

Examining Parental Attitudes on Infant Prone Positioning Involving Infants with
Congenital Heart Defects

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Abstract

Time that an infant spends in the awake prone position (“Tummy Time”) may affect physical and motor developmental outcomes later on in the child’s life. However, little is known about how caregivers of neonates with a congenital heart defect (CHD) feel about placing their newborn baby on his or her stomach following a cardiac heart surgery. Seeing as this is a major procedure for the baby and their family, we hypothesized that parents of these infants would be more hesitant and fearful to put their newborn on his or her tummy, even while supervised. We administered a ten question survey and gathered demographic information, both from parents of standardly “healthy” babies and parents of babies who had undergone open heart surgery because of a CHD, in order to assess their opinions on tummy time importance and implementation. It was found that parents of infants with CHDs thought they would be too busy to practice tummy time compared to the parents of healthy babies. Significant differences were also found among the CHD parent cohort when accounting for demographic variables, such as other children in the household, baby’s age at time of survey, and parent’s age at time of survey. These results suggest that there could be a small difference in attitudes and therefore implementation regarding tummy time for infants with a congenital heart defect.

Keywords: Tummy Time, CHD, Physical Development, Parent, Infant, Attitudes

Examining Parental Attitudes on Tummy Time Involving Infants with Congenital Heart Defects

Throughout past generations, parents have been told to always place their newborn infants on their backs to avoid the chance of Sudden Infant Death Syndrome (SIDS). They may be unaware though, is that SIDS is only a small part of the problem. SIDS is merely a subset of a larger complication called Sudden Unexpected Infant Death, which includes all unexpected infant deaths (SIDS) as well as deaths where the cause is known (i.e., suffocation) (SIDS is Not, 2015). While keeping infants off of their stomachs does decrease the chances of suffocation and strangulation during sleep, SIDS is not completely preventable, as most of the time its causes and findings are undeterminable (What is SIDS, 2015). Evidence suggests that infants who die from SIDS have some type of congenital brain defect that is undetectable and ultimately affects signaling from the brain to organs controlling basic functions, such as breathing, heart rate, and blood pressure. Therefore, until more knowledge is attained about these causes, there is no way to completely prevent SIDS, except to increase awareness and attention to the baby while they are on their stomachs and during sleep (What Causes SIDS?, 2015).

Meanwhile, recent research strongly supports the notion that time spent in the prone position while awake and being watched by an adult (known as “tummy time”), is extremely important for an infant’s health and development (American Academy of Pediatrics, 2015). This new concept has been labeled “Back to Sleep, Tummy to Play” and is now recommended by a majority of medical professionals nationwide. If a baby is always on his or her back, they could develop a flat spot on their head, as well as not endure enough strengthening and exercise in the head, neck, and shoulder muscles to improve development as they mature (Babies Need Tummy Time!, 2015). With just a small amount of tummy time, totaling one to three hours administered every day, babies have shown not only earlier development of motor skills, but more superior

motor abilities as well (Babies Need Tummy Time!, 2015; Jones, 2004; Wen, 2011).

Furthermore, starting tummy time at an earlier age (less than four weeks old) has led to even further advances in development when tested at a 12-month follow-up compared to babies who started tummy time at greater than one month of age (Wen, 2011).

Congenital Heart Defects in Neonates

Unfortunately, not all infants are healthy at birth. Approximately 40,000 births per year in the United States result in an infant who has a congenital heart defect (CHD), which accounts for nearly 1% of all newborns (Hoffman & Kaplan, 2002). In addition, over 30% of all defect-related infant deaths are caused by a heart defect, making it the most prevalent congenital deficiency (Critical Congenital Heart Disease, 2016). CHDs can range in both type and severity, from a simple arrhythmia (irregular heartbeat) to something as complicated as full transposition of the great arteries (What are Congenital Heart Defects?, 2014). While care and treatment for these babies has been improving and hospitals are implementing stricter requirements to screen for serious CHDs prenatally, heart defects and their complications continue to cause lifelong difficulties and hardships (Quartermain et al., 2015; Koren, Reece, Kahn-D'angelo, & Medeiros, 2010). Furthermore, at least 15% of all CHDs are known to be associated with genetic conditions and abnormalities, such as Down Syndrome, Trisomy 18, Trisomy 13, and Turner's Syndrome (Lin, 2012). Furthermore, approximately 30% of babies with CHDs will present with other physical, developmental, or cognitive disabilities or delays (Congenital Heart Defects, 2015). Current research shows that with regular observation, evaluation, and screening, certain delays can be detected earlier and therefore prevented by implementing more appropriate and specialized therapy to improve development and functioning later on in the child's lifetime (Hoffman & Kaplan 2002).

Parental Actions for Unwell Infants

Not surprisingly, parents tend to be more protective, worrisome, and precautionary when they are taking care of a child who has a congenital heart defect of any severity. From the moment of birth, concerns over life expectancy, life quality, and treatment intensity arise (Koren et al., 2010). While healthcare professionals generally tend to be more optimistic and confident about the outcomes of their patients, the patients themselves as well as their parents and close relatives tend to be more uncertain (Marino et al., 2009). Different parental attachment styles, behaviors, and actions have been analyzed and tested through numerous studies. The majority of the research seems to point to the fact that parents of CHD infants scored higher in anxiety on the maternal worry scale, and were more protective of their children in any given situation. (Berant, Mikulincer, & Florian, 2001; Koren et al., 2010). Furthermore, it was observed that different attachment styles could predict the health and response of the entire family (Koren et al., 2010).

Moreover, recent studies suggest that tummy time is especially important for infants who have any type of birth defect in general. More extensive research has already been conducted regarding the correlation between improved developmental outcomes with increased length and intensity of tummy time for Down Syndrome patients (Latash, Wood, & Ulrich, 2008).

Therefore, it is suspected that similar results could hold true for infants born with congenital heart defects, seeing as CHDs are often associated with Down Syndrome, and the two disorders have several commonalities when evaluating progressive development (Freeman et al., 1998).

