PARENTS' PERCEPTION OF HEALTH-RELATED QUALITY OF LIFE AND HOPE FOR THEIR CHILD LIVING WITH PLAGIOCEPHALY: A CASE SERIES

Honors Thesis

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Abstract

Purpose: To examine Positional Plagiocephaly and its relationship to the parents' perception of the quality of life (QOL) and hope for the future of their child.

Study Design and Methods: For the purpose of this honors thesis, a descriptive case series with parent interviews of their experience, with infants and toddlers with Positional Plagiocephaly was conducted. In addition themes from parental postings from a web-based social network for parents of children treated for Positional Plagiocephaly were constructed.

Results: A convenience sample of three cases with six parents and themes from the social network were obtained. Two of the case studies were family members and the third case study was a friend of a colleague. Posts made by parents from three pages on a social network were obtained. Consent was obtained prior to the start of the interviews. This project was accepted by the Institutional Review Board (IRB) at Salem State University. The student researcher also completed the Collaborative Institutional Training Initiative (human subject training). This research demonstrated that larger case series are needed to look at the long term effects of this diagnosis. Both qualitative and quantitative studies on the nurse's role, health- related quality of life (HRQOL), and hope measures need to be conducted. This research may also help nurses, and other medical personnel, address issues that parents, whose child has Positional Plagiocephaly, are concerned about.

Keywords: Positional Plagiocephaly, Parents' perception, Health-related Quality of Life (HRQOL), hope for the future, Case study

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Introduction

The purpose of this study is to examine Positional Plagiocephaly (PP) and its relationship to the parents' perception of the quality of life (QOL), and hope for the future of their child. After completing an initial literature search on Positional Plagiocephaly, there is little published on this topic outside of medical diagnosis, and treatment. Thus, more investigation on this topic is clearly needed. There needs to be more research about the effects and perception of this diagnosis not only on the child, but also on the perspective of the parents. There is extensive literature regarding parental perception, on the quality of life for their child who has a certain chronic condition (Drotar, 1998). However, after the initial literature search was performed, there was a lack of any research regarding the parental perception for children who have Positional Plagiocephaly. The results of this research will enable this author to draw practical conclusions about how best, as a nurse, to help address issues for families with children diagnosed with Positional Plagiocephaly. This research may also help nurses, and other medical personnel, address issues that parents, whose child has Positional Plagiocephaly, are concerned about.

Aside from the lack of literature and research on this topic, this research is being done to find out more information, because there is a personal connection to the subject. One family member has a three year old daughter who had Positional Plagiocephaly, and was treated with a cranial remodeling helmet. The second family member has a ten month old son who had Positional Plagiocephaly, and was also treated with a cranial remodeling helmet. Based on personal experience, the question that is raised from this diagnosis is; are there any repercussions from this diagnosis? The other questions that are raised are; how do the parents feel about this diagnosis and do they have any future concerns about their child?

Background and Significance

In April 1992, the American Academy of Pediatrics (AAP) recommended to place children on their sides or on their backs for sleeping (Kattwinkel, Brooks, Keenan, Malloy, & Willinger, 1996). The purpose of this recommendation was to decrease the likelihood of Sudden Infant Death Syndrome (SIDS) (Kattwinkel et al., 1996). After the recommendations from the American Academy of Pediatrics were released, the "Back to Sleep" campaign was launched (Kattwinkel et al., 1996). The purpose of this campaign was to decrease the likelihood of Sudden Infant Death Syndrome (SIDS). Since the recommendation of American Academy of Pediatrics was released there has been a decrease in the occurrence of Sudden Infant Death Syndrome (SIDS), however, there has been an increase in the occurrence of children with Positional Plagiocephaly (Bialocerkowski, Vladusic, & Ng, 2008; Elwood, Petronio, & Wood, 2005; Govaert, Michels, Colla, & van der Hulst, 2008; Hutchison, B., Hutchison, L., Thompson, & Mitchell, 2004; Katzel, Koltz, Sbitany, & Girotto, 2011; Kelly, Littlefield, Pomatto, Manwaring, & Beals, 1999; McGarry, Dixon, Greig, Hamilton, Sexton, & Smart, 2008; Miller, Johnson, Duggan, & Behm, 2011; Steinbok, Lam, Singh, Mortenson, & Singhal, 2007; van Vlimmeren, van der Graaf, Boere-Boonekamp, L'Hoir, Helders, & Engelbert, 2007; van Vlimmeren, van der Graaf, Boere-Boonekamp, L'Hoir, Helders, & Engelbert, 2008; Xia, Kennedy, Teichgraeber, Wu, Baumgartner, & Gateno, 2008).

The American Academy of Pediatrics released another recommendation in 1996, stating that all children should be placed in a supine position for sleeping (Kattwinkel et al., 1996). In this updated recommendation, it was noted that a certain amount of "tummy time" should be implemented while the child is awake. The American Academy of Pediatrics recommends the practice of "tummy time" to prevent flat spots on the occipital region of the child's head, and for developmental reasons (Kattwinkel et al., 1996). Along with "tummy time" it was suggested for the parents to limit the amount of time that the child spends in one position, for example, on their back or in the car seat (Hutchison et al., 2004; Miller et al., 2011). According to Miller et al., (2011) the key intervention for preventing gross motor delays and Plagiocephaly in infants is "tummy time". When the child is on their stomach or in a prone position during "tummy time", the child is challenged physically and is able to begin to develop head control and muscle strength (Miller et al., 2011). According to the literature, parents have been placing their child in the supine position, to comply with the recommendation from the American Academy of Pediatrics (Miller et al., 2011).

