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ANDROID APPLICATION TO ALLEVIATE STRESS IN ALZHEIMER CAREGIVERS. AN 'INVISIBLE' CRISIS: ADDRESSING THE NEGLECT OF MENTAL HEALTH BURDENS IN ALZHEIMER'S CAREGIVERS

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by

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ABSTRACT

ANDROID APPLICATION TO ALLEVIATE STRESS IN ALZHEIMER CAREGIVERS. AN 'INVISIBLE' CRISIS: ADDRESSING THE NEGLECT OF MENTAL HEALTH BURDENS IN ALZHEIMER'S CAREGIVERS

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Alzheimer's is a progressive disease characterized by a gradual loss in memory, thinking skills, and the ability to carry out simple tasks. As a result, patients require caregivers to play a critical role by managing household tasks, aiding in personal care, and performing medical procedures. Caregivers often balance family life and/or a career while averaging between 14- 34 hours weekly on patients. This develops into high levels of depression, anxiety, and low quality of life. Limited resources have left this demographic to suffer alone while bearing the burden of caring for a loved one. A mobile application was created to simultaneously collect data for patient care planning and alleviate mental stress in caregiving. This resource provides a platform where caregivers can seek

professional assistance, record social activity, and track mental health. Additionally, Google Analytics was implemented to track user traffic and engagement to provide insight for data collection/application improvement.

TABLE OF CONTENTS

LIST OF ILLUSTRATIONS

CHAPTER 1

INTRODUCTION

1.1 Statement of Problem

Caregivers of Alzheimer's and other related Dementia's suffer from increased burden levels, mental stress, and emotional strain. Does an increase in physical/social activities decrease caregivers' burden levels, and can a mental health tracking application alleviate this stress?

1.2 Background

Alzheimer's (the most common form of dementia) is a progressive disease that results in a decline in cognitive abilities. It is one of the leading causes of death and affects over 5 million people in America with the numbers expected to project to about 13.8 million by 2050. The increase in numbers can be attributed to the growing aging population in the United States particularly, from the baby boom generation. As the numbers of patients soar, a health crisis is likely as there would be an increased demand for patient support. Unlike in previous generations, Generation X (born between1961-1979) is still working full time and is unlikely to provide caregiving support to their parents (the baby boom generation). The demand for caregivers (both formal and informal) will skyrocket as Generation X slowly approaches the Alzheimer's high-risk age (65 years and above). The Center for Disease Control and Prevention cites age as the biggest risk factor for Alzheimer's but does not rule out other factors such as genetics or pre-existing health conditions such as high blood pressure. What will happen when the demand for caregivers

surpasses the current supply rate? What happens to the quality of care? And who will be responsible for taking care of America's aging population?

There is often confusion surrounding the symptoms of Alzheimer's as they may present in a similar manner to symptoms of aging. However, it is important to note that the difference between the two is that Alzheimer's affects how people carry out their day to day tasks. Patients may start to experience memory loss that causes wandering, repetitive activities, forgetting family, friends, or past events. This can progressively worsen because they will not perform their daily chores, including making bank transactions, cooking, or even bathing. It becomes increasingly dangerous when they must handle machinery, be exposed to naked flames in cooking, or do simple things like crossing the road.

Additionally, changes in personality or moods can make it difficult for those who must live with them as they become highly unpredictable. Currently, doctors can only treat the symptoms of Alzheimer's to improve the quality of life as there is no cure. Treatment plans can be used to stabilize mental function, manage behavior problems, and delay the progression of the disease. An example of the Federal Drug Administration (FDA) approved drugs on the market for Alzheimer's include Donepezil (Aricept), Galantamine (Razadyne), and the Exelon patch. These are efficient because they attempt to decrease behavioral symptoms by regulating neurotransmitters. However, these drugs are not effective in fully preventing the disease's progression and only work on some but not all people. Better treatment options are required to halt the growth of the disease. The need for caregivers becomes apparent in this community to improve the quality of life for Alzheimer's patients.

