

# Shaping your child's future?!

An explorative study into the factors influencing the treatment decision of parents of children with deformational plagiocephaly or brachycephaly



H.M.E. Nijland

Enschede, May 2010

Supervisors:

Dr. J.A. van Til

Dr. M.M. Boere-Boonekamp

**UNIVERSITY OF TWENTE.**

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'I haven't failed, I just found 10,000 ways that don't work'  
Thomas Alva Edison

H.M.E. Nijland

Enschede, May 2010

University of Twente  
Faculty of Management and Governance  
Department of Health Technology and Services Research (HTSR)  
Master thesis

Supervisors:

Dr. J.A. van Til

Dr. M.M. Boere-Boonekamp

**UNIVERSITY OF TWENTE.**

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### Preface

This report is the result of a master thesis study concerning the factors influencing the decisions to be made in the treatment of deformational plagiocephaly or brachycephaly. I became interested in this topic because my sister has a son who developed plagiocephaly and my sister also faced the abovementioned decisions.

I would like to thank my supervisors dr. Van Til and dr. Boere-Boonekamp for their supervision and support during this research period. This research would not have been possible without the cooperation of parents, pediatric physical therapists, pediatricians, the outpatient clinic of the 'Deventer Hospital', 'Bernhoven Hospital' in Veghel and 'Roessingh Revalidatie Techniek' in Zwolle.

And last but not least, I would like to thank all who showed their interest in my research and motivated me to continue this project.

Hilde Nijland

### Samenvatting

Plagiocefalie is een term die gebruikt wordt voor mensen met een schedelasymmetrie. Om wiegedood te voorkomen wordt het advies gehanteerd om zuigelingen op hun rug te laten slapen. Sinds dit advies, is het aantal kinderen met een schedelasymmetrie fors gestegen. Wanneer de schedelasymmetrie bij zuigelingen ernstig is, kunnen deze in aanmerking komen voor helmbehandeling. Deze vorm van behandeling is nooit bewezen door middel van gerandomiseerd onderzoek. Doel van het uitgevoerde onderzoek was uit te vinden welke factoren van invloed zijn op de beslissing van ouders om wel of niet voor helmbehandeling te kiezen.

Een literatuurstudie is uitgevoerd om topics te verzamelen voor de interviews met professionals en ouders. Vijf hoofdfactoren die van invloed zijn op de beslissing van ouders om voor helmbehandeling te kiezen werden gevonden: lange termijn angsten van ouders omtrent de toekomst van hun kind, de invloed informatiebronnen, perceptie van het probleem schedelasymmetrie, verwachtingen van behandelopties en angsten van ouders rondom helmbehandeling.

De bovengenoemde factoren zijn gebruikt om de interviews met ouders en professionals vorm te geven. De uitgevoerde interviews met ouders en professionals waren op zichzelf relevant en dienden als input voor de vragenlijst.

Een vragenlijst werd ontwikkeld om de resultaten uit de interviews te kwantificeren. De bovengenoemde vijf factoren werden gebruikt om de vragenlijst te ontwikkelen. De vragenlijst is verspreid in diverse poliklinieken in Nederland. Onder de respondenten waren ouders die de keuze voor helmbehandeling al gemaakt hadden en ouders die nog moesten kiezen. Onder de laatste genoemde groep zaten ouders die liever wilden afwachten en ouders die de voorkeur voor helmbehandeling hadden. De verschillen tussen de groepen op de verschillende topics werden geanalyseerd.

De vijf topics die naar voren kwamen in de literatuurstudie bleken allen relevant te zijn voor ouders, dit bleek uit de interviews en de vragenlijst. Maar er zijn verschillen in de graad waarin de verschillende topics onder de ouders meespeelden. De factoren die professionals benoemden de interviews kwamen overeen met wat ouders als belangrijk benoemden in de interviews. De resultaten uit de interviews kwamen niet altijd overeen met de resultaten uit de vragenlijst, met name op het gebied van angsten van ouders. Deze angsten gaan over de helm zelf en over de toekomst van kinderen. Deze tegenstellingen zijn interessant om verder te onderzoeken onder een grotere groep respondenten.

### Summary

Deformational plagiocephaly is a term used for people with a cranial asymmetry. The number of children with deformational plagiocephaly has dramatically increased, since the advice to place children in a supine sleeping position to prevent sudden infant death syndrome. When the plagiocephaly of children is severe, orthotic helmet treatment is in the Netherlands often offered to parents as a treatment option. However, this treatment option is not scientifically proven with a Randomized Controlled Trial. The objective of this study was to find out what factors influence the decision-making of parents regarding the choice for helmet treatment.

A literature study was performed to yield topics for the interviews with professionals and parents. Five main factors influencing the decision whether or not to choose helmet treatment surfaced during this literature study: the information sources, long-term fears of parents concerning the future of their child, perception of the skull deformation of children, expectations of helmet treatment, expectations of wait and see and fears of helmet treatment.

The factors mentioned before, were used to construct qualitative interviews with professionals and parents. The interviews with professionals yielded relevant information for this research itself, and served as input for the questionnaire. The interviews with parents were also both input for the questionnaire and relevant in itself.

The questionnaire was set up to quantify the results found in the qualitative interviews. The five factors mentioned above were used to formulate and structure individual items of this questionnaire, together with the results of the interviews. The questionnaire was distributed in several outpatient clinics. Among the respondents were parents with children that already started helmet treatment, and parents that had yet to make the decision. The latter group consisted of parents that were positive towards helmet treatment and parents that preferred to wait and see. The differences between these groups within the topics were analyzed.

The five topics found in the literature study were all found to be of importance among parents, both in the interviews and in the questionnaire. However, the extent to which specific topics were relevant varied in the wait and see group versus the helmet treatment group. The factors of influence mentioned by the professionals matched with what parents themselves considered to be of importance. The results found in the interviews, however, sometimes contradicted the results found in the questionnaire, especially when it comes to fears expressed by parents. These fears concern the helmet itself and the future of children with plagiocephaly. These contradictions are an interesting topic to investigate further using a larger sample group.

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## 1 Introduction

*Elise is a 30 year old mother. She recently gave birth to her second child. The pregnancy did not go smoothly, during the seventh month of her pregnancy the fetus turned in transverse position which caused a lot of pain in her abdomen. Due to the unusual position the baby was delivered by c-section. Immediately after birth, her baby boy named Joshua presented a positional preference to the right. This positional preference flattened the right side of Joshua's skull. In medical terms this condition is called deformational plagiocephaly. When Joshua was two months old, the youth health care clinic advised her to consult a pediatric physical therapist. The pediatric physical therapist gave Elise the advice to alternate the sleeping positions of Joshua and also gave her advice on how to handle and feed him so that his positional preference would disappear. Elise followed-up on all the advice that the pediatric physical therapist gave her and Joshua soon recovered from his positional preference but the skull deformation was still present. When Joshua was six months old he was referred to the pediatric policlinic to discuss his condition with the pediatrician. The pediatrician explained that this problem was cosmetic and that helmet therapy was an option and that Elise had to decide whether or not she wanted helmet therapy for Joshua.*

This case illustrates the main topic of this study: decision making of parents in the treatment of skull deformations of infants. In the first chapter the study will be introduced. This chapter includes the background of the research (paragraph 1.1), problem formulation (paragraph 1.2), research objectives and questions (paragraph 1.3 & 1.4) and will be concluded with the reader's guide (paragraph 1.5).

### **1.1 Background**

In this section the background is presented. In first paragraph the topic skull deformation of infants is explained (1.1.1). The possible treatment options are presented in paragraph 1.1.2. Finally the preferences of parents towards treatment are described in paragraph 1.1.3.

#### **1.1.1 Skull deformation of infants**

Plagiocephaly is a term used for people with a cranial asymmetry (Teichgraeber, Seymour-Dempsey, Baumgartner, Xia, Waller & Galeno, 2004). It literally means a

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'skewed head'. The number of children with plagiocephaly has increased since the advice of the Dutch National Youth Health Care in 1987 (de Jonge, Burgmeijer, Engelberts, Hoogenboezem, Kostense & Sprij, 1993) and the American Pediatric Association (1992) to place infants in a supine position during their sleep to avoid Sudden Infant Death Syndrome (Argenta, David, Wilson & Bell, 1996 & Turk, McCarthy, Thorne & Wishoff, 1996). In 2001 the prevalence of plagiocephaly in The Netherlands was calculated at 8.2% of the total number of children below the age of six months. At the 2- to 3-year follow up 2,4% of all children would still have a restricted range of motion and/or flattening of the skull (Boere-Boonekamp & van der Linden Kuiper, 2001).

Two types of plagiocephaly exist. The first type is caused by the premature fusion of cranial sutures. This type of skull deformation needs to be corrected with surgery (Sterling & Clarren, 1981) and is therefore not part of this study. The second type of plagiocephaly is caused by external forces shaping the infant's skull such as intra-uterine constraint, twinning, or an invariant sleeping position (Sterling & Clarren, 1981). This type of plagiocephaly is called deformational plagiocephaly. Conditions that have an influence on the infants' mobility, such as torticollis, hypotonic and cervical spine anomalies are also associated with deformational plagiocephaly (Sterling & Clarren, 1981).

In brachycephaly, a condition that is also part of this study, the head flattens uniformly causing a much wider and shorter head (high cephalic index) (Hutchinson, Hutchinson, Thompson & Mitchell, 2004). In plagiocephaly the head flattens to one side, causing asymmetry of the head. When not specifically mentioned, both terms are used interchangeably in this report or the more general term 'skull deformation' is used.

The long-term effects of plagiocephaly are unclear. Some research suggests that when plagiocephaly is left untreated, children are left with a cranial asymmetry, ear misalignment and facial asymmetry (Littlefield, Kelly, Pomatto & Beals, 2002).

From left to right: plagiocephaly and brachycephaly (Collet 2005, page 380)

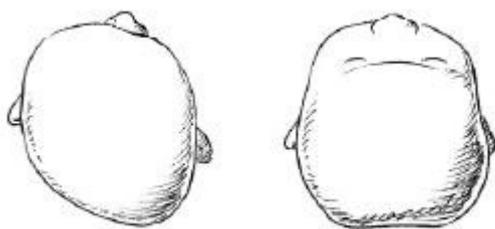


Figure 1: types of skull deformation

### 1.1.2 Treatment of positional preference and skull deformation

Skull deformations are related to or aggravated by a positional preference (Van Vlimmeren, 2007). Youth Health Care Centres (Dutch: consultatiebureaus) in the Netherlands try to prevent positional preference in newborns by giving advice on handling and positioning of the infant. When the positional preference perseveres, children can be referred to the pediatric physical therapist. The pediatric physical

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therapist is specialized in the treatment of children with a positional preference. In some cases children are treated by alternative therapists, such as the manual therapist or osteopath.

Positional preference can be prevented by active counter positioning. Active counter positioning consists of the advice to place infants in the supine position and to alternate sleeping positions of the head. The infant should spend minimal time in car seats and should be placed on his/her tummy regularly (American Academy of Pediatrics, 2005). If deformational plagiocephaly has occurred, infants should be placed with the rounded side of their head against the mattress. Also, parents are advised to rearrange the room and to place any interesting objects opposite of the flattened side of the infants head (Loveday & de Chalain, 2001 & American Association of Pediatrics, 2005).

The Dutch paediatric physical therapist Van Vlimmeren (2007) has developed an instrument to measure the degree of plagiocephaly, the 'plagiocephalometry' method. A thermoplastic band is moulded around the skull and indicates the exact shape of the head. The results of this measurement are used to indicate the severity of the skull deformation and may lead to the advice for treatment.

When the skull asymmetry is still severe at five to six months of age, parents may get the advice to start orthotic helmet treatment (Van Vlimmeren, 2007). Orthotic helmets make use of the rapidly developing and malleability of the skull. The orthotic helmet has openings in the desired areas, which helps the skull to develop evenly. (Loveday & de Chalain, 2001 & Livit, 2009). Treatment of plagiocephaly with a helmet usually starts when the child is six months old and continues until the infant is twelve months old (Livit, 2009).

Bialocerkowski, Vladusics & Howell (2005) performed an extensive review into the conservative interventions of positional plagiocephaly. They conclude that both active counter positioning in combination with natural recovery and helmet treatment seem to reduce the skull asymmetry, but due to methodological problems of the studies included in the review no definite conclusion can be drawn.

### 1.1.3 Treatment preferences of parents

As mentioned above, the clinical evidence concerning the additional effects of an orthotic helmet are not clear (Bialocerkowski, Vladusic & Howell, 2005). In the Netherlands, orthotic helmet treatment is currently a treatment option and not a standard of care. Therefore, parents are offered a choice between a conservative approach (awaiting natural recovery, also known as: "wait and see") or active treatment with an orthotic helmet.