According to some literature, Positional Plagiocephaly can potentially cause developmental delays, but there has not been any reliable causational relationship found (Kattwinkel, Hauck, Keenan, Malloy, & Moon, 2005; Hutchison, Stewart, & Mitchell, 2011; Miller et al., 2011). Based on the literature it is implied that the parents are avoiding placing their child in other positions. The lack in changing positions can cause some of the children to develop Positional Plagiocephaly. However since there is little research done on this topic, it is difficult to conclude what problems are caused by Positional Plagiocephaly. Specifically, there is not enough research on the parents' perspective of the child's quality of life (QOL), or the parents' hope for their child's future. It is important to determine what concerns the parents have and what needs to be addressed by medical personnel. Positional Plagiocephaly is treatable, and any concerns that parents have, need to be addressed so they are informed of all of the options when treating Positional Plagiocephaly. By researching this topic, it is the hope that awareness will be raised and research about this topic will increase.

The Related Literature

Positional Plagiocephaly

Positional Plagiocephaly is also known as Deformational Plagiocephaly (DP), or non-synostotic plagiocephaly (Bialocerkowski, et al., 2008; Hutchison et al., 2004; Kelly, Littlefield, Pomatto, Ripley, Beals, & Joganic, 1999; Kelly, Littlefield, Pomatto, Manwaring, & Beals, 1999; McGarry, et al., 2008). Positional Plagiocephaly refers to a condition where the head is an asymmetrical shape that has arisen from extrinsic molding factors, rather than intrinsic synostotic events (Kelly, Littlefield, Pomatto, Ripley, Beals, & Joganic, 1999; Kelly, Littlefield, Pomatto, Manwaring, & Beals, 1999).

There are many risk factors that may contribute to developing Positional Plagiocephaly. Some of the risk factors that have been identified are: male gender, first born child, prematurity, developmental delays, lower activity levels, torticollis or any imbalance of the neck muscle function, difficult delivery, positional preference, and supine position (Bialocerkowski, et al., 2008; Hutchison et al., 2004; Hutchison et al., 2011; Kelly, Littlefield, Pomatto, Ripley, Beals, & Joganic, 1999; Looman, & Flannery, 2012; van Vlimmeren et al., 2007; van Vlimmeren et al., 2008).

The two options that are available for treating Positional Plagiocephaly are cranial orthotic (helmet) therapy or repositioning (Bialocerkowski, Vladusic, & Howell, 2005; Elwood, et al., 2005; Xia et al., 2008). Treatment with the use of cranial helmets or headbands applies pressure to the prominent areas of the head while allowing room for growth for the areas of the head that are more flat (Steinbok et al., 2007). Cranial helmets and headbands are custom made for each child (Elwood, et al., 2005; Steinbok et al., 2007). The helmet is made from a shell made of a lightweight plastic and this hard outer shell is lined with foam (Boston Children's Hospital, 2013). Repositioning or active counter-positioning is the easiest therapy to introduce, and is also the least expensive treatment, because there is no associated cost (Steinbok et al., 2007). With repositioning therapy, the child's head is placed on the side that does not have the occipital flattening (Steinbok et al., 2007). Physical therapy can also be used to help treat children with Positional Plagiocephaly and/ or torticollis (Flannery, Looman, & Kemper, 2012).

Treatment for Positional Plagiocephaly with the use of a cranial helmet to reshape the infant's head shape usually begins after the age of four months. Before the age of four months, the infant is not able to their head up without support (Looman et al., 2012). This is the reason that treatment is not started before the age of four months. The reason the age of the child at treatment is important, is due to the importance of capturing the growth spurts of the child (Kelly, Littlefield, Pomatto, Ripley, Beals, & Joganic, 1999; Kelly, Littlefield, Pomatto, Manwaring, & Beals, 1999). To correct the head shape, with the use of a cranial helmet, it needs to be worn 23 hours a day for 3 to 6 months to obtain the best results (Boston Children's' Hospital, 2013; Steinbok et al., 2007).

When looking at studies that compare helmet vs. repositioning therapy, there were only three studies found in the literature review, that examined the long-term outcomes of treatment for children with Plagiocephaly (Hutchison et al., 2011; Lee, Teichgraeber, Baumgartner, Waller, English, Lasky, Miller, Gateno, & Xia, 2008; Steinbok et al., 2007). Of these three studies, two of the studies had a very small number of participants. The study by Steinbok et al. (2007), only had 27 participants, and the study by Lee et al.

