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**Parental Perceptions of Oral Health Related Quality of Life for Children that Receive Care
on Give Kids a Smile Day**

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science
in Dentistry at Virginia Commonwealth University

By

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Table of Contents

Acknowledgements.....	ii
List of Tables	iv
List of Figures	v
Abstract	vi
Introduction.....	1
Materials and Methods.....	4
Results.....	6
Discussion.....	8
Conclusions.....	13
Literature Cited	15
Table 1. Questionnaire Results	18
Table 2. Individual Section Averages	19
Table 3. Individual Question Averages	20
Figure 1. Mean Questionnaire Score	21
Figure 2. Mean Score of Each Section.....	22
Appendix.....	23
Vita.....	27

List of Tables

Table 1. Questionnaire Results	18
Table 2. Individual Section Averages	19
Table 3. Individual Question Averages	20

List of Figures

Figure 1. Mean Questionnaire Score	21
Figure 2. Mean Score of Each Section.....	22

Abstract

PARENTAL PERCEPTIONS OF RELATED QUALITY OF LIFE FOR CHILDREN THAT RECEIVE CARE ON GIVE KIDS A SMILE DAY

By Andrew Clayton Gibson DDS

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Dentistry at Virginia Commonwealth University.

Virginia Commonwealth University, 2016

Thesis Advisor: Elizabeth Berry, DDS, MS, MPH
Vice Chair, Assistant Professor, Department of Pediatric Dentistry

Purpose: The purpose of this study is to evaluate the oral health-related quality of life for patients treated at Give Kids a Smile. **Methods:** Participants were asked to complete a 25-question survey regarding their child's oral health-related quality of life (OHRQoL), with answers ranked on a 0 to 4 point scale. **Results:** A total of 78 questionnaires were completed, with the mean score of 5.19. **Conclusions:** Give Kids a Smile was created to treat children with unmet oral healthcare needs, therefore it was hypothesized that the OHRQoL for the children treated would be negatively impacted and thus this score high. This was not demonstrated in the current study and these findings could be due to a variety of factors, including relying on the parent to report the child's symptoms as well as low oral health literacy for parents completing the questionnaires.

Introduction

Dental caries is the most common childhood disease, resulting from an interaction of cariogenic bacteria, such as *Streptococcus mutans*, and sugar rich foods with the enamel of the teeth.¹ Early childhood caries can begin very early in life and progresses rapidly in patients, specifically those at high risk, and frequently goes untreated.^{2,3} A variety of risk factors and behaviors have been identified as contributing to the development of both early childhood caries and severe early childhood caries. One main factor is the amount as well as the frequency of consumption of fermentable carbohydrates, especially fruit juice consumption. For very young children, prolonged breastfeeding can also contribute to an increase in caries formation. Another important variable is adequate oral hygiene and mechanical removal of the biofilm from the dentition. Lastly, completion of a routine periodic dental examination has demonstrated a significant decrease in the development of caries.⁴

The consequences of dental decay often affect both the immediate and the long-term quality of life of the child. Additionally, it can create significant social and economic consequences for the family as a whole.⁵ It is important to recognize the impact of dental decay on the subjective aspects of the child's life, not simply the objective clinical implications. These subjective aspects include the child's emotional, social, and physical well-being. This broadened perspective is important for us to properly acknowledge the child's experiences as a critical evaluator of the consequences of dental disease. These functional and psychosocial impacts of dental disease on

children, specifically as perceived by their caretakers, can be defined as their oral health-related quality of life.⁶

The relationship between dental disease and oral health-related quality of life (OHRQoL) has been well established by many studies. One of the leading studies in this area, by Jokovic et al., found a significant correlation between OHRQoL and the number of decayed tooth surfaces. Furthermore, they found that children with decayed teeth had a lower overall OHRQoL than did caries-free children.⁷ It is also important when analyzing the comprehensive effects of dental disease on children to understand the highly variable impact the disease has on each individual child. The extent of the impact of dental disease on the child's life is not solely determined by the nature and severity of the disease, but rather is also influenced by many personal and environmental characteristics.⁸