Developmental psychologist, Mary Ainsworth, proved long ago that parenting styles and attachment patterns can impact a baby's health, attitude, and personality (Ainsworth, Blehar, Waters, & Wall, 2015). However, lesser-known studies have shown that babies born with a CHD have notable physical, mental, and behavioral delays, all of which can also be affected, either

positively or negatively, by parenting styles and parenting choices. Therefore, caregiving behaviors can be an important target for therapeutic intervention when attempting to maximize long-term outcomes in children at risk for neurodevelopmental delays. Since children with a CHD may be quite ill after birth and throughout infancy, it is evident that parenting choices may differ between this population of babies compared to healthy children (Uzark et al., 2008). This raises a concern that some healthy activities, such as tummy time, may in fact be discouraged by parents due to concerns that these actions might be too stressful or dangerous for an infant with a significant CHD. Given the known positive correlations between tummy time and development in healthy neonates, any disinclination toward tummy time by parents of children with CHDs may have an important negative impact on these youth, who are already at a higher risk for adverse long-term neurodevelopmental outcomes.

Current Research

This research study was conducted in association with the University of Michigan Health Congenital Heart Center Neurodevelopment Team. This group is involved in assessing long-term neurodevelopmental outcomes in patients with congenital heart defects. Specifically, this project was synergistic with the Team's programmatic goals in that it examined the attitudes of parents of infants with CHDs towards tummy time and the possible resulting effects of these outlooks on neurodevelopmental outcomes. The way parents behave towards and view the tummy time process could have a significant impact on the child's long-term neurodevelopmental outcomes. Assessing whether the CHD itself led to differing attitudes was the main focus of the study, but other lifestyle conditions and demographic factors that also tend to impact parenting were additionally included in the research. While this project centered simply on the similarities and differences in tummy time attitudes between parents of children with CHD and parents of

healthy infants, continued follow-up of these patients and families by the Pediatric Cardiology Neurodevelopment Team will allow for later evaluation of whether or not parental differences in tummy time attitudes affects later actions and neurodevelopmental performance in the CHD cohort.

Method

This study was approved by the University of Michigan Medical School Institutional Review Board (IRBMED) and was conducted in accordance with the associated guidelines and restrictions for non-manipulative survey administration research studies. No personal identifiers will be used or reported in the results or discussion of this research study.

Participants

A cross sectional sample, totaling 116 participants ($N = 86$ controls; $N = 30$ cases with congenital heart disease (CHD)) participated in this study. Refer to Table 1 for the full demographic characteristics of all respondents. The control group parents, ranging in age from 18 to 51 years old, were recruited through face-to-face contact and were located in the Childbirth Center of the University of Michigan's C.S. Mott Children's Hospital. The parents of the children with CHD were identified and followed via the UMHS MiChart documentation system, then approached face-to-face in the Pediatric Cardiology Center of the University of Michigan's C.S. Mott Children's Hospital.

Measures

In this study, the survey administered to both groups was based on a previously utilized questionnaire which was modified to include demographic data that were deemed to be possible confounding variables that might affect the subject's responses.

As part of their thesis for the Occupational Therapy Doctorate Program at The University of Toledo, Alissa Ricard and Alexia Metz administered a questionnaire, "*Caregivers' Knowledge, Attitudes, and Implementations of Awake Infant Prone Positioning*," to parents at 46 daycare centers throughout Northwest Ohio and Southeast Michigan to assess their previous knowledge, attitudes, and actions about tummy time regarding healthy term infants four months of age or younger (Ricard & Metz, 2014). These items have been previously validated related to assessing one's opinions regarding tummy time.

It was from this study that the current research survey obtained ten survey questions regarding parent's attitudes on tummy time. The attitudes of parents towards tummy time for their infants were initially measured through ten Likert-ranked questions. Answers were reported on a 1-5 point Likert scale, with 1 being "Strongly Disagree," 5 being "Strongly Agree," and 3 being "Neutral." Accounting for the full sample of respondents, the internal reliability of this study's attitude questionnaire was evaluated using Cronbach's alpha. The 10-question survey of parent's attitudes on Tummy Time had a Cronbach's alpha of 0.835, which indicated a high reliability of these statements as a measure of surveying attitudes and suggests these questions could give a trustworthy and inclusive picture of overall opinions.

In addition to the ten items from Ricard and Metz's questionnaire, it was determined in this study that several demographic factors might contribute to tummy time attitudes. These demographics were also collected in the modification of the survey and assessed for their associations and correlations to the results. Variables such as baby's age at time of survey, parent's relationship to baby, parent's age at time of survey, people residing in the parent's household, and age of other children (if any) residing in the parent's household were all collected.

Procedure

For the recruitment and survey handling, all subjects were given the same information pre-survey and were administered the same survey. Any follow-up questions or further commentary and discussion occurred after the survey was completed and all data had been collected.

Control Subjects. During initial admittance into the University of Michigan C.S. Mott Children's Hospital Birthing Center, potential subjects were approached with face-to-face contact in their hospital room a minimum of 6 hours after giving birth. It was determined by the hospital physicians and staff that these subjects had delivered healthy neonates and neither the parents nor the babies had suffered any irregularities during or after the birthing process. The conditions and basic parameters of this research study were explained to the parents and written consent as well as a telephone number were obtained at this time. Two weeks after the consent was obtained, the subjects were called via the telephone number provided and were read and administered the Tummy Time Survey over the telephone. Responses were recorded by hand, then entered into a secure computer database. If the subject was unavailable to take the survey at two weeks' post-discharge, they were called on subsequent days until able to take the survey. If no survey response had been obtained by 90 days after discharge, the subject was then withdrawn from the study.