(2008), only had 28 participants. The third study by Hutchison et al. (2011), had 129 participants. The first study looked at cosmetic outcomes in children who were five years old or older and had been treated with a helmet or headband (Steinbok et al., 2007). This study sent out a questionnaire asking parents about the cosmetic appearance of their child's head. Of the 278 total questionnaires sent out, they received 65 completed questionnaires (23% response rate) (Steinbok et al., 2007). Of the total 65 questionnaire responses, there were 50 parents who indicated that they had no concern about their child's head shape in the past year (Steinbok et al., 2007). The authors found that those children treated with a cranial orthotic such as a helmet or headband, had more of an improvement in the symmetry of the child's head shape (Steinbok et al., 2007). The second study by Lee et al. (2008), looked at children who had been treated with helmet therapy, and were at least five years old at the time of the study. The authors found that there was very little change that occurred in the post treatment phase. However, there was a significant change while being treated with helmet therapy (Lee et al., 2008). The third study by Hutchison et al. (2011), looked at 129 children who were between the ages of three and four years old, whose parents had treated their child's Plagiocephaly using repositioning therapy. The authors found that 85% of the parents were 'very' or 'somewhat' concerned, and 15% of the parents were 'not very' concerned, at the initial assessment of their child's head shape (Hutchison et al., 2011). At the follow-up, the authors found that 13% of parents were 'very' or 'somewhat' concerned, 28% of the parents were 'not very' concerned, and 59% of the parents were 'not at all' concerned. The studies by Hutchison et al. (2011), and Steinbok et al. (2007), were the only two studies that looked at the parental perceptions of the child's head shape, out of the three studies that looked at the long-term outcomes of treatment for Plagiocephaly. Both of these studies found that the parents were satisfied with the shape of their child's head.

Parents' Perception of Health-Related Quality of Life (HRQOL) with Positional Plagiocephaly

Previous research has been done regarding the quality of life and parental satisfaction concerning the shape of their child's head, after molding therapy. For example, Govaert, Michels, Colla, and van der Hulst (2008) asked parents of children with Positional Plagiocephaly to answer two questionnaires about their child. The first questionnaire, the TNO-AZL Preschool Children Quality of Life (TAPQOL) scale, asked the parents about twelve different areas of interest related to quality of life, for their child. The items from the twelve areas were evaluated, which gave a total score of the quality of life (QOL). The second questionnaire asked parents to rate the shape of their child's head on a scale of zero to ten. Parents were also asked if they would repeat the treatment, and if they had any health-related problems or other issues prior to start of the study. The results indicated that there were no significant differences, between the control group (typically healthy children) and the children who had molding helmet therapy, in the areas that were covered by the TNO-AZL Preschool Children Quality of Life (TAPQOL) scale. The study did find that there was a significant improvement of the parents' subjective rating of the child's head shape, after the molding helmet therapy. At the beginning of the study, the average score for the parents' subjective rating for their child's head shape was 3.6. At the end of the study, the average score for the rating of their child's head shape was 7.5 (Govaert, et al., 2008). The authors concluded that based on the results of the study, molding helmet therapy is an effective treatment for Positional

Plagiocephaly. The authors discussed that there have been no previous studies evaluating the long-term quality of life for children, who were treated with molding helmet therapy after being diagnosed with Positional Plagiocephaly. Their findings, along with the little research found, supports the claim that more research needs to be done, in order for medical professionals to be able to fully understand this diagnosis, and the effects this diagnosis may have on the family.

Parents' Perception of Hope for their Child's Future

Previous research has been done regarding family functioning, and hopes for the future with children who have intellectual disabilities and other chronic illnesses. For example, Connelly (2005) examined how chronic illnesses affected the family's hope, functioning, and quality of life. The author found that "family functioning was related to the degree of hope [that the] children expressed" (Connelly, 2005, p. 248). The author also stated that "family functioning is an important factor that is related to the nursing care of children with a chronic illness" (Connelly, 2005, p. 248). The author also discussed that childhood illnesses can have a negative impact on the ability of the child to complete psychosocial developmental tasks (Connelly, 2005, p. 245). Overall the author stated that "assessment of pediatric QOL [quality of life] ought to encompass physical functioning, emotional functioning, social functioning, and school functioning" (Connelly, 2005, p. 247).

According to Bally (2012), previous studies have shown that hope is a tangible essence to parents, and is therefore associated with concepts such as depression and self-efficacy (Bally, 2012, p. 222). As Bally (2012) stated in his article, since hope has been identified "as being important, gaining a clear understanding of parental hope in the context of caring for a child with an LLI [life-limiting illnesses] or LTI [life-threatening illnesses] is imperative (p. 217). Authors Lloyd and Hastings (2009) also state that research regarding hope and families with children who have intellectual disabilities, has been researched very little. The reasoning that more research needs to be done, is that Lloyd and Hastings (2009) state that hope has a "significant potential as a parental resilience factor" (p. 958). According to Bally (2012) the importance of hope has been realized by nurses. However what science, nurses have to base their practices on related to hope, is not available (Bally, 2012, p. 217). Unfortunately since hope is neither concrete nor simple, it is difficult to gain observable and measureable data (Bally, 2012, p. 222). Hope therefore needs to be further researched and scrutinized.

