

How do ethical considerations affect the effectiveness of voice based assistive technology for Alzheimer's patients and their caregivers?

IMT 570 Analytic Methods for Information Professionals

Team OUTWIT

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EXECUTIVE SUMMARY

The aim of conducting our research was to identify the factors which affect the ethical use of voice based assistive technology and help frame design considerations for assistive technology developers in a manner that ensures ethical use of technology and avoids discomfort caused to the patient by using the technology unethically. Our secondary research point towards the adverse effects of using assistive technology unethically and its relation to the degree of impairment of the patient. We performed quantitative analysis to figure out the factors that affect the ethics for Alzheimer's patients and the data from the surveys we conducted to describe the level of awareness of unprofessional caregivers about the ethics of using assistive technology. Our findings show that age and race are two factors which affect the severity of Alzheimer's in patients, and that, depending on how severe the disease is, the ethics of usage of technology are different. Moreover, the secondary data tells us that most of the caregivers in the United States are unprofessional, and they are unaware of ethics of using assistive technology. Unethically used assistive technology causes harm to the patient. Our qualitative analysis results found that, due a loss of memory it is difficult for the patients to understand what the technology used is and how it is supposed to help them. As a result, they develop fear towards the technology and resist its use as they find it threatening. Enforcing the technology on the patients even when they find it threatening is unethical as it harms them mentally. We suggest that while designing voice-based assistive technology, age and race of patients should be considered as they affect the level of impairment which in turn affects the ethical usage. Also, there should be an increase in awareness about ethical use of assistive technology

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INTRODUCTION

Background:

In the broad umbrella of dementia, our research will be focusing on Alzheimer's disease. The disease disrupts your daily functions and makes you severely incapable of taking your own decisions in some cases. The disease shows symptoms of lack of cognitive function and was regarded as the fifth-leading cause of death in the United States. There was an 89% increase in the deaths because of Alzheimer's, from all ages between 2000 and 2014. In every 100,000 people, 29.3% die of Alzheimer's in the United States (Gaugler, Johnson, James, & Weuve, 2017).

Caregivers are the primary means of health maintenance for Alzheimer's. People who act as caregivers are mostly people who are directly related to the dementia patient and in most cases, family. The purpose of assistive technology primarily is to ease the burden on the caregivers and help the patients in their daily activities. Despite the widespread use of assistive technology, patients go through emotional imbalance due to its imposition against their consent. The patient might not be able to vocalize his concern, due to his/her medical condition, regarding the discomfort caused (Alzheimer's Association, 2017).

- More than 5 million Americans are living with Alzheimer's and it is predicted that by 2050 this number could rise as high as 16 million.
- More than 15 million Americans provide unprofessional and unpaid care for people with Alzheimer's or other dementia (Gaugler, Johnson, James, & Weuve, 2017).
- In 2016 these care givers provided an estimated 18.2 billion hours of care valued at over \$230 billion. (Alzheimer's Association, 2017).

Statement of research problem:

We want to focus on ethics of using voice-based assistive technology by non-professional caregivers for Alzheimer's patients in the state of Washington. Technology, in general, is difficult to understand and apply daily, even for completely healthy individuals. So, one can imagine how much of a struggle it is, for Alzheimer's patients to embrace assistive technology for support. We strongly feel that there is a need to study the ethics behind the usage of assistive technology. Once the caregivers employ these guidelines, assistive technology will play a much better role as a support system. Hence, our statement of research problem is "How do ethical considerations affect the effectiveness of voice based assistive technology for Alzheimer's patients and their caregivers?"

Justification of study:

Though assistive technology has made it possible to support independence of the patient along with support and ease for the caregiver, it tends to attack the privacy, freedom and consent of the patient, which should be given priority. Despite understanding the usefulness of assistive technology, we are unable to understand the importance of the ethics behind their usage (Anderson Wayne, The Impact of Assistive Technologies on Formal and Informal Home Care, 2013). There has been a lot of research on the use of ethical guidelines for using assistive technology, but we found no literature that explores how ethical standards affect the use of voice based assistive technology by non-professional caregivers as they do not know the ramifications of unethical use of assistive technology.

Research Questions:

Our research statement revolves around improving the experience of patients with the assistive technology employed towards their betterment. Alzheimer's disease has no cure yet, and the aim of the technological equipment is to make caregiving easier for family, reduce the suffering and bridging the void between the caregivers and patients with respect to perception of the problem faced by the patient and if the technology used is truly addressing it. Keeping this in mind, the major research questions are:

1. How does unethical use of voice base assistive technology cause discomfort to the patient?
2. Why do patients resist the use of assistive technology and not accept it for their betterment?
3. What are the ethical standards to be taken into consideration while using assistive technology?
4. What are the factors to be kept in mind by technology makers to ensure ethical usage of technology?
5. What are the misconceptions of non-professional caregivers regarding the use of voice-based assistive technology in the state of Washington?