CHD Subjects. Subjects evaluated within this group were assessed based on the infant's medical course over the first days or weeks of life. At birth, it was confirmed that these infants had a congenital heart defect and were entered into the UMHS MiChart Electronic Medical Record (EMR) system. Once entered into the system, these patients were tracked during their hospital stay. Infants that required open heart surgery were kept on the tracking list, while the

neonates that had their defect managed non-invasively were excluded from the study. Neonates that had other abnormalities or defects that severely altered their medical course or were not commonly associated with a CHD were also excluded from the study. Furthermore, infants not discharged from the Pediatric Intensive Care Unit (PICU) before three months of age were removed from the study. After open heart surgery and monitoring for stability in the PICU, the infant was then transferred to the general Pediatric Cardiology floor. Once this infant had been transferred out of the PICU to general care, parents were approached with face-to-face contact in their hospital room. The conditions and basic parameters of this research study were explained to the parents and written consent was obtained. The survey was then distributed to the parent and completed directly on the paper at this time. If the subject was not present in the hospital room, they were approached at another time until completion of the survey was possible. Immediately following completion of the survey, the data was entered into a secure computer database.

Data Analysis

First, all of the Tummy Time Survey data was cleaned and standardized. The data was re-scaled from the 5-point Likert scale to a continuous scale so that 1 = 0, 2 = 25, 3 = 50, 4 = 75, and 5 = 100, prior to analysis. This was done for the purpose of generating comparison results and does not change the statistical properties of the data. A Shapiro-Wilk Test of Normality was performed to assess whether or not the response data for each survey question was normally distributed ($\alpha = .05$). Since the data was significant ($p < .01$ for all questions), the data was determined to not be normally distributed. Therefore, a median with an interquartile range (IQR) was used to report the data instead of a mean and standard deviation.

Due to the non-normal distribution of data, a non-parametric Student's T-Test analog, the Mann-Whitney U test (also known as the Wilcoxon Rank-Sum test), was performed on each

survey question to compare tummy time belief scores for CHD cases and “healthy” controls. Descriptive statistics were conducted for each question regarding the sample as a whole, as well as for the control group and for the CHD case group individually. In order to account for the skewedness of question responses and test the accuracy of the questionnaire as a whole for measuring and assessing attitudes on Tummy Time, the scoring of questions one through six were kept the same, and the answers to questions seven through ten were reverse-scored. This allowed for a more consistent measurement and investigation throughout the entire survey.

Next, a Mann-Whitney U test was performed while accounting for the different demographic variables to compare tummy time attitude scores for: new parents vs. parents with other children, baby age at time of survey, and parent age at time of survey. Descriptive statistics were found for each question within each variable for the control group and for the CHD case group separately.

Results

The first six questions in the survey had a more negative connotation associated with them. The responses to these statements reveal that overall, the 116 participants disagreed with the fact that infant prone positioning had severe negative impacts, and additionally thought it was an important action to pursue. The sample was more neutral regarding discontinuation of Tummy Time if the baby starts to cry or visibly dislikes being on their stomach at that moment (See Appendix D and Appendix E for the distribution of responses). This is interesting to note because even though the majority of parents reported that they did not think their infant would be hurt or in danger if placed on their stomachs, they were willing to stop pursuing the Tummy Time session.

The next four questions in the survey were more positively oriented towards Tummy Time and the 116 participants had a much higher level of agreement with these statements. The majority of all subjects strongly agreed that Tummy Time is important and safe for infants. While respondents still agreed that it was common sense for parents to practice Tummy Time with their infants, there was a lower level of agreement than with the other statements in this subset of questions. Most parents did state several times throughout the duration of the survey that while they think Tummy Time is important and safe, the infant must be under constant supervision and must only start tummy time when they are at an age and developmental stage advanced enough to support him or herself in this prone position. See Table 2 for full descriptive statistics of survey responses.

When assessing the responses to each question for the control group versus the CHD case group (with a 95% confidence interval) there were no significant differences except for question number five. Refer to Table 2 for full analysis and significant values. Both groups had a median report of “Strongly Disagree” (0.0), but the CHD case group had much wider variability within the distribution of their responses. This may indicate that parents of infants who had undergone heart surgery had a higher level of agreement to account for being too busy to practice Tummy Time with their baby due to other responsibilities, appointments, and commitments associated with caring for a CHD baby. Even though they thought they might not have as much time for tummy time as the parents of the control group, it is important to note that they still felt that tummy time was important.

Hypothesis Testing and Exploratory Analyses

Overall Beliefs. Overall beliefs about tummy time did not significantly differ between parents of children with a CHD and parents of “healthy” children. Whether the respondents felt

positively or negatively towards practicing tummy time with their infant was not influenced by whether their baby had a congenital heart defect and had undergone open heart surgery.

However, having a baby who had endured surgery for CHD appeared to influence how much time these parents thought they would have to place their baby on his/her tummy (Mann-Whitney $U = 951.0$; $p < .05$).

First-Time Parent vs. Having Other Children. A comparison was performed on the median responses of the subjects using a Mann-Whitney U Test and regulating for number of other children that were already living in the parent's household. Within the control group, there was not a significant difference in responses and levels of agreement to the ten survey questions between first-time parents of newborns and parents who previously had one or more children. Within the CHD case group, parents with older children and first-time parents did show significant differences in response attitudes on survey question three ($U = 35.0$; $p = .018$) and question nine ($U = 38.5$; $p = .037$). Within this cohort, first-time parents showed a higher level of agreement about feeling discouraged if their baby were to cry while on his or her tummy compared with parents who had other children living in their household. Additionally, first-time parents showed lower levels of agreement that it is common sense to place babies on their tummies some of the time compared with the attitudes of parents with older children. All other questions did not show a significant difference within this group. Refer to Table 3 for significant results, and see Appendix A for full statistics and analysis.

Baby's Age. A Mann-Whitney U Test was used to perform a comparison on the median responses of the subjects about tummy time beliefs while accounting for baby age. The median age of the neonate in the survey responses (17 days) was used as the split for choosing the group divisions. Within the control group, parents who took the survey with newborns less than 17

days of age compared with parents of babies older than 17 days did not differ significantly in their responses and levels of agreement to the ten survey questions. Within the CHD case group, responses and attitudes of parents of newborns less than 17 days of age compared with parents of babies older than 17 days differed significantly on survey question six ($U = 55.5; p = .030$).

Parents of babies older than 17 days showed a higher level of agreement with the statement that placing babies on their tummies while awake is not that important. All other questions did not show a significant difference within this group. See Table 3 for significant results, and refer to Appendix B for complete descriptive statistics and analysis.

