

Tech Trio

<https://sites.google.com/scarletmail.rutgers.edu/techtrio/home>

Project Description:

There is currently a lack of tools and resources available for dementia caregivers to effectively monitor, understand, and cope with changes in their patients. Therefore, we are designing a smartphone app that will make it easier for dementia caregivers to interact with their patients while providing them with a variety of new resources and methods that may ease the stress of caregiving and provide better help to the patient. By increasing the availability of resources to caregivers, we are also indirectly helping dementia patients and giving them a better quality of life.

INTERVIEW TRANSCRIPTS

Interviewee 1 - Sheila

- Q1. Tell me about yourself.
 - I have a Masters degree in higher education. I work part-time in fundraising. I care give for my husband who has early onset dementia.
- Q2. Why did you choose to be a caregiver for dementia patients (if you chose it)?
 - It wasn't a choice, there's nobody else who could do it.

Topic 1: Understanding Needs for the Caregiver

- Q3. How satisfied do you feel with your job?
 - I am not satisfied at all. I don't like anything that comes with caregiving. None of it - I don't like to cook or clean not a nurse. I'm not nurturing. It's not my area of interest. I do not have the capacity to be a full-time caregiver.
- Q4. Do you think your employment as a caregiver has affected your health in any way and if so, why?
 - It definitely has. It's stressful things to do for my husband. My husband is not pleasant to be around. He is depressed or anxious because of his dementia. There are no fun times, no vacations, no entertainment - just caregiving. I do hire people to come in when at work then take over when at home.
- Q5. Tell me about the last time you felt seriously stressed at your job.

- Everyday. Last night, he was restless. It is hard to get rest in the house. That makes it so stressful.
- Q6. What is the most difficult part of your job and why?
 - Being something that your not. I'm not an old woman. I don't want to be living the life of an old woman. I am 60 but I'm not that old. I want to be able to do other things. You give up everything for something else.
- Q7. What do you enjoy the most about the job and why?
 - I get to hire and people and leave. I guess that's the best part.

Topic 2: Understanding the Needs of a Caregiver when Working with a Dementia Patient

- Q8. What are some typical interactions that occur between you and your patient?
 - A typical interaction is I will be trying to give instructions and him not comprehending. It gets frustrating because he won't listen. He doesn't want to view himself as incapable. It can also be him asking me questions or arguing how things should be done.
- Q9. Give me examples of difficult activities/tasks that need to be done to care for the patient.
 - Getting through a day with agitation, anger
 - Getting through the day without losing him or myself
- Q10. What happens if you are not able to take care of your patient because of an emergency?
 - Everyone else disappears, nobody comes around
 - I just hire someone to take care of him when I'm gone.
- Q11. How do you feel when you are away from your patient?
 - Skipping and singing
 - It feels fantastic.
 - I do have cameras to keep watch of him at home to make sure things are going well.

Topic 3: Identify what areas can be improved or elaborated upon.

- Q12. Does your patient currently engage in any memory enhancing/strengthening practices? (e.g. mind games, puzzles, etc.)
 - Get him to do that and just wont do it he gets frustrated
- Q13. Does your patient ever have trouble communicating his or her needs to you? If yes, can you describe these situations?
 - He communicated pretty well
 - Loud in an angry voice
 - Sometimes would ta
- Q14. Do you feel you have a community you can depend on or go to if you need help providing care for your patient?
 - No, everybody disappears. Only people I have are the people I hire to take care and come to stay with him.
- Q15. Have you ever used an application or technology that had such a difficult learning curve that it has prevented you from trying to use it?
 - No, I am pretty tech savvy. I work the Nest app pretty well.
- Q16. How do you feel about using health/wellness mobile applications or wearable technology?
 - Cameras are best the help for me because I can see if everything is good. I can see if the caretaker is in danger or is my husband is in danger. I can see everything. It's the best monitoring system used on my iPhone.