It is known that decision-making in health care becomes more difficult when the decision is an option instead of a standard of care (Eddy, 1992). According to the literature multiple factors can be identified that may influence the decision making process of parents

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concerning helmet treatment. These include (1) information from professionals, (2) experience and expectations of possible treatment options, (3) information from the environment (internet), (4) fears of parents concerning helmet treatment and (5) long-term fears of parents concerning their children

The literature suggests that when the effect of treatment is debatable, the opinion of the physician is important (Eddy, 1992). In the Netherlands the pediatric physical therapist and the pediatrician are closely involved in the care for children with a plagiocephaly. Believers and non-believers of orthotic helmet treatment exist. Their opinion towards helmet treatment might have an influence on the type of information given to parents.

Collet, Breiger, King, Kunningham & Speltz (2005) indicate that clinical experience shows that some parents feel guilty for the fact that they caused the plagiocephaly of their child. Parents also express the fear that they will be criticized by their children of whatever decision they make (Bradbury, Kay, Tighe & Hewison, 1994). According to Collet et al. (2005) some websites refer to the psychosocial effects of an abnormal appearance, such as teasing or poor self-perception.

Also fears concerning helmet treatment may play a role in the decision-making. Orthotic helmets can become hot and sweaty and can cause heat rash and pressure points on the infants' skull. Also some children can become distressed by the helmet (Loveday et al. 2001, Sterling et al. 1981). Some parents may worry about this and therefore decide not to treat their child with an orthotic helmet. Sterling et al. (1981) mention that children developed normally during helmet treatment, however the development of children was not measured objectively.

In the Netherlands these problems are discussed on the internet ([www.redressiehelm.tk](http://www.redressiehelm.tk)). In general, a lot of information concerning deformational plagiocephaly can be found on the internet. Collet et al. (2005) mentions that parents seek information and advice on the internet and become more aware of the plagiocephaly of their child. However Collet et al. (2005) indicate that no empirical evidence for this exists.

At present, no empirical evidence suggests that parents of children who choose helmet treatment are different from parents who decline treatment (Collet, et al., 2005).

Another aspect in this case is the difficulty of the decision experienced by parents. This does not influence the decision itself but has an impact on the decision making process. Decisional conflict is a nursing diagnoses and is described by North American Nursing Diagnoses Association (1992, page 46) as 'the uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret, or challenge to personal life values'.

Two sources of decisional conflict exist: the first source of conflict is facing a choice among several options. The option of orthotic helmet opposed to "wait and see" has advantages and disadvantages. The second source of decisional conflict are the factors that

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make the decision making more difficult such as lack of knowledge, unrealistic expectations, unclear values, unclear perceptions of others, social pressure, lack of support, lack of skills or self-confidence, and lack of resources (Connor et al., 2002, page 571). Carpenito (2003) describes that one of the counselling strategies for decisional conflicts is to provide information about treatment options to patients.

### ***1.2 Problem formulation***

In recent years the number of helmets prescribed to children increased dramatically. In 2003, approximately 3000 children in the Netherlands were treated with an orthotic helmet (L van Vlimmeren, personal message, 2009). However, the effectiveness of this treatment was never proven and the costs of helmet treatment are substantial. According to Moss (1997) the costs of helmet treatment are equivalent to a minor neurosurgical procedure. In the Netherlands most insurance companies reimburse helmet treatment (Roessingh Revalidatie Techniek, 2009).

Although helmet treatment is prescribed quite often, no prior studies have been performed to investigate the factors that influence the decision of parents concerning the treatment of plagiocephaly. Incorporating patient preferences into health care is an important element of patient centred care (Institute of Medicine, 2001). When the reasons of the decision are clear they can be used to optimize health care for children with deformational plagiocephaly or brachycephaly. Also identifying patients' preferences can be helpful to optimize decision making at health policy level (Harries & Stiggelbout, 2005). If the effect of helmet treatment is proven, the treatment procedure can be adjusted to the patients' preferences. On the other hand, if parents choose helmet treatment because of wrong motives, it becomes clear that parents need more information about wait and see.

### ***1.3 Research objective***

The objective of the study is to retrieve the factors influencing the decision of parents to choose wait and see or helmet treatment.

### ***1.4 Research questions***

Based on the research objective the following main research question was formulated:

*What factors influence the decision of parents in the treatment of children with deformational plagiocephaly or brachycephaly?*

The following sub questions were formulated:

- Which information sources are consulted by parents concerning the decision making about possible treatment options regarding deformational

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plagiocephaly/brachycephaly and are there differences between parents that choose helmet treatment or wait and see?

- To what extent does the perception of parents concerning the problem of plagiocephaly play a role in the decision making regarding the treatment of deformational plagiocephaly/brachycephaly and are there differences between parents that choose helmet treatment or wait and see?
- To what extent do expectations concerning the treatment options influence the decision making and are there differences between parents that choose helmet treatment or wait and see?
- How much decisional conflict is experienced by parents about their decision concerning the treatment of deformational plagiocephaly and are there differences between parents that choose helmet treatment or wait and see?
- What is the view of the pediatric physical therapist and the pediatrician concerning the treatment options of deformational plagiocephaly/brachycephaly and what information do these professionals give to parents concerning the treatment options of deformational plagiocephaly/brachycephaly?

### *1.5 Readers guide*

This paragraph shows the outline of the report. First, a literature study was conducted. Next, the research methods are described in chapter two. This was the input for the qualitative interviews with professionals in the field of the treatment of children with deformational plagiocephaly/brachycephaly. From the literature study and the results of the interviews (described in chapter three) a questionnaire with parents was extracted. This questionnaire is presented in chapter four. The results of the questionnaire were analysed and are shown in chapter five. This report will be concluded with the conclusions and recommendation of the study in chapter five.

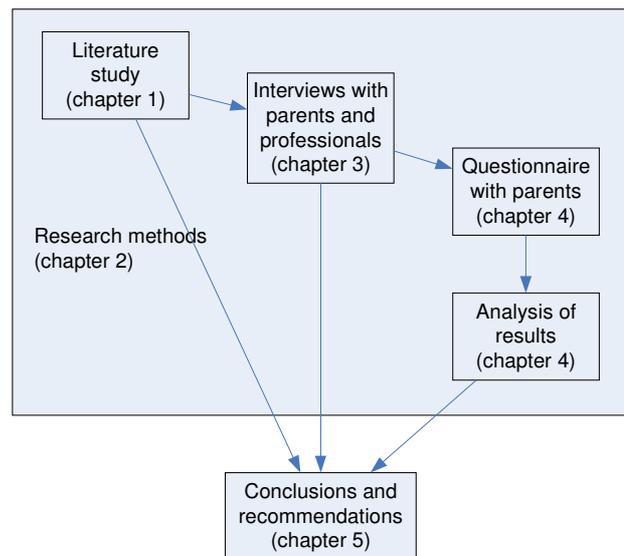


Figure 2: readers guide

## 2 Research methods

In this chapter the methods that were used in this study will be explained. Paragraph 2.1 will deal with the method used in the first phase of the study; the interviews with parents and professionals. Paragraph 2.2 will elaborate on the second phase of the study; the questionnaire which was distributed among parents of children with a skull deformation.

### 2.1 *Qualitative interviews*

The first phase of this study consisted of qualitative interviews with parents, pediatric physical therapists and pediatricians. Due to time restrictions and size of the study, five parents of children with plagiocephaly were interviewed using convenience sampling (Castillo, 2009). Parents were approached via an internet forum ([www.redressiehelm.nl](http://www.redressiehelm.nl)), pediatric physical therapists and personal contacts of the researcher.

Qualitative interviews offer the opportunity to discuss the matter in depth and to get a better insight in the personal considerations of parents. A topic list was used to conduct the interviews. This topic list was composed with the help of the literature study and can be found in the appendix.

The following topics were discussed with parents during the interviews:

- Perception of the severity of the skull deformation of children
- Consulted information sources
- Long-term fears of parents
- Expectations of helmet treatment
- Expectations of wait and see
- Fears of helmet treatment

A dyadic interview with two parents was performed. Two people who are closely related are interviewed at the same time. The advantage is that a dyadic interview offers the opportunity to elaborate on the topic in more detail (Sohier, 1995). Also, three parents with children with a skull deformation were interviewed one on one. The results of the interviews were coded (Babbie, 2007) and used to develop a questionnaire

Two pediatric physical therapists were interviewed because they treat infants with a positional preference. Pediatric physical therapists and pediatricians are involved in the health care for children with deformational plagiocephaly or brachycephaly and therefore they offer a valuable insight in the treatment preferences of parents. Also their opinion of helmet treatment and the information about orthotic helmet treatment given to parents was discussed in the interviews. Professionals were also interviewed using a topic list. Both topic lists can be found in the appendix.

### ***2.2 Quantitative phase***

The purpose of the quantitative phase was to identify and quantify the factors influencing the decision to choose helmet treatment or wait and see, found in the literature study and qualitative interviews, in a larger group of parents. The complete questionnaires can be found in the appendices. The questionnaire consisted of two versions, one for the group that still had to make the decision. And one group that made the decision for helmet treatment, the decision helmet group. Questionnaire 1 was used for the group that still had to make a decision and questionnaire 2 was for the group that already started helmet treatment.

#### **2.2.1 Development of questionnaire**

The questionnaire was developed with the help of the qualitative interviews. The questionnaire consisted of four parts: general information of respondents, decisional conflict scale, consulted information sources and statements concerning the influencing factors of decision-making.

#### **2.2.2 Set-up of questionnaire**

##### *General information of respondents*

Questionnaire 1: questions number 1 to 15

Questionnaire 2: questions number 1 to 15

This part of the questionnaire consisted of questions concerning the general information of respondents. This was to gain a general picture of the respondents and their children.

- Age of child
- Age of parents
- Questionnaire completed by mother/father
- The decision for treatment made by parents
- Number of children of parents
- Presence of skull deformation in other children
- The presence of a positional preference
- Ethnic background of parents
- The type of skull deformation of the child
- Treatment options chosen in the social environment

##### *Decisional conflict scale*

Questionnaire 1: questions 16 to 29

Questionnaire 2: questions 16 to 31

To measure the degree of uncertainty concerning the decision whether or not to choose for helmet treatment the Decisional Conflict Scale (DCS), developed by O'Connor (1995), was used. The DCS measures the level of decisional conflict of patients when they make

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health care decisions (Koedoot, 2001). The DCS was used in many patient groups such as postmenopausal woman making a decision whether or not to use hormone replacement treatment (O'Connor et al., 1998).

The decisional conflict scale is a twelve-item scale. Three questions concerning the decision satisfaction were included in the questionnaire for the decision helmet group. Respondents have to give their answer on a five point Likert Scale (Babbie, 2007), which runs from 'completely agree' to 'completely disagree'. Koedoot et al. (2001) translated and validated the DCS into Dutch. Some items were added in the Dutch DCS (Babbie, 2007). One item was split into two items in this study to improve the readability of the questions.

### Consulted information sources

Questionnaire part 1: questions 50 to 58

Questionnaire part 2: questions 46 to 54

Respondents were asked which information sources they consulted and what the view concerning the treatment options of these information sources was: pro wait and see, neutral or pro helmet treatment. The information sources are the lay-men and professionals.

#### Lay-men

- Family
- Friends
- Internet

#### Professionals

- Pediatric physical therapist
- General practitioner
- Pediatrician
- Helmet maker

### Influencing factors of decision making

Questionnaire part 1: 30 to 49

Questionnaire part 2: 33 to 45

The influencing factors were again divided into a five-point scale according to the Likert scale, 'completely agree' to 'completely disagree'. The following topics were taken into account:

- Questions concerning the long-term fears of parents of the future of their children
- Questions concerning the perception of the severity of the problem plagiocephaly/brachycephaly of parents
- Questions concerning the expectations of helmet treatment and wait and see.
- Questions concerning the fears of helmet treatment of parents.

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The topics concerning the fears of helmet treatment were not included in the decision helmet questionnaire, this because they made the decision for helmet treatment and therefore those questions are not valid for them.

### 2.2.3 Validation of questionnaire

The questionnaire was pilot tested by four parents and two lay-men that did not have a child with a skull deformation. This was done to find out if the questions were clear. Subsequently a few alterations to the questionnaire were made.

### 2.2.4 Distribution of questionnaire

In June 2009, questionnaires were spread among parents. About 75 questionnaires were distributed in the waiting rooms during the special consultation hours for children with a skull deformation. The hospitals in which the questionnaires were spread were 'Deventer Ziekenhuis', 'Bernhoven Ziekenhuis' in Veghel, and 'Roessingh Revalidatie Techniek' in Zwolle, which is a centre for orthotic devices. Both parents that did not yet make the decision for helmet treatment and parents that made the decision for helmet treatment were approached to complete the questionnaire.

Due to this way of distribution a 'convenience sample' was created (Castillo, 2009). This is a sample where subjects are selected at the convenience of the researcher.

### 2.2.5 Analysis of questionnaire

A total of 37 questionnaires were returned. Subsequently the respondents were divided into three groups to perform statistical analysis. The groups consisted of:

- The wait and see group, respondents that made the decision to wait and see (n=7)
- The helmet treatment group; respondents that started helmet treatment (n=14)
- The decision helmet group, respondents that made the decision to start helmet treatment (n=16)

Data was analyzed using SPSS. Some respondents gave values lying in-between two answering options. Those answers were rounded up (1,5 became 2,0 and 4,5 became 5 etc.).