Parent's Age. A comparison was performed on the median responses of the subjects using a Mann-Whitney U Test and sorting by the age of the responding parent. The cut-off for each group was measured along the median age of the responding parent (30 years old). Within the control group, parental age at the time of answering the survey did not significantly impact responses and levels of agreement to the ten survey questions. Within the CHD case group, parents who were 30 years old and younger and parents who were over 30 years of age did have significantly different responses and attitudes on survey question four ($U = 51.0; p = .018$). Parents who answered the survey at 30 years old or younger showed more support that it is "OK to stop trying to place the baby on their tummy while he/she is awake" if the baby cries or dislikes being on his or her tummy. All other questions did not show a significant difference within this group. Refer to Table 3 for significant results, and see Appendix C all descriptive statistics and analysis results.

Discussion

Chizawsky and Findlay's "Tummy Time!" paper added support to previous evidence that showed placing an infant in the prone position, while they are awake and being watched by an

adult, led to increased physical development and capabilities later on in life (Chizawsky & Scott-Findlay, 2005). While these effects should still hold true for neonates who have been diagnosed with a CHD that necessitates open heart surgery, these children consistently suffer from both mental and physical delays from birth and on throughout their lifetimes (Limperopulos et al., 2002). Koren et al have described that, in the congenital heart patient cohort, parental apprehensions increase and outlooks on life are significantly less optimistic (Koren et al., 2010). Thus, the purpose of this study was to assess if parents of these CHD babies are more fearful or worrisome when it comes to placing their infant on their stomach after surgery, not allowing their baby to reap the full benefits of tummy time.

Overall Attitudes

Surprisingly, the health and condition of the newborn baby did not consistently alter parental attitudes towards Tummy Time. Contrary to what was hypothesized, general attitudes about infant prone positioning were only slightly different for parents of healthy babies and parents of babies who had undergone heart surgery early in life. These findings imply that parents are not more overtly afraid, on a day-to-day basis, to practice tummy time with their baby if the infant has a CHD. It is also possible that there was not a more distinguishable difference in attitudes between the two groups due to the fact that the parents of healthy babies had been at home with their infant for at least two weeks at time of survey, while parent's of babies with a heart defect were still at the hospital and had no exposure to attempting tummy time with their infant. If parents of CHD babies had time at home with their baby post-surgery, it is possible they might become more afraid and their fearful emotions would dominate any previous knowledge or inclinations on tummy time.

While the outlook on safety and importance of tummy time was not different between the two groups in this study, parents of babies with a CHD did have a higher level of agreement that they would be too busy to practice tummy time with their infant than the parents of healthy babies. This gives reason to suppose parents who are taking care of a newborn that has a heart defect believe they will be additionally occupied because of the extra care they will have to provide to their infant and the extra time they will need to devote to administering medications, taking their baby to supplementary appointments, etc. This is consistent with our original hypothesis that these two groups could have different outlooks on implementing tummy time on a consistent basis.

Demographic Variables

Suitably, the parents of healthy neonates had no significant differences in their survey responses when number of children, age of baby, or age of parent were taken into account. This makes the control group of the study a reliable comparison when assessing the results of the CHD-parents. When accounting for these differences in demographics and living conditions, there was, however, noticeably larger variation in responses for numerous different questions within the cohort of parent's who had an infant with a CHD.

Number of Children

Within the group of respondents who had a baby with a CHD, those who were first-time parents indicated a significantly higher level of agreement that they would be discouraged if their baby were to cry while on his or her tummy. Furthermore, they denoted a notably lower perception that it is common sense to place babies on their tummies some of the time.

Alternately, parents who had already had one or more children previously to their infant with a

CHD expressed a lower level of discouragement with tummy time and thought it was more obvious to practice prone positioning with their newborn baby.

It is logical that these significant differences between current and first-time parents were discovered, most likely due to the fact that first-time parents are more unaware of infant development, temperaments, and tolerance regarding certain actions, such as tummy time. These findings further suggest that there might not be an adequate level of education and comprehension concerning tummy time and the infant's natural reactions to being placed on their stomachs, unless the parent has already gone through this experience with a previous child.

Age of Baby

Again among the CHD-parent cohort only, there was a significant difference found regarding how important the parents believed tummy time was for their infants' development. Surprisingly however, the younger the baby was, the more important tummy time was to the parent. We found that the parents whose infants were over 17 days when the parents completed the survey were more likely to respond that placing babies on their tummies while they are awake is not important. Those parents who responded when their baby was less than 17 days were more likely to respond that time on the tummy while awake was important. While it was thought that demographics would influence opinions about tummy time, it was unexpected that the parents of older babies thought it was less important.

As physicians and therapists have found, parents are more likely to begin implementing tummy time when they feel their infants are old enough and strong enough to support themselves (Pumerantz, 2013). This means that we should expect to see increasing amounts of and interest in tummy time as the baby grows older. Our findings could be explained by the fact that the survey was administered while the neonate was still admitted in the hospital under close

observation and care. Often, if the baby needs to be kept in the hospital for a longer period of time, it means their defect is more serious or their hospital course did not go as smoothly as hoped. Therefore, if the baby was over 17 days old, it could be speculated that he or she was less healthy than a baby who was under 17 days, and it was because of this reason that the parent was more reluctant to believe tummy time was important at that moment.

Age of Parent

Similar to the previous conditions, the parental population of the CHD infants showed a significant difference in opinions about pursuing tummy time when the cohort was divided based on the age of the parent. When the parent was 30 years of age or younger, they showed a substantially higher agreement that it is okay to stop placing their baby on his or her tummy if he or she cries/dislikes the tummy time. This result is not surprising, as younger parents might be less aware of the importance of tummy time; and furthermore would not be as experienced in knowing that the majority of all infants dislike being placed on their tummy (Koren et al., 2010). This finding suggests that it is increasingly important to make the significant benefits of tummy time well known, especially to younger parents who likely have less experience with babies and their development. Additionally, it could be beneficial to educate parents that it is common for infants to initially cry or dislike being placed on their stomachs.