Wrap-Up:

- Q17. Is there anything else you'd like to share about your experience as a caregiver?
 - I wish there was more resources, understanding, and awareness about being a caregiver. Caregivers, unless they are hired which they are usually not, have a stressful job and it probably takes life off that person - like years off their life. Caregivers give up a lot. We need more awareness and support for these people.
 - I'd love an app that helps look for the patient's information. It has all their information that you can just share to someone or a caregiver you hire. Time,

date, where they are, what's happening are things [dementia patient] tend to forget. If an app can help them with that, it would be perfect.

- Thank you so much for your time. This information will be very valuable to us. If you have any other questions for the team and I, please don't hesitate to email us.

Interviewee 2 - Riz

- Q1. Why did you start caregiving?
 - I started caring for my grandmother when I was very young. I was about 8 yrs old when I was slowly learning how to help my grandmother go from point A to point B. I started helping her out because I didn't understand what Alzheimer's meant and I thought I could understand it better if I helped out. I imitated the ways my family helped her in order to be as efficient as I could. Then I became a professional caregiver/nurse because I really enjoy the work and taking care of people.
- Q2. Why did you choose to be a caregiver for dementia patients (if you chose it)?
 - I didn't really choose dementia patients but from my experience with my grandma, I thought it was a familiar field.
- Q3. What is your motivation for caregiving?
 - For my grandma, my main motivation would be because it was my grandmother. She is my inspiration for everything and I wanted to help her in anyway I could. As a professional, I want to make sure these patients – a lot of their families leave them – have someone to care for them.

Topic 1: Understanding Needs for the Caregiver

- Q4. How satisfied do you feel with your job?
 - I feel happy when I help my patients. It reflects how I would take care and treat parents.
- Q5. Do you think your employment as a caregiver has affected your health in any way and if so, why?

- Yes, I use to work the 11pm-7am shift, which really affected the way I slept. I gained weight because of the shift, and had extreme headaches from the lack of sleep. There's a lot of lifting involved as well, so there's a lot of aching in my body.
- Q6. Tell me about the last time you felt seriously stressed at your job.
 - The last time I was stressed with a patient with Alzheimer's, was when the patient would constantly stand up on their own and try running out of the facility.
- Q7. What is the most difficult part of your job and why?
 - The most difficult part is dealing with a contracted patient. A contacted patient is someone who is unable to assist you. It gets difficult to help them if they cannot move a certain part of their body.
- Q8. What do you enjoy the most about the job and why?
 - When the patient talks about his/her life, or complement how you work. When they are able to talk about themselves or give complements, you really know that they don't see you as a stranger. Knowing that the patients are satisfied is a great feeling.

Topic 2: Understanding the Needs of a Caregiver when Working with a Dementia Patient

- Q9. What are some typical interactions that occur between you and your patient?
 - When I was taking care of my grandma, everyday I would have her stand up from the bed, bring her to the bathroom and give her a shower. I would then bring her to the dining room to give her some breakfast for the morning, and then bring her to the couch where she is most comfortable. I would bring medicine when needed.
- Q10. What activities do you perform that are not necessarily needed for the patient's care but facilitate you when you work?
 - If I have a patient that is one-on-one than I would clean her room or fix her up snacks even though it is not necessarily in the schedule of that patient.
- Q11. Give me examples of difficult activities/tasks that need to be done to care for the patient.

- When assisting the patient to the cafeteria, sometimes they would try to walk to a different are of the facility to do something else. Many times they don't realize they didn't eat yet, so they would resist going there.
- Q12. What happens if you are not able to take care of your patient because of an emergency?
 - You would have to finish your job with the patients, before you go to the next patient. At work you are not working alone, so there is multiple people who are able to work with the patient in emergency. Once all work is done with the patient you are currently working on then you can move to the next patient.
- Q13. How do you feel when you are away from your patient?
 - For my grandmother, when I was away from her, I felt very anxious because I didn't know what would happen to her. I was always preoccupied with thoughts on if she was content with how things were. I would wonder if she was hungry or in pain and she wasn't able to show us what she needed.

