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## ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorders
ANOVA	Analysis of Variance
CFSS-DS	Children's Fear Survey Schedule–Dental Subscale
CFSS-SF	Children's Fear Survey Schedule–Short Form
CI	Confidence Interval
CWC	Child Welfare Centre
DAS	Dental Anxiety Scale
DBMP	Dental Behaviour Management Problems
DF	Dental Fear
DFA	Dental Fear and Anxiety
DMFT	Decayed, Missing, or Filled Teeth
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders (4 <sup>th</sup> ed.)
EASI	Emotionality, Activity, Shyness, Sociability and Impulsivity
EMOREA	Emotionality, Emotion Regulation, and Adaptation
GF	General Fear
HADS	Parental Hospital Anxiety and Depression
ICC	Intraclass Correlation Coefficient
MASC	Multidimensional Anxiety Scale for Children
OR	Odds Ratio
PDC	Public Dental Clinics
ROC	Receiver Operating Characteristic
SDQ	Strengths and Difficulties Questionnaire
SES	Socio-Economic Status
SPDC	Specialized Paediatric Dental Clinic
SPLUS	Statistical Package
SPSS	Statistical Package for Social Sciences
STATA	Statistical Package
StatXact	Statistical Package

## INTRODUCTION

In Sweden, all children and adolescents between the ages of 3 and 19 years are offered free regular dental care, often on an individual basis. The general aim of the Public Dental Service is to improve and maintain dental health by offering children and adolescents necessary prevention and free treatment, while a specific aim is to increase their interest in and knowledge of good oral health and behaviour (The National Board of Health and Welfare). Ideally, adolescents should leave this free health delivery system at the age of 19 with no treatment needs, the ability to maintain their good oral health, and recognition of the importance of regular dental checkups.

In Sweden, 1.3% of all children and adolescents (0–19 yrs) were referred to specialized paediatric dental clinics in 2003 [1]. This is a 28% increase since 1983 [1]. One of the most common reasons for referral was lack of cooperation with dental treatment (37%) [1], often in combination with a serious need for dental treatment [2-3].

In contrast to the improved oral health of children and adolescents in general, the problems among uncooperative children did not decrease from 1983 to 2003 [1]. It is notable that 10% to 20% of the child population have a high frequency of dental decay with subsequent treatment needs, and the polarization between ‘healthy’ and ‘unhealthy’ patients has increased [4]. To a great extent it is the group labelled unhealthy, with substantial need for dental treatment, who shows uncooperative behaviour [4]. These patients are very time-consuming, both in ordinary dental care and at specialist clinics [4]. Therefore, to improve not only children’s dental health and treatability, but also the planning of competent and well-functioning dental care, a better understanding of patients with this combination of problems is needed. This becomes even more important when dentistry, along with other health care areas, suffers from limited personnel and financial resources and priorities are necessary.

Children with uncooperative behaviour do not constitute a homogenous group [2, 5-6]. The expression of dental behaviour management problems (DBMP) differs between groups of children, as well as between individuals, and it interacts with personal characteristics and other psychological and social concomitants [7-8].

Dental fear is considered the primary source of both DBMP [5, 9-11] and irregular dental care (non-attending behaviour) [9, 12-15]. Therefore, the first paper was a methodological study exploring cut-off scores for dental fear and assessing the concordance between different informants regarding child and adolescent dental fear. The most commonly used questionnaire to assess dental fear among children and adolescents is the Dental Subscale of the Children’s Fear Survey Schedule (CFSS-DS) [16]. However, previous studies among children have found that dental fear explains only a part of DBMP [5-6, 10] and other personal characteristics (i.e. temperamental and behavioural aspects) clearly contribute [5-6].

This thesis, therefore, investigated whether personal characteristics and psychosocial concomitants, over and above dental fear, were also associated with DBMP and discontinuity of dental treatment among older children and adolescents.

## Dental behaviour management problems - definition and prevalence

Many children and adolescents perceive the dental treatment situation as stressful and demanding. A visit to the dental clinic may include stress-evoking components such as meeting new adults, experiencing novel sounds and tastes, having to lie down, and holding one's mouth open. All those experiences can lead to uncooperative behaviour, commonly described as Dental Behaviour Management Problems (DBMP). DBMP is defined as uncooperative behaviour resulting in delay of treatment or rendering treatment impossible [7], and DBMP is thus based on evaluations made by dental personnel. The prevalence of DBMP has been reported in two Swedish population-based studies, the latest 15 years old, as 8% and 10.5% respectively [17, 18]. DBMP and dental fear both peak in children at a young age and are followed by a clear age-related decline [3, 17].

## The relationship between dental behaviour management problems and dental fear

DBMP and dental fear (DF) are not synonymous, but overlap (Fig.1). This overlap was clearly shown by Klingberg through combining parental ratings of children's DF with DBMP notes in the dental records [10]. In their Swedish urban sample of 4505 children (3 to 11 years old), 27% of children with recordings of DBMP were also assessed as dentally fearful, while among fearful children, 61% showed DBMP [10]. More recent studies have shown that children (4 to 12 years old) referred because of DBMP form a heterogeneous group, with DF representing only part of the problem [5-6]. DF, however, still stands out as such an important factor in explaining DBMP [5, 9-11] that the distinction between DF and DBMP has not always been made clear [19].

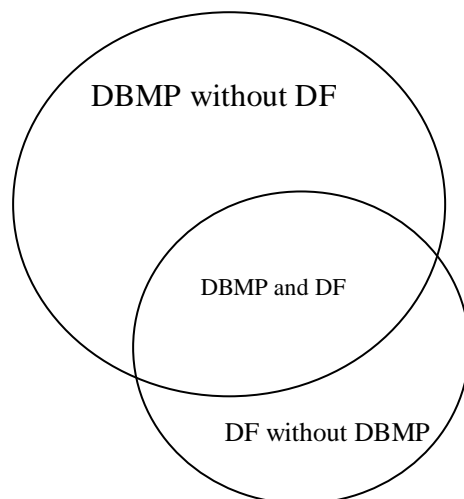


Figure 1. The relationship between dental behaviour management problems (DBMP) and dental fear (DF). Figure adapted by Arnrup from Klingberg [10, 129].

The distinction between DF and DBMP is very difficult to make in clinical situations. A child presenting refusal, acting out, or crying loudly when entering the dental office is unlikely to be overlooked, compared with a child who remains passive and silent during treatment. From a clinical point of view, many referrals are based only on the child's

or adolescent's uncooperative behaviour (i.e. avoidance, refusals, anger, crying), and these patients exhibiting DBMP are labelled as dentally fearful.

Many studies are based on children referred because of uncooperative behaviour and labelled as fearful by the dentist and the accompanying person, therefore the difference between DBMP and DF is difficult to discern. In this thesis we sometimes use the collective term DBMP/DF.

### *Dental fear among children and adolescents*

Among young children, mild dental fear is normal [20]. However, fear reactions may complicate dental treatment and sometimes become disproportionate to the actual threat; this is a concern for both the patient and the dental profession. Dental fear, dental anxiety, and dental phobia describe different types and levels of fear reactions. Dental fear refers to the fear of a specific threatening situation, while dental anxiety refers to a more general, and often anticipatory, state of apprehension [20]. The distinction between dental fear and dental anxiety is, however, far from clear, and it is hard to make, particularly in clinical settings. Dental phobia is a severe fear of dental treatment, characterized by consistent fear or anxiety related to specific objects or general situations, which often leads to avoidance of dental treatment and to functional impairment [21]. In this thesis we use the term DF.

About 10% of children as well as adults suffer from fear of dental treatment [19, 22]. The reported prevalence of DF among children represents a wide range (5.7% to 19.5%) and varies due to different study designs, populations, cultures, measures, and informants [19]. DF has been reported to be more common in girls than in boys and, although inconsistently, to be more common in younger than in older children [19].

### **Measures of dental fear**

Different measurement techniques have been used to assess DF: behavioural ratings, psychometric scales, physiological measures, and projective techniques. Two broad types of measurement techniques are most frequently used in research: (i) observations by the dental staff or an independent observer of the child's behaviour during dental treatment, and (ii) the child's own reports of anxiety, or reports from the accompanying parent, using psychometric scales. Self-reports are most often used when studying adolescents, while parental reports are normally used when assessing DF in younger children.

The most commonly used questionnaire to assess DF among children and adolescents is the Dental Subscale of the Children's Fear Survey Schedule (CFSS-DS) [16]. This instrument has been translated into several languages [11, 23-28] and is available in two versions, one for parents and one for the children and adolescents themselves. Normative data have been reported from several countries including China, Croatia, Denmark, Finland, Japan, the Netherlands, and Sweden [11, 24-27, 29-30].

To establish cut-off scores for clinical DF, parent-rated CFSS-DS scores have been validated against dentists' clinical ratings of child fear during the dental visit [11, 25, 28]. In a Swedish study, scores equal to or exceeding 38 indicated DF in children 4 to 11 years of age referred to a Specialized Paediatric Dental Clinic [25].

