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 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 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 2 3 (4)
4 Do you feel embarrassed over your **relative's behaviour?**	0 1 (2) 3 4
5 Do you feel angry when you are around your relative?	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 1 2 (3) 4
7 Are you afraid what the future holds for your relative?	0 1 2 3 (4)
8 Do you feel your relative is dependent on you?	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 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) 1 2 3 4
12 Do you feel that your social life has suffered because you are caring for your relative?	0 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

60.

Patient last name: . . . .   Date of birth: . . . . / . . . . / . . . .

Patient first name: . . . .   Date: . . . . / . . . . / . . . .

INFORMAL CAREGIVER 1- INTERVIEW

1. The Zarit Burden Interview
    a. http://dementiapathways.ie/_filecache/edd/c3c/89-zarit_burden_interview.pdf
2. Then for each functionality:
    1. GPS Tracking
        a. safety
        b. burden: stays the same, since her dad doesn't wander
        c. for patient if they should have functionality: yes
    2. Security
        a. thinks of it as how secure the app is
        b. S; what makes it secure? what is insecure
            i. passwords
            ii. since it has sensitive information
        c. burden: goes down if shes using app
        d. for patient if they should have functionality: yes
        e. helpful if there is a actual formal caregiver
    3. Memory Prompting
        a. Good, game, helpful with relating words that can prompt the memory of the other words, that's how there are games like that
        b. patient and caregiver would both use, working together
        c. charades
        d. burden: down, if it does help, if it's useful.
        e. for patient if they should have functionality yes
    4. Patient Page Ability
        a. safety, annoying
        b. would enjoy the functionality to block this ability
        c. in her case, she doesn't want, but seeing other patients, she thinks it is a good ability.
        d. burden: up
        e. for patient if they should have functionality no
    5. Reminders
        a. Really likes this.
        b. s: how do you see it being used?
            i. reminders on your phone, like take your pills, whenever he has to.
            ii. Take your pills, you don't owe anyone money, etc
            iii. Notification, popup on your phone, can cancel, accept, just like a regular phone reminder
            iv. As caregiver, would put in the reminders. Patient would accept or decline, and then caregiver will be able to see this

      c. burden: down, not a lot, but would be nice

      d. for patient if they should have functionality yes

          i. they can put reminders themselves

6. Journal

      a. annoying since you have to fill it out but if there are prompts there would be better, (how are you feeling, and then options)

      b. in terms of pictures and dates and times and places, where everyone has a tag, that would be good, related to memory prompting.

      c. word bank for patients. "How are you feeling?" [Sad, Calm, Angry, Happy...]

      d. there are daily journals (this is what she thinks of) -> today i did this this this, i felt like this

          i. helps express themselves, word bank helps remind of different emotions, reminds patient of certain words, help the patient express themselves to different people

      e. ella: not that useful, if you post a photo, it'll auto tag if it recognizes the people in previous photos

      f. burden: barely down

      g. for patient if they should have functionality yes they can put in pictures

7. Panic Button

      a. not sure how that would work initially, after knowing, would be annoying and misused.

      b. unless it's easy to get to aka notification page, not very helpful

      c. not sure if it's that good of an ability, not very functional

      d. burden: same

      e. for patient if they should have functionality no

8. Specialized Checklist

      a. checklist = daily things, [steve: suppose doctor told fam, patient must walk 45 mins a day], understands that different people need different info

      b. functionality: just like reminders, did he do this, did he do this, going specifically to one caregivers phone.

      c. doesn't want specialized info.

      d. hypothetically, if sister was 10, wouldn't want sister to have the app.

      e. burden: if it works, goes down

      f. for patient if they should have functionality yes

          i. what would he add to it?

1. her dad would add very odd things, just not relevant things
      ii. times they would need to do things, appointments, medicine, etc
         1. could be too much work depending on person
      iii. caregiver should be able to see what the patents are writing so she can confirm
9. Brain Game
   a. memory prompts but in terms of a game
   b. luminosity, sudoku, crossword, games like that
   c. approves of games like memory prompts
   d. where you have pictures and you say what it is, saying it verbally, not through text
      i. describing pictures
   e. burden down if it helps (help def: if it improves his memory)
   f. quantifies" how it helps" if you can do it faster, if you are able to do it better, etc.
   g. if brain game was a set of pictures, and after so and so time, and different pictures over time,
      i. suppose you have 1 pictures with 10 details
      ii. first week you have 6 details name 4
      iii. next week have 3 details, must name the rest
      iv. next week have 7 details, must name the rest
      v. if they were able to name all details in every single week, does that mean memory increased?
         1. not sure lol
      vi. does ability to finish hard puzzles mean improve? no, but at least stay the same
   h. wants ability to choose game for patient. reminds her of speech therapy.
10. Information Portal
   a. doesn't know
      i. fancy dictionary
   b. s: what about in terms of such that one page leads directly to information about certain things, for example, it could be like closest healthcare facility is here, more info about so and so here, more info about this this and this, here
   c. E: in general, ideally, there would be two different versions of app, one for caregiver and one for patient, as this sounds all encompassing, more information for caregivers, less for patients
   d. burden: down

     e. for patient if they should have functionality yes, they should be able to see where doctor is and such
       i. also, doesn't mind her dad reading up on alzheimer's. access their condition and be able to show other people very easily
   11. Feels app should be very simple
     a. looking from caregivers perspective:
       i. top 5 functionalities used daily
         1. checklist
         2. information portal
         3. gps tracking
         4. journal
  b. What did you think of when we mentioned *functionality*?
  c. *Explain functionality* Does this make your burden go up or down?

3. Are there any functionalities that you think we missed and should be added onto the app? - No. Everything so far is good.