Taking analysis of the relationship between dental disease and OHRQoL one step further, it is important to assess any changes in OHRQoL resultant from oral rehabilitation. In one study, the predominant outcome observed following dental rehabilitation was a reduction in pain. Importantly, they also noted an improvement in eating, sleeping, and overall health.⁹ Another study noted improvements of both physical and social quality of life measures following dental rehabilitation.¹⁰ Furthermore, Filstrup et al. demonstrated a significantly improved quality of life following dental rehabilitation by both parents as well as children.⁵ This clearly illustrates the far-reaching and diverse impact of dental disease, with effects reaching beyond the child and extending to the family as a whole.

Many of the children most affected by dental disease are without dental insurance, the same children that are treated on Give Kids a Smile day. Little research has been done to show the

effects of not having dental insurance on children. While Give Kids a Smile day is implemented nationwide and sponsored by the American Dental Association, the long-term effects of the project are not well-documented or researched. One study found that children from a Give Kids a Smile project in Kentucky exhibited an association between having untreated caries and not having dental insurance. However, the quality of life of these children has not been researched. Many children that are seen on Give Kids a Smile day have untreated dental needs. As a result, attaining a better understanding of the patient population being treated at Give Kids a Smile day as well as researching if the project results in an improvement in the overall quality of life of a child is needed.¹¹

Dental disease clearly has a multifactorial impact on the lives of children. Between its prevalence as the most common disease in children and its far-reaching effects, it is clear that this interaction needs to be better understood. It is the goal of this study to evaluate the oral health-related quality of life for patients treated at Give Kids a Smile day. This information will allow us to achieve our aim to better understand this population in order to provide more successful and comprehensive treatment to children suffering from dental disease through the Give Kids a Smile program.

Materials and Methods

This project was approved under exempt status from the Virginia Commonwealth University Institutional Review Board (VCU IRB #HM20003738).

All data was collected the day of the event, February 6, 2015. Participants were recruited from the parents/guardians of patients participating in the event. Potential participants were approached after registering for the Virginia Commonwealth University Give Kids a Smile day at the VCU Pediatric Dentistry clinic. All parents/guardians of patients were eligible for participation in the study. The only exclusion criterion was for non-English speakers, as IRB approval was only obtained for the required information sheets and questionnaires in English. Potential participants were given an information sheet with basic information about the study and were informed about the objectives and goal of the study. They were also provided with contact information for the investigators should they have any questions following the study. Participants were given the OHRQoL Survey established by Jokovic et al., and asked to complete the survey based off of their observations of their child's behaviors and symptoms.⁷ They then completed the survey while waiting for their child to be treated. Upon completion of the survey, participants were compensated with five dollars. The answers to the 25 question OHRQoL survey were then ranked on a zero to four point scale, with the total representing the child's overall OHRQoL. This data was then compiled and analyzed using REDcap to estimate prevalence at a 95%

confidence interval in order to better understand the OHRQoL of the children seen at Give Kids a Smile.

Results

A total of 78 OHRQoL questionnaires were completed as part of this study. All questionnaires were completed in their entirety, with no questions left unanswered. As seen in Table 1, the minimum observed score was zero, with the maximum observed score being 29. The mean score was 5.19 (3.80, 6.53). There was a significant floor effect observed in our study, with 18 surveys being completed with a score of zero. If these 18 studies are considered as outliers, the mean score was then 6.75 (5.14, 8.29).

The OHRQoL questionnaires can be broken up into four categories of questions, as seen in Table 2. The first section is comprised of the first five questions, all aimed at understanding the oral symptoms. The average total score of these five questions across all 78 surveys was 3.05. The second section consists of questions six through ten, focused on evaluating the functional limitations of the child. The average total score of these five questions across all 78 surveys was 1.00. The third section is derived from questions eleven through fifteen, examining the emotional well-being of the child. The average total score of these five questions across all 78 surveys was 0.78. The last section of the questionnaire, questions sixteen through twenty five, is designed to evaluate the social well-being of the child. The average total score of these ten questions across all 78 surveys was 0.36.