Purpose of Study:

We plan to do this by gaining perspectives from caregivers about how patients react to technology and improve it. The study will aim towards understanding the awareness of unprofessional caregivers towards ethical use of technology, factors affecting ethical considerations and improvements in assistive technology. The major types of ethical violations identified by us based on our secondary research are:

- Consent: Employ assistive technology only in area(s) of competence of caregivers and patients.
- Fidelity: Maintain the confidentiality of privileged information.
- Beneficence: Identification of potential consequences of Assistive technology and balancing of positive and potentially harmful aspects to maximize benefit to the individual.
- Autonomy: Providing patients focus on freedom of action and choice.
- Non-maleficence: Not causing harm to patients or caregivers directly or through avoidance of actions that risk harming others.

We directed our research towards finding practices which violate these ethics and recommend ways to improve those practices.

Scope of Our Research:

1. Nonprofessional Caregivers: We are limiting our research to non-professional caregivers because they are unaware of the ramifications caused due to the unethical use of assistive technology.
2. State of Washington: Our research is limited to the state of Washington which serves as a geographical scope for our study.
3. Financial Affordability: We want to limit the cost of assistive technology within a range which is employed by the mainstream caregivers and patients. We want to focus our research to cater to the typical employers of voice based assistive technology and consideration of very expensive voice based technology can cause bias or faulty observations.
4. Limiting patients' age above: We are not considering early onset of Alzheimer's and limiting our patients' age above 65.

METHOD

To justify our research problem and formulate our recommendations, we used a mix of primary and secondary data collection procedures which were used simultaneously to justify our results. We describe the data collection methods further.

Data Collection Procedures

We collected data from 4 sources as follows.

1. NACC (National Alzheimer's Coordinating Center, 2016) database (Secondary Data).
2. PEW Transcripts (PEW Research), Cleveland Clinic Caring for Alzheimer's transcripts (Cleveland Clinic, 2012), US against Alzheimer's (Genova, 2017) (Secondary Data).
3. 31 surveys conducted around the University of Washington (Primary Data).
4. 8 telephonic interviews of caregiving centers around the state of Washington (Primary Data).

Each data collection method had its own significance in terms of supplementing our research. 1 & 2 are secondary data collection methods which were used to understand the demographics of Alzheimer's patients and various issues related to caregiving for Alzheimer's. 3 & 4 are primary data collection methods where the latter was used to obtain expert opinion on the use of assistive technology by non-professional caregivers while the former was to get an idea of the awareness level of ethics in using assistive technology. All the collection methods complemented each other and played a part in formulating our recommendations. Below is a detailed description of each collection method's purpose and outcome

NACC (National Alzheimer's Coordinating Center, 2016) database:

The NACC database provides demographic data of more than 35,000 Alzheimer's patients. It gives subject demographics in terms of age, gender, race, ethnicity, education versus the level of impairment amongst other variables. The purpose of this data was to perform hypothesis testing to deduce relations between different demographic factors and the level of impairment associated with the patient. We were able to establish a relationship between age and level of impairment as well as race and level of impairment. We will elaborate more on this in the Quantitative Analysis section.

PEW Transcripts (PEW Research, 2013):

The PEW transcripts provided data on 467 caregiver interviews. We used the transcripts to find recurring themes across the interviews which would help formulate as well as strengthen our recommendations. We built a Python script to find the most occurring words in answers which have a particular keyword in the corresponding question. The explanation can be found in the Qualitative Analysis section.

Surveys:

From our secondary research on caregiver.org (Family Caregiver Alliance, 2016), we found that 48% of non-professional caregivers lie in the age bracket of 18-49 years. Also, our research focused on non-professional caregivers specifically since they have a lesser idea on the ethics of using assistive technology. We used **convenience sampling** since we were limited by our mobility. We want to try and formulate the ethical needs in such a way that people whether non-professional or professional can

understand as well as follow them. Hence, we conducted 31 surveys in and around the University of Washington targeting people in this age bracket. The statistics of the results are described in the Quantitative Analysis section.

Telephonic Interviews:

To get an expert opinion on the existing ethics being followed while using assistive technology for Alzheimer's patients, we conducted 8 telephonic interviews to caregiving centers across the state of Washington. These centers were selected through **cluster sampling** so as to get separate groups and not concentrate on a particular area. We have drawn some recommendations based on these inputs and the questionnaire prepared is described in the Qualitative Analysis section.

