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Vocabulary Size in Children with Down Syndrome:

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VOCABULARY SIZE IN CHILDREN WITH DOWN SYNDROME:
THE EFFECT OF HEART DEFECTS, HOSPITALIZATION, HEARING IMPAIRMENT,
AND PARENTAL CONCERNS

by

BRITTANY HESS

Under the Direction of Dr. Lauren B. Adamson

ABSTRACT

Children with Down Syndrome (DS) experience cognitive delays with language being one of the most impaired domains. Exploring the effects of congenital heart defects (CHD), hospitalization, hearing impairment, and parental concern can provide a more precise view of factors affecting language development. Participants were 49 children with DS, 22 to 54 months of age. Expressive and receptive vocabulary size was obtained using a word count with the MacArthur Communication Development Inventory (MCDI). Medical information was obtained from the child's medical file. Results showed expressive vocabulary was marginally significantly different between children with DS and no CHD, a CHD that did not require surgery, and a CHD that did require surgery, such that children with a CHD requiring surgery had the smallest vocabulary. Children had significantly more health problems when they had a CHD that required surgery. Expressive and receptive vocabularies were significantly smaller for children with hearing impairment.

INDEX WORDS: Down syndrome, Congenital heart defects, Language

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BRITTANY HESS

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Georgia State University

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DEDICATION

This work is dedicated to my family for their continued love and support, especially to my parents for their tough love in not letting me quit and come home. Also, to my brother, for his understanding of the life of a student and his continued encouragement. Finally, to the Blessed Trinity for the wisdom and strength given, and for filling in the gaps in my ability. Also, for placing so many wonderful people into my life at the times I needed them the most, with the things I needed most to hear.

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1. INTRODUCTION

Down syndrome (DS) is a genetic disorder affecting 1–2 children per 1000 live births every year in the United States (Vis et al., 2009). Down syndrome is characterized by mild to moderate cognitive delays, impaired language, and varying health problems (Abbeduto, Warren & Conners, 2007; Frenkel & Bourdin, 2009). Congenital heart defects (CHD) affect 40–50% of children with DS (Newberger, 2000). Despite the prevalence of severe heart defects and delays in language development, research has often focused on comparing language development of children with DS to typically developing children, and it has neglected the effect of health-related factors such as heart surgery, hearing impairment, and hospitalization that are prevalent in children with DS. It is also important to consider concerns parents have about how these health factors relate to their children's language development. Exploring the various health problems and experiences of a child with DS can provide a more precise view of factors influencing the child's language development and may lead to future advances in treatment options for these children. This study will consider: (1) presence and severity of CHD, (2) hospitalization, (3) hearing impairment, and (4) parental concern.

The current research explored expressive and receptive vocabulary size in children with Down syndrome. Of particular concern was the relationship between presence and severity of CHD and the size of expressive and receptive vocabularies. We also considered how overall health of the child and parental concern about the child's development related to the presence and severity of a CHD and vocabulary size. Hospitalization was considered to see if expressive and receptive vocabulary size

differed by frequency of hospitalization. Hearing impairment was also considered for its relationship with the presence and severity of a CHD, as well as expressive and receptive vocabulary size and child's overall health. One final interest of the research was the relationship between parental concern about language and the child's expressive and receptive vocabulary size.

Language Development in Children with DS

Language is one of the most impacted abilities for a child with DS, with deficits in expressive language, vocabulary production, and speech intelligibility (Kumin, 1996). Previous research found that for children with DS expressive language skills are behind receptive language skills. For example, Ypsilanti, Grouios, Alevriadou, and Tsapkini (2005) reported that children with DS are weak in aspects of expressive language, but receptive vocabulary and comprehension are less impaired. When tested using the Test of Word Knowledge, children with DS produced significantly more errors on expressive vocabulary than mental age-matched controls.

For children with DS, expressive language generally progresses through the same milestones as typically developing children but at a delayed rate; the period of canonical babbling is often extended and first words delayed. It is not uncommon for a child with DS to produce his or her first words at 21 months or later (Abbeduto et al., 2007). Berglund, Eriksson, and Johansson (2001) found overall a 36-month-old child with DS paralleled the language performance of a 16-month-old typically developing child, and the language development of a 48-month-old child with DS was close to a 20-month-old typically developing child's language development. Despite the chronological

age difference between typically developing children and children with DS, both groups produce first words at approximately the same mental age (Chapman, 1997).

Chapman (1997) noted children with DS may have a delay in the acquisition rate of expressive language. In a study by Berglund et al. (2001), 80% of 3–5 year old children with DS had acquired first words, but 10–20% still had fewer than 10 spoken words in their vocabulary. At 3 years of age the children averaged a vocabulary size of 36 words, with a range of 0–165 words. Twenty-five percent of the children had achieved the 50 word milestone by 3 years of age, 50% had achieved this milestone by age 4, and 75% by age 5. These findings again highlight the diversity of language development in children with DS.

One of the most important steps when considering language development for children with DS may be to consider expressive and receptive vocabulary separately instead of only as a composite language score. Although receptive language provides a foundation for expressive language, both require unique skills. By considering only a composite language score, researchers may miss specific areas of difficulty for children with DS. Looking at expressive and receptive language scores show if a child is having apparent difficulty learning and understanding words, or if there is a break down in production of words. Finding areas of difference in expressive and receptive language development can allow for more precise interventions and more effective support for these children.

Congenital Heart Defects

The presence of a CHD is an important consideration when looking at the health and development of children with DS. Several studies have shown that there are

considerable differences in the severity of CHDs (Fudge et al., 2010; Weijerman et al., 2010). One of the primary differences is not all CHDs require surgery, a procedure that may provide additional stress to the child and parents, elevating parental concern and disrupting the family dynamic. Therefore, it is possible the delay in language may not be due to the presence of a CHD alone.

For every 1000 live births, 6–8 infants have a CHD. Nearly half of children who survive a CHD will develop impairments in fine motor skills, visuospatial skills, memory, attention, and higher-order language skills. Shillingford et al. (2008) found that of 109 participants who had a CHD, 49% were receiving some form of remedial academic services and 15% were placed in special-education classes. These findings highlight the role CHDs play in the cognitive challenges children face. In addition, Hovels-Gurich et al. (2008) found speech performance for children with a CHD was below the normal range when compared to age matched children without a CHD. Research by Majnemer et al. (2008) on children with a CHD revealed impaired expressive higher order language skills and slightly delayed receptive language skills. They suggested that:

Before surgery, both prenatally and postnatally there may be poor oxygen delivery because of arterial hypoxemia, impaired cerebral perfusion, or both.