**Table 1. Cut-off scores on the CFSS-DS**

Author	Study design	N	Age (years)	Informant: self- or parent	Cut-off scores CFSS- DS[16]
Cuthbert et al. [16]	School children	603	5-14	self	42 (based on sample mean+1 SD)
Klingman et al. [31]	Highly fearful group	38	8-13	self	37 (based on sample mean + 1 SD)
Chellappah et al. [23]	Population based	505	10-14	self	$\geq 42$
Klingberg et al. [18]	Population based	3166	4-11	parent	$\geq 38$
Raadal et al. [74], Milgrom et al. [45]	Population based, low income	895	5-11	self	$\geq 40$
Ten Berge et al. [11]	Population based	2144	4-11	parent	$\geq 39$
Wogelius et al. [26]	Population based	1281	6-8	parent	$\geq 38$
Lee et al. [28]	school children	96	5-8	parent	$\geq 39$

Ten Berge et al. in Holland suggested the following cut-off scores among 4- to 12-year-old children referred to a paediatric specialist clinic, using parental ratings: below 32 (non-clinical range, i.e. no or low dental fear), between 32 and 39 (borderline range indicating a risk of developing dental fear), and equal to or exceeding 39 (clinical range, i.e. high dental fear) [11]. Lee et al. reported high sensitivity and specificity on the parental version of CFSS-DS using 39 as the cut-off among 96 Taiwanese children aged 5 to 8 years [28]. In one group of highly fearful children (8 to 13 years old), a cut-off score of 37 has been used for self-ratings [31] and among 10- to 14-year-old children in Singapore, 42 (mean score of CFSS-DS plus 1 standard deviation) has been suggested as a cut-off score [23] (Table 1).

To summarize, the cut-off score of 38 or greater on the CFSS-DS has been commonly used to define DF irrespective of age, gender, and informant. Parents are often solicited as reporters on behalf of their children in everyday life, as well as in psychological practice and research, since young children cannot be assumed to give reliable responses. However, the practice of relying solely on parental reports has come increasingly under question in psychological research [32-37]. Several studies have shown frequent discrepancies between different informants (i.e., mothers, children, teachers) in ratings of child psychopathology [32, 33, 36]. The agreement between self- and parental ratings has been reported to be weaker for internalizing as compared to externalizing problems [33, 34], which may be explained by the fact that externalizing behaviours are easier for observers (such as parents and teachers) to recognize than internalizing or emotional problems such as anxiety or depression [38].

We expect that large variation between parental and self-ratings of fear can occur, since the child dental patients may, on the one hand, show more uncooperative behaviour than their level of fear would normally predict (risk of overestimation) or, on the other hand, suffer from a higher degree of dental fear than their uncooperative behaviour would normally indicate (underestimation risk).

## DBMP in a multifactorial context of personal, environmental, and situational factors

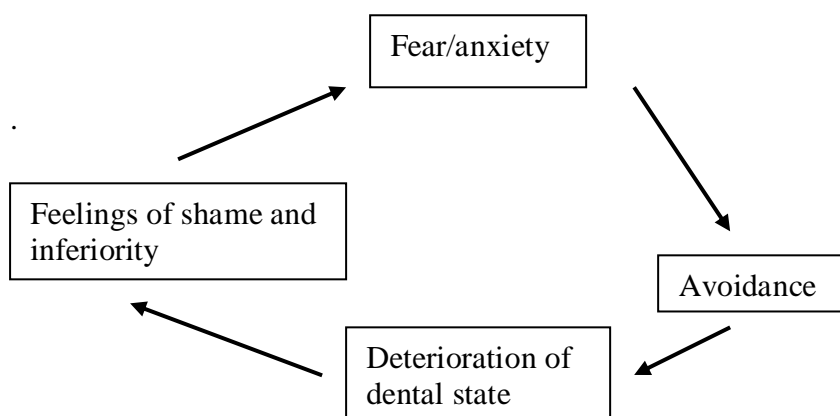
DBMP and DF can be considered interconnected results of multifaceted relations between personal characteristics and environmental and situational factors [8]. Personal characteristics (temperament and behavioural profile) may be seen as aspects of predisposition and vulnerability, while treatment experiences (situational factors) may serve as stressors with triggering and/or maintaining functions. The varying amount of stress needed to trigger DBMP/DF depends upon the child's vulnerability [39]. Environmental factors (i.e. socioeconomic status, cohabitation status, parental attitudes) are also seen as risk factors as they can affect the parent's ability to support the child during stressful occasions.

### *Personal characteristics*

Children and adolescents vary with respect to age, gender, competence, temperament, emotionality, personality, and intellectual capacity. They also differ greatly with regard to experience, family situation, and cultural background. All these aspects affect their ability to handle the dental situation [39]. Some children are able to cope well with potentially stressful situations such as a visit to the dentist; other children are more vulnerable and need more time in order to feel secure.

Personal characteristics, such as fear and anxiety, behavioural symptoms, and aspects of temperament previously associated with DBMP may be seen as facets of this vulnerability. As stated before, DF stands out as a particularly important determinant of DBMP [5, 9-11] and is one of the most common fears among people in the industrialized world [41-42]. The development of dental fear in adults has been described in terms of a vicious cycle including deteriorated oral health, social consequences, avoidance, and increased dental fear (Fig. 2) [40].

Fig 2. Vicious cycle of dental fear according to Berggren



*General fear.* Associations between DF and general fear have been regularly confirmed [43-45]. A population-based study including 2257 children with DBMP had higher scores of general fear [44], although a case-control study did not report any differences in general fear between children referred because of DBMP and children in ordinary dental care [5]. General fears and anxiety symptoms in children are normal developmental phenomena and young children may have several fears and anxiety symptoms without having an anxiety disorder (i.e. functional impairment) [46-47]. Specific fears change with increasing age, in a developmentally meaningful way: separation fears in 1-year-olds give way to fears of the dark and of animals in pre-school children and social fears in school-aged children and adolescents [48]).

*Anxiety.* No reports have been found of a specific association between DBMP and anxiety disorders. Anxiety disorder seems to be a common problem in older children and adolescents, with prevalence figures varying from 8% to 12% [49]. Different forms of anxiety disorders have been described (separation anxiety disorders, generalized anxiety disorders, panic disorders, social phobia, specific phobia, and obsessive-compulsive disorder [21]), as have their consequences in everyday life [49]. Children at risk of developing internalizing disorders (anxiety, depression) tend to score high on DF [50, 51], while the relationship to DBMP is not clear-cut [3, 5]. Despite this unclear relationship, however, a relationship between DBMP and internalizing disorders might be expected among children and adolescents who tend to be more genetically prone to react with fear and anxiety to a variety of threatening stimuli.

*Emotional and behavioural problems.* The prevalence of emotional and behavioural problems varies greatly, and it has been estimated from different studies that around 18% to 22% of adolescents have signs of significant adjustment problems [52]. Among 14- to 15-year-old Swedish adolescents, girls reported more emotional symptoms and more prosocial behaviour, and boys reported more conduct problems and somewhat more peer problems [53].

Among children referred because of high levels of DF, psychological problems in general have been found to be more common, in particular emotional [50] and peer relationship problems [54]. A previous study has identified four subgroups (based on cluster analysis of measures of DF, temperament, and internalizing and externalizing problems) among 4- to 12-year-old children referred because of DBMP [5]. One subgroup was characterized by shyness, negative emotionality, and an internalizing behaviour profile, whereas another showed moderate DF and was characterized by an externalizing behaviour profile (externalizing-impulsive). The externalizing-impulsive subgroup had a temperament and behavioural profile similar to that of children diagnosed with oppositional defiant disorder or conduct disorder [55].

The knowledge from the few studies considering the relationship between psychological problems in general (emotional and behavioural) and DBMP/DF is based mainly on parental ratings for children aged 4 to 12 years [50, 54, 55].

*Temperament.* Temperament is normally used as a collective term for a set of developed traits that (i) manifest in a structured way during early life; (ii) are quite consistent across situations; (iii) are relatively constant during significant periods of life; (iv) have neurophysiologic characteristics; and (v) are in part heritable [56].



Thomas and Chess [57] described three categories of infants with regard to temperamental profiles. Easy children (40%) were predictable and regular in their basic functions and approached novel situations happily. The second group (15%), which reacted to novelty with withdrawal and mild emotional distress, was classified as 'slow to warm up'. The third group, difficult children (10%), was characterized by minimal regularity, frequent irritability, and poor adaptation. The remaining 35% were considered mixed in their temperament. Temperament has been found to operate as a moderator of children's and adolescent's reactions to stressful experiences [58].

Temperament is often conceptualized in terms of 'reactivity' and 'emotion regulation' [59]. Reactivity is the child's intensity and rapidity of reactions (e.g. frustration, anger, shyness, fear) to different stimuli. Emotion regulation describes the child's ability to control emotional arousal in order to maintain social functioning [60]. Every child has to learn ways to control his or her emotions and to cope with challenging situations. From a functional perspective, emotions are not only responses to be regulated, but also themselves regulators of environmental interaction [61]. Poor regulation of anger and exuberance has been associated with externalizing problems; poor regulation of fear, with internalizing problems [62]. Reactivity and control are important issues in dental treatment, since inability to control both reactivity and emotional arousal will most probably cause the child patient difficulties in sitting still and following instructions. Emotion regulation can be effected as self-control or control with help from others [63].