Caregivers' tasks differ from case to case. Their responsibilities range from simple tasks such as feeding or bathing to more advanced tasks requiring 24-hour comprehensive care. Due to the complexity of the work and the nature of Alzheimer's, caregivers are often under immense pressure and stress. This does not include any additional pressure from personal lives such as other jobs, family, and health. The Center for Disease Control and Prevention estimates that family caregivers of Alzheimer's and other dementia's have a higher risk of exhibiting symptoms of anxiety, with 40% being more likely to suffer from depression and having a lower quality of life [1]. Additionally, they were found to have difficulty performing daily tasks such as getting out of bed compared to caregivers of other related diseases. There is a great concern on how the burden can be reduced in these caregivers to increase the quality of life they live and the quality of care they provide to their patients.

1.2.1 Caregiver Stress

Caregiver stress is an overlooked problem by government and healthcare officials. The lack of support, resources, or guidance provided to caregivers by these agencies is little to none and underwhelming. Paper-based tests that diagnose mental health are available but are inaccessible without an appointment with a professional service. Though these tests serve the essential purpose of diagnosis, they lack a supporting solution to decreasing caregivers' burdens. Mobile application use has increased in the healthcare industry to access mental health and provide educational material, but few possess the ability to provide methods of care. Currently, the affected demographic has a limited range of applications that can record and report their mental activity or tries to generate useful data for research. Research done by Kwang et al. suggests that an increase in social support can

reduce levels of loneliness and fatigue in patients resulting in a better mood with higher levels of energy. The correlation between increased social and physical activity with lower levels of stress has been highlighted in articles with reports of "pleasure and positive mood" being documented after bouts of exercise. [2] Others went further to suggest a "causal link between physical activity and reduced risk of cognitive decline" [3].

1.2.2 Project Purpose

In our project, we create an android application that will simultaneously collect data to investigate further the relationship between increased social/physical activity with lower burden levels and alleviate stress in caregivers. The application created in this project aims to collect user burden levels and correlate them to their social activities. Leading researchers Dr. Lee and Dr. Jaworski, hope to investigate how increased social activity can affect a caregiver's mental well-being. This data will be collected using survey questions created from the Zarit Caregiver Burden Interview (ZBI) and will be analyzed by social workers. Google Firebase will serve as the analytic tool to better measure application metrics that can help the researchers understand their clientele background better. User engagement assessments and turnovers rates will quantify the usefulness of the app's resources, allowing room for future improvement. In this project, I was responsible for the creation of the Interview layout, contact us page layout, providing resources (videos and dealing with stress), editing the app aesthetics, creating surveys for the focus groups, making in-class progress reports, and giving the test-subjects alternative material for the focus groups. Contributions are summarized in the figure below.