## 2.3 Data analysis

In the analysis of the results of the questionnaire a non parametrical test was used. This test will be described in this section. The alpha level was set on 0,05; which means that p values lower then 0,05 are statistically significant. Also the mean sum score of the items of the decisional conflict scale (O'Conner 1995, Koedoot 2001) was added. Some parents did

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not complete some questions of the scale. Those respondents were not included in the analysis because a total score cannot be calculated.

### 2.3.1 Mann-Whitney test

The differences between the sample sizes are large. Therefore a non-parametric test was used. Tests that do not make assumptions about the population distribution are referred to as non-parametric tests. For this study the Mann-Whitney test was used. A Mann – Whitney is a non-parametric test for assessing whether two independent samples of observations come from the same distribution ((Moore & McCabe, 2006). Ordinal measurement is assumed. By ranking the observations of both samples and comparing the ranks of both samples the value for  $U$  can be calculated. In this study, SPSS computed a p-value and this indicates whether there is a significant difference between two groups ((Moore & McCabe, 2006).

### 3 Results of qualitative interviews

In this chapter the results of the qualitative interviews are presented. In paragraph 3.1 the results of the interviewed parents are described. In paragraph 3.2 the results of the interviews held with professionals can be found. In paragraph 3.3 a table concerning the influences on the decision of parents, mentioned in the interviews will be presented.

#### 3.1 Results interviews parents

This section describes the results of the conducted interviews with parents. First, general information of the parents is presented. The other paragraphs describe the perception of skull deformation (3.1.2), long-term fears of parents (3.1.3), consulted information sources (3.1.4), experiences and expectations of the treatment options (3.1.5) and the fears concerning helmet treatment.

##### 3.1.1 General information on parents

Five parents were interviewed with reference to their preferences in the treatment of deformational plagiocephaly or brachycephaly. These five parents have different characteristics with reference to the phase of treatment. Two parents still had to make the decision whether or not to choose helmet treatment. Two parents had children with who were receiving helmet treatment during the time of the interview. One parent had a child that went through the process of pediatric physical treatment and chose to wait and see. Parents one and two were interviewed using a dyadic interview. In the following table the characteristics of the interviewed parents can be found.

Table 1:  
*characteristics interviewed parents*

<b>Respondent</b>	<b>Characteristics</b>
One	Parent is a 30-year-old mother with an 8-month-old child, they were advised not to start with helmet treatment.
Two	Parent two is a 33-year-old mother with an 8 months old child who started helmet treatment.
Three	Parent three is a 32 year old mother with a 9,5 month old child who started helmet treatment.
Four	Parent four is a 28-year-old mother with a 3, 5 month old child. Parent four did not yet decide for helmet treatment.
Five	Parent five is a 32-year-old mother with a 4, 5 month old child. Parent five did not yet decide for helmet treatment.

##### 3.1.2 Perception of skull deformation

Parents were asked how they perceived severity of the skull deformation of their child. All interviewed parents were not satisfied with the appearance of their child's skull. The

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fact that an asymmetric appearance is not considered as attractive was important to all interviewed parents.

*Parent five: 'Helemaal symmetrisch vind ik niet zo belangrijk, maar symmetrie vind ik wel belangrijk. Ik vind wel dat als je echt kunt zien dat ze scheef is, als het niet nodig is, dan vind ik het gewoon zonde'*

Parent three indicated that her child had both brachycephaly and plagiocephaly. She mentioned that in general people from Africa have a slightly brachycephalic head. At the moment of the interview she was satisfied with the intermediate results of the helmet treatment of her son.

Parent three made a comment about the fact that for boys a symmetric face is important but that she would not have chosen differently if she had a girl. Parent one indicated that boys have shorter hair and therefore also indicated that a symmetric head is important for boys. Parent two indicated that for girls an asymmetric head is noticeable when girls wear a ponytail. Both parents one and two agreed that action should be undertaken when a child develops a skull asymmetry, no matter the sex. Parent five indicated that especially girls might feel insecure about their appearance. Parent four who has a girl indicated that she would feel the same way about skull symmetry if it were a boy.

*Parent three: 'als hij zich kaal zou willen scheren, dan wil ik gewoon dat ie dan een mooi rond hoofd heeft. Zover ik daar invloed op kan uitoefenen wil ik dat heel graag. En dan is het dus een jongetje maar voor een meisje uiteraard precies hetzelfde natuurlijk. Dan wil je natuurlijk dat een meisje staartjes in kan'*

### 3.1.3 Long-term fears parents

The long-term fears of parents concerning their child were discussed with parents. Parent one expressed the fear that her child may be bullied when he child is older. She feared her child might feel insecure about his skull appearance. She was also scared that her child might blame her for not choosing helmet treatment. Parents four and five also indicated that they were worried that their child might be bullied.

*Parent one: "je wilt wel dat je kind je later niet kan zeggen van: 'mama, waarom heb je dat niet gedaan het was zo simpel geweest om mijn hoofd mooi te maken en ja, nu word ik gepest of nu vind ik mijn eigen hoofd niet mooi en ben ik er onzeker door"*

Parent five indicated that she might regret not choosing helmet treatment due to the fact that the skull deformation may not improve without helmet treatment.

### 3.1.4 Consulted information sources

Parents were asked how they perceived the advice given to them by the professionals involved in the care for their child. This to find out what influence professionals have on the decision made by parents concerning helmet treatment of their child.

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Parent two visited the pediatric physical therapist when her child almost had the required age for helmet treatment. This visit was mainly for the purpose of the plagiocephalometry. Both parent two and three indicated that the youth health care centres did not recognize the problem of the skull asymmetry. Also they indicated that the general practitioner did not take the problem seriously.

*Parent three: 'mijn huisarts kent het helemaal niet: een redressiehelm'... 'hij vond het helemaal niet nodig en hij had zoiets van als jij dat wilt dan ga je maar lekker naar de kinderarts, maar volgens mij is het niet nodig'*

Both parents four and five who did not yet decide for helmet treatment indicated that they would base their decision whether or not to choose for helmet treatment on the advice of the professionals involved.

*Parent five: 'ik weet het echt nog steeds niet. Ik moet echt wel een bevestiging van de arts hebben dat het beter is, zo'n helmpje'*

Also parent one based her decision on the advice of the physical therapist not to start helmet treatment. During the interview she indicated that she regretted this because she was not satisfied with how the asymmetry of her child improved. Parent two indicated that it was made clear to her by the physical therapist that the helmet was only meant for cosmetic purposes.

All parents indicated they searched for information about helmet treatment on the internet. Parents two and three already made the decision that they wanted helmet treatment for their child based on the information found on the internet. Parent three was also active at the helmet treatment forum and asked questions about helmet treatment to other parents.

### 3.1.5 Experience and expectations of possible treatment options

#### Helmet treatment

The parents were asked about their expectations of the effect of helmet treatment and wait and see. All parents indicated that they expect that the helmet will help diminish the skull deformation of their child.

*Parent two: 'ik heb er geen seconde over nagedacht dat dat niet zou werken'*

Parent four specifically indicated that the pediatric physical therapist informed her that the effect of helmet treatment was never proven and therefore that this might be a reason for her not to choose for helmet treatment. Also parent five said that the physical therapist indicated that the effect of helmet treatment was unproven

*Parent five: 'maar het zekere voor het onzekere zou ik wel voor zo'n helm gaan. Dan weet je zeker dat het weer goed komt lijkt mij'*

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Parent three indicated that the pediatrician said that the skull deformation would improve with helmet treatment.

Both parent two and three expressed the fear that without helmet treatment the asymmetry would not dissipate. They also indicated that the skull asymmetry and brachycephaly improved rapidly with helmet treatment.

Helmet treatment should be started when the child is approximately six months old and the potential effect diminishes with the increasing age of the child. Time pressure might be a reason for parents to choose helmet treatment; therefore this topic was discussed with them. Both parents four and five indicated that time pressure was a topic that they did not give much consideration. Both parent two and three indicated that helmet treatment can only be started at five months of age was an important reason to start helmet treatment.

*Parent three: 'het probleem is gewoon, je weet pas of het gelukt is als hij twee jaar is en dan kun je er dus niks meer aan doen'*

### Wait and see

The expectations of wait and see were also discussed with parents. It was explained to the interviewed parents that wait and see means that no helmet treatment would be started.

Parent four indicated that her first child also had deformational plagiocephaly and did not receive helmet treatment. This asymmetry resolved over time. Therefore she indicated that she had the confidence that wait and see would also have a positive effect on the skull deformation of her child.

Parent five said that she did not know what to expect of a wait and see approach. She hoped that this would have a good effect because she did not like the idea of helmet treatment.

*Parent five: 'ja ik weet het eigenlijk niet. Ik denk dat ik meer hoop dat het uit zichzelf wel goed komt'*

The other three parents indicated that they did not have positive expectations of wait and see and that they therefore started helmet treatment. Parent one was advised not to start helmet treatment but worried whether or not the asymmetry would dissipate. She was anxious because the asymmetry of her child did not improve.

The parents that started helmet treatment indicated that they did not expect that the asymmetry would improve with a wait and see approach.

The parents that did not yet decide for a treatment option would have faith in a wait and see approach if the pediatrician indicated this was an option.

### 3.1.6 Fears concerning helmet treatment

#### Comfort of helmet treatment

The fears concerning helmet treatment were discussed with parents, because helmet treatment may cause inconvenience for children. Parents four and five indicated that the pediatric physical therapist indicated that children accept the helmet well. Also, they found information on the internet that confirmed that helmet treatment causes no inconvenience for infants.

Parent five was more reserved about helmet treatment and specifically indicated that she did not like the idea that her child might be limited in her mobility. She also indicated that the helmet treatment is hard because her child would have to wear the helmet during the summer period.

*Parent five: 'Ja ja, het gevoel als ik me inleef in haar, dat er zo'n groot zwaar ding op het hoofd meebungelt'*

Parent one thought that the helmet treatment is not comfortable for children, but that she would continue treatment as long as no pressure points would develop. Parent two said that she heard that children accept the helmet well, but that she does not believe that the helmet is just as comfortable as no helmet. She indicated that the helmet treatment is for the future wellbeing of her child.

*Parent two: 'ja, nou ja, iedereen zegt gewoon dat kindjes daar geen last van hebben. Nou geloof ik heus niet dat een helm net zo lekker zit als geen helm. Hij zal er heus wel iets last van hebben, maar ja, dat moet dan even'*

Both parents two and three indicated that in general their child accepted the helmet really well.

*Parent three: 'dat moet ik heel eerlijk zeggen: hij heeft er echt geen last van'*

But parent two indicated that her child had pressure points and that she visited the orthotic device centre for helmet adjustment. Parent three also indicated that her child developed some pressure points and that the helmet needed to be adjusted several times.

#### Visibility of helmet treatment

Helmet treatment is noticeable for the social environment. Therefore, the problem of visibility of the helmet was discussed with parents. Parent four indicated that she did not care about what other people think of her child.

Parent one expressed that the visibility of the treatment was not a problem for her. Both parent two and three indicated that people paid attention to the helmet of their child and this was sometimes difficult for them.

*Parent two: 'het is wel echt minder leuk, dat moet ik wel heel eerlijk zeggen. Mensen kijken ook wel echt van: 'wat heeft dit kindje? Zal die epilepsie hebben?', Of in ieder geval dat gevoel heb ik. Maar ja, het liefst heb je toch gewoon een kindje wat niks apart heeft.'*

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Parent five said that this might be a reason for her not to choose helmet treatment. She indicated that she did not like the idea that the social environment would pay attention to the helmet of her child.

*Parent five: 'dat je er tegenaan moet kijken dan vind ik eigenlijk best wel erg..dat ze je nakijken zeg maar.'*

### Emotional contact helmet

Parent two and three expressed that they had trouble following the treatment regime. Parent two also mentioned that cuddling was less fun when her son was wearing the helmet. Both parents indicated they made time to cuddle with their child without the helmet.

## **3.2 Results of interviewed professionals**

In this section the results of the topic interviews with both pediatricians (3.2.1) and pediatric physical therapists (3.2.2) are presented.

### **3.2.1 Pediatricians**

Two pediatricians were interviewed. The pediatricians were selected because they have different opinions towards helmet treatment: a pediatrician, who is an advocate of wait and see and a pediatrician, who is neutral about both treatment options, were interviewed.

#### Position of pediatrician in health care process

The pediatricians were asked how they perceive their position in the health care process for children with a skull deformation. Pediatrician one indicated that a skull deformation is in most situations not the main problem of the infant. Many parents visit the pediatrician because their child has a positional preference and the neurological development is delayed. The pediatrician examines if there is an underlying illness that causes developmental delay, which she considers to be her task. She indicates to parents that the problem of a skull asymmetry is a cosmetic problem and not a medical problem. Pediatrician one indicated that she has the opinion that in most situations the asymmetry is not severe and that the asymmetry will diminish over time. She indicated that she has never seen cases in which the asymmetry was so severe that she felt that helmet treatment had to be prescribed. The pediatrician pointed out that when parents insist on helmet treatment they are provided with the names and addresses of orthotic helmet makers and that parents can make an appointment there. Afterwards, the interviewed pediatrician does not follow up on the children.