Contrary to what was originally hypothesized, the remaining statements included in the survey did not yield any strong or significant differences among the CHD parent cohort when including demographic factors in the analysis. However, these results imply that for the majority of beliefs and scenarios presented in the survey, all parents of infants who underwent heart surgery held relatively consistent feelings about tummy time practice and its implications.

Implications

While the exact start time and session length of tummy time with a newborn infant varies depending on his or her health, strength, and capabilities, it is beneficial for every neonate (healthy or otherwise) to have some amount of tummy time as soon as possible to increase their physical and motor development. This is especially important for babies born with cardiac defects and whom have undergone corrective open heart surgery, as they are part of a subset of infants at a greater risk for severe developmental delays throughout their lifetime (Lin, 2012; Freeman et al., 1998). While the drastic differences that were hypothesized to exist between parents of babies with a congenital heart defect and parents of standardly healthy babies were not found in this study, there were still significant variations in parental attitudes and outlooks regarding the importance of tummy time. These dissimilarities in opinions were present both between control and case parental groups, as well as just among the CHD-parent group when accounting for other possible demographic variables. Given that there was not complete symmetry in responses, it is possible that more extensive clinical involvement could be beneficial. Extra time and attention must be given to the CHD parent cohort by medical professionals to underscore the importance and safety of performing tummy time with their infant. These findings also suggest there might be other mental fears or factors of a CHD-infant parent that are limiting their desire to undertake tummy time with their baby. Addressing these disinclinations and working more personally with the caretakers, both during inpatient and outpatient time, to ease their worries could prove extremely valuable to the baby and the family.

Limitations and Future Directions

Despite the success of the study in that some significant results supporting the hypothesis were found, there were also several limitations that stood in the way of making broader and more

conclusive findings. Most notably, time constraints limited how long the data collection could persist and the number of subjects able to be contacted. This low sample size, in particular within the CHD group of respondents, most likely restricted the ability to detect more significant findings and relationships. Therefore, future studies would benefit from having more time and a larger sample size. This would allow for more conclusive, reliable, and significant overall findings. But most importantly, it would also permit the ability to conduct multivariate analysis of the data and determine further causes and associations among the responses. Additionally, only one parent per family was ever surveyed throughout this study, possibly restricting the results to not fully account for both caregiver's attitudes regarding tummy time. More extensive collection of data would be extremely advantageous in future research and continuing studies.

It is also important to note that, while the set of ten survey questions did reflect a high level of reliability, this was only a limited number of statements that could not fully grasp an individual's complete outlook, expectation, and stance regarding their infant and the practice of tummy time. Therefore, in the future, a more comprehensive assessment and analysis of parental attitudes could give a more telling and complete representation of how parents of infants suffering from a congenital heart defect feel about tummy time. Beyond simple analysis of opinion, conducting a longitudinal study over a multi-year time period may be valuable to obtain more telling data about how these opinions play into the parents' actual implementation of tummy time at home. Longer term follow-up could also facilitate understanding whether practicing tummy time does significantly improve the development of CHD patients, how much their physical and/or mental development is affected, and how much parental involvement plays a role in the baby's growth and progress.

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Table 1.

Demographic Characteristics of Parents and Infants

Variable	Overall (n = 116)		Control (n = 86)		CHD (n = 30)	
	N	%	N	%	N	%
Respondent Age						
30 yr. & Under	63	54.3	44	51.2	19	63.3
31 yr. & Over	53	45.7	42	48.8	11	36.7
Baby Age						
17 day & Under	60	51.7	50	58.1	10	33.3
18 day & Over	56	48.3	36	41.9	20	66.7
Relationship to Baby						
Mother	84	72.4	81	94.2	27	90
Father	32	27.6	5	5.8	3	10
Number of Other Children						
0	41	35.3	34	39.5	7	23.3
1+	75	64.7	52	60.5	23	76.7

Note: Respondent age is reported in years; baby age is reported in days

Table 2.

Descriptive Statistics, Mann-Whitney Analysis, and Significance of Survey Responses

Question	Overall (n = 116)	Control (n = 86)	CHD (n = 30)	U-Value	p-value
	Median (IQR)	Median (IQR)	Median (IQR)		
Q1) It is dangerous to place babies on their tummies.	25.0 (0 – 50)	25.0 (0 – 75)	25.0 (0 – 50)	1087.5	0.186
Q2) I'm afraid my baby might die on his/her tummy.	0.0 (0 – 50)	0.0 (0 – 50)	0.0 (0 – 25)	1148.0	0.334
Q3) I would feel discouraged if my baby were to cry while on his/her tummy.	25.0 (0 – 50)	25.0 (0 – 50)	25.0 (0 – 50)	1185.5	0.500
Q4) If a baby cries or dislikes being on his/her tummy while awake, it is OK to stop trying to place the baby on their tummy while he/she is awake.	50.0 (0 – 75)	50.0 (25–75)	25.0 (0 – 50)	1011.0	0.072
Q5) I am/will be too busy to place my baby on his/her tummy, while he/she is awake.	0.0 (0 – 25)	0.0 (0 – 0)	0.0 (0 – 25)	951.0	0.009
Q6) Placing babies on their tummies while awake is not that important, most babies turn out fine.	0.0 (0 – 25)	0.0 (0 – 25)	0.0 (0 – 50)	1281.5	0.957
Q7) Setting aside time for my baby to spend on his/her tummy is important.	100.0 (75–100)	100.0 (75-100)	100.0 (75-100)	1288.5	0.992
Q8) I think placing my baby on his/her tummy is important for my baby.	100.0 (75–100)	100.0 (75-100)	100.0 (75-100)	1248.5	0.751
Q9) It is common sense to place babies on their tummies some of the time.	75.0 (50–100)	75.0 (50-100)	75.0 (50-100)	1290.0	1.000
Q10) I am confident that my baby will be safe when I place him/her on his/her tummy while awake.	100.0 (75–100)	100.0 (75-100)	100.0 (75-100)	1120.0	0.200

Note: Interquartile Range (IQR) is referring to how much spread, or variability, there is in the middle half of the data.