Nursing Implications: Expert Nurse Communication

To obtain more information, an expert nurse from a large hospital associated clinic in New England was consulted. A telephone interview was conducted with Nurse A. She has been a Pediatric Registered Nurse for eight years, and has been working with the Positional Plagiocephaly department for five years. When asked what she does upon meeting the patients and the parents, she stated that she obtains a health history about the child. She said that if patients are premature, they are more likely to have Deformational Plagiocephaly. The reason for this occurrence is that "they don't move as much, or as quickly" (A.D'Eon, personal communication, January 30, 2014). Upon meeting the parents, the nurse finds that they are nervous. She stated that parents are "concerned that there is something wrong with the brain, development, long term effects, [and worry that] their child [will] be made fun of later in life" (A.D'Eon, personal communication, January 30, 2014). When asked what she tells the parents, the nurse stated that she tells the parents that "in a developmentally appropriate child, Plagiocephaly and its treatment should not negatively affect future growth and development". At the appointment the child's head shape is measured and is then classified into one of three categories; mild, moderate, and severe Positional Plagiocephaly. The concerns that are expressed by the parents to the nurse are: "Should I treat? Is it worth treating? Does insurance cover it? Does my child need to wear it 24 hours a day, 7 days a week? Can I take the helmet off? Are there any concerns related to treatment? Will my child be upset for not treating?" (A.D'Eon, personal communication, January 30, 2014). One of the deciding factors for whether or not parents treat this condition, according to the nurse and based on her experience, is whether or not insurance will cover the cost of the treatment. According to the nurse, the cost of the treatment can be expensive and some insurances do not pay for the helmet and follow-up treatment. The decision to treat is left up to the parents, but the "physicians are more likely to encourage the use of the helmet in patients where the flattening is moderate to severe". The decision about treatment needs to be made right away. According to the nurse, "helmeting is generally only used as an intervention until the age of 12 months. The reason for this is that the rate of skull growth slows by this age, and the potential growth becomes more difficult to capture with helmeting. Also it can be increasingly difficult to keep the children compliant as they become more active".

Methods

Design

The design of this thesis was a case series with parent interviews, and constructing themes from social network postings made by parents. A case series was completed thru parent interviews to find out the parental perception, of health related quality of life and hope for the child with Positional Plagiocephaly. The demographics form (Appendix B) was designed to obtain characteristics of the family related to each case. Question 18 was adapted from Steinbok, Lam, Singh, Mortenson, & Singhal, (2007). Questions 19 through 21 were adapted from Elwood, Petronio, & Wood, (2005). The interview questions (Appendix C) was designed to address different areas that may be of concern for parents. Multiple questions in the interview were adapted from the TNO-AZL Preschool Children Quality of Life (TAPQOL), a quality of life instrument for 1-5 year old children by Fekkes, Theunissen, Brugman, Veen, Verrips, Koopman, Vogels, Wit, & Verloove-Vanhorick, (2000).

Informed Consent

Consent was obtained prior to the completion of the demographics form, and prior to the start of the interview. Participants were informed that their participation was voluntary and their information would remain anonymous. Each parent was asked to read and sign the consent form (Appendix A) prior to the start of the interview. In the consent form, the parents were asked for permission to record the interviews. This project was approved by the Institutional Review Board (IRB) at Salem State University. The student researcher also completed the Collaborative Institutional Training Initiative (human subject training). A modification to include an additional case study, and parent postings from a web-based social network, was submitted and approved by the Institutional Review Board (IRB) at Salem State University.

Data Collection

Parent Interviews

The participants for the three case studies were identified from personal connections. Two case studies were family members, and the third case study was a friend of a colleague. Information was obtained from the parents of children with Positional Plagiocephaly, through interviews. Both parents were spoken to separately. After obtaining consent the parents were asked to fill out the demographics form (Appendix B). Following the demographics form, the parents were interviewed using the interview form (Appendix C). All six of the parent interviews were attempted to be done face-to-face. The parents from case study one and two were done in a face-to-face interview, and the third case study was a telephone interview, with the demographic forms returned by mail, to the author. The information from the interviews conducted will be locked in a drawer that only the author has access to. The interviews will then be destroyed after 2 years.

Ancillary Data Collection

Mid way in the interview process, a new source of information was identified: information from selected group page posts focused on raising a child with Plagiocephaly, made by parents, from the social networking website, Facebook. An IRB modification was submitted to the Salem State University Institutional Review Board (IRB), to include this new source of information and was approved.

Constructed Themes from Social Networking

Additional information was gathered from posts on the Facebook pages entitled, “Plagiocephaly Awareness and Support”, “Plagiocephaly Parents”, and “Plagiocephaly Support Group”. The themes from the posts made by parents were gathered covering postings made during the time frame of January 2013 to February 2014. This time frame was selected to look at the most recent feelings and concerns that parents had, when they posted on Facebook. All data found from the postings on the social network website was collected without parent identifiers and will be destroyed after completion of this paper.

Results

A convenience sample of three child case series (six parent participants) and themes constructed by the author from multiple parent postings on the social network were obtained. Two of the case studies were family members and the third case study was a friend of a colleague. Posts made by parents from three pages on Facebook, entitled “Plagiocephaly Awareness and Support”, “Plagiocephaly Support Group”, and “Plagiocephaly Parents”, were obtained. The themes from the numerous posts were constructed. The following are the results of the three case series of six parents, and the themes from the social network website.