Several studies have associated different temperamental aspects with both behaviour during dental treatment and DF [19, 64-67]. DBMP has more often been associated with activity (corresponding to tempo and vigour) and impulsivity (impatience and lack of perseverance) [19]; DF has been more linked with temperamental aspects such as shyness and inhibition and with internalizing psychological problems; and both DBMP and DF have been related to negative emotionality [5-6, 66].

Difficulties approaching novelty or new people (a characteristic of shyness) have been reported to be a discriminating factor for DBMP [65, 66, 68, 69]. The shyness dimension seems to be particularly important in situations such as dental care, although for young children this may be a normal reaction, due only to their age [39]. The influence of temperament on treatment acceptance was evaluated in a Swedish study of 50 preschool-aged children referred for dental extraction and treated under sedation with Midazolam [67]. Shyness predicted a poorer acceptance of treatment. This was true also for negative emotionality, which was linked to a more agitated behaviour already evident upon the child's arrival at the clinic.

Information regarding different temperamental aspects and their relationship to both DBMP and DF is based mainly on parental ratings for younger children. In addition, many children and adolescents find the dental treatment situation stressful and demanding; studies focusing on the emotion-regulation and control aspects of temperament (i.e. emotion-vs. problem-focused coping) are needed to achieve better treatments.

### *Environmental factors*

Social gradients have been consistently related to physical health, psychological problems, and dental disease among children. The relationship between socio-economic status (SES)

and dental disease is well established [70, 71], and it has also been shown that SES is one of the strongest social environmental factors influencing physical health [72]. Both physical and psychological symptoms are more common among socially disadvantaged children, whose health and well-being reflect those of their parents [73]. Raadal et al. [74] noted social deprivation and poverty as risk factors for behavioural problems in children. In addition, SES and family situation have been suggested as risk factors for DBMP, although contradictory findings have been reported [10, 75]. However, it is not SES or family situation per se which should be presumed to influence the child's behaviour in dentistry, but their effect on parents' attitudes and behaviours, and thus their ability to guide and support their child.

Further, among environmental factors, parental dental fear (mostly in mothers) is the one that most powerfully correlates to dental fear in children and seems to predispose them to dental fear reactions [10, 68]. Children may also acquire DF through social learning from fearful parents or other family members [76]. Some children and adolescents are vulnerable to developing dental fear due to their genetic make-up [77]. Frequent missed appointments and/or DBMP have also been shown for the children of parents with high levels of dental fear [78].

Studies focusing on social factors and everyday life in relation to DBMP, however, are rare. An impact among children has been indicated, but little is known about the effect in adolescents.

### *Situational factors*

Experience of pain and discomfort [2, 79-81, 82], perceived lack of control [79], or rude behaviour from a dentist [83] have all been reported to be important situational factors adding to the risk of developing DBMP/DF. According to parents these are very important for the development of DBMP/DF in children [2, 80, 83, 84]. Previous treatment was the most common cause of uncooperative behaviour as reported by 54% of the parents in a study of preschool children referred because of DBMP, while the referring dentist considered attitudes in the family to be the main reason for uncooperative behaviour [2]. It has also been noticed that children with a record of DBMP were more likely to have received restorative treatment without local anaesthetics [3]. The parents' explanations parallel findings in the adult population, where the origin of dental anxiety is reported to be childhood experience of painful dental treatment [76, 85] in combination with a rude dentist [86]. Hospital stay and a history of medical problems have also been related to DF among children [80, 82] and mentioned as an explanation for DBMP [2].

DBMP has been discussed in a multifactorial context where personal characteristics, family situation, and situational factors interact [7, 8]. Irrespective of age, some children are very robust and tolerant, while others are vulnerable and respond negatively to even slight stress stimuli. This may in part explain why some children do not develop DBMP/DF despite traumatic dental experience.

## **Consequences of DF and/or DBMP in children and adolescents**

Avoidance may be seen as the extreme of DBMP, varying from irregular dental attendance to dropping out entirely from dental treatment. Avoidance behaviour among adolescents and adults has been consistently related to DF [9, 12-15, 87]. It is well known that dental fear with avoidance behaviour has negative effects on an individual's oral health [88]. Negative dental behaviours can be described in terms of a 'vicious cycle', in which non-attending among fearful patients may result in deteriorated oral health, and associated negative psychological consequences subsequently strengthen fear and cause increased anxiety ([40, 88] Fig. 2). Adult avoiders or adults with irregular dental care have significantly more missing/extracted teeth as compared to regular adult attendees, while attendees have more filled teeth, although there is no difference between attendees and non-attendees in total DMFT (decayed, missing, filled teeth) [87]. This indicates more radical treatment among avoiders when they do apply for dental care.

In adolescents, dental anxiety and avoidance of dental treatment have been shown to be associated with poor oral health [89-91], which is seen in higher scores of DMFT [12] and more teeth endodontically treated due to caries [91].

Factors that have been reported to increase the risk for carious lesions in children are families with irregular dental care, children showing DBMP, and parents avoiding dental care [92]. In addition, children with missed appointments were rated more likely by their dentist to show DBMP and had more carious lesions but fewer filled surfaces [3], indicating incomplete care.

Why older children and adolescents avoid dental appointments is not clear, nor is the reason for non-attendance even for young children. The patients' subjective norms and attitudes seem to play an important role in their intention to visit the dentist [81, 93] and irregular dental care in late adolescence is related to a number of negative social factors, such as early school leaving and unemployment [93].

In view of the definition of DBMP causing delay of treatment or rendering treatment impossible [7], the consequence of inadequate dental treatment is obvious. Thus, the concept of a vicious cycle, as mentioned previously among adult patients with dental phobia [40], may also be valid for children and adolescents with DBMP/DF.

## **The rationale for the study**

To summarize, knowledge about the development of DBMP/DF in children and adolescents comes mainly from parental ratings of their children's dental fear and personal characteristics and from behavioural ratings during dental treatment by the dental staff. DBMP is a multifactorial problem, where fears, personal characteristics (intelligence, maturation, temperamental aspects, behavioural), environmental factors (socioeconomic status, family situation, parental dental fear), situational factors, and previous experience of both dental and medical care interact [19].

In light of the close relationship between DF and DBMP, it would be interesting to see how well parental and self-ratings of dental fear agree, particularly in the group of children and adolescents referred because of DBMP, since the validation of the measure

CFSS-DS was performed in the general child population. Although DBMP and DF have been frequently investigated, limited attention has been paid to some areas. There is a further need to explore DBMP and DF among older children and adolescents and to discover how their personal characteristics, everyday lives, and family situations interact with their DBMP and their own ratings of DF and other personal characteristics.

## **AIMS OF THE THESIS**

The general aim of this thesis was to search for a deeper understanding of the interactive importance of dental fear, personal characteristics, and psychosocial concomitants for DBMP and dental attendance in older children and adolescents.

The specific aims of the study were:

1. to evaluate the impact of referral status and type of informant (self vs. parent) on the usefulness of the Children's Fear Survey Schedule–Dental Subscale (CFSS-DS) as a measure of DF and to suggest age- and gender-differentiated cut-off scores (Study I);
2. to describe socioeconomic status, family situation, everyday life, and psychosocial history in age- and gender-differentiated groups of older children and adolescents referred because of DBMP as compared to children and adolescents in ordinary dental care (Study II);
3. to investigate whether DBMP could be predicted by dental fear and other personal characteristics (anxiety, behavioural symptoms, temperamental reactivity, and emotion regulation) by comparing age- and gender-differentiated groups of older children and adolescents referred for specialized paediatric dental care because of DBMP with children and adolescents in ordinary dental care (Study III); and
4. to investigate to what extent some children's and adolescents' failure to reach treatment continuity at the specialized dental clinic could be predicted by simultaneously taking into account dental history, fear and personal characteristics, family factors, and psychosocial concomitants (Study IV).

## MATERIALS AND METHODS

### Subjects and procedures

The investigations on which the thesis is based were performed in Sweden from January 2004 to December 2006, with data for study and reference groups collected mainly within the county of Östergötland. Östergötland County has about 420 000 inhabitants, of which approximately 100 000 are children and adolescents 0–19 years old. Paediatric dentistry is organized mainly within the public dental care system, with 25 public dental clinics offering regular recall examinations and routine dentistry for children. Specialized paediatric dentistry is offered, after referral, at specialist clinics in Linköping (population 140 000), Motala (42 000), and Norrköping (127 000), where altogether about 900 children and adolescents per year are treated.