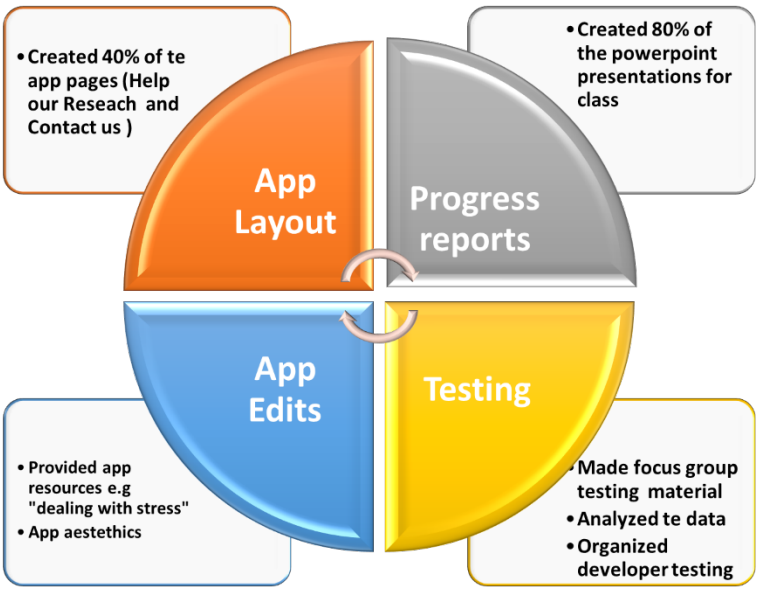

Figure 1.1: Summary of Project Contribution

CHAPTER 2

METHODOLOGY

2.1 Materials and Methods

The application was created according to the specifications provided by Dr. Kathy Lee (Faculty Project Mentor) using the Java Programming language in Android Studio. To create the first prototype, each student in the group created a layout that was in accordance with the agreed-upon constraints. The requirements demanded an application that had to be resourceful, reliable, interactive, user friendly, and efficient. Upon completion of the task, a decision matrix was used to choose the best design. The layout done by Nathan Fernandez was chosen as the skeleton for the optimum layout for its unique menu. Features of the other designs were then incorporated into this skeleton to create five tabs accessed via a pull-out menu. The application tabs included a contact us page, a resources page, an about us page, a 'Help our research' page, and a Surveys page. The aesthetics of my pilot design was adopted into the application for its minimalist approach that complimented the Alzheimer's Awareness theme as well as the splash screen feature and "back" button. The application "buttons" or pages were then delegated among members. The pages were delegated in the following way: Mental Health and Social Activities Survey page: Aisha and Austin. About Us Page and Resources Page: Nathan. Help Our Research (formerly Interview Page, Figure 2.1) and Contact Us Page (Figure 2.2): Chidochashe.

The 'Help our Research' (formerly Interview) feature functions to provide first-time caregivers with a safe space to learn about their new role. With the help of a social

worker, they can receive personalized resources and referrals. The Contact Us Page serves as a tool to give application users a chance to ask questions or raise concerns.

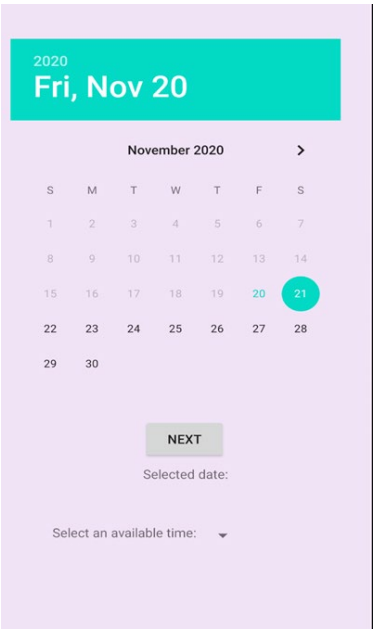

Figure 2.1: 'Help Our Research'

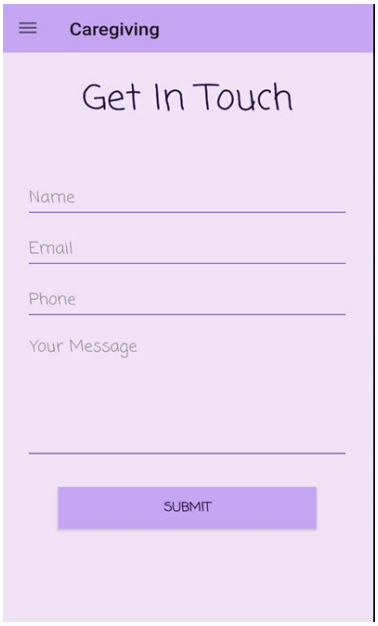

Figure 2.2: Contact Us Page

Creating these pages required watching countless hours of tutorials, reading materials, and trying different codes. The steps taken in creating the application are provided in the image below (Figure 2.3).