Validity and Reliability

The secondary data collected by us has been from the websites of trusted Alzheimer's care organizations and the source are not old, enough to raise issues about its validity. Moreover, while observing the ethical concerns about assistive technology, all four of us found information independently and then discussed our observations together. This ensures no bias while identifying ethical concerns as we all had our individual perspectives which were integrated later.

When we collected the primary data from the surveys and telephonic interviews we ensured that people participating had genuine interest. We also ensured a good mix of people in our samples, which included people having some context about the disease. The telephonic interviews were conducted with Alzheimer's organizations which are active and genuine. These measures ensure reliability of the data.

Ethical Considerations

The following were the ethics kept in mind by us while conducting the research:

1. We maintained the confidentiality of privileged information of the patients and their caregivers by making subjects sign consent forms which ensured confidentiality of released information.
2. While stating our recommendations, we discussed their consequences and made sure that there are only positive outcomes to it and no kind of harmful aspect of assistive technology is being added.
3. Ethical consideration of the patient's freedom of choice and action does not apply to our research as at no point it involved any kind of interaction with the patient.
4. During our interaction with people being surveyed and interviewed, there was no dissemination of harmful or wrong information about usage of voice based assistive technology which might inspire one to use the technology adversely for the patient.

For the future pilot studies that this research might be expanded to, we would like to mention the following ethical concerns to be taken care of:

1. When comparing the effect of ethical assistive technology on patients directly, make sure that the patient's freedom of choice and action is not compromised in any manner.
2. During the pilot study, ensure that the patients privacy is not compromised by wrongfully gathering patient data or wrongfully monitoring the patient.

FINDINGS AND ANALYSIS:

Quantitative Analysis:

We performed quantitative analysis in order to understand the awareness of ethics while using assistive technologies and also to determine relationships between variables in the NACC dataset. During our secondary research, we found out that the ethics for using assistive technology change with the severity of the disease for a patient. Considering consent of the patients and caregivers individually while conducting research, tells us about the level of understanding of ethics like consent, privacy, freedom and non-maleficence shown by Alzheimer's patients is based on how deeply the disease affected them. Patients at an earlier stage tend to understand situations when they want to give consent and when they do not, but highly affected patients do not understand if the technology is harming or not harming them (Mahendra, 1984). Hence, since level of impairment proves to be a deciding factor for the ethics considered, we tried finding factors that affect level of impairment, as these factors will indirectly then affect the ethics which are to be considered while employing assistive technology.

NACC Dataset:

The NACC dataset gives a query system to determine and extract statistics about Alzheimer's disease patients. As shown in Figure 1, we can create frequency tables across two variables one of which might be from subject demographics while the other might be the level of impairment. The purpose of carrying out hypothesis testing on these pivot tables was to establish a relation between subject demographic variables and the level of impairment in order to utilize the results in our recommendations and formulate our phone interview questionnaire. We carried out chi-square hypothesis tests on 3 variables:

1. Age vs. Level of Impairment:

Since we are dealing with assistive technologies, it was important to analyze the relationship between age and level of impairment as the ethics of using those assistive technologies are different for different age groups. We chose to address the type-2 error since we do not want a false acceptance of an incorrect null hypothesis. The critical chi-square value is much less than the Chi square test statistic (ref: Appendix 4) and hence we reject the null hypothesis and accept the alternate hypothesis.

NULL HYPOTHESIS (H_0): There is no relationship between age and level of impairment a person has

ALTERNATE HYPOTHESIS (H_1): There is a relationship between age and level of impairment a person has.

As you can see in the graph below, the graph is showing the highest amount of impairment in the 70-79 age range and also each level of impairment is seen highest in the same age range except mild impairment which is higher in the 80-89 age range. This graph shows that as age increases, the number of people suffering from a higher level of impairment over time also increases.