### Study group

The main study group consisted of children or adolescents referred to the specialist clinics for both their lack of cooperation with dental treatment at the public dental clinics and their need for restorative dental treatment. Referrals were made by their ordinary dentists. Patients were at least 7 but not yet 20 years of age at the time of referral. The inclusion criteria were: (i) the patient was accompanied by a parent when visiting the specialist clinic, (ii) both patient and parent were able to read and understand Swedish, (iii) the patient had no communication disorder, such as blindness or hearing impairment, and (iv) the patient had no known psychological or psychiatric diagnosis according to the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> ed.) [21]. Following the inclusion criteria, 253 consecutive patients and their accompanying parents were asked to participate. Participation was agreed to, and introductory baseline assessments completed by, 230 patients (118 girls; 51%). Most of the responding parents were mothers (87%). Due to missing data on single items, the valid *n* varies between measures and analyses.

For the agreement analyses reported in Paper I (Fig. 3), 10 patients under the age of 8 years and 10 patient/parent pairs with incomplete data were excluded, giving valid *n* = 210 (104 girls, 106 boys; age 8–19 yrs at referral) from the counties of Östergötland, Örebro, and Jönköping. In the part of Paper I that deals with differentiated cut-off scores on the Children's Fear Survey Schedule–Dental Subscale (CFSS-DS) [16], previously collected data were added for study group participants from Göteborg (*n* = 195; 4–12 yrs of age at referral) and Örebro (*n* = 86; 8–12 yrs).

For paper IV, the study group was restricted to those patients who were referred to and offered specialist treatment in the county of Östergötland (*n* = 179 patients; 94 girls = 53%).

### Reference group

Reference group patients and their parents were consecutively asked to participate when they came for routine recall examination (*n* = 217) at four public dental clinics (three in Östergötland and one in Jönköping) or made orthodontic check-up visits (*n* = 31) at three

orthodontic clinics in the county of Östergötland. The dental clinics were selected to represent both urban and rural areas as well as areas of different socio-economic structure. The reference group patients had no known history of DBMP, which was controlled for in their dental records by their dentists (Fig. 2). Other inclusion criteria paralleled those of the study group (i–iv). A total of 248 patients (142 girls; 57%) and their accompanying parents (84% mothers) formed the reference group.

For the agreement analyses reported in Paper I (Fig. 3), 5 patients below the age of 8 years and 15 patient/parent pairs with incomplete data were excluded (valid n = 228; 135 girls, 93 boys; age 8–19 yrs). Reference group data from Göteborg (n = 168; age 3.5–12 yrs old) and Örebro (n = 108; 8–12 yrs) were added into the analyses dealing with differentiated cut-off scores on the CFSS-DS (Fig. 3).





## **Study procedures**

Study group patients and their parents were interviewed according to a semi-structured interview protocol at their first visit to the specialized paediatric dentistry clinics. The interview dealt with background, including socio-economic factors and family situation, medical and psychosocial history, the child's daily life and psychosocial adjustment/interaction. Another purpose of the interview was to initiate interaction between dentist, youth, and parent and to reach an agreement on treatment structure and content.

Following the interview, the patient and the parent each filled in separate questionnaires, which included aspects of the patient's dental and general fear or anxiety, temperament, and emotional or behavioural problems. The questionnaires for parental ratings also assessed parents' own dental fear, anxiety, and depression. The study procedures (interview, filling out questionnaires) took place in the dental surgery. Baseline assessments were completed before any introductory or dental treatment was performed.

Reference group participants were interviewed by personnel at their ordinary dental clinics according to a similar semi-structured protocol, modified for use among patients in ordinary dental care. The same questionnaires as for the study group were distributed, and the entire study protocol was completed at one single visit in conjunction with their regular recall or control scheme.

## **Ethical considerations**

All data were treated confidentially. All participants received both verbal and written information about the study, including that participation was voluntary. Approval from the research ethical committees of the Linköping County Council, the Örebro County Council, and Göteborg University was obtained prior to the different data collections.

## **Measures**

As a measure of socio-economic status, both parents' occupations were assessed using the Hollingshead four-factor index of occupational status [94] (range 1–9; total possible scores 8–66), modified for use in Sweden by Broberg 1992 [95]. Scores below 30 indicate low socio-economic status.

Cohabitation rather than marital status of the parents was used to describe the family situation, since many Swedish parents who live together are not married. From the questionnaires, data on patients' experiences of hospitalization, other separation from both parents, or serious disease or death within the family were indexed as separation experience (yes/no).

Social interaction was evaluated in 5 items asking for the parent's opinion of the child's interaction with siblings, interaction with other children, conduct towards parents, ability to play or work alone, and school performance. For each item, the parent rated their child as doing worse (0), equal to (1), or better (2) than most children of the same age. As a global measure of social interaction problems (yes/no) we used a dichotomy based on individual mean ratings from the 5 items. Mean ratings below 1 indicated social interaction

problems (yes), while mean ratings equal to or exceeding 1 indicated no social interaction problems. Other questions dealt with peer interaction and leisure-time activities, professional personal support, and perceived problems at medical visits.

## **Psychometric measures**

The CFSS-DS [16] is a 5-point Likert scale consisting of 15 items used to assess dental fear and anxiety. The Swedish version of CFSS-DS [25], designed primarily for parental ratings, was adapted with minor modifications for children's and adolescents' self-ratings. The items range from 1 (not afraid at all) to 5 (very afraid), giving a range of possible scores of 15–75. Scores equal to or above 38 have been suggested to indicate high fear of going to the dentist among Swedish children [25].

General fear was assessed using the Swedish parental version [10] of the short form of the children's fear survey schedule (CFSS-SF) [96], containing 18 items to be rated from 1 (not afraid) to 5 (very afraid), giving total scores of 18–90.

The Multidimensional Anxiety Scale for Children (MASC) ([97], in Swedish translation [98]), was used for children's and adolescents' self-ratings of their anxiety problems. MASC contains 39 items to be rated from 0 (the symptom never applies to me) to 3 (the symptom often applies to me) and has four subscales describing physical symptoms (12 items), social anxiety (9 items), separation anxiety/panic (9 items), and harm avoidance (9 items).

The Strengths and Difficulties Questionnaire (SDQ) ([99], in Swedish translation [100]), was used as a generic measure of emotional and behavioural problems. The SDQ, which can be used for both parental and self-ratings, has 25 items to be rated from 0 (not at all like my child/me) to 2 (very much like my child/me), divided between five scales of five items each, generating scores for parental and self-ratings of emotional symptoms, conduct problems, hyperactivity-inattention, peer problems, and prosocial behaviour.

The EASI temperamental survey ([101], in Swedish translation [102]), was used to measure five aspects of temperament. It contains 25 items on a Likert-type scale from 1 (not at all like my child) to 5 (very much like my child) and was adapted with minor modifications for use in self-assessments. The EASI measures negative emotionality (a tendency towards high autonomic arousal, expressed as irritability or aggression), activity level (tempo and vigour), sociability (a tendency to prefer the presence of others to being alone), shyness (a tendency towards being inhibited or slow to warm up in new situations or when meeting strangers), and impulsivity (a tendency towards impatience and lack of perseverance). Each temperamental dimension is measured by a 5-item subscale of the EASI instrument, giving mean scores ranging from 1 to 5 for each dimension.

The Emotionality, Emotion-Regulation, and Adaptation questionnaire (EMOREA) [103] was used for parental ratings of children's temperamental reactivity and capacity to regulate emotion. The items focus on four emotions: sadness, anger, fear, and positive emotions/exuberance. All items are scored on 5-point Likert-scales from 1 (doesn't apply at all) to 5 (applies very well to my/this child). Temperamental reactivity was measured with 16 questions regarding the occurrence and intensity of reactions (positive and negative reactions showed high correlation and were merged to a single scale, reactivity; range 16–80).

Independent regulation of emotion was measured by 12 questions regarding the child's ability to regulate anger, fear, and sadness independently (regulation–self; range 12–72); regulation with help from others was measured by 12 additional questions (regulation–parental; range 12–72).

Parental dental fear was assessed using Corah's Dental Anxiety Scale (DAS) [104]. The DAS measures reactions to four imagined dental treatment situations, including appointment tomorrow and three different treatment situations. For each situation responses are scored from 1 (calm) to 5 (terrified) giving total scores from 4 to 20. Average DAS scores of 8 to 9 in ordinary patients and 15 or above among dental phobic patients have been reported in several studies [105, 106].

The parental Hospital Anxiety and Depression Scale (HADS) was developed in 1983 by Zigmond and Snaith [107]. It is a brief, 14-item questionnaire, originally designed to assess emotional disturbance in non-psychiatric patients treated at hospital clinics. The scale measures both anxiety (HAD-A) and depression (HAD-D) on two separate subscales, each containing 7 items [108-110]. All items are scored on a 4-point scale from 0 to 3 giving total subscales scores ranging from 0 to 21. Swedish population data and tests of reliability and validity reveal that cut-offs of 7 or 8 can be used to detect probable cases of hospital anxiety or depression [109].