Pediatrician two on the other hand indicated that she receives parents of children with a skull deformation who are approximately five months old and where a decision should be

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made whether or not to choose helmet treatment. She wants to reply to the demand of parents of children with plagiocephaly/brachycephaly who want advice whether or not to start helmet treatment.

The advice of pediatrician two to choose for orthotic helmet treatment is based on the development of the asymmetry of children. Also, whether or not the child still has a positional preference in bed, is important for the advice given to parents. Pediatrician two indicated that physical therapists often refer children to the pediatrician based on plagiocephalometry but the pediatrician indicated that her advice is never based on numbers of plagiocephalometry.

Pediatrician two also points out that she does not provide parents with a medical advice, but that she is there to help parents make the correct decision.

*Pediatrician two: 'ik zie ook legio ouders die komen om samen met mij de voors en tegens tegen elkaar af te wegen en pas dan te beslissen'*

Pediatrician two indicated that most parents listen to her advice to choose for orthotic helmet treatment or to wait and see. There are also parents that already decided that they want helmet treatment, even when the pediatrician does not share this opinion. According to the pediatrician two this decision is not necessarily related to degree of asymmetry of the child. Pediatrician two follows up on the children at the age of nine and twelve months.

### Opinion pediatricians helmet treatment

The pediatricians were asked how they feel about orthotic helmet treatment such as the effect and the comfort of helmet treatment. Both pediatricians had different opinions about helmet treatment. Pediatrician one indicated that the effect of helmet treatment is unclear and she finds the treatment incriminating for the infant. Also she mentions the high costs of the helmet treatment in combination with the effects of helmet treatment that are unknown, are reasons for her to have a critical attitude towards helmet treatment.

*Pediatrician one: 'of ik wel of niet tegen helmtherapie ben? Ik ben niet tegen, alleen er is op dit moment geen duidelijk bewijs dat helmtherapie leidt tot uiteindelijk minder afplatting van de schedel. En omdat daar geen bewijs voor is en het voor mij niet een heel ernstig probleem is en ik het wel een behoorlijk belastende en kostbare behandeling vind, ben ik heel erg terughoudend in het voorschrijven van helmtherapie'*

Pediatrician two was neutral towards helmet treatment and refers parents for helmet treatment when she feels this is indicated. Although she is aware of the fact that no Randomised Controlled Trial has been performed, there are studies that show that orthotic helmet treatment has a positive influence on the skull asymmetry of children. Furthermore, she has seen good results in practice.

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### Information on treatment options provided by pediatricians

Pediatricians were asked what information concerning treatment options they give to parents. Pediatrician one indicates that most parents were informed by the pediatric physical therapist about the option of helmet treatment for their child. The pediatric physical therapist often indicates to parents that helmet treatment is necessary and they are referred to the pediatrician. The pediatrician relaxes the information given by the pediatric physical therapist.

*Pediatrician one: 'maar er zijn ook ouders die hier speciaal komen om te vragen: 'mag ik een helm?' En meestal is dat omdat iemand dat tegen ze gezegd heeft. Namelijk de fysiotherapeut die zegt: 'nou uw kind heeft nu een helm nodig en dat gaat helpen', dat is wat ik vaak hoor van ouders.'*

Pediatrician one informs parents that helmet treatment is not proven and that the asymmetry will dissipate over time. Most parents are reassured by this advice and decide to wait and see. In the minority of cases the parents want orthotic helmet treatment and they make an appointment with an orthopaedic centre by themselves.

*Pediatrician one: "ik zeg gewoon tegen ouders dat ik niet weet of dat helmpje gaat helpen ja of nee en dat ik dus ontkracht wat die fysiotherapeuten tegen die ouders hebben gezegd... Zo zeg ik het tegen ouders dat niemand weet of helmtherapie helpt, want er is nooit goed onderzoek naar gedaan'*

Pediatrician two indicates that she explains to parents the good short-term effects of helmet treatment but weakens the expectations of the helmet treatment. Parents for example expect that the helmet corrects the asymmetry of the ears, which is not the case.

*Pediatrician two: 'de ouders hebben vaak verwachtingen dat het hoofd helemaal fraai symmetrisch rond wordt, de oren mooi recht tegenover elkaar komen te staan en ook het voorhoofd herstelt. Wat wel in de literatuur naar voren komt, is dat de scheefstand van de oren niet behandeld wordt en ook het voorhoofd minimaal verbetert .En dat is iets wat ik heel duidelijk van tevoren met ze bespreek. Anders hebben ze valse verwachtingen. Wat mijn ervaring in de praktijk wel is dat toch die scheefstand van de oren iets bijtrekt'*

Pediatrician two points out to parents that helmet treatment will influence the emotional contact that they have with their child. Cuddling is more difficult when a child is wearing a helmet.

*Pediatrician two: 'Ja dat is wel het warme contact met zo'n warme zuigelingenbolletje. Ja dat is heel belangrijk; 23 uur per dag is erg lang'*

Pediatrician two points out to parents that when they choose orthotic helmet treatment they should follow the treatment protocol/instructions.

### Reasons to choose helmet treatment indicated by pediatricians

The pediatricians were asked what the reasons are for people to choose helmet treatment. Pediatrician one indicated that only a very small proportion of the parents that consulted

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her choose helmet treatment. Pediatrician two mentions that parents are worried about the skull asymmetry and are afraid that it will not dissipate over time. Parents have good expectations of orthotic helmet treatment. Also parents are afraid that their child might blame them for not choosing helmet treatment.

*Pediatrician two: 'toch bang zijn dat straks hun kind gaat zeggen als hij een scheef hoofd overhoudt van 'waarom heb je dat niet aangepakt?', dat is eigenlijk toch de meeste gehoorde opmerking'*

### Reasons of parents to choose for wait and see indicated by pediatricians

According to both pediatrician one and two most parents choose for wait and see because they are reassured by the information given to them. Also some parents indicate that they find helmet treatment a 'big thing' and are relieved that helmet treatment is not necessary. According to both pediatricians a lot of parents follow the advice to wait and see and have faith that the asymmetry will dissipate over time.

*Pediatrician two: 'er een aantal ouders dat echt voor het esthetische resultaat gaat, maar er is ook een groep die dat helemaal niet zo belangrijk vindt en die dan veel meer luistert naar je uitleg: dat natuurlijk ook tussen zes en twaalf maanden bij het doorbreken van de voorkeurshouding en goede hanteringadviezen zeker nog dat traject van verbetering op de natuurlijke weg gewoon doorgaat. Zij durven daarvoor te gaan'*

The pediatrician two mentions that some parents have difficulties with the treatment modality and also some parents are afraid that they will lose the emotional contact with their child.

### **3.2.2 Pediatric physical therapists**

Two pediatric physical therapists were interviewed using a topic list. Both have experience in treating children with a skull deformation and a positional preference. Both physical therapists are trained in the application of the plagiocephalometry.

#### Information on treatment options provided by physical therapist

Both physical therapist use information folders of a rehabilitation centre in which helmet treatment is being explained to provide parents with information about helmet treatment. Both physical therapist indicate that they are aware of the great influence they have on the decision making process of parents but try to stay as neutral as possible in their information about helmet treatment. But when their opinion is asked by parents they give their opinion about the possibility of helmet treatment to parents

When the pediatric physical therapists have the opinion that parents do not take the skull asymmetry seriously, they try to play upon the feelings of the parents by telling them that they have to decide for their child and that when a child is not treated with helmet and stays asymmetric he or she may be teased at school.

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*Pediatric physycial therapist two: 'ik probeer altijd wel heel duidelijk te stellen: je kind is op dit moment zelf nog te jong om erover te beslissen, maar hou er rekening mee dat als je er niks aan doet en de natuur zijn gang laat gaan, kan het zijn dat het helemaal goed komt. Maar het kan ook zijn dat het niet helemaal goed komt. En wat nou als hij een jaar of tien is en huilend uit school komt en wordt gepest omdat hij een scheef bolletje heeft en zegt: 'pap of mam waarom heb ik dat?' Ja en dan moet je wel als ouder de verantwoording nemen van: 'ja wij wilden destijds niet voor die helm gaan'.*

Both pediatric physical therapists indicate that they advice a wait and see approach when the plagiocephalometry indicates a grey area and when the child is very active and for example sleeps on his or her tummy. Also when the child's asymmetry has decreased rapidly, then often physical therapists advice to wait and see, because they expect that the asymmetry will diminish on its own.

### Influence relatives

Both the physical therapists indicated that relatives could have a great influence on parents in their perception of the brachycephaly and skull asymmetry and in their perception of treatment options. Pediatric physical therapist two indicated that some parents, who are not sure of what treatment option to choose, might be more likely to listen to the advice of relatives. For example when people in the social environment of parents have negative experience with helmet treatment they might develop a negative perception of the helmet.

Also pediatric physical therapist two pointed out that it is also important for parents to both agree to helmet treatment.

### Expectations parents of possible treatment options

The pediatric physical therapists indicated that the most important incentive to choose for helmet treatment is the fact that the helmet treatment has proven its effect and that with a wait and see approach the effect is unsure.

Both pediatric physical therapists were positive about helmet treatment. They inform parents that the effect of helmet treatment is not proven, but that they give a good short-term effect. Most parents expect that the helmet treatment will have a positive effect on the skull asymmetry of their child.

Pediatric physical therapist two pointed out that parents that choose a wait and see approach usually have the confidence that the skull asymmetry will dissipate over time. Also she usually informs the parents about the fact that the asymmetry becomes less noticeable when the head of the child grows.

### Fears of helmet treatment

The physical therapists indicated that the comfort of helmet treatment is often a cause of concern for parents but that they explain to the parents that most children accept the helmet well.

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*Pediatric physical therapist one: 'de helmpjes worden kind eigen gemaakt, dus in principe wat mij altijd geleerd is en wat ik ook vasthoud, is dat een kind geen last heeft van de helm. De helm is niet zwaar en hij beperkt niet in het motorisch functioneren en het heeft geen invloed op de herseninhoud'*

Pediatric physical therapist one said that parents often need a longer time to get used to the helmet than children. According to one physical therapist there is only a small number of parents that do not choose helmet treatment because they think that the helmet is uncomfortable for the child.

The complications of helmet treatment were not specifically mentioned by the physical therapists as something that parents worry about. But they do explain that helmet treatment is harmless for the child. Pediatric physical therapist one mentioned that some parents are worried about the complications of a skull asymmetry and others believe that the flat side of the skull contains less brain, and therefore the child will develop asymmetrically.

Both physical therapists indicated the impact of helmet treatment on parents must not be underestimated. Helmet treatment is started when the child is five months old and the treatment is finished on the child's first birthday, which is a long time in the life of a young child. Also physical therapists indicated that the hair of the children has to be removed before helmet treatment.

*Pediatric physical therapist two: 'je kindje is een half jaar en je een gaat dan voor het komende half jaar en dat is net zo lang als dat een kindje op de wereld is, ga je bepalen dat een kind een helm moet gaan dragen. Dat is best heel erg lang'*

Also children with helmets are observed by others, and often strangers ask the parents about the helmet, which is something parents have to deal with.

### Decision making under uncertainty

Both pediatric physical therapists mentioned the fact that parents have to make a decision under uncertainty. It is unclear what result wait and see will have on the skull deformation of their child. Both physical therapists mentioned that when the effects of wait and see are clear in comparison to helmet treatment, which is thought to have a good result, then fewer parents might choose for helmet treatment.

*Pediatric physical therapist one: 'ik denk dat die tijdsdruk, noem ik het maar, dat dat voor hen wel heel vaak een doorslaggevend iets kan zijn. Zo van: 'nou ja, we kunnen niet meer afwachten, doe maar dan'*

### Perception of severity skull deformation

Both physical therapists indicated that hereditary also has a great role in the perception of the appearance of a skull asymmetry. Often brachycephaly runs in the family. Children from Asia are slightly brachycephalic, which is not considered a problem in those

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countries. Also, if within families a skull asymmetry is present, then parents are less worried about the child being asymmetric. Especially when grown ups do not consider their brachycephaly as problematic.

When children have a lot of hair than asymmetry is less noticeable and parents are then less likely to be worried about the skull asymmetry, whereas children who have little hair, parents are worried about the skull asymmetry. Therefore, the pediatric physical therapists indicate that some parents perceive the skull asymmetry in girls as less important because girls usually have long hair. Both pediatric physical therapists explain to parents that for both sexes a symmetric appearance is important.

*Pediatric physical therapist two: 'en dan weegt het bij mij niet zwaar of het een jongetje of een meisje is, want dat wordt over het algemeen ook gezegd hè. Bij meisjes kan je het verdoezelen met haartjes, maar ik denk een meisje met twee staartjes die scheef zitten, dat vind ik ook niet fraai'*

### Reasons of parents to wait and see

Both physical therapists indicated that most parents choose for helmet treatment when this is advised, or they already pointed out this option to the physical therapist. Reasons for parents to wait and see are a combination of reasons; they do not notice the skull asymmetry and they find helmet treatment incriminating for the child. Also the physical therapists indicated that some parents may not choose helmet treatment because they are not happy about the treatment modality.