Bolded p-values indicate significant differences at a 95% confidence interval

Table 3.

Descriptive Statistics and Analysis for Significant Results

Variable		Controls			CHD		
		Median	IQR	p-value	Median	IQR	p-value
Number of Other Children							
Q3	0 Children	25.0	0-50	0.931	50.0	50-75	0.018
	1+ Children	25.0	0-50		25.0	0-50	
Q9	0 Children	75.0	50-81.25	0.168	50.0	50-75	0.037
	1+ Children	75.0	50-100		75.0	75-100	
Baby Age							
Q6	17 & Under	0.0	0-50	0.077	0.0	0-0	0.030
	18 & Over	0.0	0-25		25.0	0-50	
Respondent Age							
Q4	30 & Under	50.0	6.25-75	0.197	50.0	25-75	0.018
	31 & Over	50.0	25-81.25		25.0	0-25	

Note: Only significant values reported. For full data, see Appendix A-E

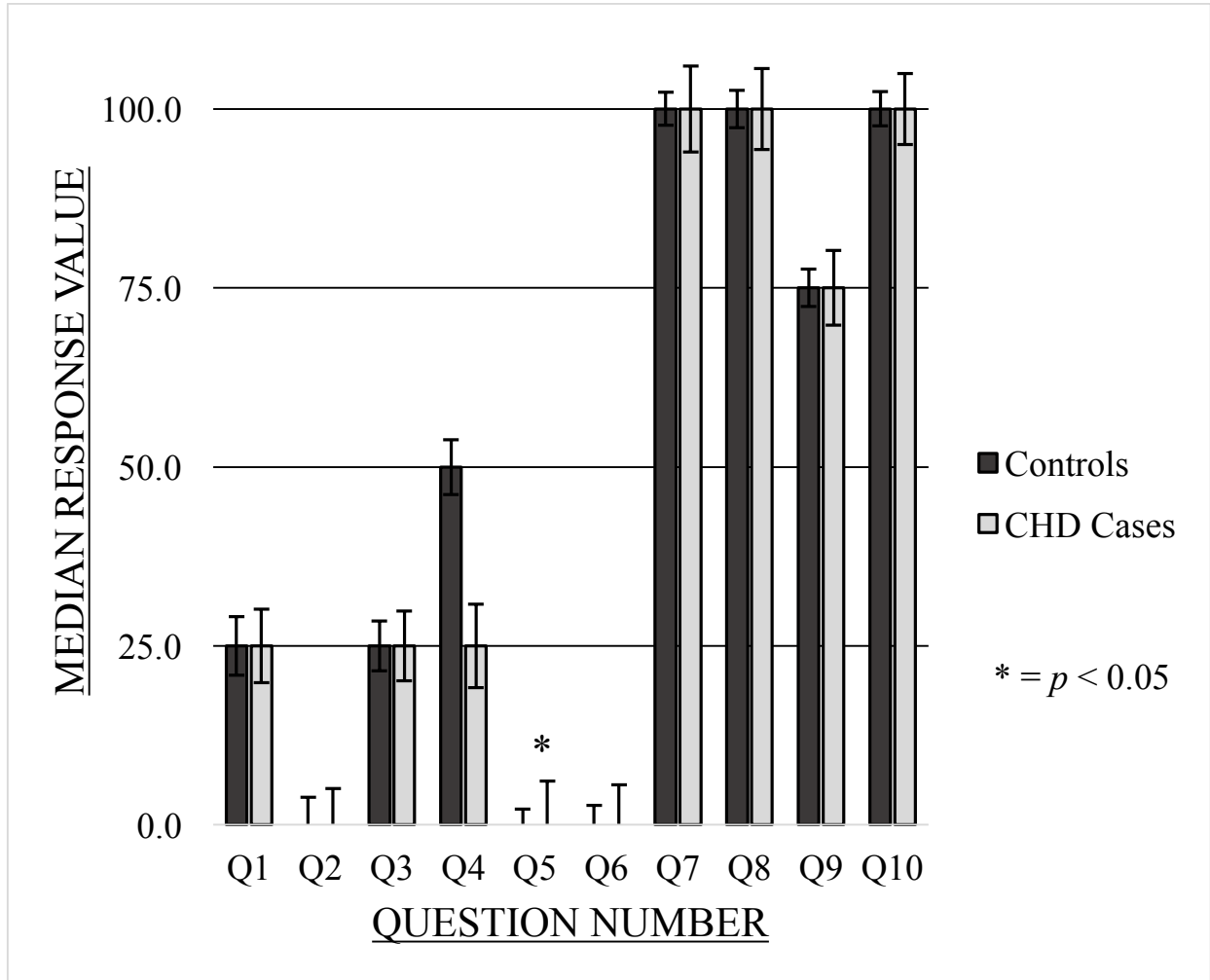


Figure 1. Bar chart of median response data with standard error bard for each survey question comparing the control group with the CHD case group. All demographic variables were not accounted for in this chart.

Appendix A

Descriptive Statistics and Analysis Comparing Number of Previous Children

Question	Controls			CHD		
	0 Children	1+ Children	p-value	0 Children	1+ Children	p-value
	Median (IQR)	Median (IQR)		Median (IQR)	Median (IQR)	
1	25.0 (0-50)	37.5 (0-93.75)	0.162	25.0 (25-50)	12.5 (0-50)	0.140
2	12.5 (0-50)	0.0 (0-75)	0.622	25.0 (0-75)	0.0 (0-25)	0.320
3	25.0 (0-50)	25.0 (0-50)	0.931	50.0 (50-75)	25.0 (0-50)	0.018
4	50.0 (25-75)	50.0 (0-75)	0.735	25.0 (0-50)	25.0 (0-50)	0.724
5	0.0 (0-0)	0.0 (0-0)	0.632	25.0 (0-25)	0.0 (0-25)	0.895
6	25.0 (0-50)	0.0 (0-25)	0.202	0.0 (0-50)	0.0 (0-50)	1.000
7	100.0 (75-100)	100.0 (75-100)	0.312	75.0 (75-100)	100.0 (75-100)	0.263
8	100.0 (75-100)	100.0 (75-100)	0.839	100.0 (75-100)	100.0 (75-100)	0.574
9	75.0 (50-81.25)	75.0 (50-100)	0.168	50.0 (50-75)	75.0 (75-100)	0.037
10	100.0 (75-100)	100.0 (75-100)	0.739	75.0 (75-100)	100.0 (75-100)	0.580

