

The Zarit Burden Interview

- 0: NEVER
- 1: RARELY
- 2: SOMETIMES
- 3: QUITE FREQUENTLY
- 4: NEARLY ALWAYS

Please circle the response the best describes how you feel.

Question	Score
1 Do you feel that your relative asks for more help than he/she needs?	0 <input checked="" type="radio"/> 1 2 3 4
2 Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 <input checked="" type="radio"/> 1 2 3 4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 <input checked="" type="radio"/> 2 3 4
4 Do you feel embarrassed over your relative's behaviour?	0 <input checked="" type="radio"/> 1 2 3 4
5 Do you feel angry when you are around your relative?	<input checked="" type="radio"/> 0 1 2 3 4
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 <input checked="" type="radio"/> 1 2 3 4
7 Are you afraid what the future holds for your relative?	0 1 2 <input checked="" type="radio"/> 3 4
8 Do you feel your relative is dependent on you?	<input checked="" type="radio"/> 0 1 2 3 4
9 Do you feel strained when you are around your relative?	0 1 2 3 4
10 Do you feel your health has suffered because of your involvement with your relative?	0 <input checked="" type="radio"/> 1 2 3 4
11 Do you feel that you don't have as much privacy as you would like because of your relative?	0 <input checked="" type="radio"/> 1 2 3 4
12 Do you feel that your social life has suffered because you are caring for your relative?	0 <input checked="" type="radio"/> 1 2 3 4

Question	Score
13 Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15 Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
16 Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4
17 Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4
18 Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19 Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20 Do you feel you should be doing more for your relative?	0 1 2 3 4
21 Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22 Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Patient last name:

Date of birth: / /

Patient first name:

Date: .21. / .5. / ...2019..

For Family Member (Grandson of patient)

1. The Zarit Burden Interview
 - a. http://dementiapathways.ie/filecache/edd/c3c/89-zarit_burden_interview.pdf
 - i. Overall score 20: **this low score could be due the time between the interview and last time interviewee had to act as a caregiver for the patient was a couple of years ago**
2. Then for each functionality:
 1. **GPS Tracking**
 - a. For my grandpa, it was not a requirement but it would be helpful
 - i. **-making it optional?**
 - b. burden: goes down
 - c. for the patient if they should have functionality: yes
 2. **Security**
 - a. thinks of it as how secure the app is
 - b. So what makes it secure? what are insecure
 - i. passwords (for patient and caregivers)
 - c. **burden: goes down if caregivers using the app**
 - d. for the patient if they should have functionality: yes
 3. **Memory Prompting**
 - a. Very good, one of the more useful functionalities
 - b. patient and caregiver would both use, working together
 - c. burden: down (most) helpful.
 - d. for the patient, if they should have functionality yes
 4. **Patient Page Ability**
 - a. **too much information depending on the design**
 - b. **avoid unimportant information**
 - c. only accessible to anyone "trusted: in the family (informal and formal caregivers"
 - d. **burden: same**
 - e. for the patient, if they should have functionality yes
 5. **Reminders**
 - a. **REALLY helpful**
 - b. **customizable**
 - c. s: how do you see it being used?
 - i. medications
 - ii. events
 1. makes it more usable
 - iii. if it is just a clone of google calendar it wouldnt be as useful but if the reminders can be linked to another function of the app would be better.

- iv. A caregiver should also have access to any information related to their care.
- d. burden: goes down but not as much as memory prompting
- e. for the patient, if they should have functionality: yes

6. Journal

- a. It could be useful
- b. a personal record of daily activities
- c. inclusion of images and other stuff to increase the link to the memory(more context).
- d. drawing function(just draw instead of writing)+++++**
 - i. can be really useful for older peoples
- e. linking entries to dates
- f. burden: for the patient itself it will go down a lot
- g. burden: for caregivers, it will go down a little
- h. for the patient, if they should have functionality: yes

7. Panic Button

- a. The patient being able to call the emergency contact
- b. may not be a good thing
- c. can be overused**
- d. caregivers wouldnt need a panic button either
- e. burden: "in my case, it goes up because" overuse of the function
- f. for the patient if they should have functionality: no

8. Specialized Checklist

- a. in the case of my grandpa is more for the caregivers
- b. "walk to the table games"
- c. account
 - i. authentication
 - ii. because if the patient forgets the checklist appropriately it will b good for the caregivers to have access to it
- d. burden: if it works it goes down.**
- e. for the patient, if they should have functionality yes

9. Brain Game

- a. memory prompts but in terms of a game
- b. Similar to memory prompting
- c. would be nice for the patient
- d. "I Imagine something like quizlet"**
- e. burden: goes down a little

10. Information Portal

- a. might be useful, don't know how it will be fit in the app
- b. can be confusing

- c. **23 and me (examples of layouts that include linked information proposed by interviewee)**
- d. burden: caregivers can see it once and retain the information, the burden goes down a little
- e. burden: patients have easier and faster access to the information burden goes down
- f. for the patient, if they should have functionality yes
- g. **If it is well designed it may just work**

3. Are there any functionalities that you think we missed and should be added onto the app?
 - a. **Forums: Different pages to talk to each other: Q&A discussions, peer help.**

How does your family interact with your family member who has Alzheimer's? How has this changed from before he was diagnosed?

Interactions with him became tasks instead of quality time. Grandma felt frustrated and that caused fights. For other family members were really empathetically visit him more often.

Have there been any incidents with the patient arising from memory loss? (issues with people trying to scam the patient, issues with patient forgetting to take the medicine, etc) [want to focus on issues that our product can actually help deal with, not just general memory loss issues such as the patient forgetting family members, since the app won't be able to help with that. So we need to shape our questions to best provide a stage for our app

Grandpa was in a more advanced stage. He was about its early that he started to forget a lot. He would try to crawl out of the wheelchair and would anger the grandma.

Wandering is a trait caused by Alzheimer's. Have there been any issues where your family member has gotten lost due to leaving the house when they were unattended?

NO!

- **"I think that people wander in the stage where they are not able to move much anymore"**

Do you or your loved one use any app at the moment for treating the symptoms or do you practice any specific type of mental exercises with the afflicted?

No, during the early 2000s, there were not mobile smartphones nor mobile apps