Intraoperatively, surgical procedures may be associated with hypotoxic-ischemic reperfusion brain injury. Postoperatively, medical complication may contribute to further risk for brain injury. (p.55)

These findings regarding the relationship between CHD and language development emphasize the importance of continued research in this area. It becomes particularly important in the DS population where CHDs are so prevalent.

In their review of the literature on Trisomy 21, Visotosak and Sherman (2008) report 40–50% of children with DS have a CHD. Children with DS and an atrioventricularseptal defect (AVSD) had a greater developmental age delay than age-matched children with DS and no CHD, and showed significant developmental delays. Specifically, children with a CHD showed a delay of 3.72 months in expressive language, 2.91 months in cognitive domains, 1.91 months in receptive language, and 1.0 months in gross motor skills. These findings support the need to consider the effect of a CHD on a child's expressive and receptive language as well as consider if other factors could be contributing to the language delay.

CHD Surgery

Walker (1991) found 25% of children with DS and a CHD will require surgery within the first year of life. Fudge et al. (2010) argued that earlier surgical repair of CHDs may be particularly important for children with DS to avoid intensifying upper airway and feeding/growth issues already being faced by children with DS. Surgery to repair a CHD is not a minor procedure and may play a critical role in a child's development. Therefore, it is an important distinction for children with DS and a CHD.

Hospitalization in Children with DS

Because hospitalization may influence vocabulary development, and not all hospitalizations are related to surgery to repair a CHD, it is necessary to examine the relationship between hospitalization, regardless of cause, and vocabulary development. So, Urbano, and Hodapp (2007) found children with a CHD were 2.3 times more likely to be hospitalized for problems not related to their CHD and had longer hospitalizations, but 30% of children without CHDs were also hospitalized. Since hospitalization may be

related to non-CHD issues, it needs to be considered separately for possible influence on the development of expressive and receptive vocabularies as it may provide some clarification about the role of CHD surgery versus just hospitalization in language development.

Hearing Impairment in Children with DS

The relationship between hearing ability and support of speech and language development has been emphasized by previous research (Moeller et al., 2010). As noted above, children with DS are at increased risk for language deficits, particularly in expressive language, and these language deficits can be further affected by hearing (Shott, 2006). Therefore it is important to consider if the child has impaired hearing.

Within the DS population, it is estimated that 38–78% of children have a hearing loss, a three times greater risk than children with other developmental delays. Chronic otitis media is a primary cause for hearing impairment and children with DS are at increased risk due to facial structure differences related to DS. The anatomy of the mid-face specific to children with DS causes the child's Eustachian tube to be more cylindrical in shape and smaller in width and predisposes the children to chronic ear disease. In addition, stenotic ear canals can cause cerumen impaction, and hypotonia can leave the tube more likely to collapse and restrict air flow to the middle ear causing build up of middle ear fluid and chronic otitis media (Shott, 2006; Shott et al., 2001).

Advancing medical technologies have supported the treatment of otitis media in children with DS, often with PETs. In a study by Shott et al. (2001), 83% (40 of the 48 participants) received PETs to treat their chronic otitis media. Forty-five percent of children received one set of PETs, 42% received two sets, 8% required three sets, and

5% required four sets of PETs. Often children underwent the procedure for the first set of PETs between 6 and 18 months of age. These children did not receive their best hearing screening results until they received their tubes, with the chance of normal hearing scores being 3.6% higher for children who had tubes in place when their hearing was tested (Shott, 2006).

Parental Concern about Language Development

Parents play a key role in the development of their child, including the child's language development. When a parent has overwhelming concerns for his or her child's health or development the concerns may interfere with the parent's capacity to support the child's development. The parent may attempt to mitigate the delays, or simply not notice the delay as they focus on more pressing concerns. Skeat, Eadie, Ukoumunne, and Reilly (2010) explored predictors of parents seeking help for their child's communication development and found gender, age, children's communication status, and parental concern were consistent predictors of parents seeking advice or help for their child's language. However, many parents with concerns do not seek help for their child, or they wait, especially with young children, thinking they will develop eventually. This can lead to critical loss of time for early intervention.

Rempel, Harrison, and Williamson (2008) investigated the worry parents feel when their child has a serious health concern. They found that if parents normalize their child's behavior and development it can decrease their worry, but it may keep parents from noticing and seeking treatment for developmental delays. Although the health problems considered were not the same as a child with DS and a CHD experiences, their study did show that serious health problems can cause worry for

parents. Worry can lead a parent to normalize a child's delay and not provide or seek extra assistance. Parents of children with DS may have been told to expect delays related to the DS and may fail to notice a problem and miss early signs and opportunities to help their child's language development. Also, parents of a child with a CHD may devote attention to treatments for the CHD and pay less attention to vocabulary development. Understanding further the relationship between parents' concern about their child's expressive and receptive vocabulary size may help inform strategies for addressing parents' needs in a way that might improve their child's language.

Pilot Study

Given the variability of language development for children with DS and the high presence of CHDs in these children, Visootsak, Hess, Bakeman, and Adamson (submitted) conducted a pilot study to probe the relationship between CHDs and language development for children with DS. The study involved 29 children with DS who were approximately 30 months of age and were participants in a longitudinal study of joint engagement and language development (Adamson, Bakeman, Deckner, & Romski, 2009). Within the group 12 children had a CHD and 17 did not. Participants' expressive and receptive language development was measured. Results showed when a child had a CHD the parent tended to report significantly smaller expressive and receptive vocabulary size for the child compared to children without a CHD ($p < .01$). Standardized assessment of language also showed smaller expressive and receptive vocabularies for children with a CHD compared to children without a CHD, although not significantly ($p = .12$, $p = .19$).

Hypotheses

The overarching aim of the current study was to consider the relationship between a child with DS having a CHD and expressive and receptive vocabulary size. Based on the findings from the pilot study, as well as research suggesting cognitive delays associated with CHDs, I hypothesized that children with DS + CHD (no surgery) have smaller expressive and receptive vocabularies than DS - CHD. In addition, we expected the smallest expressive and receptive vocabularies would be seen for children with DS + CHD (surgery).