Table 1: Parent Demographics for Case Study 1

	Parent A (Mother)	Parent B (Father)
Age (in years)	33	42
Gender	Female	Male
Marital Status	Married	Married
Financial concerns about child	No	Yes
Education Level	Bachelors	High School Graduate
Type of work	Registered Nurse	Auto Technician
Number of children	2	2
Birth order of child with Plagiocephaly	First	First
Gender of child	Female	Female
Perinatal (pregnancy/ birth) issues	No	No
Child's age now	35 months	2 yrs. 11 months
Age of child at diagnosis	3 months	6 months
Age of child at treatment	6 ½ months	6 months
Length and time of helmet wear a) Weeks/months b) Hours/day c) Days/week	a) 3 months b) Start out with 1 hour on, 1 hour off, and work up to on 22 hours. Off for 2 hours for skin care. c) 7 days	Did not provide answer.
Daycare or informal child care (babysitting); Any concerns	No	Yes (Informal child care); No
Rating of the shape of the child's head prior to helmet wear (see Appendix B for scale explanation)	2	3/4
Rating of the improvement of the shape of the child's head after wearing the helmet (see Appendix B for scale explanation)	4	4/5
Would they repeat the treatment?	Yes	Yes
Would they recommend this treatment?	Yes	Yes

*Some of the results may have changed (e.g. age). Answers were based on information provided at the time of the interview. There may be discrepancies between answers for the mother and father of each child, but the results in the table reflect the answers provided by the parents.

Case study 1

Patient A is a three year old white female, who was treated for Positional Plagiocephaly. She was treated with a cranial remodeling helmet. Patient A was diagnosed at three months old. She began treatment with the use of a cranial remodeling helmet when she was six and a half months old. The patient had to wear the helmet every day for twenty-two hours for three months. The two hours that it was removed was for skin care. When each parent was asked about perinatal problems, they both reported that there were no perinatal problems. The patient was born healthy and was delivered by a Cesarean Section.

Each parent was asked to report on a scale of one to five, with one being abnormal and five being normal, about the shape of the patient's head prior to wearing the helmet. Patient A's father reported that the shape of his child's head prior to treatment was 3.5. Patient A's mother reported that the shape of her child's head was 2, prior to treatment. Both parents were then asked to report on a scale of one to five, with one being least improvement and five being most improvement, about the improvement of their child's head shape. The father of patient A reported that the improvement of her head shape was 4.5. Patient A's mother reported that the improvement of the shape of her child's head was 4. Both parents agreed that there was a significant improvement in their child's head shape after treatment.

Table 2: Parent Demographics for Case Study 2

	Parent A (Mother)	Parent B (Father)
Age (in years)	36	37
Gender	Female	Male
Marital Status	Married	Married
Financial concerns about child	No	No
Education Level	Associate in Nursing	Masters
Type of work	Registered Nurse	Environmental Health
Number of children	1	1
Birth order of child with Plagiocephaly	First	First
Gender of child	Male	Male
Perinatal (pregnancy/ birth) issues	No	No
Child's age now	10 months	10 months
Age of child at diagnosis	6 months	6 months
Age of child at treatment	7 months	7 months
Length and time of helmet wear a) Weeks/months b) Hours/day c) Days/week	a) 2 months b) 22 hours c) 7 days	a) 2 months b) 22-23 hours c) 7 days
Daycare or informal child care (babysitting); Any concerns	Yes; No	Yes; No
Rating of the shape of the child's head prior to helmet wear (see Appendix B for scale explanation)	4	4
Rating of the improvement of the shape of the child's head after wearing the helmet (see Appendix B for scale explanation)	5	2
Would they repeat the treatment?	Yes	Yes
Would they recommend this treatment?	Yes	Yes

*Some of the results may have changed (e.g. age). Answers were based on information provided at the time of the interview. There may be discrepancies between answers for the mother and father of each child, but the results in the table reflect the answers provided by the parents.

Case study 2

Patient B is a 10 month old male, who was diagnosed with Torticollis (persistent stiff neck to one side) at approximately three months old. The parents of patient B began to take their child to physical therapy to help with the Torticollis. He was then diagnosed at six months old with Positional Plagiocephaly. He was treated with a cranial remodeling helmet, and began treatment with the use of a cranial remodeling helmet, when he was seven months old. The patient had to wear the helmet every day for twenty-two hours for two months. The two hours that it was removed was for skin care and extra cuddle time. The parents of patient B have continued to bring the child to physical therapy. Physical therapy is twice a week, and the parents perform stretching and exercises at home. When each parent was asked about perinatal problems, they both reported that there were no perinatal problems. The patient was born healthy and was delivered vaginally.

Each parent was asked to report on a scale of one to five, with one being abnormal and five being normal, about the shape of the patient’s head prior to wearing the helmet. Patient B’s father reported that the shape of his child’s head prior to treatment was 4. Patient B’s mother also reported that the shape of her child’s head was 4, prior to treatment. Both parents were then asked to report on a scale of one to five, with one being least improvement and five being most improvement, about the improvement of their child’s head shape. Interestingly, both parents did not agree about the significance of improvement in their child’s head shape after treatment. Patient B’s mother reported that the improvement of the shape of her child’s head was 5. However, the father of patient B reported that the improvement of his child’s head shape was 2.