### **Clinical registration**

The number of decayed teeth (primary or permanent) at baseline indicated the patient's dental health status. The individual caries experience was recorded at the time of referral using the DMFT (decayed, missing, and filled teeth) index, which counts teeth with decay (clinical cavities and/or lesions extending into dentin according to bite-wing radiographs; score D3 as described by Gröndahl)[111], missing teeth (extracted due to caries), and filled teeth, for a score of total number of teeth affected by caries.

Data on cancellations, missed appointments, or discontinuations (interrupted treatment periods) were collected from treatment protocols from baseline to first invasive treatment (i.e. during the introductory and behavioural management treatment period).

### **Statistical methods**

Descriptive statistics were given as means, standard deviations, frequencies, and percentages in Papers I–IV, and were presented graphically in Paper II. Group differences were tested with Student *t*-test for parametric data and Chi square test for proportions (Papers II–IV) or trends (Papers II and IV), and effect sizes were estimated with Cohen's *d* (Paper III).

Intraclass correlation coefficients (ICC) with 95% confidence intervals (CI) were computed for assessment of agreement between parental assessments and self-ratings. Differences in ICC between groups were tested by an analogue of large sample *t*-tests for group differences using standard errors from the CI computations. In addition, the agreement was illustrated with Bland-Altman plots [112] (Paper I). Cut-off scores on the CFSS-DS scale were determined using receiver operating characteristic (ROC) analysis (Paper I). Additionally, possible cut-off scores were examined by assessing the scores of the 90<sup>th</sup>

percentile from the reference group. The 90<sup>th</sup> percentile was estimated from the cumulative distribution and a 95% confidence interval (CI) was derived by interpolation using binomial distribution [113] (Paper I).

Multivariate comparisons were performed using logistic regression analyses with group (study vs. reference group in Papers II and III; non-attending vs. attending group in Paper IV) as outcome variable and selected measures as potentially discriminatory variables. As a complement to the logistic regression analyses, we used tree-based modelling or recursive partitioning [114-115] (Paper III, IV).

The level of significance was set at 5% (i.e.  $P < 0.05$ ). The statistical analyses were performed using SPSS version 15.0 (Papers I–IV), STATA version 10 (Paper I), StatXact 7 (Paper II), and SPLUS 2000 (Papers III and IV).

## RESULTS

### Dental fear and the usefulness of CFSS-DS

The study group had, as expected, significantly higher scores for both parental assessments and self-ratings on the CFSS-DS (means 38.8 and 35.0, respectively) as compared with the reference group (means 20.5 and 22.5;  $P < 0.001$ ) (Paper I, Table 2; Paper III, Table 2).

#### *Agreement*

Regarding the concordance between parental and self-ratings in the study group, parent-rated DF exceeded self-rated DF (mean difference 3.8, SD 12.3), while the reverse was true in the reference group (mean difference -2.1, SD 6.6). With the exception of adolescent girls, these patterns were stable across age and gender subgroups (Paper I). The correlation between parental ratings and self-ratings of child dental fear was ICC = 0.29 in the study group as compared with ICC = 0.46 for the reference group ( $P = 0.04$  for difference in ICC; Paper I, Table 2). The most obvious difference between study and reference groups was found for 8- to 12-year-old girls, where ICC was 0.14 in the study group as compared with 0.57 in the reference group ( $P = 0.005$  for difference in ICC; Paper I, Table 2). ANOVA showed a significant main effect for group (study versus reference) regarding differences between parental ratings versus self-ratings of child dental fear ( $F = 34.1$ ;  $P < 0.0001$ ), with the study group having the largest difference between the readings (Paper I, Fig 1).

#### *Cut-off scores*

Age- and gender-differentiated cut-off scores, using parental ratings on the CFSS-DS, estimated according to the 90<sup>th</sup> percentile in the reference group, ranged from 24.7 (adolescent girls) to 42.5 (pre-school boys) with a mean of 33.4 (Paper I, Table 3; Fig. 3). The optimal cut-off score estimated from the ROC analyses was 27.5 for the total sample and ranged from 18.5 (boys, 3.5–6 yrs) to 33.5 (girls, 3.5–9 yrs) in age and gender subgroups (Fig. 3). All optimal cut-off scores were below the standard cut-off score of 38 (Paper I, Table 4).

The same sequence of cut-off exploration analyses was performed on self-ratings on the CFSS-DS. Estimated cut-off scores, using the 90<sup>th</sup> percentile, ranged from 27.0 to 35.6 with a mean of 31.0. The optimal cut-off score estimated from the ROC analyses was 24.6 for the total sample and ranged from 22.8 (boys, 10–12 yrs) to 30.0 (girls, 16–19 yrs) for subgroups (Fig 3). For self-ratings, all estimated cut-off scores (90<sup>th</sup> percentile and optimal) were lower than the standard cut-off score (38).

### Psychosocial concomitants

#### *Socio-economic status and family situation*

Children and adolescents referred because of DBMP more often lived in families with low socio-economic status (SES) compared with children and adolescents in ordinary dental care (29.4 vs. 38.2;  $P < 0.001$ ; Paper II). They also more commonly had parents not living together

(51% vs. 26%;  $P < 0.001$ ; Papers II and III), a difference which was even more pronounced between the adolescent subgroups (59% vs. 28%;  $P < 0.001$ ; Papers II and III).

Within the study group, 23 individuals (10% vs. 0 in the reference group) had, as a result of interventions by social authority, experienced separation from both parents and had been living with relatives or foster parents. Parental dental fear was significantly higher in the study group (10.7) than in the reference group (7.5;  $P < 0.001$ ; Paper II).

### *Everyday life*

The children and adolescents in the study group were significantly less engaged in organized leisure time activities. Half of the study group reported no regular activity, while this was reported by less than 20% of the reference group. The most evident difference was revealed between the groups of adolescent boys, of whom 77% in the study group, as compared with 28% in the reference group, reported no leisure time activity ( $P < 0.001$ ). Differences between groups were also obvious regarding number of close friends, with study group children and adolescents reporting fewer close friends (Chi-square test for trend  $\chi^2 = 12.38$ ;  $P < 0.001$ ).

### *Medical and psychosocial history*

The proportion of children and adolescents having support from school psychologists or other professionals was almost four times higher in the study group than in the reference group (55% vs. 15%;  $P < 0.001$ ; Paper II, Table 2). The support was most commonly related to school problems, personal psychosocial problems (depression, anxiety, suicide attempt, parental separation), and behaviour problems, including neuropsychiatric disorders. Violence or abuse in the family was reported exclusively by the study group children and adolescents (6%; Paper II).

Both groups' parents tended to rate their children's and adolescents' psychosocial adjustment in different situations equal to others of the same ages. However, some study group parents indicated that their children and adolescents did worse in some situations, particularly in school performance. The difference between the groups was more pronounced after dichotomization into social interaction problems or not, where such problems were three times higher in the study group than in the reference group (30% vs. 9%;  $P < 0.001$ ; Paper II).

### **Fears and personal characteristics**

General fear was significantly higher among the referred study group children (mean difference 9.6;  $P < 0.001$ ;  $d = 1.0$ ; Paper III, Table 2). Study group children and adolescents had also significantly higher scores on four of the five MASC subscales (physical symptoms, social anxiety, separation anxiety, and anxiety disorders; Paper III, Table 2).

In terms of strengths and difficulties, significantly higher scores were revealed for the study group on all problem-related subscales of the SDQ (emotional symptoms, conduct problems, hyperactivity-inattention, and peer problems; Paper III, Table 2).

The temperamental assessments using the EASI revealed significantly higher scores for study group patients than for the reference group on the subscales for negative emotionality, shyness, and impulsivity (Paper III, Table 2). The study group had higher scores on emotional reactivity (emotional reactions were reported to occur more often and to be more intense) and were rated by their parents as less able to regulate their emotions both on their own (regulation–self) and with help from others (regulation–parental; Paper III, Table 2).

## **Prediction of dental behaviour management problems – multivariate analyses**

### *Socio-economic status and family situation*

Low socio-economic status, not living with both parents, professional personal support, and parental dental fear were factors predicting referral because of DBMP (i.e. being in the study group). Low SES was the only variable with predictive ability in both the main model and the subgroup models (Paper II, Table 4). Subgroup models for male children and adolescents of both sexes revealed increased odds ratios (from 3.7 to 6.3–7.2) for professional personal support, pointing to its clear and significant contribution (Paper II, Table 4).

### *Dental fear and personal characteristics*

Dental fear (DF; both parent- and self-rated), social anxiety, emotional symptoms, peer problems, and impulsivity were differentiated between study and reference groups in the final logistic regression model. Emotional symptoms and peer problems showed the highest ORs for allocation to the study group (Paper III, Table 3). DF was the only variable that had predictive ability for referral in both the total sample and the different subgroups.

In the youngest subgroups, emotional symptoms stand out with increased ORs (2.2–7.1). For the adolescent girls, self-rated DF and conduct problems predicted referral. For the adolescent boys, physical symptoms were the only predictor in addition to dental fear (Paper III, Table 3).