I also hypothesized that children with DS + CHD (surgery) would have more health problems than children with DS + CHD (no surgery), and DS - CHD. Also, when the child has DS + CHD (surgery), the parent will express more overall concern for the child than when DS + CHD (no surgery), and less still when DS - CHD.

For hospitalization, I hypothesized that children with DS + CHD (surgery) would have the most hospitalizations, and DS - CHD would have the least number of hospitalizations. In addition, I hypothesized that regardless of presence and severity of CHD, children who have a higher number of hospitalizations will have smaller expressive and receptive vocabularies.

A secondary aim of the study was to explore the relationship of suspected hearing impairment with the presence and severity of a CHD for children with DS and the relationship with expressive vocabulary, receptive vocabulary, and child's overall health. First, it was hypothesized that children with DS + CHD would not have a higher incidence of suspected hearing impairment than DS - CHD, regardless of severity of CHD. Previous research has shown a relationship between hearing and language, so it

was hypothesized that children with suspected hearing impairment would have smaller expressive and receptive vocabularies than children without hearing impairment regardless of presence of a CHD. Finally, it was hypothesized that suspected hearing impairment would not be significantly related to overall health problems.

Another secondary aim was to consider parental concerns about language development. Parents are one of the greatest resources a child has when beginning language development. Parents often structure interactions with the child in order to facilitate communication and build vocabulary. However, if the parent is facing pressing medical concerns with the child, he or she may not have as many opportunities or be as focused on language. It was hypothesized that when a child has DS + CHD (surgery), the parent will report lower levels of concern about their child's language. In addition, children will show smaller expressive and receptive vocabularies when their parents report more concern about their child's language development.

2. METHOD

Participants

Participants were 49 children between 18 and 54 months of age who had been diagnosed with Down syndrome. Children were divided into three groups: children with DS - CHD ($n = 25$), children with DS + CHD (no surgery; $n = 13$), and children with DS + CHD (surgery) ($n = 11$). For the overall sample, 45% were male, and the groups did not differ significantly by gender, $\chi^2(2, N = 49) = 0.02, p = .99$. There was a significant age difference between the groups; $\eta^2 = .17, p = .01; F(2, 49) = 4.8$. A post hoc Tukey test showed that children with DS + CHD (no surgery) ($M = 32$ mo., $SD = 8.4$) were

significantly younger than children with DS + CHD (surgery) ($M = 41$ mo., $SD = 9.5$) and DS - CHD ($M = 41$ mo., $SD = 8.7$). Information about race and ethnicity was not available for the participants. English was the primary language in the home.

Mothers of children participating in the study ranged from 25 to 47 years old ($M = 36$, $SD = 5.4$). Fathers of the children participating in the study ranged in age from 26 to 52 years old ($M = 37$, $SD = 5.9$). The parents tended to be well educated with 90% of mothers and 87% of fathers having completed at least some college or an associates degree.

Participants were recruited from the Emory Down Syndrome Clinic. Dr. Jeannie Visootsak, developmental pediatrician at the Emory Down Syndrome Clinic, compiled a list of patients who were between the ages of 18 and 54 months old and who had signed a consent form to be contacted for additional research studies. The child's name and parent's phone number were released to the researchers; no additional information was shared at this time point.

There were 143 possible participants on the list; 11 were unreachable due to invalid phone numbers and 50 did not answer the phone or reply to messages. In all, 82 families were contacted, 68 agreed to participate, and 49 (72% of the 68 who agreed to participate) completed the study.

Parents of possible participants were contacted by the researcher by phone. The researcher followed a script (Appendix A) to inform the parent about the study and ask if he or she would be willing to have his or her child participate. After answering any questions, if the parent was willing to have his or her child participate the researcher collected the parent's name and mailing address for the research materials. Children

were enrolled in the study independent of other health problems. Specifically, children with and without a CHD were recruited.

Procedure

Possible participants were called four times in an attempt to reach individuals who were not previously reached. Calls were at least a week apart. If a parent agreed to consider participation in the study, he or she was mailed a participation packet. Participation packets were mailed the same day the parent was contacted. Participation packets contained a letter explaining the study and providing contact information for the researcher (Appendix B), two consent forms (Appendix C), a medical record release form (Appendix D), the MacArthur Communication Development Inventory–Words and Gestures (MCDI), the Parents Evaluation of Developmental Status (PEDS; Appendix E), a brief demographic-history questionnaire (Appendix F), and a postage paid return envelope. All questionnaires were marked with a participant ID number assigned to the child before they were sent out. Parents were asked to sign and return one consent form and keep the other for reference. By signing and returning the medical record release form they were giving permission for the research to review and document information from the child's medical file at the Emory Down Syndrome Clinic.

Follow up calls were conducted approximately one week from the time the packets were mailed. This call was to ensure the packets arrived and to see if the parents had any initial questions. Two weeks before the conclusion of the study, all parents who had received packets but had not returned them were given another follow up call to assess if they still wished to participate and if they had any questions.

When a packet was returned the researcher verified the consent form and medical record release form for a signature, which were then removed to separate files. The three questionnaires (the MCDI, PEDS, and demographic-history questionnaire) were then placed in a folder with the participant's ID number and were read to make sure there was no identifying information on the forms. The questionnaires were also reviewed for any items that would require a follow up call to the parent for clarification. Folders were kept in a locked drawer in the researcher's office and away from the key linking the participants' names and ID numbers.

Measures

Language development.

Language development was the primary outcome variable of interest for the study. Language was considered as *expressive vocabulary* size and *receptive vocabulary* size. Parental report of expressive and receptive vocabulary for each child was obtained from the MCDI. The MCDI contained a 396-item vocabulary checklist, which allowed parents to differentiate between words the child understands but does not say and words the child produces. Although the assessment is designed for typically developing children 8–16 months of age, it has been used for assessing language in older children with DS (Caselli et al., 1998; Zampini & D'Odorico, 2009). The MCDI has a reliability of .95 for the vocabulary comprehension section, and .96 for the vocabulary form production section using Cronbach's coefficient alpha (Fenson et al., 1993). In addition, the validity of the measure has been shown in multiple comparisons with other language measures. Full information is available in the user's guide and technical manual (Fenson et al., 1993). The MCDI was modified with a note for

parents to mark any word their child signed in either American Sign Language or Baby Sign with a “*”.