Note: Bolded p-values indicated significant differences at a 95% confidence interval

Appendix B

Descriptive Statistics and Analysis of Survey Responses Accounting for Age of Infant (in days)

Question	Controls			CHD		
	17 & Under	18 & Over	p-value	17 & Under	18 & Over	p-value
	Median (IQR)	Median (IQR)		Median (IQR)	Median (IQR)	
1	25.0 (0-81.25)	25.0 (0-50)	0.193	12.5 (0-50)	25.0 (0-50)	0.748
2	25.0 (0-75)	0.0 (0-25)	0.074	12.5 (0-37.5)	0.0 (0-25)	0.548
3	25.0 (0-50)	25.0 (0-50)	0.848	25.0 (0-50)	25.0 (0-50)	0.646
4	50.0 (25-100)	37.5 (0-75)	0.073	37.5 (0-56.25)	25.0 (0-50)	0.609
5	0.0 (0-25)	0.0 (0-0)	0.239	0.0 (0-43.75)	25.0 (0-25)	0.410
6	0.0 (0-50)	0.0 (0-25)	0.077	0.0 (0-0)	25.0 (0-50)	0.030
7	100.0 (75-100)	100.0 (75-100)	0.132	100.0 (100-100)	100.0 (75-100)	0.113
8	100.0 (75-100)	100.0 (100-100)	0.153	100.0 (100-100)	100.0 (75-100)	0.111
9	75.0 (68.75-100)	75.0 (50-100)	0.417	100.0 (68.76-100)	75.0 (50-100)	0.130
10	100.0 (75-100)	100.0 (75-100)	0.826	100.0 (75-100)	87.5 (75-100)	0.343

Note: The age of 17 days was determined using a median split as the cutoff

Appendix C

Descriptive Statistics and Analysis of Survey Responses Accounting for Age of Parent (in years)

Question	Controls			CHD		
	30 & Under	31 & Over	p-value	30 & Under	31 & Over	p-value
	Median (IQR)	Median (IQR)		Median (IQR)	Median (IQR)	
1	25.0 (0-68.75)	25.0 (0-75)	0.815	25.0 (0-50)	25.0 (0-50)	0.671
2	12.5 (0-50)	0.0 (0-50)	0.980	0.0 (0-25)	0.0 (0-25)	0.880
3	25.0 (6.25-50)	25.0 (0-56.25)	0.928	25.0 (0-50)	25.0 (0-50)	0.734
4	50.0 (6.25-75)	50.0 (25-81.25)	0.197	50.0 (25-75)	25.0 (0-25)	0.018
5	0.0 (0-0)	0.0 (0-12.5)	0.530	25.0 (0-75)	25.0 (0-25)	0.181
6	0.0 (0-43.75)	0.0 (0-25)	0.740	0.0 (0-50)	25.0 (0-25)	0.819
7	100.0 (75-100)	100.0 (75-100)	0.677	100.0 (75-100)	100.0 (100-100)	0.187
8	100.0 (75-100)	100.0 (75-100)	0.927	100.0 (75-100)	100.0 (75-100)	0.426
9	75.0 (50-100)	75.0 (50-100)	0.673	75.0 (50-100)	75.0 (75-100)	0.328
10	100.0 (75-100)	100.0 (75-100)	0.970	100.0 (75-100)	87.5 (75-100)	0.448

Note: The age of 30 years was determined using a median split as the cutoff

Appendix D

Control Group Survey Response Count Distribution

Question	Percent				
	Strongly Disagree (0)	Disagree (25)	Neutral (50)	Agree (75)	Strongly Agree (100)
Q1) It is dangerous to place babies on their tummies.	37.2	18.6	17.4	7.0	19.8
Q2) I'm afraid my baby might die on his/her tummy.	51.2	18.6	10.5	7.0	12.8
Q3) I would feel discouraged if my baby were to cry while on his/her tummy.	30.2	29.1	22.1	7.0	11.6
Q4) If a baby cries or dislikes being on his/her tummy while awake, it is OK to stop trying to place the baby on their tummy while he/she is awake.	23.3	20.9	19.8	18.6	17.4
Q5) I am/will be too busy to place my baby on his/her tummy, while he/she is awake.	77.6	12.9	5.9	2.4	1.2
Q6) Placing babies on their tummies while awake is not that important, most babies turn out fine.	55.8	22.1	16.3	1.2	4.7
Q7) Setting aside time for my baby to spend on his/her tummy is important.	2.3	2.3	9.3	22.1	64.0
Q8) I think placing my baby on his/her tummy is important for my baby.	4.7	1.2	8.1	16.3	69.8
Q9) It is common sense to place babies on their tummies some of the time.	2.3	4.7	23.3	32.6	37.2
Q10) I am confident that my baby will be safe when I place him/her on his/her tummy while awake.	2.3	1.2	9.3	17.4	69.8

Note: Bolded values indicate median response for that particular question

Appendix E

CHD Group Survey Response Count Distribution

Question	Percent				
	Strongly Disagree (0)	Disagree (25)	Neutral (50)	Agree (75)	Strongly Agree (100)
Q1) It is dangerous to place babies on their tummies.	43.4	26.7	23.3	0.0	6.7
Q2) I'm afraid my baby might die on his/her tummy.	60.0	20.0	10.0	6.7	3.3
Q3) I would feel discouraged if my baby were to cry while on his/her tummy.	40.0	16.7	33.3	10.0	0.0
Q4) If a baby cries or dislikes being on his/her tummy while awake, it is OK to stop trying to place the baby on their tummy while he/she is awake.	36.6	23.3	20.0	13.3	6.7
Q5) I am/will be too busy to place my baby on his/her tummy, while he/she is awake.	53.3	26.7	3.3	6.7	10.0
Q6) Placing babies on their tummies while awake is not that important, most babies turn out fine.	60.0	13.3	16.7	3.3	6.7
Q7) Setting aside time for my baby to spend on his/her tummy is important.	10.0	3.3	3.3	16.7	66.7
Q8) I think placing my baby on his/her tummy is important for my baby.	10.0	0.0	3.3	20.0	66.7
Q9) It is common sense to place babies on their tummies some of the time.	6.7	0.0	26.7	26.7	40.0
Q10) I am confident that my baby will be safe when I place him/her on his/her tummy while awake.	3.3	6.7	6.7	26.7	56.7