Table 3: Parent Demographics for Case Study 3

	Parent A (Mother)	Parent B (Father)
Age (in years)	51	50
Gender	Female	Male
Marital Status	Married	Married
Financial concerns about child	No	No
Education Level	Bachelor's Degree	High School
Type of work	Registered Nurse	Construction
Number of children	1	1
Birth order of child with Plagiocephaly	First	First
Gender of child	Female	Female
Perinatal (pregnancy/ birth) issues	No	No
Child's age now	5 years 6 months	5 years
Age of child at diagnosis	4 months	4 months
Age of child at treatment	6 months	6 months
Length and time of helmet wear a) Weeks/months b) Hours/day c) Days/week	a) 8 weeks b) 18-24 hours c) 7 days	a) 8 weeks b) 18 hours c) 7 days
Daycare or informal child care (babysitting); Any concerns	Yes; No	Yes; No
Rating of the shape of the child's head prior to helmet wear (see Appendix B for scale explanation)	2/3	4
Rating of the improvement of the shape of the child's head after wearing the helmet (see Appendix B for scale explanation)	4/5	4
Would they repeat the treatment?	Yes	Yes
Would they recommend this treatment?	Yes	Yes

*Some of the results may have changed (e.g. age). Answers were based on information provided at the time of the interview. There may be discrepancies between answers for the mother and father of each child, but the results in the table reflect the answers provided by the parents.

Case Study 3

Patient C is a five and a half year old white female, who was treated for Positional Plagiocephaly. She was treated with a cranial remodeling helmet. Patient C was diagnosed at four months old. She began treatment with the use of a cranial remodeling helmet when she was six months old. The patient had to wear the helmet every day for eighteen to twenty-four hours for eight weeks. The time that it was removed was for skin care, and extra cuddle time. When each parent was asked about perinatal problems, they both reported that there were no perinatal problems. The patient was born healthy and was delivered by a Cesarean Section (author uncertain to the reason for Cesarean Section).

Each parent was asked to report on a scale of one to five, with one being abnormal and five being normal, about the shape of the patient's head prior to wearing the helmet. Patient C's father reported that the shape of his child's head prior to treatment was 4. Patient C's mother reported that the shape of her child's head was 2.5, prior to treatment. Both parents were then asked to report on a scale of one to five, with one being least improvement and five being most improvement, about the improvement of their child's head shape. Patient C's mother reported that the improvement of the shape of her child's head was 4.5. The father of patient C reported that the improvement of her head shape was 4. Interestingly, the father's rating of his child's head shape prior to, and after treatment did not change. However, both parents did agree that there was improvement in their child's head shape after treatment.

Table 4: Parents impressions of the shape of their child’s head prior to and after treatment with a remodeling helmet (N = 6)

Parent	Prior to Treatment	Post Treatment	Improved/Change (%)	
Father A	3.5	4.5	1	20%
Mother A	2.0	4.0	2	40%
Father B	4.0	2.0	-2	-40%
Mother B	4.0	5.0	1	20%
Father C	4.0	4.0	None	
Mother C	2.5	4.5	2	40%
	Mean= 3.33	Mean= 4.0	Mean= 0.66	13.33%

Constructed Themes from Social Networking

To find more information about how parents felt and any questions or experiences they had, a search for pages related to “Plagiocephaly” was conducted. Three of the numerous results for pages about Plagiocephaly were chosen. The three pages were entitled “Plagiocephaly Awareness and Support”, “Plagiocephaly Support Group”, and “Plagiocephaly Parents”. The timeline for looking at the posts made by parents was limited to January of 2013 to February of 2014. This time frame was selected to look at the most recent feelings and concerns that parents had posted about in the last year. Posts made by the parents from three pages on Facebook, were obtained and read by the author. After looking at the three pages from Facebook, the posts by the parents were organized into themes. The themes from the numerous posts were constructed into a table. The following are a few of the overall results of the themes from Facebook that the author noted. Following the themes noted by the author, is the table with the results of the themes.

One theme that was noted while looking at the posts was the concern by the parent about kissing their child on the forehead. While the child has the helmet on, the child’s forehead is covered. When the parent or any family member goes to kiss the child’s forehead, the helmet is in the way. Numerous parents commented that the time that they removed the helmet was “the best time of the day”. The parents missed cuddling but used the time when the helmet was off, to cuddle and to try to make up for the time that the helmet was on. One parent posted, “I miss the snuggles and closeness though so we do our morning feed without it [the helmet] and it’s a lovely way to start the day”.

Another theme that was noted by the author was that the parents were supportive of each other. One parent posted that “you do what you have to do for your child” and to look at putting a helmet on your child, like putting braces on. The parent posted saying, “Think of it like braces, its an accessory that he has to wear for a little while to help, but there will be a day that comes when he will not need it anymore”. Another parent posted, “[…] As for two children needing a band- to me it says you’re a superior parent for listening to the research on SIDS and following the “back to sleep’ campaign. I’d rather had a baby with a flat head than a baby that perished- harsh, but a reality”.