Expressive vocabulary was the total number of words the parent reported on the MCDI to indicate that the child produced either in speech or sign language. *Receptive vocabulary* was the total number of words reported by the parent on the MCDI that the child understood.

CHD.

Participants were grouped based on the presence and severity of a CHD. Information about the CHD was obtained from the child’s medical file at the Emory Down Syndrome Clinic. Reports showed whether the child had a CHD, and if there was a CHD, whether it required surgery for repair. A *CHD* was considered any heart abnormality present in the child from birth. A *DS + CHD (surgery)* was any type of CHD that had already been repaired surgically.

Health problems.

Information about any health problems the participants had was obtained from reports in the child’s medical file that had been written by Dr. Visootsak summarizing the child’s visit to the clinic. These reports compiled the information obtained by the physical exam as well as the parent report and other doctors’ reports of medical concerns. *Child’s overall health* was a rating of the child’s overall health created by doing a count of how many of the reported health problems the child had. There were eight health problems of interest: having a CHD, history of otitis media, receiving PETs, being hospitalized, diagnosis of hypothyroidism, diagnosis of acid reflux, diagnosis of sleep apnea, and any other major health concern. Having the condition was scored as

1, not having it 0. Items were totaled for a possible maximum score of 8. The first 7 items were considered due to their known relationship with DS, and the final item was to include any other major health problems the child may have, such as leukemia or feeding problems requiring medical intervention.

Hospitalization.

Hospitalization was defined as any stay of the child in the hospital for at least one night or for any major medical procedure. This information was also obtained from the child's medical file at the Emory Down Syndrome Clinic. Hospitalization was a coded variable: 0 = 0 hospitalizations, 1 = 1 hospitalization, 2 = 2 hospitalizations, 3 = 3 or more hospitalizations.

Suspected Hearing impairment.

Hearing information was obtained by Dr. Visootsak from a report provided from the child's other doctors. Information obtained reported whether the child passed or failed a hearing screening and the age when the screening was conducted. Since the test were pass/fail *Hearing* was defined as a binary variable with children having no hearing impairment, or having an inconclusive hearing screening or hearing loss.

Parental concern.

Overall parental concern for their child's development as well as concern about expressive language development and receptive language development were of interest in this study. Information about parental concern was obtained from self-report on the PEDS. The PEDS is a brief parent report measure of the parent's concern about his or her child's development (Glascoe, 2009) consisting of eight questions about parent concerns. Parents report if they have concern about the child's expressive as well as

receptive language, motor movement, behavior, and social skills. The measure can be used from birth to 8 years of age and takes about two minutes for parents to complete. The PEDS has been standardized on a national sample of 2,800 children and validated on over 1229 children in various settings. With a high sensitivity, this measure identifies 74–80% of children with disabilities, and high specificity identifying 70–80% of typically developing children.

Parents were able to answer if they have no concern, a little concern, or yes they are concerned. *Expressive concern* was the parent's response to a question about whether he or she has concern about how his or her child produces words on the PEDS. *Receptive concern* was the parent's response to a question about whether he or she had concerns about how his or her child understands what is said. *Overall parental concern* was created by calculating the percent of total questions for which the parent reported they had at least a little concern about.

3. RESULTS

Expressive and receptive vocabulary size was of particular interest for this study. The overall sample showed considerable variability in vocabulary size. For expressive vocabulary children ranged from having 6 words to 393 words ($M = 121$, $SD = 96.7$). Receptive vocabulary sizes ranged from 39 to 396 words ($M = 242$, $SD = 102$).

Effect of CHD on Expressive Vocabulary, Receptive Vocabulary, Parental Concern, and Health

Oneway Analysis of Variance (ANOVA) was conducted to explore the relationship between the severity of CHD with expressive vocabulary, receptive

vocabulary, overall parental concern, and the child's overall health individually. Findings are reported in Table 1. For expressive vocabulary, findings were as expected: DS - CHD > DS + CHD (no surgery) > DS + CHD (surgery). Children with DS - CHD showed larger expressive vocabularies than DS + CHD (no surgery). Children with DS + CHD (surgery) presented the smallest expressive vocabularies. These group differences were marginally significant.

Receptive vocabulary did not differ significantly based on the presence or severity of CHD in the child. However, the expected trend was seen: DS - CHD > DS + CHD (no surgery) > DS + CHD (surgery). Children with DS + CHD (no surgery) have smaller receptive vocabularies than children with DS - CHD, and children with a CHD requiring surgery had the smallest receptive vocabularies. Overall, receptive vocabulary was larger than expressive vocabulary for children in every group.

Child's overall health did vary significantly by group. Prevalence of health problems was DS + CHD (surgery) > DS + CHD (no surgery) > DS - CHD. A post hoc Tukey test revealed children with DS + CHD (surgery) had significantly more health problems than DS - CHD. Children with DS + CHD (no surgery) did not vary significantly from DS + CHD (surgery) and DS - CHD in the average number of health problems.

Parents overall concern for their child's development did not vary significantly by the presence or severity of a CHD. Parents of children with DS + CHD (surgery) did show slightly more concern, but again it was not significantly different from the percent of concern parents had for their children with DS - CHD, or DS + CHD (no surgery).

Table 1. Differences Among CHD and Surgery Groups for Key Variables

Variable	DS - CHD	DS + CHD (no surgery)	DS + CHD (surgery)	η^2	p	F
Expressive Vocabulary	151	90	87	.11	.08	2.7
Receptive Vocabulary	265	227	208	.06	.26	1.4
Child's Overall Health	2.2 _a	3.4 _{a,b}	3.6 _b	.18	.01	4.9
Overall Parental Concern	44%	48%	50%	.01	.85	0.16

Note. Scores are means; $n = 25, 13,$ and 11 for no CHD, CHD no surgery, and CHD surgery groups, respectively. Means that share a common subscript do not differ significantly per a Tukey post hoc test, $p < .05$.