Topic 3: Identify what areas can be improved or elaborated upon.

- Q14. Does your patient currently engage in any memory enhancing/strengthening practices? (e.g. mind games, puzzles, etc.)
 - For my grandmother, we spent a lot of time cooking and eating together. In a way we sort of tested her memory by cooking. She loved cooking food for her family and we used recipes to see if she still remembered how to cook it. If she forgot about something we would remind her and then give her another try a week later. Another way we tested her memory was to have her say her children's name and then have her say her grandchildren's name.
- Q15. Does your patient ever have trouble communicating his or her needs to you? If yes, can you describe these situations?
 - Yes, my grandmother lost most of her motor functions about 2/3 years before hand. She lost her memory on how to speak about 1.5 years before. Many times she would not be able to say she was thirsty, we would only notice that her lips are dry or her breathing was heavy. In her last two weeks, she would make sounds

like moaning and her breathing would be very different which indicated pain. When she breathed she would breath like there was a heaviness that she was holding onto. You can physically see a difference in her normal breathing and her breathing with pain. We would give her morphine to help the pain and then she was breathing better.

- Q16. Do you feel you have a community you can depend on or go to if you need help providing care for your patient?
 - I had my family as a support system.
- Q17. Have you ever used an application or technology that had such a difficult learning curve that it has prevented you from trying to use it?
 - No, but there is difficulties with older patients using more the new technology. A lot of times the patient become forgetful on what step to do first which makes it more difficult for them to use it.
- Q18. How do you feel about using health/wellness mobile applications or wearable technology?
 - I think it would be very beneficial if we were able to give mobile application and wearable technology to patients. In those cases, we would be able to give some patients back their independence, because that becomes an issue to a lot of the older patients. I think it could help patients where they need help and the call bell is too far, It would be more time efficient with wearable technology.

Wrap-Up:

- Q19. Is there anything else you'd like to share about your experience as a caregiver?
 - None
- Thank you so much for your time. This information will be very valuable to us. If you have any other questions for the team and I, please don't hesitate to email us.

Interviewee 3 - Xin

- Q1. Why did you start caregiving?

- I have limited work experience and thought I could help support my husband and my kids by becoming a professional caregiver. I took care of my elderly grandparents when I was a teenager, and I took care of my elderly parents before they passed, so I thought that this would have been a good career choice for me.
- Q2. Why did you choose to be a caregiver for dementia patients (if you chose it)?
 - I didn't choose dementia patients specifically, but I've had experience working with them, so I don't mind.
- Q3. What is your motivation for caregiving?
 - My main motivation is to help support my family and my kids.

Topic 1: Understanding Needs for the Caregiver

- Q4. How satisfied do you feel with your job?
 - I'm pretty satisfied with my job. I work in hospice, so there are always doctors, nurses, and other caregivers available around me if I need help or can't handle something on my own.
- Q5. Do you think your employment as a caregiver has affected your health in any way and if so, why?
 - Yes, a large portion of my job includes physical labor, like lifting beds or helping patients who aren't mobile. I'm getting older, and my back and joints have been aching more and more. I work 10 hour shifts and don't get take many breaks in between, so sometimes, I don't have time to eat a good lunch or dinner either.
- Q6. Tell me about the last time you felt seriously stressed at your job.
 - The last time I was stressed with a patient with an Alzheimer's patient was when he got sick and had to have his blood drawn and began to resist the doctors and nurses that were trying to help him.
- Q7. What is the most difficult part of your job and why?
 - I would say that my day-to-day tasks are pretty routine, but my job gets difficult when a patient starts acting up. Sometimes, patients can end up breaking equipment or items around them. A lot of times, they can't help themselves, and

we can only do our best to restrain them, but the patient's family end up blaming me for not doing a better job. I wish they were more understanding.