Pediatric physical therapist two pointed out that it also may have something to do with the educational level of parents. Due to the impact of treatment, the regular check ups etc. parents with a low educational level might choose to wait and see.

### 3.3 Conclusion qualitative interviews

The following factors were mentioned by the interviewees to be influencing on the decision whether to choose helmet treatment or wait and see. The topics that were mentioned most often are ranked first.

Table 2:  
*Influencing factors decision helmet treatment or wait and see*

Influence decision	Respondents type								
	Physical therapist		Pediatrician		Parents				
	1	2	1	2	1	2	3	4	5
Fear of teasing children	+	+	+	+	+	+	+	+	+
Influence internet	+	+	+	+	+	+	+	+	+
Future appearance children	+	+	+	+	+	+	+	+	+
Blame parents wait and see	+	+	+	+	+	+	+	/	/
Uncertain effect wait and see	+	+	+	+	+	+	+	/	/
Time pressure decision	+	+	/	+	+	+	+	/	/
No harm in trying	+	+	/	+	+	+	+	+	/
Uncertain effect helmet treatment	/	/	+	/	/	/	/	/	+
Visibility of treatment	+	+	+	+	/	/	/	/	+
Comfort helmet treatment	+	+	+	/	/	/	/	/	+
Emotional contact child helmet treatment	/	/	/	+	/	/	/	/	/
Heredity	+	+	/	/	/	/	/	/	/
Level of education parents	/	+	/	/	/	/	/	/	/
Type of information about treatment options given by professionals	+	+	/	/	/	/	/	/	/
Influence family/friends	+	+	/	/	/	/	/	/	/
Influence season	+	/	/	/	/	/	/	/	+
Previous experience in family Brachycephaly/plagiocephaly	/	/	/	/	/	/	/	+	/

+ influence decision parents, / not specifically mentioned by respondent

The factors mentioned in the interviews were subdivided into several topics and served as input for the questionnaire.

- Perception of the severity of plagiocephaly or brachycephaly
  - heredity of skull deformation,
  - perception of parents of the degree of skull deformation
  - previous experience with skull deformation
- Long-term fears of parents
  - fear teasing children
  - fear insecurity of children
  - fear regrets wait and see
- Expectations of possible solutions
  - expectations effect wait and see
  - expectations effect helmet treatment

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- expectations side effects helmet treatment
- Fears concerning helmet treatment
  - visibility helmet treatment
  - fear comfort helmet treatment
  - diminished emotional contact child when wearing helmet
- Influence professionals
- Influence lay-men
  - internet
  - family and friends
- Other factors
  - no harm in trying
  - decision making under time pressure
  - influence weather season.

## 4 Results of the questionnaire

The results of the responses to the questionnaire are presented in this chapter. The questionnaire consisted of multiple parts; each part is presented in a different paragraph.

In paragraph 4.1 the general information concerning respondents is shown. The results of the Decisional Conflict Scale can be found in paragraph 4.2. Furthermore the results of the questions concerning the influencing factors are described in paragraph 4.3.

### 4.1 General information of parents

After handing out questionnaires to parents in the waiting rooms of several hospitals, a total of 37 questionnaires were returned. The response rate was about 50%. In table 3 the number of respondents, subdivided into treatment groups, are presented per respondents group. The helmet treatment group is the group that did not make the decision but were positive about helmet treatment. The wait and see group is the group that did not yet make the decision but indicated on the questionnaire that they preferred to wait and see. The decision helmet group is the group that made the decision to start with helmet treatment. As can be extracted from the table generally the mothers were the ones that completed the questionnaire.

Table 3:  
*Number of respondents*

Respondents	N	Father	Mother	Together
Helmet treatment group	16	0	11	5
Wait and see group	7	1	4	2
Decision helmet group	14	4	4	6

Table 4 indicates that the majority of the group were boys in this sample. Two values were missing because parents forgot to fill out what the gender of the child was.

Table 4:  
*Gender of children*

	Boy	Girl	Missing
Helmet treatment group	13	1	2
Wait and see group	4	3	
Decision helmet group	11	3	

In the decision helmet group the majority of children had brachycephaly. In the helmet treatment group and the wait and see group the type of skull deformation was evenly present in the sample as can be seen in table 5.

Table 5:  
*Question 9 Type of skull deformation*

	Brachycephaly	Plagiocephaly	Both
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Helmet treatment group	4	10	2
Wait and see group	3	3	1
Decision helmet group	6	5	3

Parents were between 24 to 40 years old. There appears to be no relation between the age of the parents and the respondent group. Furthermore, there is no relation between the positional preference of the child and the preferred treatment option.

### 4.2 Decisional conflict

The Decisional Conflict Scale (DCS) (O'Connor, 1995 & Koedoot, 2005) was used to assess the degree of decisional conflict of the respondents concerning the decision whether or not to choose helmet treatment. The DCS can be subdivided into three separate scales: 'decision uncertainty scale', 'contributing factors' and the 'decision satisfaction' scale.

The mean and standard deviation of responses to individual items of the DCS are presented in table 6. Table 6 presents the mean and the standard deviation of the items in the questionnaire. The responses varied between subjects on the various items. The responses to the statements are ranked from 1, being 'strongly agree', to 5, being 'strongly disagree'.

Table 6:  
Scores on individual items decisional conflict scale (question 16-28 in the questionnaire)

Item	Helmet treatment group	Wait and see group	Decision helmet group
	Mean (std)	Mean (std)	Mean (std)
16.Decision difficult	1,81 (0,75)	2,43 (0,96)	1,57 (1,02)
17.Unsure of decision	2,25 (1,29)	2,56 (0,79)	1,62 (0,87)
18.Clear what best choice is	3,31 (1,49)	4,14 (0,69)	3,93 (1,64)
19.Aware of choice	1,94 (1,18)	2,00 (1,67)	1,36 (0,63)
20.Aware advantages	1,95 (1,06)	2,33 (0,82)	1,79 (0,97)
21.Aware disadvantages	2,38 (1,31)	2,00 (0,89)	1,93 (1,21)
22.More information options	2,94 (1,34)	3,00 (1,55)	2,29 (1,54)
23.Advantages wait and see	2,87 (1,36)	3,17 (0,17)	3,00 (1,52)
24.Disadvantages wait and see	2,00 (0,93)	3,00 (1,41)	1,43 (0,65)
25.Advantages helmet	2,25 (1,34)	2,67 (1,37)	1,43 (0,65)
26.Disadvantages helmet	2,56 (1,26)	2,50 (1,22)	2,21 (1,31)
27.Pressure others	1,31 (0,79)	1,83 (1,33)	1,46 (0,67)
28.Support others	1,69 (1,19)	2,50 (1,52)	1,50 (0,65)

Respondents could indicate their answer on a scale from 1 to 5, 1=strongly agree 5=strongly disagree

The table shows that in general the wait and see group has more problems during the decision making process. This group is in general less positive on the majority of the statements in the questionnaire. The helmet treatment group and the decision helmet group differ less from each other. These two groups indicate that they are more sure about their decision because they appear to have more confidence in the treatment options and their advantages and disadvantages. However, no significant differences on the individual items of the DCS were found between the three groups.

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The decision uncertainty scale deals with the first three items of the DCS. Table 7 shows the results of the summed scores over these three items.

Table 7:  
*Decision uncertainty scale (constructed from question 16-18)*

	N	Mean	Standard deviation
Helmet treatment group	16	7,37	2,47
Wait and see group	6	8,83	1,17
Decision helmet group	13	7,38	4,05

The helmet treatment group (mean 7.37;std 2,47) experienced less uncertainty on the decision uncertainty scale in comparison to the wait and see group (mean 8,83; std 1,117) but the results were not significant. The decision helmet group also appears to have experienced less decisional conflict on the decision uncertainty scale in comparison to the wait and group.

The contributing factors are the factors that contribute to the decision-making and consist of the items four to thirteen of the Decisional Conflict Scale.

Table 8:  
*Mean sum scores contributing factors (constructed from question 19-28)*

	N	Mean sum score	Standard deviation
Helmet treatment group	15	25,47	4,29
Wait and see group	6	27,33	5,32
Decision helmet group	14	21,50	4,88

In comparison to the other groups the group that already made the decision for treatment experienced the least conflict in the contributing factors with a mean score of 21,50 (std 4,88). The group that experienced the most conflict was the wait and see group with a mean score of 27,33 (std 5,32).

The decision helmet group also completed the last part of the DCS that measures the effectiveness of decision making of parents. Table 9 presents the results of this part.

Table 9:  
*Effective decision-making (questions 30 - 32)*

Items	Mean, standard deviation
30.Satisfied with decision	1,57 (1,09)
31.Decision reflects importance	1,64 (1,08)
32.Well informed	3,70 (1,59)

Respondents could indicate their answer on a scale from 1 to 5, 1=strongly agree 5=strongly disagree

The decision helmet group was satisfied with the decision (mean score 1,57; std 1,09). Although the parents were quite satisfied with their decision, they still indicated that they were in general not well informed (mean score 3,70: std 1,09).

With a minimum score of three and maximum score of 15 that an individual can score on the decisional conflict scale, the decision helmet group was more then average satisfied with the decision for helmet treatment as can be extracted from table 10.

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Table 10:

*Mean sum score effective decision-making decision helmet group (questions 30-32 of the decision helmet group questionnaire)*

	N	Mean sum score	Standard deviation
Decision helmet group	14	6,92	1,82

When all questions of the DCS are combined (question 16 to 28), a general measure for the total decisional conflict can be constructed. Overall, the group that experienced the most decisional conflict was the wait and see group with a mean score of 33,83 (std 7,16) compared to the helmet treatment group which had a mean of 29,53 (std 5,60) and the decision helmet treatment group with a mean sum score of 25,69 (table 11). However due to the large standard deviations these differences are not significant.

Table 11:

*Mean sum scores decisional conflict scale*

	N	Mean	Standard deviation
Helmet treatment group	15	29,53	5,60
Wait and see group	6	33,83	7,16
Decision helmet treatment	14	25,69	6,47

### 4.3 Questions concerning the influencing factors of decision-making

This section describes the factors influencing the decision-making. First the consulted information sources are described (4.3.1). Furthermore, the long-term fears of parents (4.3.2), perception of severity (4.3.3), the experiences and expectations of treatment options (4.3.4) and fears concerning helmet treatment (4.3.5) are analyzed.

#### 4.3.1 Consulted sources of information concerning treatment options

Parents could indicate which information sources they consulted and how parents perceived what attitude these sources have towards the treatment options.

##### Lay-men

The following information sources were consulted by parents: internet, family and friends. Table 12 shows the number of respondents that consulted these sources. Table 13 shows the perceived views of internet.

Table 9:

*Consulted information sources (questions 50-56)*

Consulted information sources	Helmet treatment group (N=16)	Wait and see group (N=7)	Decision helmet group (N=14)
50.Internet	75%	57%	100%
51.Family	67%	67%	88%
52.Friends	79%	67%	46%
53.Pediatric physical therapist	100%	100%	79%
54.Pediatrician	50%	100%	86%
55.General practitioners	55%	60%	55%
56.Orthopaedic specialists	46%	80%	91%

Table 10:

*View internet (if consulted)*

Internet	Helmet treatment group (N=12)	Wait and see group (N=3)	Decision helmet group (N=12)
Helmet treatment	67%	33%	64%
Neutral	33%	67%	27%
Wait and see	-	-	9%

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All respondents of the helmet treatment group and the wait and see group that consulted the internet thought the internet was either neutral or positive towards helmet treatment. 67% of the helmet treatment group thought that the information found on the internet was positive towards helmet treatment. One respondent (9%) of the decision helmet group indicated that the internet was an advocate of wait and see. No other respondents indicated that internet was an advocate of wait and see.

In table 14 the results of the consulted family members can be found.

Table 11:  
*View family*

Family	Helmet treatment group (N=10)	Wait and see group (N=4)	Decision helmet group (N=11)
Helmet treatment	70%	13%	50%
Neutral	30%	50%	40%
Wait and see	-	37%	10%

50% of the respondents of the decision helmet group and 70% of the helmet treatment group indicated that family was an advocate of helmet treatment. A lower back up of helmet treatment was found in the family of the wait and see group.

It seems that the majority of respondents is affected by the advice of family, but as a result of the small sample size and the format of the questionnaire this cannot be statistically proven.

Table 15 shows the results of the consulted friends.

Table 12:  
*View consulted friends*

Friends	Helmet treatment group (N=11)	Wait and see group (N=4)	Decision helmet group (N=5)
Helmet treatment	54%	13%	70%
Neutral	46%	50%	30%
Wait and see	-	37%	-

Both in the wait and see group and the decision helmet group one respondent indicated that their friends had different views towards the treatment options and therefore filled out multiple views in the questionnaire. These multiple responses were taken into account as a half response for both options.

The decision helmet group did not consult their friends in 50% of cases. The other groups consulted their friends more often. 54% of the friends of the helmet treatment group were an advocate of helmet treatment. Apparently the opinion of friends is important to parents.