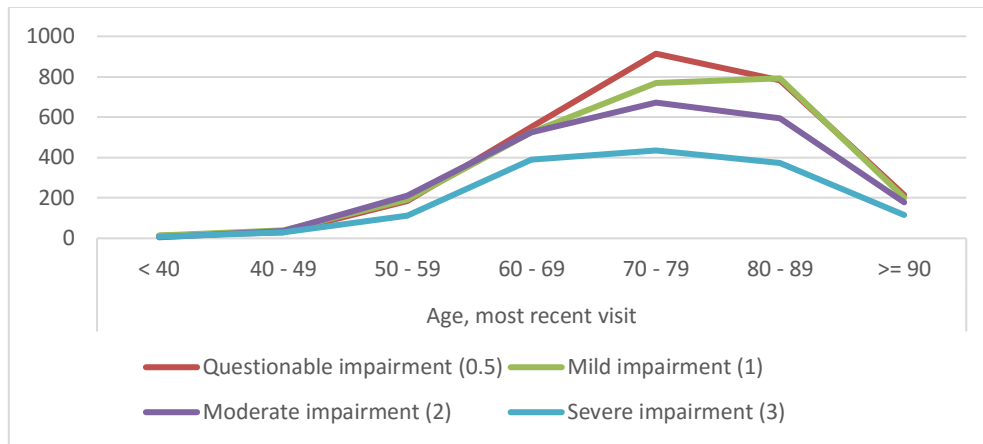


Figure 1 Relationship between Age and Level of Impairment

2. Race vs. Level of Impairment:

Different races have different metabolisms and hence different immunity and fitness levels. To ascertain this statement, we carried out this chi-square hypothesis test to check if there is a relationship between different races and level of impairment. Similar to the first test, we chose to address the type-2 error since we do not want a false acceptance of an incorrect null hypothesis. As observed in the below figure, the critical chi-square value is much less than the Chi square test statistic and hence we reject the null hypothesis and accept the alternate hypothesis.

NULL HYPOTHESIS (H_0): There is no relationship between race and level of impairment a person has

ALTERNATE HYPOTHESIS (H_1): There is a relationship between race and level of impairment a person has.

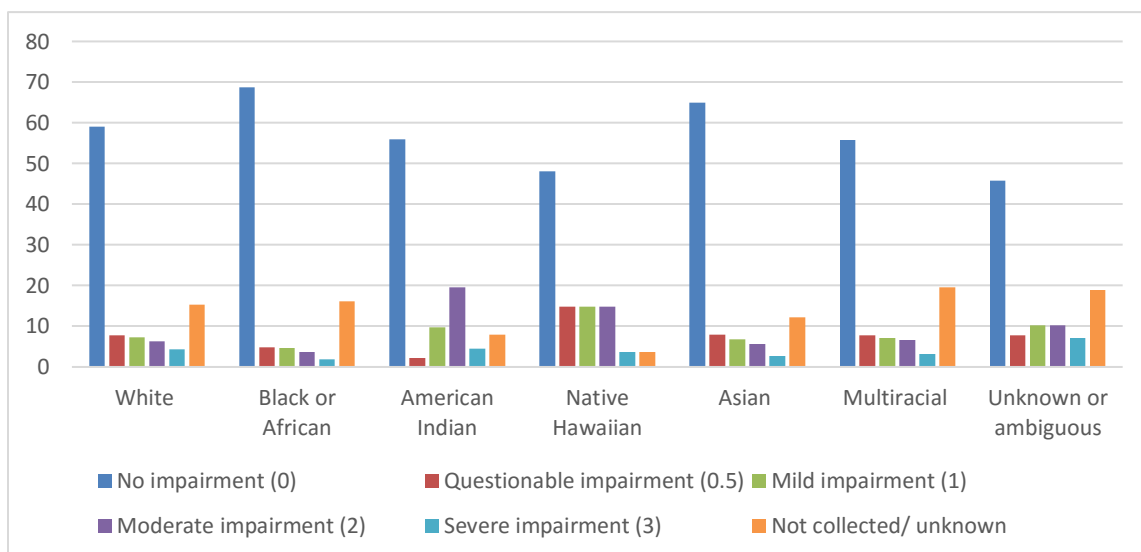


Figure 2 Relationship between Race and Level of Impairment

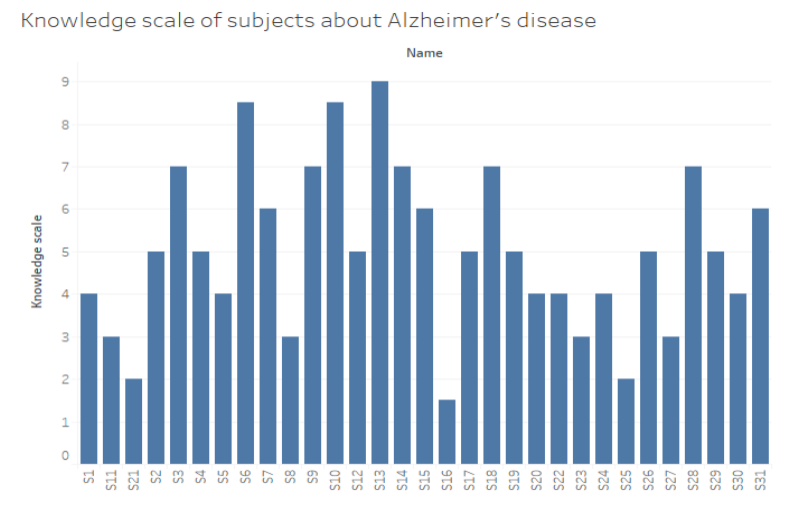
The bars show the percentages of people from a particular race having a particular level of impairment. We have represented the percentage of people instead of the number of people since more than half of the

respondents were white to balance the data representation. As observed in the graph, there is a higher percentage of Native Hawaiian people suffering from moderate and mild impairment than the other races. This test helped us establish a relationship between race and level of impairment which in turn will help strengthen one of our recommendations as seen further.