Effect of Hospitalization on Expressive and Receptive Vocabulary

Groups did vary on frequency of hospitalization, $\chi^2(6, N = 49) = 14.9, p < .05$. Since children were grouped by severity of CHD, and severity of CHD was related to hospitalization, the grouping by presence of severity and CHD were not considered in this analysis. However, as expected, percent of children with no hospitalizations was high for children with DS - CHD (48%) and decreased with presence of a CHD. When considering children who had been hospitalized two times, only 16% of children with DS - CHD had been hospitalized twice, but 23% of children with DS + CHD (no surgery) had been hospitalized twice, and 55% of children with DS + CHD (surgery) had been hospitalized twice. Children with DS + CHD (surgery) had a higher frequency of hospitalization compared to children with DS + CHD (no surgery) and DS - CHD.

A oneway ANOVA revealed that the four groups (no hospitalizations, 1 hospitalization, 2 hospitalization, 3 or more hospitalizations) did not vary significantly from each other in size of either expressive or receptive vocabulary. For expressive

vocabulary, children who had been hospitalized 3 or more times had the smallest vocabulary ($M = 78$). Surprisingly it was not children with no hospitalization who had the largest expressive vocabulary size ($M = 120$), but children with one hospitalization ($M = 144$). For receptive vocabulary, children with 3 or more hospitalizations had the smallest vocabulary ($M = 204$) and children with no hospitalizations had the largest vocabulary ($M = 281$). And again, children with DS + CHD (surgery) had the greatest percentage of children with 3 or more hospitalizations.

Effect of Hearing on Expressive Vocabulary, Receptive Vocabulary, and Health

Presence of hearing impairment was explored. Overall, 33% of the sample had suspected hearing impairment. Of the 49 participants, 33 children had a report of normal hearing, 12 received inconclusive results, and 4 had a specific diagnosis of hearing impairment. Those with inconclusive results and a specific diagnosis were combined, due to the small numbers, into a suspected hearing loss group. There was not a significant difference in presence of suspected hearing impairment among the CHD groups, $\chi^2(2, N = 49) = 0.35, p = .84$.

Since presence of suspected hearing impairment was not significantly related to the presence or severity of a CHD, hearing was looked at independent of CHD group for its relationship with expressive vocabulary, receptive vocabulary, and child's overall health. Values can be found in Table 2. As expected, presence of a suspected hearing impairment was significantly related to expressive and receptive vocabulary. When children had a suspected hearing impairment they had significantly smaller expressive and receptive vocabularies than children with no hearing impairment. Child's overall health was not significantly related to the presence of hearing impairment so children

with suspected hearing impairment did not show significantly more health problems than children without hearing impairment.

Table 2. Differences Between Hearing Groups for Key Variables

Variable	No Hearing Impairment	Suspected Hearing Impairment	η^2	p	F
Expressive Vocabulary	145	69	.14	.01	7.7
Receptive Vocabulary	264	197	.10	.03	5.1
Child's Overall Health	2.5	3.4	.07	.06	3.6

Note. Scores are means; $n = 33$ and 16 for suspected hearing impairment and no hearing impairment, respectively.

Parental Concern and Vocabulary

Analysis of overall parental concern was reported in Table 1. Parental concern about expressive vocabulary and receptive vocabulary was then considered for its relationship with expressive and receptive vocabulary size. Percent of parents who reported expressive language concern can be found in Table 3. Percent of parents with concern did not vary significantly between children with DS - CHD, DS + CHD (no surgery), and DS + CHD (surgery), $\chi^2(4, N = 49) = 6.4, p = .17$. More parents reported greater concern for expressive language development when their child had DS + CHD (no surgery) or DS + CHD (surgery) compared to parents of children with DS - CHD, with the most reporting the greatest concern when their child had DS + CHD (surgery).

A oneway ANOVA was run to explore the relationship between parental concern for expressive language development and the size of the child's expressive vocabulary. Reports of level of concern did vary significantly, $\eta^2 = .16, p = .02; F(2, 49) = 4.4$. Post hoc Tukey analysis revealed the mean expressive vocabulary size was not significantly

different between parents who reported no concern ($n = 4$, $M = 64$) and a little concern ($n = 14$, $M = 101$). Mean vocabulary size was also not significantly different between parents who reported a little concern and yes concern ($n = 31$, $M = 179$). However, there was a significant difference between no concern and yes concern; children's mean expressive vocabulary was larger when parents reported yes concern.

For receptive language, percent of parents reporting each level of concern by group can be found in Table 4. As expected, when the child does not have a CHD, the higher percent of parents report no concern. When the child has a CHD more parents report concern about their receptive language than when children do not have a CHD. Surprisingly, when the child has had surgery for a CHD, there was a lower percentage of parents reporting concern than when the child has a CHD but has not had surgery.

A oneway ANOVA was run to explore the relationship between parental concern for receptive language development and the size of the child's receptive vocabulary. Reports of level of concern did vary significantly; $\eta^2 = .21$, $p = .01$; $F(2, 49) = 6.0$. A post hoc Tukey analysis revealed the mean vocabulary size was not significantly different between parents who reported yes concern ($n = 9$, $M = 186$) and a little concern ($n = 12$, $M = 192$). There was a significant difference between no concern ($n = 28$, $M = 282$) and yes concern and a little concern such that mean receptive vocabulary was larger when parents reported no concern.

Table 3. Parents' Expressive Language Concern

Group	No Concern	A Little Concern	Yes Concern
No CHD	12	40	48
CHD No Surgery	8	23	69
CHD and Surgery	0	9	91

Note. Scores are percentages; $n = 25, 13,$ and 11 for no CHD, CHD no surgery, and CHD surgery groups, respectively.

Table 4. Parents' Receptive Language Concern

Group	No Concern	A Little Concern	Yes Concern
No CHD	64	28	8
CHD No Surgery	62	8	31
CHD and Surgery	36	36	27

Note. Scores are percentages; $n = 25, 13,$ and 11 for no CHD, CHD no surgery, and CHD surgery groups, respectively.

4. DISCUSSION

The main interest throughout this research has been to explore both expressive vocabulary and receptive vocabulary in children with DS. Chapman and Bird (2012) in their chapter reviewing language development in children with DS stressed expressive language is more affected than receptive language in children with DS, and initially delays are not seen in comprehension vocabulary. This claim supports the decision to consider expressive and receptive vocabulary separately. The lack of initial delay in comprehension vocabulary also offers some insight into why the vocabulary sizes were

larger for receptive vocabulary, the delay is not as severe yet in these children. Also, children in the current study were under the age of five and previous research has shown early receptive vocabulary reported on the MCDI was similar to mental age matched peers with increased differences as children with DS got older.