Tree-based modelling was performed for complementary discriminating analyses between study and reference groups (Paper III). In the tree-based modelling, continuous variables showing discriminatory capacity during any step in the sequence of multiple logistic regression analyses were included. In the first tree-based modelling, the classification procedure (into study vs. reference groups) was allowed to continue until subsets including a minimum of 20 individuals and 16 terminal nodes were revealed, with an overall probability of correct classification of 90% (Paper III). Parent-rated DF higher than 40.7 by itself predicted placement in the study group (Paper III, Fig. 1, node 16; probability 100%) and parent-rated DF below 24.8 predicted placement in the reference group (Paper III, Fig. 1, nodes 1–5; probability 96%). The second tree modelling was performed to search for easy screening measures to identify patients in possible need of special attention due to their risk of developing DBMP. By pre-specifying the minimum size of subsets to 150 subjects, thus reducing sampling variability, the tree modelling was restricted to four terminal nodes (87% correct classification), with DF as the outstanding predictor. With a cut-off at 24.8, parent-rated DF clearly discriminated between study and reference groups (Paper III; Fig.2).

## **Failure to reach continuity**

The group of children and adolescents referred because of DBMP were divided into two groups according to their frequency of missed and/or cancelled appointments. One hundred and twenty-three patients (51% girls), with a mean age of 12.8 years, had no missed appointments and fewer than 20% cancellations at the specialized paediatric dentistry clinic; they were labelled 'attending group'. The rest, labelled 'non-attending group', consisted of 56 patients (55% girls) with a mean age of 13.4 years. Of this group, 16 patients had interrupted their contact with the specialized paediatric dentistry clinic by remaining absent despite several reminders (Paper IV; Table 1). All children and adolescents irrespective of subgroup attended their first scheduled visit at the specialized paediatric dentistry clinic (baseline).

Children and adolescents with non-attending behaviour more often lived in families with even lower socio-economic status (SES) than those patients who reached continuity of treatment. They also more commonly had parents not living together (68 % vs. 45.0 %;  $P = 0.003$ ; Paper IV) and experienced more separation from both parents (11.0 % vs. 4%; Paper IV, Table 4). Parental anxiety and experience of hospital stays was barely higher in the non-attending group than in the attending group (Paper IV, Table 3). The proportion of children and adolescents having support from school psychologists or other professionals was significantly higher in the non-attending group than in the attending group (66% vs. 51%;  $P = 0.04$ ; Paper IV, Table 3).

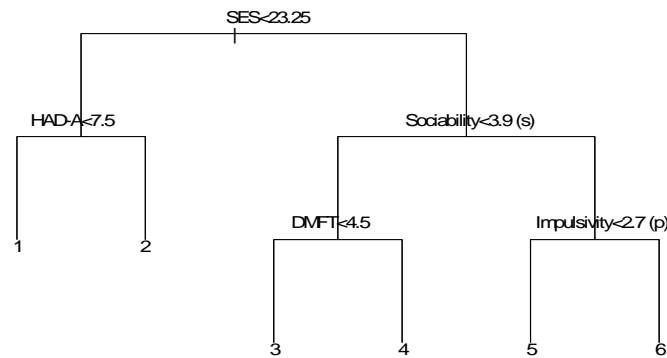
There were limited differences regarding personal characteristics between the two groups; however, impulsivity, sociability, and peer problems were rated higher among the non-attenders (Paper IV, Table 2).



*Prediction of non-attending behaviour – multivariate analyses*

Low socio-economic status, not living with both parents, peer problems, sociability, and DMFT predicted allocation to the non-attending group (75.5% correct classification).

In the complementary tree-based modelling, continuous variables showing discriminatory capacity during any step in the sequence of multiple logistic regression analyses were included (Paper IV). The classification process (non-attending vs. attending groups) proceeded until subsets including a minimum of 20 individuals and 6 terminal nodes were revealed, with an overall probability of correct classification of 73% (Fig. 4). SES below 23.3, and parent’s own anxiety (HAD-A) predicted placement in the non-attending group with a probability of 65% (Fig. 4).



Node	1	2	3	4	5	6
<b>n (percentage within group)</b>						
Non-attender	10(21)	<b>13(28)</b>	2(4)	5(11)	7(15)	10(21)
Attender	18(17)	7(7)	<b>38(36)</b>	15(14)	17(16)	11(10)
<b>n (percentage within node)</b>						
Non-attender	10(36)	<b>13(65)</b>	2(5)	5(25)	7(29)	10(48)
Attender	18(64)	7(35)	<b>38(95)</b>	15(75)	17(71)	11(52)

Fig. 4. Tree-based modelling with a minimum size of the final subsets (terminal nodes) of 20 subjects. Percentage of correct classification 73%. Fulfilment of the classification criterion leads to the left, non-fulfilment leads to the right. (SES=socioeconomic status, Sociability=EASI sociability (s), Impulsivity=EASI impulsivity (p), HAD-A=parental anxiety, DMFT=decayed, missed, filled teeth).

## DISCUSSION

The primary aim of this thesis was to study dental fear, personal characteristics, and psychosocial concomitants in relation to dental behaviour management problems (DBMP) among older children and adolescents. The study group consisted of 7.5- to 19-year-old children and adolescents referred to the Clinic of Specialized Paediatric Dentistry because of DBMP and a need for dental treatment. They were compared to a reference group of same-aged dental patients in ordinary dental care.

The main findings from the studies, in summary, are:

- ❖ From as young as 9 or 10 years of age, whenever possible, children should be asked for self-ratings of dental fear to complement parental ratings, since we showed poor agreement between parental and children's self-ratings on the Children's Fear Survey Schedule–Dental Subscale (CFSS-DS). This was most evident among children in the study group referred because of DBMP. The results further indicate the need for age- and gender-differentiated cut-off scores for dental fear as measured by the CFSS-DS, and also for cut-offs differentiated by informant (child's self-report vs. report by the accompanying parent) (Paper I).
- ❖ Many children and adolescents referred because of DBMP live a burdensome life, with more difficulties in their family situations and everyday lives than same-aged children and adolescents in ordinary dental care. They rated themselves as having fewer friends, participating in fewer activities, and needing more professional support in various ways (Paper II).
- ❖ Children and adolescents referred for DBMP had significantly higher scores on fear and anxiety, behavioural symptoms, and temperamental reactivity than those in ordinary dental care. Dental fear was the first and most important predictor of DBMP, and the role of dental fear was consistent between age- and gender-differentiated subgroups (Paper III).
- ❖ Patients with a non-attending behaviour (i.e. interruption, missed appointments, or more than 20% cancellations) more often lived in single-parent families with low socio-economic status and reported even more burdensome lives than children referred because of DBMP in general. They reported a more outgoing and somewhat impulsive temperament, and were in need of more professional support of various kind (Paper IV).

### **Dental fear as measured with the CFSS-DS – agreement and cut-offs**

Measuring dental fear (DF) in children involves many problems. Very young children are, for obvious reasons, not able to fill out questionnaires. Therefore, investigators are obliged either to study older children or to use the parent or the accompanying person as the child's proxy to assess the child's DF. Self-reports are most often used to study adolescents, while parental reports measured by the Dental Subscale of the Children's Fear Survey Schedule (CFSS-DS) [16] are normally used to assess DF in younger children. Since several studies have shown frequent discrepancies in ratings of child psychopathology by different informants (i.e.,

mothers, children, teachers) [32-33, 36] we found it important also to evaluate the agreement between parental and self-ratings of child DF.

The level of DF, both parent- and self-rated, was significantly higher among the referred children and adolescents than among those in ordinary dental care. We found a poorer agreement, however, between parental- and self-ratings on the CFSS-DS [16] among the referred children and adolescents and their parents than among the reference group pairs. One possible explanation for the poorer agreement could be that the study group parents' own DF [116] and anxiety may influence their rating of the child's DF. From a theoretical point of view, supported by results from developmental psychopathology [34, 117], it is reasonable to assume that parents underestimate their children's fear as parents often under-report emotional problems in their children. Because worry, anxiety, and depression are subjective, interior emotional problems, they can remain unexpressed and therefore escape parental notice more easily than behavioural problems [35]. Behaviour, however, is more easily noticed, although the emotions underlying it may be misinterpreted. Study group patients are likely to show more uncooperative behaviour (i.e. refusal, anger), which, if interpreted by parents as fearfulness, may lead to their overestimation of their child's fear. On the other hand, cooperative behaviour arising from the child's desire to please may be interpreted as non-fearfulness and lead to an underestimation of the child's fear. One possible consequence of parents basing their ratings on their child's behaviour during dental treatment is a larger variation between parental and self-ratings of children's fear, which has been shown by scattergrams (Bland Altman's plots), where both directions of difference occurred with equal frequency.