Key finding: Race and Age affect the level of impairment, which in turn affects the ethical considerations to be taken care of while using assistive technology. For example, for a race like Native Hawaiian, the disease affects mildly, and the consent and privacy of the patient should be taken care of as the patient is sane enough to decide what is good or bad for him. However, for some other race like African, which shows high level of impairment, the ethical considerations for consent, privacy etc. should not be as serious and should be left to the perception of the caregiver as the patient is deeply affected by the disease, enough to make him/ her not capable of deciding his/ her preferences.

Survey Analysis:

To understand the level of awareness regarding ethics of using assistive technology within the unprofessional caregiver's demographic, we carried out 31 surveys in and around the University of Washington. The survey, consent form and questionnaire can be found in the Appendix. All the participants had signed the consent form prior to undertaking the survey. While transcribing the data, we made sure not to include the names in our analysis and not disclose them in any form of presentation. As mentioned in the Data Collection section, more than 50% of non-professional caregivers are in the age group of 18-49 which strengthened our analysis since all our survey takers were in that age bracket. Out of the 31 people, only 6 had complete knowledge about assistive technology and out of them only 3 had some idea about the ethics of using it which is less than 10% of the total respondents. This presented a strong knowledge void which we are addressing through our recommendations. Below are some visualizations constructed using Tableau of the responses.



The graph shows us the rating of knowledge about Alzheimer's, assistive technology and ethics possessed by the people who we surveyed. X axis is the survey number while the Y axis shows the knowledge rating. We can see that 35% people have partial knowledge while 45% have incorrect or no understanding of these topics.

Figure 3 Knowledge Scale of subjects about Alzheimer's disease

Knowledge about voice-based assistive technology and its ethics	Number of survey subjects	Percentage
People with complete understanding of voice-based assistive technology	6	19.35%
People with partial understanding of voice-based assistive technology	11	35.48%
People with incorrect or no understanding of voice-based assistive technology	14	45.16%
Total number of subjects	31	100

Figure 4 Knowledge about voice based assistive technology

Key Finding: The unprofessional caregiver’s demographic does not possess enough knowledge to understand and employ ethics of assistive technology. This adversely affects the patients as they unethical use of assistive technology. The adverse effects of doing that was discussed previously in the purpose and statement of research.

Limitations of Quantitative analysis:

1. The dataset webpage has many sources of data which presents a limitation of the validity of the sources. Since we are not able to see the actual data and only have the statistics on which we are performing the tests. The webpage mentions that these are rough measures and should not be taken into account for publishable research. This again brings into question the validity of the data statistics.
2. Since the survey was only carried out around the University of Washington, it limits the geographical scope of the study. Also, the number of surveys taken due to time constraints is less. In order to generalize properly, we need a higher number of survey respondents spread throughout the country of all age ranges.

For both the quantitative analysis methods, further research can be undertaken to find better sources of data and increase the validity by taking more surveys.

Qualitative analysis:

To generate more comprehensive and better-quality insights about the behavior of patients towards assistive technology and ethical considerations understood and employed by the caregivers, we felt that there is a need of analyzing more than just quantitative data. W

We decided to conduct telephonic interviews of people with previous experience of caregiving. During these telephonic interviews, we asked them questions about fundamental instructions given to new caregivers for attending Alzheimer’s patients, ratio of professional and unprofessional caregivers, commonly used assistive technology, their effectiveness over time, how patients react to them and ethical consideration for protection of freedom, privacy and confidentiality. We ensured that the voice based assistive technology being discussed is restricted to most affordable forms and not the very costly ones. At the end of every interview, we questioned them about what recommendations do they give to improve development of voice based assistive technology for Alzheimer’s patients. The transcripts analyzed, included interviews conducted by Cleveland Clinic [a], US against Alzheimer’s [b] and PEW transcripts we received for group exercise of qualitative analysis [c]. We found overlapping themes between the transcripts data and interview data. Though an overlap does not ensure complete conformation between

the two, we identified overlapping trends as stronger and more credible characteristics. One example of matching ideas between the transcripts and telephonic interviews was:

“Try to incorporate stuff from their youth. They tend to forget their current state and remember only the earlier times. New technology seems threatening.”

- Tanya, Mountain View HealthCare, WA.

“African-American community or religious communities, who remember religious songs, or gospel singing or others that will connect to songs from the 50's or 40's, because that's the song from their childhood so finding the mechanism by which you deliver the memories that are still there”.