In light of this information, there are many possibilities for advancing future research. Research should continue to explore expressive and receptive language separately for children with DS. In addition, it would be important to consider both early and later language, since expressive impairment will present earlier than receptive impairment. Also, since participants will be advancing in age the MCDI will most likely not provide the best assessment of the child's language. Assessments conducted with the child to observe language and utterance length would be very informative, combined with formal assessments such as the Peabody Picture Vocabulary Test (Dunn & Dunn, 1997) and Expressive Vocabulary Test (Williams, 1997).

Age of the participant is always critical when considering language development. It is well known that for young children in the early stages of language development, their vocabulary spurts can present great change in vocabulary in a short time (Dapretto & Bjork, 2000; Ganger & Brent, 2004). In the current study 24 participants, 50%, still had fewer than 100 words, 14 of those participants had fewer than 50 words, and 2 of the 24 participants had fewer than 10 words; all the children were over 2 years of age. For our sample it was critical to evaluate the age of children with no CHD, a CHD that did not require surgery, and a CHD that did require surgery since these groups would be compared for vocabulary size. We had an unexpected age difference in the groups,

with children with a CHD which did not require surgery being significantly younger than children without a CHD and children with a CHD that required surgery.

It is possible the age difference may be related to the severity of the child's CHD. There are three particular forms of CHDs which generally occur: atrioventricular septal defects (AVSD), ventricular septal defects (VSD), and atrial septal defects (ASD). AVSDs are heart lesions resulting from the endocardial cushions not fusing (Weijerman et al., 2010). Surgical repair is often early for an AVSD. VSDs are an opening in the ventricular septum resulting from faulty ventricular division during development. VSDs can vary in size from a pinhole to a full absence of the septum. Very small VSDs can heal on their own with no medical intervention, but larger VSDs require surgical repair when the child is approximately 2 years old. Finally, ASDs are a hole in the atrial septum that occurs from improper septal formation. If an ASD requires surgery it is usually not until the child is 4 years old or later, with many not requiring surgery. The information available for our sample suggested that our participants followed the same pattern. Children with an AVSD required early surgical repair, while most with a VSD or ASD did not have surgery and the hole had spontaneously closed. There were a few participants who were under observation to see if a hole would close, but currently there was no need for surgical repair.

Although Walker (1991) found 25% of children with DS and a CHD will require surgery within the first year of life, many of the CHDs do not require repair until the child is 2–4 years old. Therefore, children who were in the CHD that required surgery group may have been older due to the timing of their surgery. It is also possible that parents with younger children with CHDs requiring more urgent medical treatment are unable to

participate until the child is older and the child's health has improved so there are fewer demands on the parent's time and attention.

It is also possible the unexpected age difference between groups was the result of the availability and willingness to participate of parents, not to factors particular to the group the child would be in. This problem could be addressed by resampling the children with a CHD that did not require surgery when they are older. It would also be beneficial to obtain nonverbal mental ages for these children and use that for grouping and analysis. This may be particularly important since Visotosak and Sherman (2008) reported children with DS and an atrioventricularseptal defect (AVSD) had a greater developmental age delay than age-matched children with DS and no CHD. Also, this was a small sample and a larger sample would be beneficial for later research. More participants for greater power would strengthen the analysis.

When considering the relationship between presence and severity of CHD with language, findings were in the direction hypothesized. When children had a CHD their expressive and receptive vocabulary were smaller than children without a CHD, with children with a CHD that required surgery having the smallest expressive and receptive vocabularies. The difference for expressive vocabulary was marginally significant and should be considered with a larger sample.

Also, as expected, when children had a CHD that required surgery they had significantly more health problems than children without a CHD. With more health concerns there may be greater time demands that restrict the family's ability to research services for the child's development, or even be able to attend services such as speech therapy. Also, the child may be medically fragile and not able to go to intervention

services for development (Brandlistuen et al, 2010). This is also supported by the finding that parents had slightly more overall concern about their child when he or she had a CHD that required surgery (Rempel, Harrison, & Williamson, 2009).

We also found that when children were hospitalized 3 or more times they tended to have smaller expressive and receptive vocabularies. Since children with a CHD that required surgery showed more hospitalizations, it is an important consideration. It also relates back to the previous statement that having these medical needs may limit the time of the child to participate in services, or the child may be too ill to participate in activities that would facilitate language development. Future research should consider the severity of the child's needs in comparison to how much time the child spends in school or activities outside the home to support development, such as speech therapy.

Given the previous research on the prevalence of hearing impairment in children with DS, we were not surprised to see almost one third of the participants had suspected hearing impairment, and that the presence of hearing impairment did not vary significantly based on presence and severity of a CHD. Since the hearing impairment is often associated with chronic otitis media, resulting from the facial structure differences in DS that impact the ear canals, there was no reason to expect a CHD would be related to suspected hearing impairment (Shott, 2006; Shott et al, 2001). Our findings supported previous findings that when there is suspected hearing impairment there is decreased expressive and receptive vocabulary. This is most likely due to restricted language exposure resulting from the hearing impairment.

Future research can build on these initial findings of the relationship between suspected hearing impairment and language by considering the severity of hearing

impairment as well as if the child has received treatment for hearing problems. Since the hearing impairment is often associated with chronic otitis media, the child is likely to have received PETs to treat the otitis media (Shott, 2006). Previous research shows the reception of PETs can improve the child's outcome on a hearing test (Shott et al, 2001). Therefore, the frequency of reception of PETs should be considered for relationship with hearing impairment and vocabulary size. It may be advantageous to consider how long the child has had PETs and try to explore how long the child was experiencing limited hearing and at what age, as this may strongly relate to the amount of language exposure they have received.