### Professionals

Table 16 shows the views of the consulted pediatric physical therapists.

Table 13:  
*View consulted pediatric physical therapists*

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Pediatric physical therapist	Helmet treatment group (N=15)	Wait and see group (N=6)	Decision helmet group (N=9)
Helmet treatment	40%	42%	56%
Neutral	57%	42%	22%
Wait and see	3%	17%	22%

Also in the case of the views of pediatric physical therapists some parents indicated that they had multiple views. These responses were taken into account as a half response for both options as well.

According to most parents the pediatric physical therapists were either neutral or an advocate of helmet treatment. In the decision helmet group the physical therapist was in 56% of the cases an advocate of helmet treatment. Although the wait and see group indicated that the pediatric physical therapist is mostly positive towards helmet treatment they tend to wait and see. This might be a sign that the influence of the pediatric physical therapist is marginal. However, in the qualitative interviews it was found that the opinion of the pediatric physical therapists was important.

Table 17 shows the views of the consulted pediatricians.

Table 14:  
*View consulted pediatricians*

Pediatrician	Helmet treatment group (N=6)	Wait and see group (N=4)	Decision helmet group (N=10)
Helmet treatment	50%	25%	80%
Neutral	50%	50%	-
Wait and see	-	25%	20%

In the decision helmet group the pediatrician was in 80% of cases an advocate of helmet treatment. In the helmet treatment group the pediatrician was in 50% of cases an advocate of helmet treatment. In the wait and see group parents indicated that the pediatrician was neither an advocate of helmet treatment nor an advocate for wait and see. Apparently the pediatrician has an influence on the decision of parents

The general practitioner was in general often not consulted. A referral of the general practitioner is not necessary for a consultation at the policlinic for children with a skull asymmetry. In table 18 the views of the general practitioner are presented.

Table 15:  
*View consulted general practitioners*

General practitioner	Helmet treatment group (N=6)	Wait and see group (N=3)	Decision helmet group (N=6)
Helmet treatment	17%	33%	33%
Neutral	83%	33%	33%
Wait and see	-	33%	33%

Respondents indicated that in general the general practitioner wasn't a clear advocate for either helmet treatment or wait and see. Because only a few parents consulted the general practitioner one can conclude that in general the general practitioner does not have a big influence on the decision making process.

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Table 19 shows the views of the consulted orthopaedic specialists.

Table 16:  
*View consulted orthopaedic specialists*

Orthopaedic specialist	Helmet treatment group (N=5)	Wait and see group (N=4)	Decision helmet group (N=9)
Helmet treatment	80%	75%	78%
Neutral	-	-	22%
Wait and see	20%	25%	-

The orthopaedic specialist was in all groups a clear advocate of helmet treatment. The view of the orthopaedic specialists was comparable. However, the wait and see group prefers to wait and see. This is a sign that the orthopaedic specialists do not have a big influence on the decision making process of parents.

### 4.3.2 Long-term fears concerning skull deformation of parents

The long-term fears of parents are fears concerning the future of children. In table 20 the responses of the helmet treatment group, the wait and see group and the decision helmet group are presented.

Table 17:  
*Long-term fears of parents*

Question	Mean (Std)		
	Wait and see group	Helmet treatment group	Decision helmet group
41.Regrets wait and see	2,57 (1,40)	1,56 (1,15)	1,71 (1,33)
42.Teasing of children	4,57 (0,79)	3,44 (1,50)	4,36 (0,93)
43.Insecurities appearance	4,00 (1,00)	3,38 (1,45)	4,29 (0,91)
44.Blame parents wait and see	2,83 (1,17)	3,19 (1,38)	3,57 (1,28)

Respondents could indicate their answer on a scale from 1 to 5, 1=strongly agree 5=strongly disagree

Respondents of all groups were not afraid that their child would be teased when he or she is older. They were also generally not worried about their children being insecure about their appearance, which is surprising because in the qualitative interviews this was often mentioned as an important reason to choose helmet treatment.

### 4.3.3 Perception of the severity of the skull deformation by parents

Several questions were asked to identify the perception of the severity of the problem of skull deformation. The results are presented in table 21.

Table 18:  
*Perception of severity of skull deformation*

Questions	Wait and see group	Helmet treatment group	Decision helmet group
	Mean (std)	Mean (std)	Mean (std)
30.Shape head of child	3,42 (1,33)	2,43 (0,96)	-
31.Shape face of child	4,57 (0,79)	4,12 (1,47)	-
39.Guilt feelings plagiocephaly	4,57 (0,53)	3,75 (1,34)	4,00 (1,38)
40.Need to act	1,29 (0,49)	1,31 (0,79)	1,29 (0,61)
42.Degree plagiocephaly compared	4,71 (0,49)	3,41 (0,95)	3,07 (1,38)
43.External consequences skull deformation	2,43 (1,62)	3,00 (1,59)	2,93 (1,59)

Respondents could indicate their answer on a scale from 1 to 5, 1=strongly agree 5=strongly disagree

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Parents of the wait and see group were more satisfied with the shape of the head of their child compared to people that choose helmet treatment (z score -2,27, alpha 0,05). Respondents did not feel guilty about the skull deformation of their child.

All respondents of the three groups felt the need to act upon the skull deformation of their child. The helmet treatment group indicated that they thought that the skull deformation of their child was more severe in comparison to other children (z score -2,43, p-value 0,027). Also the decision helmet group indicated that they perceived the skull deformation to be more severe compared to other children.

### 4.3.4 Experience and expectations of possible treatment options

Parents were asked what their expectations were of both treatment options. Also respondents were asked how they perceived the risk of side effects due to helmet treatment. In table 22 the experience and expectations of possible treatment options of parents are presented.

Table 19:  
*Experience and expectations of possible treatment options*

Question	Mean (std)	
	Wait and see group	Helmet treatment group
Expectations wait and see	4,17 (1,16)	2,50 (1,01)
Expectations helmet	5,00 (0,00)	4,34 (0,98)
Risk pressure points helmet	3,00 (1,79)	3,31 (1,14)
Risk irritation helmet	3,84 (1,170)	3,19 (1,28)
Risk acceptance problems helmet	1,83 (0,75)	2,25 (1,24)

Respondents could indicate their answer on a scale from 1 to 5, 1= small change, five large chance

Parents that were positive about helmet treatment had significantly less expectations concerning the effect of wait and see (z score -2,62, p 0,008). No significant differences were found concerning the expectations of helmet treatment. Both the helmet group and the wait and see group have approximately the same expectations concerning the reported side effects of orthotic helmet treatment. Reported side effects may be hard to predict beforehand.

### 4.3.5 Fears concerning helmet treatment

The fears of parents concerning helmet treatment can be found in table 23.

Table 20:  
*Fears parents concerning helmet treatment*

Question	Mean (std)	
	Wait and see group	Helmet treatment group
45.Fear remarks helmet	4,00 (1,00)	3,19 (1,38)
46.Fear disease helmet	3,71 (1,11)	3,93 (1,18)
47.Emotional contact helmet	3,86 (1,07)	3,25 (1,29)
48.Fear inconvenience helmet	3,28 (1,50)	3,56 (1,38)

Respondents could indicate their answer on a scale from 1 to 5, 1=strongly agree 5=strongly disagree

Responses of the parents varied between the subjects in both groups, also the standard deviations are large. Therefore no significant differences were found concerning the fears of helmet treatment among respondents. There seems to be no clear relation between the

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fears concerning helmet treatment and the decision whether or not to choose for helmet treatment.

## 5 Conclusions and recommendations

Let's go back to the case of Elise introduced in chapter one:

*Elise had to make the decision whether or not she wanted helmet treatment for her son Joshua. Elise didn't know what to choose. She thought that helmet treatment was uncomfortable for Joshua but on the other hand she wanted to protect him for bullying later on. Finally, she made an appointment with the special office hours for children in the hospital. There, the pediatrician indicated that Joshua was a good candidate for the treatment and that his skull deformation would improve. Two weeks later the helmet was made and Joshua started helmet treatment.*

Paragraph 5.1 of this chapter provides an overview of the performed research. In the next paragraph (5.2), the main and sub-questions of this research will be answered. In paragraph 5.3 the results of this research will be connected to other literature. In paragraph 5.4 the limitations of this research will be discussed. Final remarks and recommendations will be made in paragraph 5.5.

### ***5.1 Overview performed research***

In this research the factors that influence the decision of parents whether or not to start helmet treatment were studied. A literature study was performed to yield topics for the interviews with professionals and parents. Five main influencing factors concerning the decision whether or not to choose helmet treatment surfaced in this literature study. After the literature study was conducted, qualitative interviews were held with a number of parents who have faced the decision whether or not to choose helmet treatment and with several experts like pediatricians and pediatric physical therapists. The five factors mentioned above were used to formulate and structure individual items of the questionnaire. Also a decisional conflict scale was added to the questionnaire to measure the amount of decisional conflict among parents.

The questionnaire was distributed in the waiting rooms of outpatient clinics of two general hospitals and one orthotic device centre. A total of 36 questionnaires were returned (response rate of approximately 50%) and were used to perform a quantitative analysis. The analysis was conducted based on the classification of respondent groups: wait and see group (parents that prefer to wait and see), helmet treatment group (parents

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that prefer helmet treatment) and, decision helmet group (parents who already chose for helmet treatment). The differences between these groups within the topics were studied.

### **5.2 Main results of research**

To gain insight in the extent to which the research questions have been answered, each of the questions will be treated consecutively.

The main research question of this study was:

*What factors influence the decision of parents in the treatment of children with deformational plagiocephaly or brachycephaly?*

Five main factors were identified during this study that have an influence on the decision of parents whether or not to choose helmet treatment: expectations of treatment options, long-term fears of parents, perception of the problem deformational plagiocephaly or brachycephaly, fears concerning helmet treatment, view of consulted information sources and long-term fears of parents concerning the future of their child. Their influence will be described in the sub-questions below.

*1) To what extent do long-term fears concerning the future of children with deformational plagiocephaly/brachycephaly play a role in the decision making regarding the treatment of deformational plagiocephaly and are there differences between parents that choose helmet treatment or wait and see?*

Long-term fears concerning the future of children were often mentioned as an important reason to choose helmet treatment by parents in the qualitative interviews. Parents indicated that they were worried that their child would be bullied with his or her skull deformation. Also the interviewed professionals identified these fears as important in the decision making process of parents. However, respondents of the questionnaire indicated that they were not worried about the future of their child. Due to this contradiction in results it is unclear how much influence long-term fears have on the decision making of parents. For this a bigger sample size is necessary. It is possible that the questions were not formulated specifically enough towards the fears of the skull deformation of children.

*2) To what extent does the perception of parents concerning the problem of deformational plagiocephaly/brachycephaly play a role in the decision making regarding the treatment of deformational plagiocephaly/brachycephaly and are there differences between parents that choose helmet treatment or wait and see?*

The wait and see group and the helmet treatment group differed on their views of the problem. The wait and see group was more satisfied with the shape of the head of the child. Therefore they may perceive the problem as minor. The helmet treatment group also indicated that they thought that the skull deformation was more severe compared to other children than was perceived by the wait and see group.

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It is unclear how the perception of the problem of parents relates to the actual skull deformation of the child, because no objective measure of the skull deformation such as a 'plagiocephalometry' (Van Vlimmeren, 2007) was included in the questionnaire. Unfortunately, little information is known about the view of parents that did not consult pediatric policlinic.

*3) Which information sources are consulted by parents concerning the decision making about possible treatment options regarding deformational plagiocephaly/brachycephaly and are there differences between parents that choose helmet treatment or wait and see?*

### Lay-men

Friends, family and the internet were consulted by most parents. Internet appeared to have a minor influence. All respondent groups indicated that internet was mainly positive towards helmet treatment. Still, the wait and see group preferred to wait and see. Apparently, the positive view on helmet treatment did not influence their preference. The respondents of the wait and see group indicated that family and friends were in general advocates of wait and see. Both the helmet treatment group and the decision helmet group indicated that their environment was an advocate of helmet treatment. This means that family and friends have an influence on the preference of parents. However, it may still be the case that the family and friends adapt their views towards the treatment preferences of parents instead of the other way around.

### Professionals

Most parents perceived the advice of the pediatrician and the pediatric physical therapist as positive or neutral towards helmet treatment. However, the wait and see group preferred to wait and see, although they indicated that the professionals were neutral or advocates of helmet treatment. This might be a sign that the influence of professionals is smaller than professionals might think. This was not statistically proven.

*4) To what extent do fears concerning helmet treatment play a role in the decision making regarding the treatment of deformational plagiocephaly/brachycephaly and are there differences between parents that choose helmet treatment or wait and see?*

The fears of parents concerning helmet treatment varied between and within both groups. Therefore it is unclear how much influence this has on decision-making of parents. In the qualitative interviews one parent had reservations about helmet treatment because she was afraid that people would stare at her child in public. Also pediatric physical therapist and pediatricians confirm that these fears are present among parents. In the questionnaire there was no sign that the wait and see group had more fears towards the helmet treatment. Perhaps the respondents gave social desirable answers (Babbie, 2007).

