comorbidity, hospitalization, and medication use and their influence on mental and motor development of young infants with Down syndrome. *Pediatrics.* 118:1633-9
- Yang, Q., Rasmussen, SA., and Friedman, JM. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: a population based study. *Lancet.* 359:1019-25

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## Further information

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