Finally, parent concern about expressive and receptive language development was explored. For expressive vocabulary it was as expected that more parents who had a child with a CHD that required surgery expressed higher concern about their child's expressive language. We had expected that if the child had a smaller vocabulary the parent would have more concern, but this was not the case for expressive vocabulary. For no concern expressed, we saw the smallest mean expressive vocabulary score. Although the number of participants in this group was very small ($n = 4$), it is nonetheless interesting to explore. When the characteristics of these participants were explored we saw 3 of the 4 children did not have a CHD. We would have expected that these children would be those with a CHD that required surgery since they tended to have the smallest vocabularies and since we expected more health problems to keep parents from being as concerned about their child's language. We were also surprised to see that the 4 children were not the youngest children. The children ranged from 25 to 45 months old. Therefore it is hard, given the current

sample, to make a definitive statement about the full relationship between parental concern about expressive vocabulary and size of the child's expressive vocabulary. It would be interesting for later research to better explore parental concern and its relationship with language development. Particularly, looking at the relationship between overall concern about the child and concern specifically about language may highlight if concern about other areas takes focus away from language concern, or if it leads to greater concern.

Findings regarding receptive concern about language were as we expected; as receptive vocabulary size increased parents reported less concern about receptive language. Consistent with the findings for expressive vocabulary, the largest percent of parents expressing the most concern about receptive language were those who have a child with a CHD. Surprisingly, slightly fewer parents who had a child with a CHD that required surgery reported the highest concern compared to parents with a child with a CHD that did not require surgery. This could be explored further with directed questions for the parents to see if the slight decrease in concern has anything to do with being more focused on the CHD.

While the PEDS was a straightforward measure, easy to have parents answer without a researcher present, and provided interesting preliminary information about parental concern related to their child's language development, it would be useful for later research to probe the relationship between parental concern and language development further. Since the PEDS was parent report it can be hard to determine the value of these answers. By doing a structured interview with the parent and asking

questions more specific to the areas and level of concerns a more precise view of the concern may be possible and a clearer relationship may emerge.

Overall this study supported the previous findings that language development in children with DS is quite varied, and it is important to consider expressive and receptive language separately as they develop at different rates. Research needs to continue investigating the relationship between language development and the presence of a CHD in children with DS with a larger sample, particularly to explore the marginally significant expressive vocabulary findings of this study. Differences are seen when the child has a CHD, as well as when you consider if the child had surgery for the CHD, and this distinction should not be overlooked and simply collapsed into CHD or no CHD. With strong advancing research in this area we may be able to better identify unique needs of children with DS as they acquire and develop their language skills and to design intervention programs which directly meet those needs and provide greater success for the child.

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APPENDICES

Appendix A

Recruitment Call:

Hello _____

My name is Brittany Hess and I am a graduate student at Georgia State University. I got your name from the Emory Downy Syndrome Clinic because you expressed interest in being contacted for research studies.

I am currently recruiting parents for participation in a study about their child's health and language development. Would you be interested in hearing more about the study?

IF YES

The main purpose of the research is to look at language development in children with Down syndrome. The study looks at the health factors a child experiences early in life and see if there is a relationship with vocabulary development. The two health factors which this study will look at are if the child has a congenital heart defect when born, and how the child's hearing has been over the course of his or her life.

If you wish to participate you will be mailed a packet containing a consent form about the study and your rights as a participant as well as a language measure for you to fill out about your child – The MacArthur Child Development Inventory – Words and Gestures. This item lists words and asks you to check if your child responds to that word and if your child speaks that word. This should take you no more than 30 minutes to complete. We would also ask you to sign a medical record release form to allow a

researcher to look at your child's medical file for heart and hearing information. No other information will be collected and no copies will be made of your child's record.

Participation will also include a phone call with a researcher to discuss the consent for the study and to answer a few questions about your child's development.

Do you have any questions?

Would you be willing to participant in our study?

IF YES

Thank you very much I really appreciate your willingness to help us with our research. Would you please provide me with the best phone number to reach you at, and the address you would like me to mail your materials to.

Also, I would like to schedule a date for a follow up call to answer any questions you have once you receive your materials, as well as to ask you a few questions. Do you have a day or time which is more convenient for you?

(This is where working through dates with them)

Ok, so just to confirm we have scheduled a call for _____ and I will be mailing your materials to you tomorrow.

Thank you again for your help and if you have any questions at any time please do not hesitate to call me or email me. My phone number is (404) 413-6297 and my email is bhess1@gsu.edu.

Appendix B

Brittany A. Hess
Department of Psychology
Georgia State University
P.O. Box 5010
Atlanta GA 30302-5010
(404) 413-6297

Dear _____:

My name is Brittany Hess. I am a graduate student in the developmental psychology program at Georgia State University. I am currently working on my master's thesis to study language development in children with Down syndrome. The study will look at the health factors a child experiences early in life and see if there is a relationship with vocabulary development. The health factors that this study will look at are congenital heart defects, hospitalizations, hearing impairment, and having pressure equalizing tubes.

I need your help to investigate this question. First, I ask you to fill out the MacArthur Child Development Inventory – Words and Gestures. This measure gives you an opportunity to tell us the words your child understands and uses. You will check the words your child says out loud or understands when you say. If your child uses the word with a gesture or a communication device, you can make a note on the sheet. The measure can be completed at home in about 30 minutes. Additionally, this research study wants to find out how you feel about your child's language development. I would appreciate if you would answer the Parents' Evaluation of Developmental Status (PEDS) and a brief history questionnaire.

Finally I ask you to sign a medical record release form. This form allows me to look at the medical file of your child kept by Dr. Visootsak at the Emory Down Syndrome Clinic. I am looking at the medical file to gather basic information about your child's health, such as if they have a congenital heart defect, have been hospitalized, and hearing information. No copies of the medical record will be made.

If you change your mind about participating in the study at any time please contact me at Georgia State University by phone or email. My phone number is (404) 413-6297. If I am not available please leave a message and I will return your call. You can email me at bhess1@gsu.edu. You can contact me at any time with any additional questions you have about the study.

Thank you for your participation.

Brittany Hess
Georgia State University Researcher
bhess1@gsu.edu
(404) 413-6297

Appendix C

Georgia State University
Department of Psychology
Consent Form

Title: Vocabulary Size in Children with Down Syndrome: the Effect of Heart Defects, Hospitalization, Hearing Impairment, and Parental Concerns

Principal Investigator: Dr. Lauren B. Adamson
Brittany A. Hess, Student P.I.