As demonstrated in Table 3, the individual questions with the highest average scores were questions four and five. Furthermore, the individual questions with the lowest average

scores were 19, 21, and 22. This information is consistent with the trends illustrated in Table 2, indicating that the highest scoring questions came from the first section regarding oral symptoms with the lowest scoring questions in the last section regarding social well-being.

Discussion

Given that Give Kids a Smile was created in an effort to treat underserved children with unmet oral healthcare needs, one would expect to see higher total scores on the questionnaires, indicating a more profound negative impact from the child's oral health on his/her overall quality of life. However, as seen in Figure 1, this was not demonstrated in the current study. Despite providing extensive care to over one hundred and fifty patients, a significant portion of which were restorative and oral surgery procedures, participants in this study did not report a high level of symptoms or negative impact on their quality of life resultant from their oral health.

When comparing these results to other studies, several important findings emerge. There was a significant floor effect in the Foster Page, Boyd, and Murray Thompson study as well. However, the current study exhibited a much more profound floor effect with over 23 percent of questionnaires scoring zero, compared to their observed 13.7 percent. Additionally, they observed a maximum score of 43. When compared to the current study's maximum score of 29, a trend towards lower observed scores in the current study begins to develop. Furthermore, and perhaps most significant, the mean score observed in their study was 7.8 compared to the average score in our study of 5.19.¹² This represents a 33 percent lower observed average score in the current study. When comparing results both individually and collectively, the findings consistently scored lower, representing an overall higher perceived quality of life amongst participants in the current study.

These skewed findings could be resultant from a variety of factors. One limitation of the current study is that it relied on the parents to report the child's symptoms and overall quality of life rather than surveying the child directly. By doing this, a confounding variable of how well the parent was aware of the child's needs and symptoms was introduced. In two separate studies Jokovic and colleagues examined this variable, resulting in two important conclusions. One study indicated that even though some parents have limited knowledge and understanding of their child's OHRQoL, the information reported by parents is still valuable, even if it is not comprehensive, since it is still representative of a different perspective compared to the child's.¹³ A second study demonstrated substantial agreement between mother and child in overall OHRQoL scores, but showed only a moderate level of agreement for subsets related to emotional and social well-being. This study concluded that although mothers can be used to report on their child's quality of life, the views of both the child and mother should be accounted for when possible.¹⁴ Although these studies, as well as many others, indicate that it is both acceptable and accurate to have a parent report and evaluate the child's quality of life, there is still inherently increased variability and potential for inaccuracy when relying on the parent to report when compared to surveying the child directly.

Another contributing factor to the results of the current study may be due to the participants' health literacy, specifically their oral health literacy. By definition, health literacy is "the degree to which individuals have the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions."^{15,16} The level of health literacy clearly impacts a person's understanding and perception of any symptoms that may be present. As a result, the health literacy of the participants in this study could also confound the data regarding their child's OHRQoL.

There are a variety of factors and predictors of health literacy, one of which is socioeconomic status. Numerous studies have demonstrated a connection between socioeconomic status and health literacy, one of which specifically linked limited health literacy with lower education level as well as with lower income.¹⁷ Despite not collecting demographic information as part of this study, it can be assumed that a significant portion of the participants in the current study have lower incomes due to the nature of Give Kids a Smile and treating uninsured and lower income families. This potentially contributed to a misunderstanding of symptoms, which inevitably influenced the reporting of their child's OHRQoL. Additionally, Wang et al. demonstrated that individuals with low health literacy are more likely to be effected by chronic diseases than individuals with high health literacy, with the most commonly reported impact being pain and discomfort. However, despite experiencing more pain and discomfort, these same individuals with lower health literacy reported less health-related quality of life impacts.¹⁸ This is an important distinction to consider when analyzing the results of this study, as it potentially led to a significant misrepresentation or under reporting of symptoms.