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*5) To what extent do expectations concerning the treatment options influence the decision making and are there differences between parents that choose helmet treatment or wait and see?*

The expectations of treatment options also play a role in the decision making of parents. Most parents thought that helmet treatment has a positive effect on the skull deformation of their children. The helmet treatment group and the wait and see group however have different expectations of the option wait and see. The helmet treatment group thought that wait and see would have a little or no effect on the skull deformation whereas the wait and see group was more positive about wait and see. So, parents seem to choose the treatment option which they perceive to have the best result. However, it is also possible that parents adapt their expectations towards their treatment preferences, maybe to justify their own decision.

*6) How much decisional conflict is experienced by parents about their decision concerning the treatment of deformational plagiocephaly and are there differences between parents that choose helmet treatment or wait and see?*

The wait and see group experienced a bit more decisional conflict in comparison to the helmet treatment group and the decision helmet group. Due to the fact that the measurement for decisional conflict, the decisional conflict scale (O'Connor, 1995) was adapted for this study, the results cannot be compared to other studies. Maybe some respondents are in the wait and see group because they experience a lot of decisional conflict, and it is easier for them to choose the treatment option that requires no further effort.

*7) What is the view of the pediatric physical therapist and the pediatrician concerning the treatment options of deformational plagiocephaly/brachycephaly and what information do these professionals give to parents concerning the treatment options of deformational plagiocephaly/brachycephaly?*

The interviewed pediatric physical therapists were positive about helmet treatment. Also one of the two interviewed pediatricians was positive about helmet treatment. One pediatrician that is an advocate of wait and see indicated that she was not convinced of the effect of helmet treatment and never prescribed helmet treatment. She indicated that most parents follow-up on her advice to wait and see.

Both the interviewed pediatricians and pediatric physical therapists indicate that they can influence the decision-making of parents but they try to stay neutral in their attitude towards helmet treatment. However, the information given about helmet treatment by the pediatric physical therapists is mostly positive. The pediatrician that is an advocate of helmet treatment indicated that she tries to be realistic about the effects of helmet treatment.

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The advice of the pediatrician and the pediatric physical therapist whether or not to start helmet treatment is based on the development of the positional preference of children and the development of the degree of the skull deformation.

### *5.3 Comparison towards other research*

Point of depart of this research was that parents can make their own decision whether or not to choose helmet treatment. This research illustrates that parents have different views on the relationship with their pediatrician. Some parents use the doctor as an agent in which the patient is the final arbiter of all important decisions (McKingstry, 1992). This relationship was illustrated by the fact that some parents overruled the advice of the physician not to start helmet treatment. Also this research illustrates that some parents perceive their patient-doctor relationship as paternalistic, in which the doctor knows what is best for the patient. A parent in the interview indicated that they will listen to the advice of the pediatrician concerning the best treatment option for her child.

The 'RAND' experiment performed in the US (Lapre, Rutten, Schut, 2001) shows that the increase of own payments decrease the use of medical care for minor symptoms, and also the use of less effective non-clinical care. Helmet treatment is a treatment for a minor symptom and the effects were never proven in a Randomized Controlled Trail. In the Netherlands, helmet treatment is available free of charge, because it is part of the health insurance plan. This could enhance the use of helmets, opposed to countries were parents have to pay for themselves.

Denig, Haaijer, Ruskamp and Zijlsing (1988) studied the prescription pattern for irritable bowel syndrome and renal colic of three drugs. They concluded that drug preferences were more related to expectancies about efficacy of the drugs then to expectancies about side effects. In this study there was no difference between the wait and see group and the helmet treatment group concerning the side effects of helmet treatment, but there was a difference in expectations concerning the option wait and see. However, in both the helmet treatment group and the wait and see group the expectations of wait and see were different, which was of more influence on the decision than the fear of possible side effects of helmet treatment, which is described by Denig et al. (1998) as well.

In the US many newborns are routinely circumcised. However, the effectiveness of the circumcision is heavily debated (Schoen, 2006). Adler, Ottaway & Gould (2001) analyzed the parental attitudes towards circumcision using a survey. The reasons whether or not to circumcise were often not related to the clinical evidence of circumcision. Also Binner, Mastrobattista, Day, Swaim & Monga (2002) found that decision making in circumcision is based on beliefs and traditions. Binner et al. (2002) investigated the influence of unbiased information about circumcision. Mothers were given brochures about circumcision and attitudes and beliefs were measured before and after reading the brochure. Binner et al. (2002) concluded that views of the parents did not change after reading the brochure. This shows that decision making of parents was not altered by objective information regarding treatment options. In this study parents mentioned that they were aware of the fact that

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the effect of helmet treatment was never proven in an Randomized Controlled Trail but still continued the treatment. It is still possible that parents want helmet treatment, although the Randomized Controlled Trail proves that this is not an effective treatment option. However, circumcision in the US is a cultural tradition, opposed to helmet treatment that is not part of Dutch culture. Therefore, the feelings concerning helmet treatment are probably not that strong.

The fears of parents concerning the skull deformation of their child may also be cured by helmet treatment, in which the helmet functions as a 'placebo' (Brody & Brody, 2000) for parents. The helmet might reduce stress because parents have the feeling that something is done about the skull deformation of their child.

### ***5.4 Limitations of research***

This study contributes to the theory concerning the factors influencing the decision making in the treatment of deformational plagiocephaly or brachycephaly. This study is the first study conducted on this topic. Two methods were used to gather data concerning the influencing factors of the decision of parents whether or not to choose helmet treatment. The first method of this study was qualitative. The interviews that were held were structured with the help of a topic list. Advantage of this method is that no important topics could be missed but due the rigor of a structured method, the interviewed respondents might have been less stimulated to come up with other topics themselves (Babbie, 2007). Also, the researcher was not experienced in performing qualitative interviews which may have influenced the direction of the interview and the answers given in the interview. The second method of this study was quantitative. Questionnaires make use of standardized answers which makes it difficult to explain responses. Also, questions might be misinterpreted by respondents. (Babbie, 2007). Some questionnaires were completed after the decision was made, and therefore the respondents might have forgotten important issues.

Due to the small group of respondents, results are difficult to generalize to a larger population. For this, a study with more respondents is necessary. The sample of the parents that wanted to wait and see was small. However, the group of parents that choose to wait and see is small in general according to the interviewed pediatric physical therapists.

A selection bias (Babbie, 2007) was present due to the fact that all parents that visited the outpatient clinic were parents that were motivated to seek help for the skull deformation of their child. This decision was made due to practical reasons; parents that decided not to consult the clinic were not part of the study.

About 60 questionnaires were spread of which 36 were returned therefore the response rate was over 50 % which is not high (Babbie, 2007). It is unclear how the non-responders differ from the group that did complete the questionnaire.

### ***5.5 Concluding remarks and recommendations***

The objective of the study was to retrieve the factors influencing the decision of parents to choose wait and see or helmet treatment. Five main influencing factors were found to be of influence to the decision of parents. More insight has been gained in how much influence these factors have on parents facing the decision. The factors of influence mentioned by the professionals matched with what parents themselves considered to be of importance. The results found in the interviews, however, sometimes contradicted the results found in the questionnaire, especially when it comes to fears expressed by parents. These fears concern the helmet itself and the future of children with plagiocephaly. These contradictions are an interesting topic to investigate further using a larger sample group.

The design of the study could be changed. If the parents are interviewed multiple times before and after the decision, the factors influencing decision making can be made clearer. This follow-up study is possible with close cooperation of youth health care centres and pediatric physical therapists. The influence of these professionals, and also the satisfaction with the decision can be monitored more closely this way.

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## Appendices

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*Appendix 1: questionnaire 1*



Kenmerk: VV1

Beste ouders,

Allereerst hartelijk dank dat u mee wilt werken aan dit onderzoek. Dit onderzoek is gericht op de behandeling van een schedelafplatting bij kinderen onder een jaar. Met een schedelafplatting wordt in dit onderzoek een rechte schedelafplatting (of brachycefalie) of een scheve schedelafplatting (of plagiocefalie) bedoeld.

Een schedelafplatting kan worden behandeld met een helm. Ook kan er voor worden gekozen om af te wachten. Met afwachten wordt bedoeld dat ervoor wordt gekozen om de natuur zijn werk te laten doen. Het is nog niet wetenschappelijk bewezen welke methode de beste is. Daarom is de Universiteit Twente geïnteresseerd welke afwegingen ouders maken in hun beslissing om wel of niet voor helmbehandeling te kiezen.

Om dit te onderzoeken hebben we de volgende vragenlijst ontwikkeld. Wilt u bij elke vraag het antwoord aankruisen dat het meest op u van toepassing is? Sommige antwoorden in de vragenlijst worden gegeven op een vijf-puntsschaal. De uitersten van de schaal zijn aangegeven bij elke vraag.

Het invullen van de vragenlijst zal ongeveer 20 minuten in beslag nemen. Neem er rustig de tijd voor. Er bestaan geen goede of slechte antwoorden.

De ingevulde vragenlijsten kunt u opsturen in de bijgevoegde envelop.

Als u vragen heeft over het onderzoek, dan kunt u contact opnemen met onderstaande personen.

Met vriendelijke groeten,

Hilde Nijland & Dr. van Til, Universiteit Twente.

Universiteit Twente  
Health Technology and Services Research  
Postbus 217  
7500 AE Enschede

E-mail           j.a.vantil@utwente.nl  
Telefoon        053 4893351 (ma, di, vr)



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<b>17.</b>	Ik weet niet zeker wat ik moet beslissen Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>18.</b>	Het is duidelijk wat voor mijn kind de beste keuze is Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>19.</b>	Ik ben mij bewust van de keuze die ik heb tussen twee verschillende opties Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>20.</b>	Ik heb het gevoel dat ik op de hoogte ben van de voordelen van de twee opties Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>21.</b>	Ik heb het gevoel dat ik op de hoogte ben van de nadelen van de twee opties Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>22.</b>	Ik heb meer advies en informatie nodig over de keuzemogelijkheden Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>23.</b>	Ik weet hoe belangrijk de voordelen van afwachten voor mijn beslissing zijn Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>24.</b>	Ik weet hoe belangrijk de nadelen van afwachten mijn beslissing zijn Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>25.</b>	Ik weet hoe belangrijk de voordelen van helmbehandeling voor mijn beslissing zijn Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>26.</b>	Ik weet hoe belangrijk de nadelen van helmbehandeling voor mijn beslissing zijn Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>27.</b>	Ik voel me bij het nemen van deze beslissing door anderen onder druk gezet Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>28.</b>	Ik krijg voldoende steun van anderen bij het maken van deze keuze Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>29.</b>	Zijn u en uw partner het eens over de te nemen beslissing? <div style="display: flex; justify-content: flex-end; align-items: flex-start; margin-left: 20px;"> <input type="checkbox"/> Ja  <input type="checkbox"/> Nee  <input type="checkbox"/> Niet van toepassing         </div>
Hieronder volgen enkele vragen naar uw mening over het hoofd van uw kind	
<b>30.</b>	Wat vindt u op dit moment van de vorm van het hoofdje van uw kind? Hierover ben ik: Helemaal niet tevreden <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Heel tevreden
<b>31.</b>	Wat vindt u op dit moment van de vorm van het gezichtje van uw kind? Hierover ben ik: Helemaal niet tevreden <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Heel tevreden
<b>32.</b>	Maakt u zich zorgen dat hij/zij later gepest zal worden? Heel bezorgd <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Niet bezorgd
<b>33.</b>	Maakt u zich zorgen dat hij/zij later onzeker zal zijn vanwege zijn/haar uiterlijk? Heel bezorgd <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Niet bezorgd
Hieronder volgen enkele vragen over de verwachtingen die u hebt van de verschillende behandel -mogelijkheden	
<b>34.</b>	Hoeveel herstel van de scheefheid van het hoofd verwacht u zonder helmbehandeling? Helemaal geen herstel <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Volledig herstel
<b>35.</b>	Hoeveel herstel van de scheefheid van het hoofd van verwacht u van helmbehandeling? Helemaal geen herstel <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Volledig herstel

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<b>36.</b>	Hoe groot denkt u dat het risico is dat uw kind drukplekken ontwikkeld ten gevolge van een helm?  Kleine kans <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Grote kans
<b>37.</b>	Hoe groot denkt u dat het risico is dat uw kind huidirritatie en eczeem ontwikkeld ten gevolge van een helm?  Kleine kans <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Grote kans
<b>38.</b>	Hoe groot denkt u dat het risico is dat uw kind problemen heeft met de acceptatie van een helm?  Kleine kans <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Grote kans
Hieronder volgen enkele uitspraken die gedaan zijn door ouders van kinderen met een schedelafplatting. Wilt u aangeven in hoeverre u het eens bent met de uitspraken?	
<b>39.</b>	Ik voel me schuldig over de schedelafplatting van mijn kindje. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>40.</b>	Ik heb de behoefte iets te doen aan de schedelafplatting van mijn kindje. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>41.</b>	Ik ben bang dat ik later spijt krijg als ik <i>niet</i> voor helmbehandeling kies. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>42.</b>	De schedelafplatting bij mijn kindje is ernstiger dan bij andere kinderen met een schedelafplatting. helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> helemaal mee oneens
<b>43.</b>	Een schedelafplatting heeft slechts uiterlijke gevolgen voor een kind. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>44.</b>	Ik ben bang dat mijn kind mij op latere leeftijd verwijten gaat maken over een blijvende schedelafplatting. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>45.</b>	Ik ben bang dat <i>als ik voor een helm kies</i> , andere mensen hierover opmerkingen zullen maken. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>46.</b>	Ik ben bang dat <i>als ik voor een helm kies</i> , andere mensen zullen denken dat mijn kindje een ernstige ziekte heeft. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>47.</b>	Ik ben bang dat <i>als ik voor een helm kies</i> , ik minder lichamenlijk en emotioneel contact kan maken met mijn kindje. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>48.</b>	Ik ben bang dat <i>als ik voor een helm kies</i> , mijn kindje hinder zal ondervinden van de helm. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>49.</b>	Ik ben bang dat <i>als ik voor afwachten kies</i> , andere mensen me zullen verwijten dat ik mijn kindje niet de beste zorg geef. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens

De volgende vragen gaan over de informatie die u hebt gezocht en gevonden over de schedelafplatting en de mogelijke behandeling ervan. Welke informatiebronnen over de behandeling heeft u gebruikt? U kunt meerdere antwoorden aankruisen. Kunt u per informatiebron aangeven wat uw indruk was van de houding van de 'informatiebron' over de mogelijke behandeling van een schedelafplatting?