I. Purpose:

Your child is invited to participate in a research study. The purpose of the study is to investigate the effect of health factors on language development in children with Down syndrome. Your child is invited to participate because he or she is between the ages of 18 and 54 months and has been diagnosed with Down syndrome. A total of 126 participants will be recruited for this study. Participation will require approximately 1-2 hours of your time. The study can be completed in the privacy of your home at your convenience.

II. Procedures:

If you decide to have your child in the study, you will receive a packet of materials in the mail. First you will read and sign this participation form. Next you will complete the MacArthur Child Development Inventory. This is an assessment of your child's vocabulary. Directions are on the inventory. You fill in bubbles as directed for each section. Overall it will take about 30 minutes to complete. Next you will complete the Parents' Evaluation of Developmental Status questionnaire. This questionnaire has eight yes or no questions. It will take less than 2 minutes to complete. The last questionnaire is a history questionnaire. The final form in the packet is a medical record release form for your child. This allows the researcher to look at your child's medical file kept by Dr. Jeannie Visootsak at the Down Syndrome Clinic at Emory University. No copies of the medical information will be made. Please sign and return this form to the researcher. If you do not wish to sign the form you do not have to. During the time you have the materials the researcher will call and discuss any questions you have. You can also call or email the researcher at any time with any questions or concerns. Once you have completed the materials put them in the enclosed stamped envelope and mail to Georgia State University.

III. Risks:

In this study, your child will not have any more risks than he or she would in a normal day of life.

IV. Benefits:

Participation in this study may not benefit you personally. Overall, we hope to gain information about the differences in language development for children with Down syndrome. In particular, we are studying if a congenital heart defect, hospitalizations, or hearing problems are related to language development.

V. Voluntary Participation and Withdrawal:

Participation in research is voluntary. Your child does not have to be in this study. If you decide to have your child in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time. Whatever you decide, you will not lose any benefits to which you are otherwise entitled. If you do not wish for your child to participate in the study, it will in no way impact the services your child receives from the Emory Down Syndrome Clinic.

VI. Confidentiality:

We will keep your child's records private to the extent allowed by law. The research team will have access to the information you provide. Information may also be shared with those who make sure the study is done correctly (GSU Institutional Review Board and/or the Office for Human Research Protection (OHRP)). We will use a participant identification number rather than your child's name on study records. The information you provide will be stored in a file specific to your child in a locked filing cabinet in the researcher's office. The key used to create the code for your child's identification will be kept in a separate filing cabinet in a different office to protect privacy. The key will be destroyed three years after the completion of the study. Your child's name and other facts that might point to your child will not appear when we present this study or publish its results. The findings will be summarized and reported in group form. Your child will not be identified personally.

We will keep your child's personal information private. Your child's privacy will be kept to the extent allowed by law. The health information you give us will be used in this research study. We will remove all information that can identify your child. We will share it only with others working on this research study. If you decide you want your child to be in this study it means that you agree to let us use and share your child's personal health information for the reasons we have listed in this consent form.

While we are doing this research, the research team may use only the personal health information that you have given us: your name, address, phone number, email, child's medical record (if release form is signed). Only Brittany Hess will be able to look at your child's personal health information in the medical record. She will look at it so

she can work on this research study. We may also share your child's health information with the Georgia State University Institutional Review Board (IRB). Your child's personal health information may be shared by the people or places we have listed, but it will be shared in a way that does not fall under the protection of federal regulations that apply to the privacy of health information. This research may be shown to other researchers. This research may be published, but we will take steps to make sure that your child cannot be identified.

If you sign this consent form you are letting us use your child's personal health information until the end of the study. You have the right to say that you do not want us to use your child's personal health information after we have collected it. If you decide you don't want us to use your child's information anymore you must write a letter asking us not to use your child's information. You will need to send the letter to the investigator who received your completed questionnaires.

VII. Contact Persons:

Contact Brittany Hess at (404) 413-6297, bhess1@gsu.edu or Dr. Lauren B. Adamson at (404) 413-6256 ladamson@gsu.edu if you have questions about this study. If you have questions or concerns about your rights as a participant in this research study, you may contact Susan Vogtner in the Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu.

VIII. Copy of Consent Form to Subject:

We will give you a copy of this consent form to keep.

If you are willing to volunteer for this research, please sign below.

Child's name (please print)

Parent or Guardian Signature

Date

Principal Investigator or Researcher Obtaining Consent

Date

*Appendix D*MEDICAL RECORD RELEASE FORM

Your child's name: _____ Date of Birth: _____

If your child has another last name at the birth hospital, please record:

Mother's name: _____ Date of Birth: _____

I authorize release of medical records on my child, named above, to:

Brittany Hess
Department of Psychology, Georgia State University

(name of parent or guardian – please print)

(relationship to child, e.g. mother)

(signature of parent or guardian)

(date)

(witness)

Please note:

This form allows the researcher mentioned above to view your child's medical file at the Emory Down Syndrome Clinic at Emory University. No copies will be made of your child's medical file, and no papers will be removed from the file. The child's file will never be removed from the Down Syndrome Clinic. The researcher is viewing your child's file to look at basic medical information related to the goals of the research. Signing this form allows the researcher to only look at your child's file.

Appendix E

PEDS

Please list any concerns about your child's learning, development and behavior.

Do you have any concerns about how your child talks and makes speech sounds?

Circle one: No Yes A little Comments:

Do you have any concern about how your child understands what you say?

Circle one: No Yes A little Comments:

Do you have any concerns about how your child uses his or her hands and fingers to do things?

Circle one: No Yes A little Comments:

Do you have any concerns about how your child uses his or her arms and legs?

Circle one: No Yes A little Comments:

Do you have any concern about how your child behaves?

Circle one: No Yes A little Comments:

Do you have any concerns about how your child gets along with others?

Circle one: No Yes A little Comments:

Do you have any concerns about how your child is learning to do things for himself/herself?

Circle one: No Yes A little Comments:

Do you have any concerns about how your child is learning preschool or school skills?

Circle one: No Yes A little Comments:

Please list any other concerns.

Appendix F

History Questionnaire

Participant ID #: _____

Please take a few minutes to answer the following questions.

1. Mother's age: _____
2. Mother's education: _____
3. Mother's employment: _____
4. Father's age: _____
5. Father's education: _____
6. Father's employment: _____

Please list any intervention activities or therapies your child is currently receiving or has received in the last six months, and how often.

Activity:	How often:	Parent Participation: Yes /No