Parental ratings on the CFSS-DS [16] seem to work well as a measure of DF for children and adolescents in the general population since most ordinary child patients are non-fearful [19]. But it seems more difficult to reach acceptable agreement between parent- and self-ratings among highly dentally fearful children and adolescents. The study group scores (parent- as well as self-rated DF) were spread out over a large range of values (i.e. high standard deviations), whereas in the reference group the scores tended to be closer to the mean. The smaller the variation, the better will the agreement between two raters be. Many children have no, or very limited, experience of invasive dental treatment. To minimize under- or overestimation in assessing child DF, self-ratings should complement parental ratings whenever possible among children aged 9 to 10 years and older.

Our explorations of cut-off scores were based on the need for validation with respect to age and gender for other age groups, as well as the need to improve our understanding of these ratings for epidemiological, screening, and clinical purposes. According to a review by Klingberg and Broberg [19], approximately 9% of children and adolescents exhibit clinically relevant dental fear and anxiety. Thus, we assumed that scores exceeding the 90<sup>th</sup> percentile in the age- and gender-differentiated subgroups of child and adolescent dental patients in our reference group (i.e. patients in ordinary dentistry without a known history of DBMP), may describe a screening range of dental fear for individuals at risk. When performing the ROC analyses, we made a second assumption by deciding to use the status of referral due to DBMP as our operational definition of clinically relevant dental fear.

Our study showed different cut-off scores for different age and gender subgroups, pointing to a risk of overlooking fearful older children and adolescents if we continue applying the commonly used cut-off score ( $\geq 38$ ). However, the inconsistent picture

in the youngest group of boys also calls for attention. Perhaps this group of referred children is the most heterogeneous with regard to DF, and it probably includes boys with general behavioural problems [118] that might explain their uncooperativeness with dental treatment. This would be in agreement with Arnrup et al. [5], who identified an externalizing, impulsive subgroup (moderate in DF scores) within a group of 4- to 12-year-old children referred because of DBMP. According to Arnrup et al. [6], however, these children's dental fear scores exceeded those of externalizing, impulsive children in ordinary dental care, which points to the need to consider personal characteristics as well when applying cut-offs for clinical purposes.

### **Beyond fear and dental behaviour – everyday life and family situation**

Social gradients have been consistently related to physical health [72], psychological problems [73], and dental health [71, 119, 120]. Studies focusing on social factors and everyday life in relation to DBMP are, however, uncommon. Our results showed that single-parent families, child-parent separations, and professional support of various kinds were undoubtedly more common among children and adolescents referred because of DBMP. These patients also lived more often in families with low SES and their parents reported higher DF of their own, which is in line with previous studies [10, 45, 75]. They had fewer close friends and fewer leisure-time activities. Their parents also rated them as performing worse at school and having more frequent problems with social interaction.

Regression analyses revealed that belonging to the study group was most clearly predicted by low SES and having had some kind of professional personal support. The study group patients had nearly four times higher occurrence of professional personal support as compared with the reference group patients. The reasons for support give a picture of a broad range of psychological, social, and environmental problems. School problems, which were reported to be the most common reason for support, may indicate a background of social interaction problems and difficulties adjusting to rules and demanding situations. A similar tendency was identified by Arnrup et al. [55], who observed that a subgroup of externalizing-impulsive children with DBMP had a temperament and behaviour profile similar to that of children diagnosed with Oppositional Defiant Disorder or Conduct Disorder. Other common reasons for support were personal psychosocial problems including depression, anxiety, and attempted suicide, which points to a more internalizing or inhibited way of functioning.

The picture of a troublesome everyday life situation, drawn for study group patients, was more obvious in the adolescent subgroups. This may, in line with findings in paediatric research [72], reflect the accumulation of problems over time, but it may also be due to different age-related reasons for referral. Both explanations seem empirically valid, since clinical experience from specialized paediatric dental care indicates more generalized problems among adolescents referred because of DBMP. In young children, many fear reactions and uncooperative behaviours can be explained by their stage of development [121], and thus by 4 to 6 years of age many preschoolers with DBMP will have overcome their difficulties and be able to cope with the demands of the dental situation. For the remaining children, DBMP will often be part of a more generalized problematic situation, as evidenced by internalizing and/or externalizing problems.

A burdensome family situation and his or her own DF may influence the parent's ability to support the child in developing adequate coping mechanisms in difficult

situations. However, it is important to remember that neither particular socio-economic factors nor general social addresses [122], by themselves, account for psychosocial outcomes. Most families with low SES will not be referred to specialist paediatric dentistry for DBMP or for any other reasons. It is the total balance between risk and protective factors that will determine whether a given child will present as a child with DBMP or not. Having a number of psychosocial problems to deal with may lead to increased difficulties in handling everyday situations, with consequences in several areas including dental situations.

### **The role of child personal characteristics**

The variable-based analyses of the role of personal characteristics were performed on the assumption that some variables, or combinations of variables, such as dental fear, personal characteristics, and environmental and situational factors would together explain the reason for referral to specialized paediatric dentistry clinics. Children and adolescents referred because of DBMP had higher DF and general fear, and they also scored higher on temperamental and behavioural problems. The relationship between DBMP and anxiety problems in general is further strengthened by the significantly higher scores for the study group patients on MASC, a well-documented measure of anxiety disorder problems among older children and adolescents [98]. In addition to the association with fear and anxiety, the relationship between DBMP and various emotional and behavioural problems that have been shown previously by others [50, 54] was replicated. Having DBMP was associated with higher scores on every subscale of the SDQ, one of the most commonly used screening instruments for psychological problems among children and adolescents. This comes as no surprise. One of the more forceful conclusions in developmental psychopathology is that, contrary to often-held beliefs, troubled children and adolescents are not *either* sad (internalizing problems) *or* angry (externalizing problems), but rather are sad *and* angry [123].

Study group patients' higher scores on negative emotionality, impulsivity, and shyness also parallel previous findings on younger children [5, 66]. In addition, these findings were extended through time (from childhood on into adolescence), which strengthens the hypothesis of heterogeneity in the group of children referred because of DBMP [5, 6], even among older children and adolescents.

### *Reactivity and regulation*

Using a new measure specifically directed towards emotional reactivity [103], we showed that children and adolescents referred because of DBMP were characterized by more emotional reactivity and less ability to regulate their emotions, either by themselves or with help from others, as rated by their parents. This indicates the difficulties study group children and adolescents may have in handling the potentially stressful dental situation using emotion- and problem-focused coping strategies [124, 125]. The dental situation commonly requires patience, cooperation, and immobility on the part of the patient, all of which may be challenging for this group.

## **Predicting DBMP – tested by logistic regression models**

Being referred because of DBMP was most evidently predicted by DF, emotional symptoms, and peer problems, with parent-rated DF being the single most important predictor. The strong association between DF and DBMP we found among our 7.5- to 19-year-old children and adolescents differs from the picture of a more limited overlap previously reported for 3- to 11-year-olds and based on the common used cut-off score (CFSS-DS  $\geq 38$ ) [10]. In addition to DF among younger (8- to 12-year-old) children, impulsivity and negative emotionality were the temperamental factors that clearly distinguished children referred because of DBMP from children in ordinary dental care [5]. We take this to indicate that as children grow older the relationship between DBMP and more externalizing problems weakens, whereas the relation of DBMP to fear and internalizing problems gets stronger. However, troubled children and adolescents, as mentioned previously, have both internalizing and externalizing problems in combination [123]. This would mean that older children and adolescents maybe more comparable to adults with dental phobia than they are to younger children with DF, implying that treatment for DBMP in older children and adolescents should be more similar to the evidence-based treatments for adults [126-128].

Considering the huge variation in age, competence, and maturity that children represent, we analysed the relationship between personal characteristics and DBMP separately for girls versus boys and for children (7.5–12 years old) versus adolescents (13–19 years old). These different age and gender subgroups present with different models, pointing to the importance of differentiation when trying to predict DBMP. Our study group of children and adolescents referred because of DBMP did not represent a homogenous group, which is in line with previous research [5-6]. In the younger groups personal characteristics such as emotional symptoms entered the model, which is in line with a previous Dutch study [54]. The impact of a lowered capacity to use the parent as an auxiliary means of emotion regulation was shown only for younger girls. This may indicate that, at least as seen by the accompanying parent, parent-aided emotion regulation was more crucial for girls than for boys in the dental situation.

The subgroup of adolescent girls deserves a specific discussion. Parent-rated problematic conduct was the only addition to DF predicting referral because of DBMP in this group. However, in the bivariate analysis, adolescent girls also had higher general anxiety and temperamental and other behavioural problems. These variables were inter-correlated (0.46 to 0.58), explaining their limited inclusion in the final logistic regression model. Thus, conduct problems (i.e. lying, rudeness, disobedience, stealing) that can be seen as externalizing problems occur together with more internalizing problems, again strengthening the hypothesis of ‘both and’ rather than ‘either or’ [123].

Finally, for the subgroup of adolescent boys, one of the MASC subscales (physical symptoms) added to DF in the model of their DBMP. This may indicate that the adolescent boys referred because of DBMP are a genuinely fearful group and that anxiety (independent of age) often presents as physical symptoms rather than worry.