Furthermore, Divaris et al. examined the association between the caregivers' oral health literacy and the child's OHRQoL, also examining and accounting for the child's actual oral health status. This study resulted in two significant findings. They observed a strong correlation between the child's actual oral health status and the reported OHRQoL. However, the magnitude of this correlation was less significant amongst caregivers with lower oral health literacy.¹⁹ This very importantly demonstrates that caregivers with limited oral health literacy are more likely to misinterpret or inaccurately report their child's symptoms and OHRQoL. These findings further support that the level of health literacy amongst the participants' in the current study potentially

impacted their responses to the questionnaire, as well as their assessment of their child's OHRQoL and symptoms.

Another factor that may have influenced the findings of the current study is financial reimbursement. Although participation involved no risk and was completely anonymous, participants were reimbursed with five dollars upon completion of the questionnaire. Multiple studies have demonstrated that even small amounts of compensation increase response rate as well as an individuals' willingness to participate.^{20,21} Participants in the current study were compensated as a means to incentivize participation, which is supported by the above studies. However, by reimbursing participants, it is possible that this influenced the sample population by recruiting individuals that were primarily motivated by financial gain rather than self-motivated to provide accurate information to further our understanding of the patients treated at Give Kids a Smile day.

Lastly, when analyzing the results, it is noteworthy that for each successive section of the questionnaire, the average score declined. This gradual decline is illustrated in Figure 2. This may be an indicator that participants were influenced by response burden, which is typically defined as the effort required by the participant to complete a questionnaire. One of the most common factors contributing to an increased response burden is questionnaire length.²² Despite the OHRQoL questionnaire utilized in this study consisting of only 25 questions, there is a potential that this length resulted in a response burden that influenced the responses of some participants. This potential may be illustrated by the decline in scores that corresponded with progression through the questionnaire. Response burden has been shown to have several impacts, including a decrease in response rates, a reduced completion rate, as well as a reduction in data

quality.^{23,24} Collectively, all of these variables associated with response burden may have contributed to the results observed in this study.

Conclusions

The purpose of this study was to evaluate the oral health-related quality of life for patients treated at Give Kids a Smile day at Virginia Commonwealth University. The results of this study indicate that the patients treated have a high oral health-related quality of life, yielding a mean score of only 5.19 (3.80, 6.53) out of a total of 100 for the 78 completed questionnaires. Even when considering the 18 surveys that were completed with a score of zero as outliers, the mean remained a low score of 6.75 (5.14, 8.29).

As a pilot study, a significant goal of the current study is to not only explore the OHRQoL of the patients treated at Give Kids a Smile day, but to also determine ways in which the current study design can be improved to obtain more accurate and meaningful data in the future. In reviewing the results of this study, several recommendations can be made to improve this study as well as identifying areas where further research is indicated.

One consideration for future research is to survey the child directly in addition to the caregiver. This would aid in minimizing and identifying any inaccuracy resultant from the caregiver alone completing the survey. Additionally, if future studies rely on the caregiver to complete the questionnaire, obtaining information about the caregiver's oral health literacy as well as demographic information, specifically socioeconomic status, would be beneficial when analyzing results and potential outcome variables. In an effort to further understand the role of

the caregiver's oral health literacy, future studies should link the questionnaire with the treatment completed. This would help verify the presence of a discrepancy present between the reported and actual OHRQoL.

Furthermore, since the study requires no risk to participants and a small time commitment, it is recommended that future participants not receive any financial compensation in an effort to avoid introducing a confounding variable or potentially skewing the study population. Lastly, since the results indicate that participants may have experienced a response bias, resulting in a potential reduction in data quality, it is worth considering using the shortened version of the child perceptions questionnaire formulated by Jokovic, which contains 16 questions instead of the 25 questions utilized in the current study.