Appendix F

**UNIVERSITY OF MICHIGAN
CONSENT TO BE PART OF A RESEARCH STUDY****NAME OF STUDY AND RESEARCHERS**

Title of Project: *Examining Parental Attitudes on Tummy Time for Infants with Congenital Heart Defects*

Principal Investigator: Rebecca Fabian

GENERAL INFORMATION

We're doing a study to learn more about how caregivers feel about tummy time and if there is a significant difference between parents of healthy children and children who have undergone congenital heart surgery. To get information, we'd like 50 people to answer a survey. You will be contacted in 2-4 weeks after signing this consent form via either in person or over the telephone. We expect it to take about 5 minutes to complete the survey.

Answering this survey is voluntary. You don't have to answer it if you'd rather not. You can skip any questions that you don't want to answer, whatever the reason, and you don't have to tell us why. Choosing not to answer our survey won't affect the medical care you might receive at the University of Michigan Health System.

It's possible that some of the questions may make you feel uncomfortable. If a question makes you uncomfortable, you can just skip it and go to the next question.

To keep your information confidential, we will not be using any personal identifiers on the survey instrument itself. Although we will keep a list of all the people who answered our survey, no one outside our study team will be able to figure out who answered the survey or which people gave which answers. We plan to publish what we learn from this study, but we will not include any personal information that could reveal who answered the survey.

Answering our survey won't benefit you directly. We hope what we learn will help other people in the future.

AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION

Signing this form gives the researchers your permission to obtain, use, and share information about you for this study, and is required in order for you to take part in the study. Your permission expires at the end of the study, unless you cancel it sooner. You may cancel your permission at any time by contacting the researchers listed below (under Contact Information).

It's possible that the researchers or others will need access to information about you during or after this study. For example:

- The researchers may need the information to make sure you can take part in the study.

- The researchers may need to use the information to create a databank of information about your condition or its treatment.

The results of this study could be published in an article, but would not include any information that would let others know who you are.

As a rule, the researchers will continue to use information about you until the study is over and will keep it secure until it is destroyed. Limited information about you may continue to be used after the study is over, for other research, education, or other activities. But use of this information would not reveal your identity.

As long as your information is kept within the University of Michigan Health System, it is protected by the Health System’s privacy policies. For more information see <http://www.med.umich.edu/hipaa/npp.htm>. Note that once your information has been shared with others, it may no longer be protected by the privacy regulations of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

CONTACT INFORMATION

To find out more about the study, to ask a question or express a concern about the study, or to talk about any problems you may have as a study subject, you may contact one of the following:

Principal Investigator: Rebecca Fabian Mailing Address: 1300 South University Ave. Ann Arbor, MI 48104 Telephone: (425) 443-8973 Email: beccaf@umich.edu	Mailing Address: Michigan Congenital Heart Center 1540 E Hospital Dr., Ann Arbor, MI 48109 Telephone: (734) 764-5176
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You may also express a concern about a study by contacting the Institutional Review Board:

University of Michigan Medical School Institutional Review Board (IRBMED)
 2800 Plymouth Road
 Building 520, Room 3214
 Ann Arbor, MI 48109-2800
 734-763-4768
 E-mail: irbmed@umich.edu

If you are concerned about a possible violation of your privacy or concerned about a study, you may contact the University of Michigan Health System Compliance Help Line at 1-866-990-0111.

SIGNATURES

Research Subject:

I understand the information printed on this form. My questions so far have been answered.

Signature of Subject: _____ Date: _____

Name (Print legal name):

Patient ID: _____ Date of Birth: _____

Legal Representative (if applicable):

Signature of Person Legally

Authorized to Give Consent _____ Date: _____

Name (Print legal name): _____ Phone: _____

Address:

Check Relationship to Subject:

Parent Spouse Child Sibling Legal Guardian Other:

[If this consent is for a child who is a ward of the state (for example a foster child), please tell the study team immediately. The researchers may need to contact the IRBMED.]

Reason subject is unable to sign for
self:

Appendix G

Tummy Time Attitudes Survey

Today's Date: _____

Phone Number: _____

Baby's age (in days) at time of survey: _____

Your relationship to baby: mother father grandparent

foster parent other: _____

Your age at time of survey: _____

With whom do you live? _____

Age(s) of sibling(s) or other children living in your home, if any:

_____	_____
_____	_____
_____	_____

Please answer the following questions by circling one number that best corresponds with your opinion, with 1 being "Strongly Disagree," 5 being "Strongly Agree," and 3 being "Neutral"

1) It is dangerous to place babies on their tummies.

 1 2 3 4 5

2) I'm afraid my baby might die on his/her tummy.

 1 2 3 4 5

3) I would feel discouraged if my baby were to cry while on his/her tummy.

 1 2 3 4 5

4) If a baby cries or dislikes being on his/her tummy while awake, it is OK to stop trying to place the baby on their tummy while he/she is awake.

1 2 3 4 5

5) I am/will be too busy to place my baby on his/her tummy, while he/she is awake.

1 2 3 4 5

6) Placing babies on their tummies while awake is not that important, most babies turn out fine.

1 2 3 4 5

7) Setting aside time for my baby to spend on his/her tummy is important.

1 2 3 4 5

8) I think placing my baby on his/her tummy is important for my baby.

1 2 3 4 5

9) It is common sense to place babies on their tummies some of the time.

1 2 3 4 5

10) I am confident that my baby will be safe when I place him/her on his/her tummy while awake.

1 2 3 4 5