	Informatiebron	Geraadpleegd?	Voorstander van	Neutraal	Voorstander van
--	----------------	---------------	-----------------	----------	-----------------

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		ja	Nee	helmbehandeling		afwachten
50.	Internet	<input type="checkbox"/>				
51.	Familie	<input type="checkbox"/>				
52.	Vrienden	<input type="checkbox"/>				
53.	Kinderfysiotherapeut	<input type="checkbox"/>				
54.	Kinderarts	<input type="checkbox"/>				
55.	Huisarts	<input type="checkbox"/>				
56.	Helmbehandelaar	<input type="checkbox"/>				
57.	Anders, nl .....	<input type="checkbox"/>				
58.	Anders, nl .....	<input type="checkbox"/>				

Dit was de laatste vraag. **Bedankt voor uw medewerking aan dit onderzoek!**

Als u nog niet definitief hebt gekozen voor de behandeling van uw kind, zouden wij u graag over een half jaar benaderen om te vragen welke keuze u heeft gemaakt. Als wij u mogen benaderen met deze vraag, wilt u dan hieronder uw contactgegevens invullen en de manier waarop u het liefst benaderd wordt?

Naam: ..... Neem contact met mij op per:

Adres: .....  post

Postcode: .....  telefoon

Telefoon: .....  e-mail

E-mail adres: .....@.....



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<b>16.</b>	Ik vond het moeilijk om deze beslissing te nemen Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>17.</b>	Ik wist niet zeker wat ik moet beslissen Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>18.</b>	Het is duidelijk wat voor mijn kind de beste keuze was Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>19.</b>	Ik was mij bewust van de keuze die ik had tussen twee verschillende opties Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>20.</b>	Ik heb het gevoel dat ik op de hoogte was van de voordelen van de twee opties Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>21.</b>	Ik heb het gevoel dat ik op de hoogte was van de nadelen van de twee opties Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>22.</b>	Ik had meer advies en informatie nodig over de keuzemogelijkheden Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>23.</b>	Ik wist hoe belangrijk de voordelen van afwachten voor mijn beslissing waren Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>24.</b>	Ik wist hoe belangrijk de nadelen van afwachten mijn beslissing waren Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>25.</b>	Ik wist hoe belangrijk de voordelen van helmbehandeling voor mijn beslissing waren Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>26.</b>	Ik wist hoe belangrijk de nadelen van helmbehandeling voor mijn beslissing waren Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>27.</b>	Ik voelde me bij het nemen van deze beslissing door anderen onder druk gezet Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>28.</b>	Ik kreeg voldoende steun van anderen bij het maken van deze keuze Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>29.</b>	Zijn u en uw partner het eens over de te nemen beslissing? <div style="display: flex; align-items: flex-start; margin-left: 40px;"> <input type="checkbox"/> Ja  <input type="checkbox"/> Nee  <input type="checkbox"/> Niet van toepassing </div>
<b>30.</b>	Ik heb het gevoel dat ik goed geïnformeerd was toen ik mijn beslissing nam Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>31.</b>	Mijn beslissing geeft aan wat voor mij belangrijk is Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
<b>32.</b>	Ik ben tevreden over mijn beslissing Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
Hieronder volgen enkele vragen naar uw mening over het hoofd van uw kind	
<b>33.</b>	Wat vindt u op dit moment van de vorm van het hoofdje van uw kind? Hierover ben ik: Helemaal niet tevreden <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Heel tevreden
<b>34.</b>	Wat vindt u op dit moment van de vorm van het gezichtje van uw kind? Hierover ben ik: Helemaal niet tevreden <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Heel tevreden
<b>35.</b>	Maakt u zich zorgen dat hij/zij later gepest zal worden? Heel bezorgd <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Niet bezorgd
<b>36.</b>	Maakt u zich zorgen dat hij/zij later onzeker zal zijn vanwege zijn/haar uiterlijk? Heel bezorgd <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Niet bezorgd

## Shaping your child's future?!

	Hieronder volgen enkele vragen over de verwachtingen die u hebt van de verschillende behandel opties
37.	Hoeveel herstel van de scheefheid van het hoofd verwacht u zonder helmbehandeling? Helemaal geen herstel <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Volledig herstel
38.	Hoe tevreden bent u met het herstel van de scheefheid van het hoofd van uw kind? Helemaal niet tevreden <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal niet tevreden?
	Hieronder volgen enkele uitspraken die gedaan zijn door ouders van kinderen met een schedelafplatting. Wilt u aangeven in hoeverre u het eens bent met de uitspraken?
39.	Ik voelde me schuldig over de schedelafplatting van mijn kindje. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
40.	Ik had de behoefte iets te doen aan de schedelafplatting van mijn kindje. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
41.	Ik was bang dat ik later spijt zou krijgen als ik <i>niet</i> voor helmbehandeling zou kiezen. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
42.	De schedelafplatting bij mijn kindje was ernstiger dan bij andere kinderen met een schedelafplatting. helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> helemaal mee oneens
43.	Een schedelafplatting heeft slechts uiterlijke gevolgen voor een kind. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
44.	Ik ben bang dat mijn kind mij op latere leeftijd verwijten gaat maken over een blijvende schedelafplatting. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens
45.	Ik ben bang dat <i>als ik voor afwachten had gekozen</i> , andere mensen me zouden verwijten dat ik mijn kindje niet de beste zorg geef. Helemaal mee eens <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Helemaal mee oneens

De volgende vragen gaan over de informatie die u hebt gezocht en gevonden over de schedelafplatting en de mogelijke behandeling ervan. Welke informatiebronnen over de behandeling heeft u gebruikt? U kunt meerdere antwoorden aankruisen. Kunt u per informatiebron aangeven wat uw indruk was van de houding van de 'informatiebron' over de mogelijke behandeling van een schedelafplatting?

	Informatiebron	Geraadpleegd?		Voorstander van helmbehandeling	Neutraal	Voorstander van afwachten
		ja	Nee			
46.	Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47.	Familie	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48.	Vrienden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49.	Kinderfysiotherapeut	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50.	Kinderarts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51.	Huisarts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52.	Helmbehandelaar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53.	Anders, nl .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54.	Anders, nl .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Appendix 3: topic list pediatrician*

**Vragen kinderarts**

- Introductie: Wat is precies uw rol als kinderarts in het zorgtraject voor kinderen met een schedelafplatting? (en open spreekuur)
- Welke ouders komen hier bij u? Welke hulpvraag hebben deze over het algemeen? (hebben ze al gekozen voor een helm of niet?)
- Hoe staat u tegenover helmtherapie? (comfort, effect, kosten)
- Hoe staat u tegenover een afwachtende houding?
- Indien er sprake is van een grijs gebied in de plagiocefalometrie meting waarop wordt het advies gebaseerd om te kiezen voor de helm of niet?
- In hoeverre denkt u dat uw advies meespeelt bij ouders in het kiezen voor een helm of niet binnen het grijze gebied (of ook daarbuiten)?
- Welke verwachtingen denkt u dat ouders hebben van helmbehandeling?
- Welke verwachtingen denkt u dat ouders hebben ten aanzien van niets doen?
- Waarom denkt u dat ouders kiezen voor helmbehandeling?
- Waarom denkt u dat ouders kiezen voor niets doen?
- Met welke angsten/attitudes/onzekerheden van ouders wordt u geconfronteerd? (op welke manier? /welke zijn dit?)
- Opmerkingen /aanmerkingen?
- Zaken gemist?

## *Appendix 4: topic list parents*

### Informatie

- In hoeverre denk heeft de informatie die je kreeg invloed gehad op je besluitvorming?
- Welke informatie wordt/werd door kft gegeven over helmbehandeling/afwachtende houding

### Mening professionals

- In hoeverre denk je dat mening jou van andere professionals meespeelt in de besluitvorming?
- Wat vinden de betrokken professionals van een redressiehelm?
- Welke informatie heb je gehad omtrent redressiehelm, zie ook vraag hierboven.

### Comfort helmbehandeling

- In hoeverre denk je dat comfort het comfort van de behandeling mee heeft gespeeld in de besluitvorming?

### Complicaties helmbehandeling

- Verhoogde hersendruk: maken ouders zich hier zorgen om?

### Cosmetiek

- In hoeverre is cosmetiek van het uiterlijk belangrijk voor je. In hoeverre speelt dit mee in de keuze voor een behandeling?
- Bestaat er een verschil tussen brachycefalie en plagycefalie? Het feit dat het een jongen meisje is?

### Verwachtingen effect van de behandeling?

- Welke verwachtingen hebben ouders van helmbehandeling?
- Wat weten ouders over het effect van de behandeling?
- Welke verwachtingen hebben ouders van een afwachtende houding?
- In hoeverre speelt dit mee in de keuze?

### Uiterlijk van de behandeling

In hoeverre is dit voor ouders belangrijk?

## Shaping your child's future?!

### Waarden, attitudes en gevoelens ouders

- Welke waarden, attitudes en gevoelens spelen mee? (schuldgevoelens, angst toekomst)
- Hoe speelt dit mee? In welke mate speelt het mee?

### Besluiten onder onzekerheid

- Wat doet dit met ouders?

### Overige vragen

- Nog aanvullingen opmerkingen?
- Is er iets dat je hebt gemist in het interview?

## *Appendix 5: topic list pediatric physical therapists*

### **Interview kinderfysiotherapeuten**

Niet vergeten: uitleg geven over topic interview aan geïnterviewde! Ook dat het opgenomen wordt.

Achterrond fysiotherapeut, werkervaring, werkgebied, etc.

### **Topic lijst en bijbehorende vragen om het gesprek eventueel op gang te brengen**

#### Informatie

- In hoeverre denk je dat informatie meespeelt in de besluitvorming?
- Welke informatie wordt door kft gegeven over helmbehandeling / fysiotherapie?

#### Mening professionals

- In hoeverre denk je dat jou mening/ de mening van andere professionals meespeelt in de besluitvorming?
- Wat vind je zelf van een redressiehelm?
- Welke informatie geven jullie omtrent de redressiehelm, zie ook vraag hierboven.

#### Comfort helmbehandeling

- In hoeverre denk je dat comfort meespeelt in de besluitvorming?

#### Complicaties helmbehandeling

- Verhoogde hersendruk: maken ouders zich hier zorgen om?

#### Cosmetiek

- In hoeverre is cosmetiek van het uiterlijk belangrijk voor ouders. In hoeverre speelt dit mee in de keuze voor een behandeling?
- Bestaat er een verschil tussen brachycefalie en plagycefalie? Het feit dat het een jongen meisje is?

#### Verwachtingen effect van de behandeling?

- Welke verwachtingen hebben ouders van helmbehandeling?
- Wat weten ouders over het effect van de behandeling?
- Welke verwachtingen hebben ouders van een afwachtende houding?

## Shaping your child's future?!

- In hoeverre speelt dit mee in de keuze?

### Uiterlijk van de behandeling

In hoeverre is dit voor ouders belangrijk?

### Waarden, attitudes en gevoelens ouders

- Welke waarden, attitudes en gevoelens spelen mee?
- Zijn hier verschillen in bij ouders?
- Hoe speelt dit mee? In welke mate speelt het mee?

### Besluiten onder onzekerheid

- Wat doet dit met ouders?

### Overige vragen

- Nog aanvullingen opmerkingen?
- Is er iets dat je hebt gemist in het interview?

### **Minimaal resultaat interviews:**

- Zijn de genoemde afwegingen die ouders maken genoemd in de topiclijst van belang in de praktijk? En in welke mate? Bovengenoemde factoren allemaal bespreken!
- De rol van de kft in het besluitvormingsproces van ouders.