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Honors Thesis – Awareness of Autism in Black and Brown Communities

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Honors Thesis –Awareness of Autism in Black and Brown Communities

A. Statement of Thesis

Autism Spectrum Disorder (ASD) affects a multitude of races and ethnicities, and its impact varies from person to person. Given the name spectrum disorder, the symptoms of Autism differ from one person to the next. Typically, ASD is diagnosed around the age of two to four years old since the signs and symptoms of Autism become apparent at that time. Increased reporting of Autism in local communities has surged primarily because of better diagnostic tools and criteria as well as greater public awareness. However, even with these improvements, delayed diagnosis remains an issue for the African American community. Delaying the diagnosis affects the families of children with Autism; the delayed diagnosis limits the opportunities for developmental services. Parents lose out on the critical time to create an Individualized Education Program (IEP) for the child that is beneficial in charting out what school and government services to apply for (Kabot., 2021). The purpose of this Honors Thesis is to first identify the significant factors that contribute to the delayed diagnosis of Autism in African American children. Secondly, to create a list of available healthcare resources to develop a better community response to reduce the incidence of delayed diagnosis. The staging area for this Honors Thesis will be the South Florida locations of Miami-Dade, Broward, and Monroe County. The Honors Thesis aims to tackle this issue with the aid of the Department of Speech-Language Pathology. The department will offer its myriad of connections to facilitate sending out surveys as well as distributing the intervention. Furthermore, the department will provide advice on upcoming steps as well as the goals of the Honors Thesis.

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B. Review of Literature

In support of this Honors Thesis, a literature review was conducted on the subject matter of Autism and its relation to African Americans and the problem of delayed diagnosis. The review crafted a perspective on the issue through multiple research databases provided by the school. The databases used were as follows: Biomedical Reference Collection: Comprehensive – EBSCO Host, CINAHL Complete – EBSCO Host, MEDLINE – ProQuest, and PubMed Central – PMC. Each database was configured to a full text, peer-reviewed, and a search restriction of articles within ten years. Articles were found using a combination of search terms like ASD, Minority, African American, Diagnosis, Intervention, Review, and Delayed. Primarily used search terms include ASD, African American, Diagnosis, and Delayed. For more expansive results Minority, Intervention, and Review were utilized to find similar case studies. These criteria resulted in several papers for review and visualization of the situation. The inclusion criteria for research articles focused on articles that discussed ASD concerning African American families, while the exclusion criteria were articles that discussed ASD without relation to African American families. Moreover, the research articles added nuance to the problem and proposed methods of reducing the issue. This literature review utilizes six peer-reviewed articles to illustrate the problem of delayed diagnosis of Autism amongst African Americans. This literature review supports the need for a health literacy project specific to the south Florida African American community. It should be noted that these studies either were data collected on a statewide basis or in specific areas. While the information is important, it is not pertinent to the South Florida area. As such, the information conducted through a literature review is applied with location-specific surveys relevant to the staging areas.

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The preliminary literature review found a factor behind the delayed diagnosis of Autism was parents missing specialty clinic appointments. The article, *Child and Family Characteristics that Predict Autism Spectrum Disorder Specialty Clinic Appointment Attendance and Alignment with Providers*, found these missing appointments were due to the distance of the household from the clinic or other detractors like socioeconomic status, health insurance, and the child's age. The study goes into further detail about how parents often hope that their child outgrows their current behaviors and how that also plays a factor in them missing critical appointments. The study presents valuable information and data on how to improve care for ASD in a clinical setting. The research paper concludes that there needs to be a reexamination of parent-to-provider communication and interaction. By forming a proper provider-to-parent relationship through means of empathetic wordage, intercultural awareness, and a sense of understanding providers are more likely to encourage parents to take more steps in the care of their child with ASD (Azad et al., 2019).

The research article *Timing of the diagnosis of autism in African American children* was able to identify any specific barriers to obtaining a diagnosis or services attributed to autism. The study had 584 African American children as participants while personal interviews were utilized for data collection. The article presented the following issues as problems that arose in the diagnosis process: repeat visits to a professional, a lack of healthcare professionals in the area, time, and cost expenses in the form of travel and insurance. The purpose of the study was to review data published by the CDC and determine what barriers African American children with Autism face when accessing services for them. The results of the interview found the average age of diagnosis in those children and the reasons behind the delayed diagnosis. Leveraging this information, the researchers concluded with a call to action to remedy the overall situation and draft ideas on how to improve diagnosis rates (Constantino et al., 2020).