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Table 1. Questionnaire Results

	n	Mean Score	Lower 95%	Upper 95%
Overall	78	5.17	3.80	6.53
After Removal of Surveys Scoring Zero	60	6.72	5.14	8.29

Table 2. Individual Section Averages

Section	Average
Oral Symptoms	3.05
Functional Limitations	1.00
Emotional Well-Being	0.78
Social Well-Being	0.36

Table 3. Individual Question Averages

Question	Mean Score	Lower 95%	Upper 95%
1	0.42	0.25	0.60
2	0.27	0.14	0.40
3	0.47	0.27	0.68
4	0.85	0.62	1.08
5	1.03	0.78	1.27
6	0.21	0.07	0.34
7	0.22	0.07	0.37
8	0.22	0.08	0.36
9	0.14	0.02	0.27
10	0.21	0.06	0.35
11	0.27	0.11	0.43
12	0.19	0.05	0.33
13	0.12	0.02	0.21
14	0.10	0.02	0.19
15	0.10	0.02	0.19
16	0.05	-0.01	0.11
17	0.04	-0.02	0.10
18	0.08	0.00	0.16
19	0.01	-0.01	0.04
20	0.03	-0.01	0.06
21	0.01	-0.01	0.04
22	0.00	0.00	0.00
23	0.03	-0.03	0.08
24	0.04	-0.01	0.08
25	0.08	0.00	0.16