## **Why do some families not show up for dental treatment?**

In our sample of children and adolescents referred because of DBMP, the frequency of missed or cancelled appointments was fairly equal to that of children and adolescents in ordinary

dental care. Results also showed that the level of DF, frequencies of DMFT, and number of decayed teeth were fairly equal between children and adolescents who did not achieve continuity (non-attending group) and those who did (attending group). The need for dental treatment, thus, was equal between groups and the differences were mainly related to psychosocial factors, parental anxiety, and child temperament. The combination of having a number of psychosocial problems to handle and a child with an outgoing and somewhat impulsive temperament may well lead to increased parental difficulties in handling everyday situations, which may in turn affect their child's dental care. In other words, parents who already have a high load of stress and problems in their daily lives have difficulties helping their children to develop adequate coping mechanisms in difficult situations. This in turn can lead to avoidant behaviour becoming the dominant strategy for handling difficult situations, and this may include not going to the dentist to avoid the immediate situation despite the long-term negative consequences of this behaviour. This is in agreement with the findings of Skaret et al. [12], who reported an increased risk of missed or cancelled appointments for adolescents with experiences of painful dental treatments and high levels of DF.

### **Tree-based analysis**

The tree-based modelling used to predict DBMP (Paper III) and non-attending behaviour (Paper IV) can be presented in different ways (within group or within node) depending on the research question. To show the probability of child being referred because of DBMP, within-node presentation is most appropriate, while the distribution of the different node-alternatives is best shown within group. For example, in Paper III the tree-based model showed that *within node* 16, 100% were referred children with high scores of DF (>40.7) and *within the group* of referred children, 40% had DF scores above 40.7. DF emerged as the first sorting variable to discriminate between study and reference group patients. A very high level of DF (>40.7) could by itself predict referral, while very low levels of DF predicted non-referral. Less than 10% of the study group versus more than 80% of the reference group patients had DF scores below 25 (i.e. <24.8; Paper IV, Fig. 1).

Our tree-based models used the opportunity for variables to enter the model at different stages in the sorting process, and revealed that at least from a screening perspective, CFSS-DS scores far below the commonly used  $\geq 38$  may be recommended. For patients scoring in the range of 25 to 40, aspects other than DF, such as physical symptoms, reactivity, and prosocial behaviour, must be taken into consideration. The second tree-model specifically searched for a clinically practical way to identify children and adolescents in need of special care. It took only two instruments (parent-rated CFSS-DS and SDQ) to classify 87% of the patients correctly (e.g. as referred because of DBMP or not).

A child dental patient living in a family with low SES (score below 23.25) and score of parental anxiety (HAD-A) higher than 7.5 will probably (65%) belong to the non-attending group, leading to the conclusion that family factors must be taken into consideration when dealing with non-attending behaviour.

### **Strengths and limitations**

The strengths of these studies are (1) the variety and number of personal characteristics we have measured, (2) the different environmental factors that have been considered, and (3) the large size of the group of children and adolescents of various ages; together these factors

generated a broader picture of DBMP than has been possible in most other studies. For several measures both parental and self-ratings were used, which gave us the opportunity to consider different informants. In addition, the instruments used were all reliable and valid. Study group inclusions were based primarily on referral forms (with many different dentists' opinions and descriptions of the children's and adolescent's dental fear and lack of cooperation), so a great variability in DBMP within the group must therefore be assumed. However, by allowing for that variability, the study clearly reflects clinical practice, thus favouring its clinical relevance.

In the reference group, children and adolescents from three orthodontic clinics were also included, although they were analysed as being representative of a child or adolescent in ordinary dental care. Since clinics were selected to represent different urban and rural as well as socioeconomic areas, they may be assumed to represent demographically the population from which the study group was also drawn.

The possibility of situational bias cannot be excluded. Although we tried to keep the settings at ordinary PDCs and the specialist clinics as similar as possible, there were differences. In addition, some of the interview questions may have been experienced as strictly personal (i.e. separations from the family, professional personal support), and reliability differences due to somewhat different settings for study and reference groups cannot be excluded (Type 1 error). Finally, the patient and accompanying parent who attended the specialist clinic for their first visit may have been more thoroughly prepared for this study, as a result of the referral procedure, compared with patients and parents in the reference sample, who attended a regular examination or control visit before knowing about the study or being asked for their participation.

### *Methodological considerations*

Most knowledge about dental fear and dental behaviour management problems among children relies on quantitative research methods. However, all methods have their limitations and shortcomings. The psychometric instruments used in the studies are well-established instruments, as well in dental fear research as in psychological research (see Method section). However, there are some specific aspects to consider.

The reference group patients were collected during normal clinical routines and a detailed description of those families who did not agree to participate, as well as of those who for different reasons were excluded, was unfortunately not available. This must be taken into account when the results are interpreted.

We defined in study I, the optimal cut-off in the ROC analysis as that value that maximized the sum of sensitivity and specificity, maximum (sensitivity + specificity), that is, equal weight attached to the two concepts in forming the sum. Sometimes the two concepts are not given equal weights, e.g. in cases where one of the them is regarded as more important. In such cases the optimal cut-off will be different from ours.



In the bivariate analysis in study III, there are aspects of the statistical analyses that must be considered. In spite of low values for Cohen's  $d$  and Cronbach's alphas on some of the psychometric measures, we choose to continue our analysis with all of the variables and discuss the results.

In the cross-sectional Study IV, there were some differences in group size (non-attending  $n=123$ ; attending group  $n=56$ ) and may also be seen as a highly selected group of children and adolescents, since they were referred because of DBMP. The results from Study IV must therefore be interpreted with caution and should be seen as a first step in the comparison of children and adolescents with an attending behaviour and those with non-attending behaviour.

A thorough, systematic logistic regression analysis was performed to control for socio-economic status and cohabitation status, whether and how these factors influenced personal characteristics, and how they were in turn influenced by different variables of personal characteristics (see Materials and Methods, Statistical Methods). As a complement to the logistic regression analyses, we used tree-based modelling or recursive partitioning [114, 115] (Paper III, IV). Tree-based modelling has the advantage of not being dependent on linear additive functions of the predictor variables.

### **Implications for future research**

Further research should focus on different patterns of DBMP development, using a longitudinal design to consider the interactive importance of personal characteristics, as well as psychosocial and situational factors. Given the prominent role of DF in the prediction of DBMP in older children and adolescents, it would be especially important to study different developmental pathways of DF from a transactional perspective, especially during early and middle childhood, when other factors have been reported to be of equal importance.

There is also an obvious need to study whether the reported associations between personal characteristics, family factors, psychosocial concomitants, and previous dental experiences on the one hand, and non-attending behaviour on the other, are limited to children and adolescents who are referred because of DBMP, or if they also hold true for those who remain in regular dental care. Finally, our lower cut-off scores for DF and the low agreement between parent- and self-rated DF among study group patients deserve to be replicated because of the obvious risk of overlooking fearful patients, especially among the adolescents.

## SUMMARY

- ❖ Our exploration supports the need for cut-off scores differentiated by age and gender, but also differentiated with regard to informant (child's self-report or report by accompanying parent). Knowledge of the sensitivity and specificity of different cut-off scores will allow applications adjusted for the context of use (epidemiological screening or clinical purposes).
- ❖ The poor agreement between parental ratings and self-ratings of dental fear, particularly among fearful children, brings into serious question the sole reliance on parental ratings of children's dental fear in clinical settings. For children 9 years of age and older, self-ratings should complement parental ratings as often as possible.
- ❖ A high proportion of children and, in particular, adolescents referred because of DBMP live a burdensome life, with more difficulties in their family situations and everyday lives than other children their age. Having fewer friends, participating in fewer activities, and needing more professional support may cause or exacerbate negative feelings, adding to a pattern of negative development, and possibly creating a vicious cycle with consequences in various spheres including dental care.
- ❖ Children and adolescents referred because of DBMP had significantly higher scores of fear and anxiety, behavioural symptoms, and temperamental reactivity compared with same-aged patients in ordinary dental care. DF was the single best predictor of DBMP among our 7.5- to 19-year-old patients, but to fine-tune our understanding of these patients' problems, other personal characteristics must be taken into consideration.
- ❖ Children and adolescents living in families where parents have more than enough to contend with in their own troubled lives may be at increased risk for non-attending behaviour. When a child or an adolescent does not show up for a scheduled dental appointment, it is a sign that it is necessary important to establish immediate contact with the family to explore ways to avert the development of a pattern of avoiding dental care.

## **CONCLUDING REMARKS**

Are dental behaviour management problems among children and adolescents just a matter of understanding? The importance of regarding children and adolescents with an uncooperative behaviour as children with problems, rather than as problem children, cannot be overstated. These children and adolescents represent a huge variety of personalities, special needs, family backgrounds, and everyday life situations.

Every child or adolescent is unique. Offering individual caretaking requires both knowledge and special attention from the dental staff. This is every child's right, regardless of which type of family the child comes from.

Incorporating knowledge from experts, such as clinical child psychologists, into dental care will increase the chances for the dental staff, as well as the children and adolescents, to succeed with dental treatment and to achieve treatment continuity.

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