Concerning location-based surveys, an ethnographic study would review how urban African American families care for their child with Autism as well as the understandings of ASD researchers on the level of care. The research article, *African American Families on Autism Diagnosis and Treatment: The Influence of Culture*, assesses a study that reviewed the effect of culture on African American parents and how they interact with caring for their child with autism and health care professionals. To determine the effect that culture played, the researchers took field observations of 24 family members and analysis from 28 ASD professionals. This data was reviewed through Leininger's phases of ethnonursing analysis to generate two universal themes an African American family goes through after an Autism Diagnosis and treatment. These two themes respectively are: Protecting by pushing for independence or acting for the child, family, and community. These two actions take place after the child had been diagnosed with Autism or when the parents suspect the child has Autism (Burkett et al., 2015)

Following this information, it was imperative to review how parents, in general, handle finding services before and after diagnosis and if this contributed to a delayed diagnosis. The research article, *Intervention decision-making processes and information preferences of parents of children with autism spectrum disorders*, followed the experiences of 23 parents in how they found information about ASD after diagnosis. To do so, the researchers interviewed the parents and reviewed verbal transcripts of the interviews. These interviews consisted of the parent's experience from diagnosis to researching ASD interventions. Like Leininger's phases of ethnonursing analysis, the researchers found themes common in all the experiences. These themes represented the types of sources that parents used in information gathering, why parents trusted certain sources, and how that information influenced the decision-making process. A common trait was parents were overwhelmed by the multitude of information as well as the quality. Many parents had to go through an arduous review process to find useful information. The research paper concludes by outlining the process parents had to take in finding appropriate treatment methods (Grant et al., 2016).

Another study*, Racial and ethnic differences in subspecialty service use by children with autism*, used statistical techniques and tests to determine differences in subspecialty service in terms of ethnicity. The study focused on χ2 statistics and mean values by using the t-test. These statistical tests were compared in differences in proportions between children after the results of the M-CHAT and ASQ-II. Both the M-CHAT and ASQ-II were used to determine the sensitivity and specificity of Autism in children as well as any potential delays in development. By using statistical tests, the researchers were able to generate models based on the results of the questionnaires. Moreover, χ2 statistics are utilized to compare model data against observed data, whereas a t-test is used to compare the mean of two groups and determine parameters of difference. The main difference between groups was the age when the child with Autism was referred to early intervention (EI) amongst developmental goals. Additionally, the researchers considered race, gender, age, ethnicity, mean income, and maternal education which might have played a part in the differences. The outcomes of M-CHAT and ASQ-II were compared to developmental milestones to determine EI referral, EI referral completion, and EI eligibility (Broder-Fingert et al., 2013).

Furthermore, an article, *Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership*, discussed healthcare experiences between adults and adults with Autism. The article located and interviewed participants via the Gateway project and participants were found from the Academic Autistic Spectrum Partnership in Research and Education. These researchers were focused on comparing the healthcare experiences of Autistic and non-Autistic individuals. The overall survey used a variety of sources to construct an airtight questionnaire. The researchers did not need to go through the process of a nontraditional setting since their main method of obtaining data was through the Gateway project. Moreover, since the researchers worked primarily online, they were unable to build a relationship with the community or engage the participants. However, their data analysis went quite in-depth into age, sex, race/ethnicity, income, and parental education. The researchers partnered with a local organization to build up the participant pool since there were no collaborative activities. The content of the study and its findings were disseminated through the NIH for clinicians to review and reflect upon (Nicolaidis et al., 2013).

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C. Methods

This Honors Thesis will employ the following methods for data collection: a combination of surveys and interview experiences. Participants involved in the study will review an NSU IRB Short Form Consent before taking part in the research study. Furthermore, a participant letter for anonymous surveys will be provided for participants to highlight the key aspects of this research project. Interviews will serve as an in-depth view of the survey results. Interviews are optional for the survey participants through the option to submit an email for further questioning. These interviews allow for survey participants to elaborate on their survey results as well as offer suggestions regarding the intervention. These interviews will occur over a private video conferencing call. These data points will serve as indicators of the level of care in communities regarding ASD and its diagnosis. Moreover, they will present information on how parents recognize signs of Autism and the diagnosis process. The data gained by the surveys will gauge how healthcare workers involve themselves with individuals with Autism and identify areas where parents can reach out for support. The overall goal of the surveys is to examine the problem on two fronts: Parental and Healthcare. The project will begin a process of statistical analysis once all data is collected. Leininger's phases of ethnonurisng analysis will identify common themes found in each data collection. Utilizing the information provided by data analysis an infographic will be created to address these issues. The proposed intervention plans to distribute the infographic through the Department of Speech-Language Pathology, local clinics, hospitals, and school centers. Moreover, the infographic will serve to guide new parents of African American children with Autism to community resources for their use. Furthermore, it will list out services that would aid in early diagnosis and potential interventions down the line for use. The stakeholders in this health literacy project are the Department of Speech-Language Pathology, parents of children with Autism, and health care professionals. Lastly, it is imperative to analyze the impact of the intervention through surveys and local reporting on ASD diagnosis. Success is measured by adding a QR code to both the brochure and video that parents could scan which will then lead to a questionnaire that requests feedback on the health literacy intervention implementation. Resources for the health literacy intervention will be either found through prior research or the following questionnaire which will be sent out to the public.