-US Against Alzheimer's, Transcripts

Both statements point towards incorporation of elements from the patient's youth, like poems, hymns, songs etc. into the design of assistive technology. This is because the patients tend to forget their current state and remember the times when they were young. This makes it difficult for them to comprehend to the technology.

Significance of Thematic analysis to the research:

- 1. Assistive technology:** With the most common issue towards assistive technology being “strange behavior”, this theme majorly identified how patients could not really comprehend to what the purpose of technology is. This leads to patients misunderstanding assistive technology as something threatening and behaving strangely towards it rather than embracing it for help. This is partially because of patients being electronic immigrants and not electronic natives.
- 2. Advice:** Usage of distraction techniques and dynamically changing your approach depending on the patient and progressing severity of the disease. Majority of the inputs were also centred on the fact that caregiving by family members is more effective.
- 3. Ethics:** HIPAA laws and permission letter signed by guardians for regulated sharing of patient information were the two ethical standards identified. Most common ethical consideration was to make sure one's methods of caregiving are not harming the patient or compromising their respect, privacy and consent.
- 4. Caregivers:** One common mistake made by caregivers, especially family members, was to make the patient feel abnormal by over caring. The caregivers need to ensure that they are behaving normally to the patients and not restricting or instructing them too much. Most patients are elderly people who took care of their family in their youth, which makes it awkward for them when their children and family are behaving abnormally careful towards them. Besides this, showing empathy towards their situation and then reacting was a common advice.

We developed a python script which took in a keyword as an input, searched all the questions in a transcript which have that keyword and made a Word cloud of the words in the answers of these questions. These are two examples where the qualitative results overlapped between the transcripts and the interviews, which are, strange behavior shown by patients in response to assistive technology and

difficulty faced by caregivers while handling privacy and consent issues of the patients. With respect to our research, this information plays a role by shaping our recommendations to assistive technology designers and caregivers for overcoming problems faced by patients.

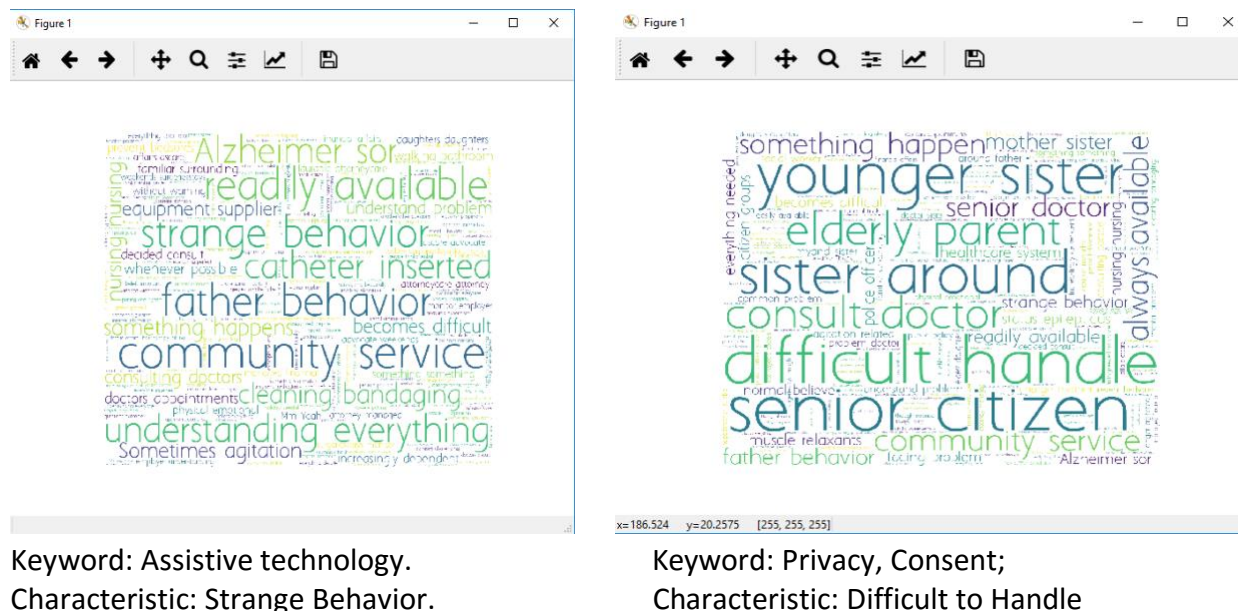


Figure 5 Wordcloud of responses in PEW transcripts

Key Findings: Due to loss of memory, patients cannot comprehend why the assistive technology is being used or what is the purpose of its presence. Hence, they misunderstand the motive of it and demonize it. They find the technology threatening and fear it. This causes emotional trauma and stress to them due to which they show resistance to technology. Incorporating memories from the youth of the patients helps them become comfortable with the technology, as their youth is the time they still remember and during the younger times of mostly elderly Alzheimer's patients, these technologies did not exist, which is why they resist it and find it threatening. It is not ethical to use threatening measures for patients.