Table 5: Constructed themes from social networks that parents posted in order of frequency of post (N= approximately 200 parents)

Quote	Number of posts (n=)	Source
"I'm so happy."	N= 35	A, B, C
"My child didn't have any problems adjusting to the helmet."/ "It didn't bother my child."	N= 31	A, B,C
"It was the best decision I made"/ "It was the best thing we ever did."	N= 27	A, B, C
"I think it is tougher on the parents than it is on the kids."	N= 20	A, B, C
"It was worth treating."	N= 14	A, B, C
"I'm amazed/ impressed with the results."	N= 14	A, B, C
"I have no regrets"	N= 8	A, B, C
"I'm glad we did it."	N= 8	A, B, C
"It works."	N= 7	A, C
"You do what you have to do"/ "You do what's best for your child."	N= 7	A, C
"We did the right thing."/ "We made the right decision."	N= 6	A, B, C
"I would recommend treating."	N= 5	A, B
"I would repeat the treatment."	N= 5	A
"There was a huge improvement."/ "My child's head shape improved."	N= 4	A, C
"I wish we treated sooner."	N= 3	A, B, C

Source Key
A= Plagiocephaly Awareness and Support
B= Plagiocephaly Support Group
C= Plagiocephaly Parents

Conclusion

Nursing Implications

The research regarding parents' perceptions of quality of life and hope for the future of their child, who has Positional Plagiocephaly, indicates that there is very little information regarding the nursing implications. Most of the literature found related to Positional Plagiocephaly, is in regards to the topics of the medical diagnosis and treatment. There needs to be more research done where the role of the nurse is recognized and specific care that nurses provide to patients and families are identified. Determining the role of the nurse and the nursing implications for Positional Plagiocephaly, would greatly help nurses in how to help these families, and help advance the medical field in this particular field.

Limitations

Due to time constraints, this paper was limited to a convenience sample. Parents who did not have children with Positional Plagiocephaly were excluded from the sample. Another limitation to this paper was the length of time that had passed between the time when the child wore the helmet, and when the interview was conducted. A third limitation to this paper was the limited resources that were available to search for articles. The search for articles was conducted using Academic Search Elite, Academic Search Premier, CINAHL, CINAHL Plus with full text, Health Source- Consumer Edition, Health Source: Nursing/ Academic Edition, Health Technology Assessments, MEDLINE, PsycARTICLES, Psychology and Behavioral Sciences Collection, and PsycINFO. A fourth limitation was that this paper was limited to what posts had been made on the Facebook pages for Plagiocephaly, for additional information. Some parents may have different feelings or concerns, but did not choose to put their feelings on the internet, or did not know about these pages.

Future Research

This research demonstrated that larger case series are needed to look at the long term effects of this diagnosis. Both qualitative and quantitative studies on the impact of the nurse’s role with families, health- related quality of life (HRQOL), and validated instruments regarding hope and other psychosocial behavioral measures, regarding parental experiences and child development, need to be established?. Research needs to be started early in the treatment and long term follow up needs to be studied regarding health-related quality of life (HRQOL), the role of the nurse, and hope.

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Appendix A: Informed Consent

Salem State University
Institutional Review Board (IRB)
Informed Consent Form

I, ____________________________, agree to participate in the *Parents' perception of health-related quality of life (HRQOL) and hope for their child living with plagiocephaly*: *A case series* conducted by Gabrielle Durgin.

This project is for an Honors thesis paper for nursing. You will be asked questions about your child and their history, and symptoms with Plagiocephaly.

Participating in the interview is completely voluntary. There is no right or wrong answer. You may stop at any time. You do not have to answer any questions that make you feel uncomfortable.

The only risk may be that you have emotional feelings regarding remembering the time of your child's diagnosis. There are no direct benefits to you by participating. If you have prolonged emotional feelings over days please contact my faculty mentor, Dr. Leger who will help you identify available resources.

The Brief Demographic Form does not have any identifiable information. If there is identifiable information regarding your family, health care providers or others on the audio tape (names, institutions, etc.) these names will not be transcribed but left blank. All of the tapes will be stored securely in a locked drawer until transcribed, and then destroyed once transcription has taken place. The nursing student and her faculty advisor will be the only ones who will have access to the tapes and transcripts. A code name or pseudonym will be used in place of your real name in any transcribed material. Neither your name nor anything identifying your child will be used in reports or presentations of the findings of this research.

The information provided to the researchers will be kept confidential with the exception of information which must be reported under Massachusetts's law including cases of child or elder abuse.

This research project has been approved by the Institutional Review Board at Salem State University.

Thank you for your help. If you have any questions about this research you can contact my faculty mentor, Robin Leger, RN, MS, PhD. at rleger@salemstate.edu or at 978-542-2613.

I have read and understand this information and agree to participate in this study. I will be offered a copy of this form to keep.

Participant's Signature: ____
(Signature) (Date)

For concerns about your treatment as a research participant, please contact:
Institutional Review Board (IRB)
Sponsored Programs and Research Administration
Salem State University
352 Lafayette Street
Salem, MA 01970
(978) 542-7556 or (978) 542-7177 or irb@salemstate.edu
A copy of this signed form is as good as the original.