D. Intended Learning Outcomes

Upon completion of the project, I, Varun Kota, will have earned a bevy of knowledge and experience critical for my journey into medicine. Heading a project such as the Honors Thesis is an opportunity to expand upon my leadership and management skills and hone them. Moreover, I will gain a deeper understanding and usage of the library database systems in addition to other services provided through the library like Ulrichsweb and Academic Writer. Furthermore, my overall knowledge of ASD, the diagnostic process, services surrounding Autism, and its overall impact on African American families will grow. I will use this education towards improving my professional writing skills and public speaking. My research skills and abilities will increase tremendously through the Honors Thesis. Finally, disseminating and presenting information regarding the project enables me to understand the publication process. I seek to gain numerous learning opportunities through the Honors Thesis.

E. Expected Research Outcomes and Product

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The impact of this Honors Thesis project will influence African American parents who suspect their child might have Autism. One of the results of this project will provide parents with literature regarding ASD's common signs and symptoms. Furthermore, parents will be educated on services to use when obtaining a diagnosis and after. Ultimately, encouraging parents to procure a diagnosis as soon as possible. Furthermore, the other outcome of this project is to foster a series of trusted professionals that parents can reach out to for their concerns and guidance. The secondary goal of the project is to promote healthcare professionals toward cultural awareness coursework. The aim is to generate a sense of understanding with healthcare professionals and families with Autism. This process could reduce the number of repeated visits a parent might have to go through to receive a diagnosis for their child. Dissemination of this Honors Thesis will occur through the Department of Speech-Language Pathology, local schools, hospitals, and clinics; I plan to present the results of the project at seminars like the Undergraduate Research Symposium.

F. Budget and Resources Needed

While the total costs of the budget cannot be calculated at this current moment, the budget will encompass aspects of travel to areas of dissemination and funding for the publication of results. The funding for the Honors Thesis will be secured through the Honors College. The budget will also be used for printing out the infographic and posters to distribute at the staging areas. Estimated 50 copies of the infographic will be submitted to the three staging areas resulting in 150 prints overall. Additionally, poster printing will occur through the NSU copy center for up to five prints serviced by the semester printing quota. $22.50 is slated to be used for the promotion of the intervention upward to $50 for any relevant future purchases. These purchases will occur from October to November of 2022. Furthermore, the budget will be essential in procuring resources to create and distribute interventions such as infographics and videos. Moreover, the funding can aid in procuring research documents typically unavailable from library databases. Lastly, the information will be disseminated at conferences, public speaking events, school workshops, and other Autism related events. This will occur from late March to April 2023 due to April being Autism Awareness month. Attendance fees and travel expenses are estimated to cost from $300 upwards of $500.

Description of Expense	Amount of Expense
Printing of small infographics (150 counts)	$30
Printing of poster-sized infographics (10 counts)	$20
Attendance fees and travel expenses (5-7 events max)	$300 - $500
Total expenditure:	$350 - $550

G. Project Calendar

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Semester 1 – Research, Survey, Interviews

The first semester will focus on researching the library databases using keywords like ASD, African American, diagnosis, and intervention to form a rationale behind the delayed diagnosis. Once that process is complete, the South Florida area will be divided into communities that feature African American residents. The project will identify local resources that parents could use both before and after the diagnosis of Autism. Noting these services, surveys tailored to each region will determine the effectiveness of each resource. In addition, patient interviews will also aid in data collection and will recount the parents' journey to receive a diagnosis for their child.

Semester 2 – Application of Intervention

During this semester, data analysis will continue once data collection is completed. Utilizing Leininger's phases of ethnonurisng analysis, common themes between all the data sets will emerge and feature areas for intervention. This semester is dedicated to reviewing the data, drafting an intervention, and applying said intervention in local areas.

Semester 3 – Write up of events.

Finally, this semester concludes with an analysis of the proposed interventions and a write-up period of the success and failures of the Honors Thesis. The report will feature aspects such as biases, limitations, and future directions. The writing serves as a method to publicize the results of the Honors Thesis for other individuals to review the project and continue. The project will be presented at seminars like the Undergraduate Research Symposium.

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