Limitations of Qualitative analysis:

1. There was no methodology employed for selecting transcripts from the internet. We selected the ones that seemed comprehensive and were conveniently available which are: PEW Research, Cleveland Clinic and US against Humanity. There is a chance that these transcripts data have bias or do not have information related to some theme.
2. There was no background check done for the people we interviewed for Alzheimer's care centres. There was no consideration for the amount of caregiving experience these people have or how satisfied the patients are with them. There is a chance of disparity between the opinions of these people due to lack of consistent experience.
3. We are students who do not have experience in conducting qualitative medical research. There is a chance that the interviews we designed or trends we identified missed some theme or had bias.

RECOMMENDATIONS

1. Incorporating memories from the patient's youth in the voice based assistive technology.

Ethics issue being addresses: It is unethical to use technology that threatens the patient. Non-maleficence ethic is compromised if we enforce technology on patients that they perceive as harmful.

Scope of improvement: Assistive technology developers should design technology that somehow replicates memories from the patient's youth. Most of the Alzheimer's patients are old and electronic immigrants. They misunderstand technology as something that will harm them rather than something that is meant to help them. Adding elements into technology that they can comprehend will help.

Line of action: Incorporation of elements like some poem or some song from their culture and youth into the voice based technology would help patients with becoming more comfortable with assistive technology. Avoiding use of modern elements which the patients find arcane or vague will also help.

2. Considering the age and race of the patient while designing assistive technology.

Ethics issue being addresses: As mentioned before, the ethical considerations required for patients of different age and race are different. Currently the technology is not modifiable for types of patients.

Scope of improvement: While designing voice based assistive technology, we need to take care of the fact that it is customizable according to the patients or has different versions for various ages and races.

Line of action: Allowing caregivers to record voice based data that is comfortable for the patient according to his/ her age and race. Making the technology more stringent for less impaired patients and a mellowed down version for highly impaired patients, as less impaired patients will not resist it as much as the latter.

3. Measures to improve the awareness of unprofessional caregivers about ethics.

Ethics issue being addressed: As seen in the result of quantitative analysis of the surveys, unprofessional caregivers are unaware of the ethics of assistive technology and they might unknowingly harm the patient by not resolving the adverse effects of unethical use. Assistive technology should not be a 'quick fix' for Alzheimer's patients, or substitute to human care. Its usefulness should be comprehensible to the patient.

Scope of improvement: Measures should be taken to educate unprofessional caregivers about ethics.

Line of action: There should be information sessions, discussions and workshops for unprofessional caregivers where they can share their issues and know more about assistive technology as its use.

Conclusion and Future Scope:

The designed recommendations are aimed towards improving the patients experience with assistive technology. We think this research provides a set of guidelines for designers of technologies. Since the recommendations provided after research results are very bold and ambitious, one major future prospect of the research would be developing pilot studies for verifying the recommendations. The pilot study should focus on finding whether addition of elements which are comprehensible to the patient from their youth make them more comfortable with technology. Besides this, comparison between subjects who used technology with and without ethical considerations should be made to draw conclusions about how much of a difference do ethics make in the process of caregiving. Its limitations are:

- **Time:** Due to time limitation of a period of only 8 weeks for proposing, planning, data gathering, analysis and presentation of findings, we could not really implement any pilot studies for testing.
- **Budget:** Due to budget constraints, we could not invest in professional data analysis methodologies and analysis methods for getting high quality and reliable data.
- **Lack of experience:** As no members of the team had any experience regarding conducting medical research or professional analytics, there might be issues regarding faulty data collection or perception.

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APPENDIX – 1 LIST OF ALZHEIMER’S CARE CENTERS FOR TELEPHONIC INTERVIEWS:

List of Alzheimer’s care centers for telephonic interviews

We shortlisted the following Alzheimer’s care centers in the state of Washington for the telephonic interviews based on cluster sampling:

1. Mountain View Health Care and Rehabilitation Centre, Marysville, WA.
2. American Healthcare Services, Seattle, WA.
3. The Hampton Alzheimer's Special Care Center, Tumwater, WA.
4. Alzheimer’s Association, Spokane, WA.
5. Alzheimer’s Research Center, UW.
6. Harborview Medical Care, WA.
7. Fisher Center for Alzheimer’s Research Foundation, WA.

APPENDIX – 2 AFFINITY DIAGRAM:

We represented the thematic analysis of the interviews and transcripts in the form of an affinity diagram.