- Q8. What do you enjoy the most about the job and why?
 - It makes me feel accomplished that I can do my best to take care of a patient and make sure they're getting the best treatment.

Topic 2: Understanding the Needs of a Caregiver when Working with a Dementia Patient

- Q9. What are some typical interactions that occur between you and your patient?
 - Every morning involves me preparing breakfast, lunch, and dinner for the patient. I try to make sure that they're comfortable, and I keep watch with them throughout the day to make sure they don't wander off or disturb other patients. We do some exercises and walk outside a little on nice days with my supervision. I also read books or the newspaper to him. I bring medication or other items when needed.
- Q10. What activities do you perform that are not necessarily needed for the patient's care but facilitate you when you work?
 - I'll bring the patient snacks or fruit every week.
- Q11. Give me examples of difficult activities/tasks that need to be done to care for the patient.
 - Getting the patient to eat can be a very difficult task. Sometimes, it might take over an hour to convince the patient to listen. Right now, my patient is on a liquid diet, so it is much easier, but it used to be much more difficult in the past with solid foods.
- Q12. What happens if you are not able to take care of your patient because of an emergency?
 - You really can't leave for an emergency because there's no one taking care of the patient. Sometimes, other caregivers will watch the patient for you for 30 minutes, but it is really your responsibility if something happens, so you really have to try your best to not leave your patient's side.
- Q13. How do you feel when you are away from your patient?

- I feel a little happier. Even though I do feel connected with the patient, caregiving is still my job, and everyone is happy when they get to go home from their job.

Topic 3: Identify what areas can be improved or elaborated upon.

- Q14. Does your patient currently engage in any memory enhancing/strengthening practices? (e.g. mind games, puzzles, etc.)
 - None
- Q15. Does your patient ever have trouble communicating his or her needs to you? If yes, can you describe these situations?
 - Yes, my current Alzheimer's patient used to be able to speak, so it was much easier to tell when he wanted to eat, drink, or go outside. He lost his ability to speak about a year ago, and it's been much more difficult to figure out what he needs. One time, he caught a cold and would make moaning sounds throughout the day, but I didn't know what was wrong until a doctor came to check on him later. It troubles me because if something happens, I really wouldn't know what to do or how to help.
- Q16. Do you feel you have a community you can depend on or go to if you need help providing care for your patient?
 - I have other caregivers at the hospice that I can go to for help, but I don't have a community that I can rely on.
- Q17. Have you ever used an application or technology that had such a difficult learning curve that it has prevented you from trying to use it?
 - No, usually I can go to my kids for help if I don't understand.
- Q18. How do you feel about using health/wellness mobile applications or wearable technology?
 - I think they could be useful. Mobile technology has improved so many other areas, so I'm sure it can help in this field as well. I'm not too knowledgeable about the subject and don't use many mobile apps, but if it could help the patient or me with my job, I would be glad to try it out.

Wrap-Up:

- Q19. Is there anything else you'd like to share about your experience as a caregiver?
 - None
- Thank you so much for your time. This information will be very valuable to us. If you have any other questions for the team and I, please don't hesitate to email us.

SURVEY DATA

We created a Google Form to collect the survey responses. A link to the raw data responses in a spreadsheet is below:

<https://docs.google.com/spreadsheets/d/1X1A3OZCMUoz-9oTWUdXaAVNIB-3SXvAQNLTQyu-Yz80/edit?usp=sharing>

Contributions:

Website: Kelly - reviewed by Anchalee and Yuhui

Interview 1 with Bonnie: Anchalee - reviewed by Kelly and Yuhui

Interview 2 with Riz: Anchalee - reviewed by Kelly and Yuhui

Interview 3 with Xin: Yuhui - reviewed by Anchalee and Kelly

Survey: Anchalee and Kelly