This research project has been reviewed by the Institutional Review Board at Salem State University in accordance with US Department of Health and Human Services Office of Human Research Protections 45 CFR part 46 and does not constitute approval by the host institution.

Appendix B: Demographics (Parent Form)

Subject ID # _____

Please fill in or circle one answer for each below.

1. Your Age: __________

2. Gender: Male or Female

3. Current marital status:

Single Married Divorced Separated Widow

4. (If applicable) Age of your spouse: ___________

5. Financial concerns about child:

Yes_____ No_____

6. Your Education level: ____

7. Your type of work: ____

8. Number of children: ______________

9. Birth order of child with plagiocephaly: ____________________________

10. Gender of child with plagiocephaly: Female or Male

11. Any perinatal (pregnancy/birth) issues, such as prematurity or multiple births? No _____
Yes (describe) ____

12. Child's age now: _________________

13. Age of child at diagnosis: _____________________

14. Age of child at treatment (helmet/orthosis): _____________________

15. Length and time of helmet wear:

weeks/ months ___________________

# of hours/day _______________________

# of days/ week ______________________

16. Did you have day care or informal child care for your child? Yes _____ No ____

17. (If applicable) Did you have any concerns while your child was at day care or during informal child care (regular babysitting)?

Yes _____ No _____

If yes, what were your concerns?

Day care during treatment ____

Informal child care (baby sitters) ____

18. Prior to helmet wear, on a scale of 1 (abnormal) to 5 (normal) how would you rate the shape of your child's head?

1 2 3 4 5

19. After wearing the helmet on a scale of 1 (least improvement) to 5 (most improvement) how would you rate the improvement of your child's head shape?

1 2 3 4 5

20. With what you know now, would you have done the helmet wearing program?

Yes _____ No _____

21. Would you recommend this treatment to a friend's child who has a similar condition?

Yes _____ No _____

Thank You for Your Time!

Question 18 was adapted from: Steinbok, P., Lam, D., Singh, S., Mortenson, P., & Singhal, A. (2007). Long-term outcome of infants with positional occipital plagiocephaly. *Child's Nervous System: Official Journal of the International Society for Pediatric Neurosurgery*, *23*(11), 1275-1283.

Questions 19-21 were adapted from: Elwood, E., Petronio, J., & Wood, R. (2005). Parental satisfaction with the CranioCap: a new cranial orthosis for deformational plagiocephaly. *Cleft Palate-Craniofacial Journal*, *42*(4), 340-343.

Appendix C: Survey/ Interview Questions

The following questions I have adapted from the Preschool Children Quality of Life (TAPQOL) for plagiocephaly.

Fekkes, M. M., Theunissen, N. M., Brugman, E. E., Veen, S. S., Verrips, E. H., Koopman, H. M., Vogels, T., Wit, J.M., & Verloove-Vanhorick, S. P. (2000). Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1–5 year-old children. *Quality of Life Research*, *9*(8), 961-972.

Subject ID # ___

1. Physical functioning

- **Sleeping**
  - How did your child sleep?
  - Were there any problems with sleeping?
  - Do you think there were any problems with sleeping related to the helmet wearing?
- **Appetite**
  - How did your child eat and drink?
- **Lungs**
  - Has your child had respiratory problems?
- **Stomach**
  - Has your child had any GI problems?
  - Has your child had any problems eating?
  - Has your child had any digestion problems?
- **Skin/ Helmet**
  - Did your child have any skin break down?
  - Did you notice your child having any discomfort?
  - Did your child have any pinching?
- **Motor Functioning**
  - Did your child have any difficulty with walking?
  - Did your child have any difficulty with balance?
  - Do you notice any other delays in your child?

2. Social functioning

- **Social functioning**
    - How was your child's behavior with other children?
- **Problem behavior**
    - How was your child's behavior?
        - Were they aggressive?
        - Were they passive?
    - Did your child exhibit behavior that concerned you?
        - If yes, what were the behaviors?

3. Cognitive functioning

- **Communication**
    - Did your child have difficulty in talking clearly?
    - Did your child have difficulty in making it clear in what she/he wanted?

4. Emotional functioning

- **Mood**
    - How was their mood before treatment?
    - Was your child different after treatment was started?
        - If yes, how?
    - How was your child's mood after treatment?
    - Was your child anxious?
    - Was your child energetic?
    - Was your child active?

5. Other

- **Stigma**
    - How did you feel when your child had the helmet on?
    - Were you embarrassed by how your child looked in their helmet?
    - Do you currently have concerns regarding the shape of your child's head?
        - If yes, what are your concerns?
- **Baby sitting**
    - Was letting anyone babysit ever a concern?
- **Fears**
    - Do you have fears for your child?
        - If yes, what are they?
    - Do you have any fears about how your child will grow up?
        - If yes, what are they?
    - Do you have fears about your child's social skills?
        - If yes, what are they?
    - Do you fear that your child will have children with the same disorder?
- **Hope**
    - What is your hope for your child for the future?

Is there anything else you would like to add or talk about?