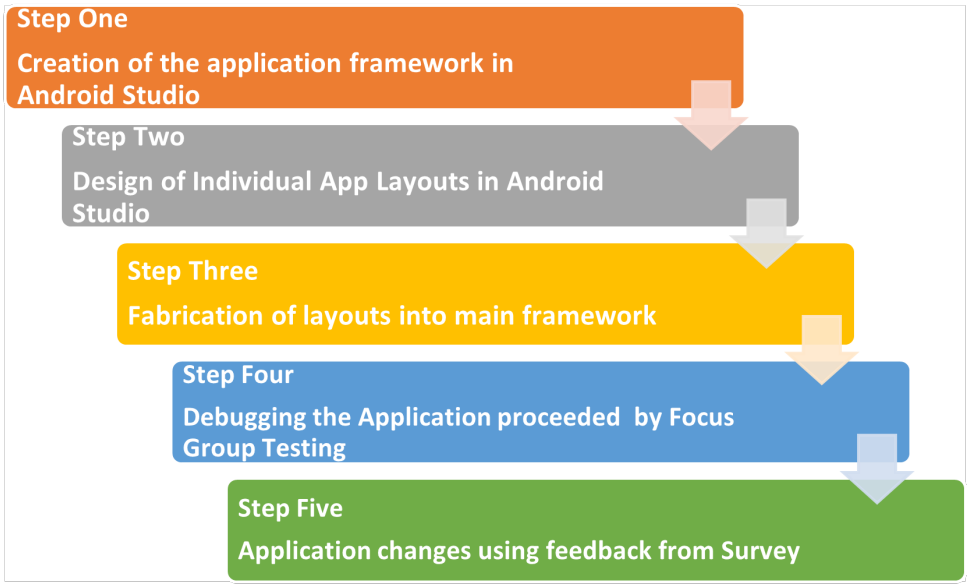

Figure 2.3: A Summary of the Application Creation Process

Once the application had been created, we started a series of tests via focus groups to investigate the functionality, ease of use, and application design. A total of three focus groups were conducted, with each focus group being tasked to use every feature of the application and provide their feedback through a google survey. Changes were then made using the given feedback, with each member being responsible for their respective pages. The focus group participants included graduate-level gerontology students from Dr. Lee's class (31 in total).

Due to COVID-19, we were unable to test the usefulness of the app on Alzheimer's Caregivers during the time frame of the class. However, the focus group participants were able to give us feedback on whether the app was accommodating to caregivers of all ages based on their expertise. Hopefully, the last stage of testing, which involves caregivers, will be able to continue as scheduled. In this test, caregivers will discuss the app's aspects

they find most helpful and give any helpful insight. The testing timeline of the application is shown in the figure below (Figure 3)