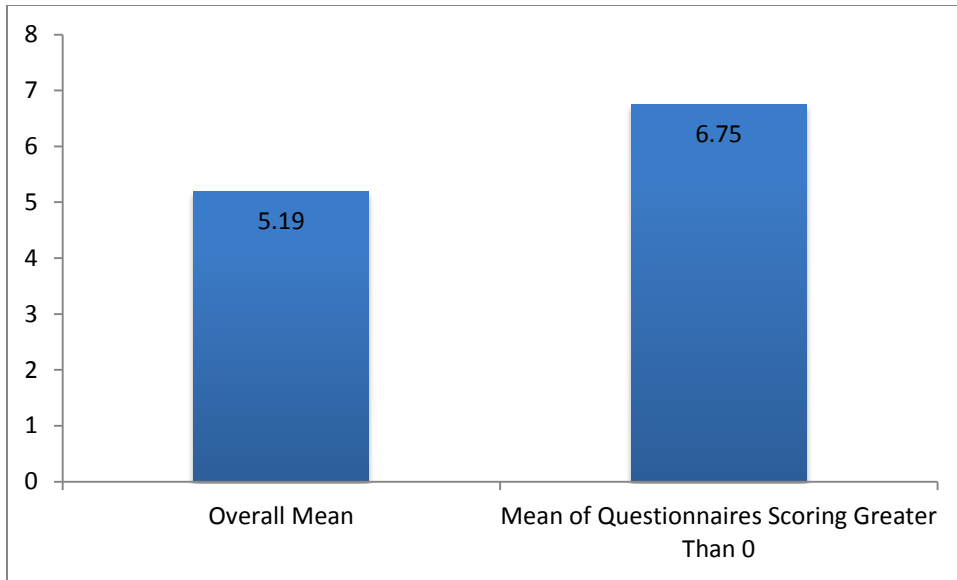


Figure 1. Mean Questionnaire Score

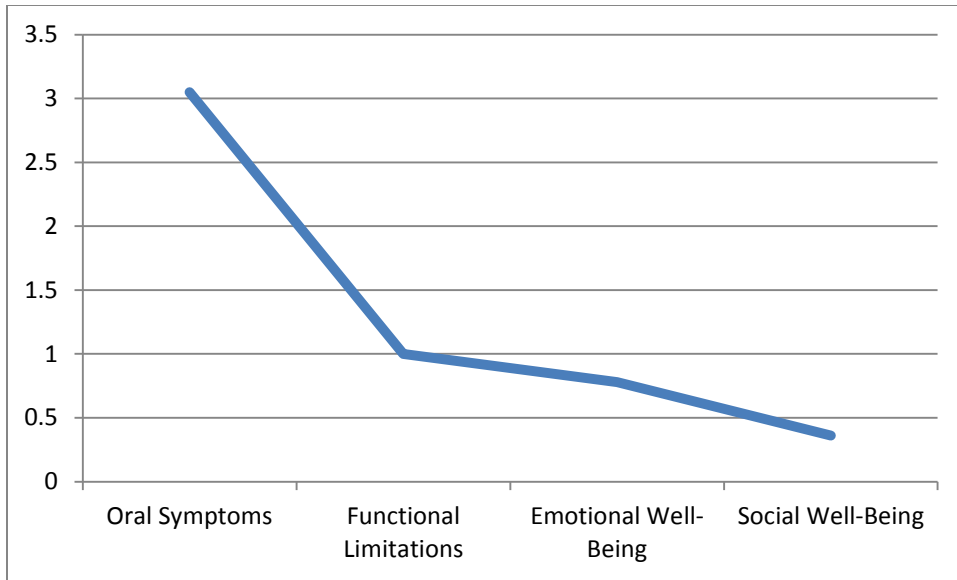


Figure 2. Mean Score of Each Section

Appendix

Oral Health-Related Quality of Life Questionnaire – CPQ 8-10

Directions – Please answer the following questions based off your observations of your child’s behavior. Please choose the best answer, circle only one.

How often has your child had:

1. Pain in his/her teeth or mouth in the past 4 weeks?

Never Once or twice Sometimes Often Everyday/Almost every day

2. Sore spots in his/her mouth in the past 4 weeks?

Never Once or twice Sometimes Often Everyday/Almost every day

3. Pain in his/her teeth when he/she drinks cold drinks or eats foods in the past 4 weeks?

Never Once or twice Sometimes Often Everyday/Almost every day

4. Food stuck in his/her teeth in the past 4 weeks?

Never Once or twice Sometimes Often Everyday/Almost every day

5. Bad breath in the past 4 weeks?

Never Once or twice Sometimes Often Everyday/Almost every day

In the past 4 weeks, how often has your child:

6. Needed longer time than others to eat his/her meal because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

7. Had a hard time biting or chewing food like apples, corn on the cob or steak because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

8. Had trouble eating foods he/she would like to eat because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

9. Had trouble saying some words because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

10. Had a problem sleeping at night because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

SOME QUESTIONS ABOUT YOUR CHILD'S FEELINGS

In the past 4 weeks, how often has your child:

11. Been upset because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

12. Felt frustrated because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

13. Been shy because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

14. Been concerned what other people think about his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

15. Worried that he/she is not as good-looking as others because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

QUESTIONS ABOUT SCHOOL

In the past 4 weeks, how often has your child:

16. Missed school because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

17. Had a hard time doing his/her homework because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

18. Had a hard time paying attention in school because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

19. Not wanted to speak or read out loud in class because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

QUESTIONS ABOUT YOUR CHILD BEING WITH OTHER PEOPLE

In the past 4 weeks, how often has your child:

20. Tried not to smile or laugh when with other children because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

21. Not wanted to talk to other children because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

22. Not wanted to be with other children because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

23. Stayed away from activities like sports and clubs because of his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

24. Other children teased your child or called him/her names because of your teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

25. Other children asked your child questions about his/her teeth or mouth?

Never Once or twice Sometimes Often Everyday/Almost every day

Vita

Andrew Gibson was born on March 22, 1988 in Henrico, Virginia. He was raised in Hanover, Virginia. He graduated magna cum laude with a Bachelor of Science in Psychology from Virginia Commonwealth University in 2010. He graduated dental school in 2014 from Virginia Commonwealth University School of Dentistry. Andrew will complete his training in Pediatric Dentistry at Virginia Commonwealth University in June 2016 and will be going into private practice in Hanover, Virginia following graduation.