APPENDIX – 3 CONSENT FORM FOR INTERVIEWS:

UNIVERSITY OF WASHINGTON

CONSENT FORM

Interview

Researchers: Names and Contact Information:

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PURPOSE OF THE STUDY

The main aim of the study revolves around identifying how many people out of a typical population are aware of the Alzheimer's disease and the ethics of using assistive technology for patients. We also want to know their attitude and preferences towards providing voluntary help for caregiving or spreading awareness.

STUDY PROCEDURES

This survey will take about **5-10 minutes** to complete. The notes and audio-recordings will be stored on a secure computer and accessed only by the research team. Audio recordings and identifiable data will be destroyed no later than December 8th 2017.

Participation is voluntary and you may withdraw at any time. All answers will be kept strictly confidential.

RISKS, STRESS, OR DISCOMFORT

If you do not feel comfortable asking these questions you may end the interview at any time.

CONFIDENTIALITY OF RESEARCH INFORMATION

All of the information you provide will be confidential.

Aditya Wakade, Hemica Saxena,

Prem Shah, Prithvi Shetty

Printed name of study staff obtaining consent *

Signature*

Date*

Subject's statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, or if I have been harmed by participating in this study, I can contact one of the researchers listed on the first page of this consent form. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098 or call collect at (206) 221-5940.

Printed name of subject

Signature of subject

Date

APPENDIX – 4 STATISTICAL CALCULATIONS:

This appendix shows the statistical calculations carried out on the NACC Dataset

CALCULATIONS	
Error	Type - 2
p-value	1.39707E-28
df	30
Chi Square Test Statistic	208.256431
Critical Chi-Square Value	50.89

Chi square test for Relationship between Age and Level of Impairment

CALCULATIONS	
ERROR	TYPE-2
p-value	1.31101E-75
df	30
Chi Square Test Statistic	445.9931493
Critical Chi-Square Value	50.89

Chi square test for Relationship between Race and Level of Impairment

APPENDIX – 5 SURVEY QUESTIONS:

Below listed are the questions we asked in our survey

1. What do you know about dementia?

Purpose of the question: To start the survey with some background of topic.

2. What do you know about Alzheimer's disease? What is the difference between Alzheimer's and Dementia?

Purpose of the question: To understand if the subject can differentiate between Alzheimer's and Dementia. This question was aimed to make the subject understand more clearly about the scope of our research topic.

3. On a scale of 1 to 10, how would you rate yourself regarding the knowledge of Alzheimer's disease?

Purpose of the question: To understand how much is the subject's general awareness of the topic. If the subject does not have a lot of knowledge, we stick to the list of questions. If the subject does have a lot of experience and knowledge, we ask him about his general experience and opinion on caregiving using assistive technology.

4. Do you know any kind of voice based assistive technologies employed?

Purpose of the question: To understand the subjects take on voice based technologies.

5. What are the ethics that should be considered while using voice based technology?

6. **Purpose of the question:** To understand the user's perception of the ethics that should be employed while using technology for patients. This question was aimed to understand the general idea of ethics and which are the most commonly identified ethics.

7. If given a chance, what kind of voluntary work would you like to do for Alzheimer's disease patients? Would you like to be a direct caregiver, spread awareness, raise funds or write/design for the patients?

Purpose of the question: We wanted to see if the subjects understand the seriousness behind the job of a caregiver. The insight behind this question was to give options to the subjects for helping the patients, which involve some secondary help jobs like spreading awareness, raising funds along with directly becoming a caregiver. We wanted to see how many people actually say that since caregiving requires a certain level of empathy, knowledge of ethics and skill which they don't have at that point, they are going to opt out of direct caregiving and go for some other option. Some people understood that while some opted for direct caregiving without thinking of the consequences.

APPENDIX – 6 TELEPHONIC INTERVIEW QUESTIONS:

Below listed are the questions we asked in our telephonic interviews to Alzheimer's disease care centers

1. What are the basic instructions you give to caregivers who go to interact with Alzheimer's disease patients initially?
2. What is the ratio of professional v/s non-professional caregivers?
3. What kind of assistive technology do you employ and do patients and caregiver families have issues affording it?
4. How effective is assistive technology as the severity of Alzheimer's disease progresses?
5. What is your policy to maintain ethics while using voice-based assistive technology for patients?
6. How do you gauge the risks and sensitivity associated with voice-based assistive technology towards patients?
7. How does voice-based assistive technology restrict the freedom & privacy of patients?
8. How do you ensure confidentiality of patient data?

NOTE: This was the script we started the interviews with. However, depending on the person being interviewed, his openness, knowledge and will, we were dynamic with asking questions and making the person comfortable enough to talk about the information he/ she thinks is useful.