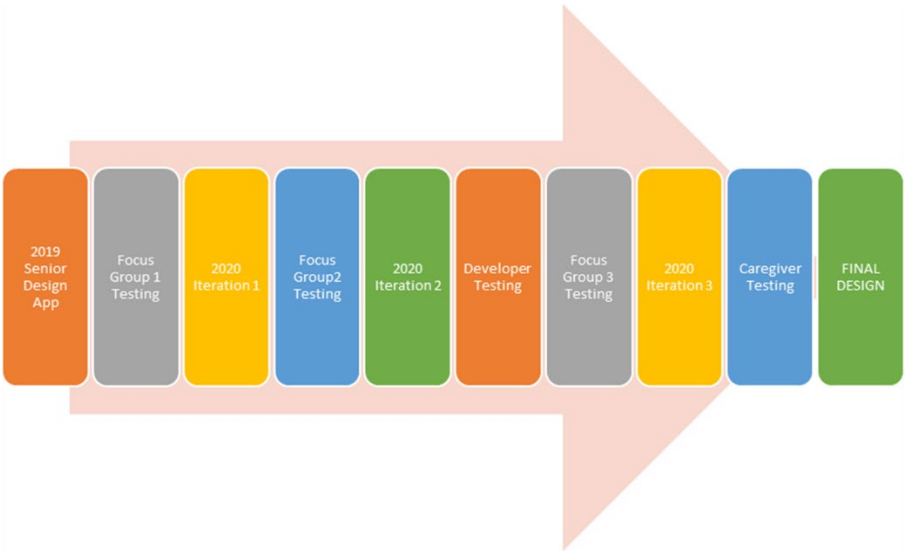

Figure 2.4: A Summary of the Application Iterations

2.2 Analytics

Previously, the application had no method to directly provide analysis that could support/refute any research hypothesis. The data collected from the app was being stored on a Google server, where it was extracted by a google script and released to the user as feedback in the form of a graph. The researcher was then able to use this data to begin their analysis. The demographics of the population using the app, for example, would have to be done manually as there was no clear method to track that information. Google Analytics (a web-based analytics service offered by Google) was implemented for its ability to track and report application traffic. This provides developers with the number of users, their demographics, and how they interact with an application. This can then be used to understand how the application can be modified to cater to this population allowing Dr. Lee to research further how the app provides stress relief for its users. The implemented

analytics feature: Google Firebase, can also conduct assessments by providing reports on how often users engage with the app, the average screen time they spend, and how often users interact with the content. The quality of the resources offered can then be checked through the app retention and session intervals. Lastly, the usefulness of the app can be conducted through the evaluation of the app churn.

Google Analytics protocol was implemented to the Alzheimer's Application by installing the Firebase SDK, adding the Alzheimer's app project to the console in Firebase, and adding dependencies to the Gradle file in Android Studio. Upon completion, customized events were created, logged, and confirmed. Customized events would give the program a place to start tracking app usage. For example, when a user clicks on a certain button or when a function of the app is initiated, Google will count that activity as an event. However, since the app will be used in a closed study, it is unclear how well this feature will be useful until the application is published. Should the app be made public on Google Play Store, the analytics would be a resourceful tool for application improvement. Metrics like the app churn could be directly calculated and related to the success of the app as a stress-relieving tool. In this project, events were created to measure how well users interacted and engaged with the app. The events listed below give an idea of how well the app performs as a research application.

Event One: Submitting the mental and social activity survey

Event Two: Participating in the "Help our Research" page

Event Three: Accessing the Weekly Tracker

When the user clicks the submit/graph button, Google Analytics records that as engagement. This can be used to calculate the number of monthly app users (MAU) or Daily App Users (DAU). The following events give an idea of how well the app is performing as a stress relief app.

Events One: Clicking on the Resources Links

Event Two: Using the helpline

Event Three: Booking an appointment with a social worker

Current data shows the effectiveness of this Analytics tool unavailable until the app is published on the Google Play Store. To check that the function was working, the analytics tool was connected to the Android Studio file of the App. As the app was used, real-time data was shown on the dashboard, proving that the feature is fully functional.

CHAPTER 3

CONCLUSION

In this project, we were able to make a functional app that allows users to book appointments, access resources, and interact with social workers. The application was linked to google firebase to allow future user engagement analysis, turnover rate, and app retention. Social workers can now make links to social activity and mental health with the data provided. Future additions of the app like a chat room, journal, and daily affirmative messages will help to increase caregiver experience with the app. The results obtained from this study will help initiate treatment plans for mentally strained caregivers, which will increase the quality of patient care.

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BIOGRAPHICAL INFORMATION

Chidochashe began her curiosity for science at an early age participating in science fairs and competitions. As a high school student in her native country of Zimbabwe, she hoped to attend medical school to follow in her father's footsteps. After graduation, her undergraduate career began in the Science department as a Biochemistry major. Upon joining the Honors College and exploring the plethora of programs offered by The University of Texas at Arlington, Chidochashe made the executive decision to change the course of her path. Though she initially desired to pursue a medical degree, she decided to still keep her goal of helping the sick by revolutionizing the medical industry through engineering and research. She volunteered in research laboratories hosted by Dr. Wei Chen (nanophysics) and Dr. Paul Chippindale (biology) over the course of her sophomore and junior years. The exposure granted by this experience sparked her curiosity for innovation in medical devices. She has since worked on projects to design scaffolds for third-degree burns, bone regeneration, and esophageal cancers. She hopes to attain her post-graduate degree in medical devices from Rice University to prepare her for a career as a Biotech Company founder.