Attitudes of Older Adults towards Self-Assessment of Mental Health, Safety and Wellbeing

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Abstract—The number of older people within our society continues to grow. At the same time, nations are looking for ways to offer the same quality of care with a lesser economic burden. One way of mitigating health-care costs is by self-monitoring and self-assessment, by which older people can follow-up their own health and wellbeing. This could be an improvement for health care professionals who can focus more on those who are in need. However, it is unclear whether seniors equally perceive self-assessments as an improvement. This qualitative study explored seniors' attitudes towards self-assessment questionnaires and how they envision self-measuring mental health and wellbeing. Such an understanding can help define user requirements for a self-assessment system that is welcomed by older adults. To this end, a focus group interview with six participants – older than 65 years and still living independently – was set up. During this focus group, various topics – self-reliance, social contact, financial means, healthy diet and active leisure – that are important to the senior's wellbeing were addressed. Not all participants were in favour of an online self-assessment. Some also indicated that questions should focus more on their capabilities and not on their failings. It is the objective of our current research project to improve GRaCE-AGE further and tailor it for self-assessments by older adults.

I. Introduction

The number of older people within our society continues to grow. By 2020 in Europe, the amount of people over 65 years old will have increased by ten percent to 142.56 million [1], [2]. At the same time, nations are struggling with rising health care costs, and are looking for ways to offer the same quality of care with a stagnating number of professional caregivers and with a fixed budget spent on healthcare [3]. One of the possibilities in which health care costs can be mitigated is by self-monitoring and self-assessment. If older people can monitor and assess their own health and wellbeing – using decision support information technology linked to sensors (e.g., activity sensors, blood pressure meters, cameras for fall detection, etc.) – this may lead to significant improvement

in the monitoring of their health and wellbeing. Besides, health professionals no longer need to spend time on those older adults who are still doing fine, and can save their energy for those patients who are in true need of specialized care.

That is the theory but although technological advancements render self-assessment and self-monitoring realistic, it is unclear to what extent older adults themselves perceive self-assessments as an improvement [4]. Do older adults embrace self-assessment and self-monitoring? And if so, what are the essential user requirements for such a self-assessment/self-monitoring system, if it is to be adopted by older adults? In this paper we start exploring these questions.

Using a focus group study with six participants, we investigated how older adults envisioned measuring quality of life and wellbeing, by sensors and self-assessment decision support systems. We also explored how we can support older people by using self-assessment questionnaires. In particular, we presented a specific online system for risk assessment of mental health and wellbeing - GRiST [5] - and discussed attitudes of seniors towards this self-assessment questionnaire. Such an understanding helps define user requirements on how to adapt a self-assessment system that is welcomed by older adults.

II. METHOD

A. Participants

Our qualitative study took the shape of a focus group, which consisted of six participants - four women and two men - who were 65 years old or older ($mean = 78\ years,\ 3\ months$; $SD = 6\ years,\ 5\ months$). These participants were recruited via an umbrella organization (www.innovage.be) [6] that facilitates the creation of products and services for older adults, by being a bridge between engineers and those institutions that deliver care for older adults. Participants were selected on the basis of the requirement that they were still living independently at home or in a service flat, taking care of themselves, and that they were still able to contribute to a constructive and insightful discussion. Besides these six participants, two researchers – one moderator and one observer – were present as well. The moderator led the session, the observer did not engage but took notes. Due to privacy issues, no recordings were made. The observer's extensive instant notes were reviewed and completed by the moderator straight after the focus group was finished.

B. Procedure

First, the participants were welcomed and introduced themselves to ensure a relaxed atmosphere. Subsequently, there was a short presentation on the GRaCE-AGE project [7]. GRaCE-AGE is a research project that aims to redesign and extend a current mental health web-based system called GRiST – Galatean Risk and Safety Tool [5] – to produce a self-assessment tool for improving the mental health, safety and wellbeing of older adults. During the introduction, a short demo was given to present the web application (see figures 1-3).

The focus group interview itself started with an exploratory conversation by asking the participants what health-related or wellbeing-related information they would like to measure or follow up. The aim was to explore what topics were brought up by older adults as related to quality of life and wellbeing. In the second part, the focus group interview zoomed in on one particular self-assessment tool, GRiST, and the screenshots from the application – to illustrate its operation – were reviewed. The GRiST tool is a web-based software application that helps older adults assess their own mental health, safety and wellbeing at home. It covers the following topics: state of mind, involvement with life, physical and mental decline, social isolation, personality and way of thinking, along with behaviors specific to risks such as suicide and harm to others. By completing the questionnaire, risks can be detected.

The focus group took approximately two hours to complete. One participant left in the middle of the session because of other obligations, and two other participants left after one and a half hour. The other three participants stayed until the end of the session.

C. Materials

Nine sequential screenshots of GRiST [7] were printed on A3 paper. Every user received a printout, so they could evaluate them. Figure 1 illustrates the homepage where users can choose
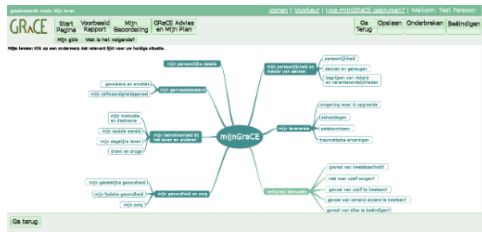
Fig. 1. Homepage

Fig. 2. Tree structure subjects

Fig. 3. Questionnaire "My Personal Details"

which questionnaire they want to complete first. "My Life" provides a complete overview of all the questions, grouped by topic (see figure 2). By selecting a topic, the related questions will be displayed, which is shown in figure 3. Alternatively, if you start with "My Wellbeing" or "My Safety", the questions will be more focused on respectively wellbeing and safety, whereby you get a shorter list of questions to complete.

D. Analysis

As aforementioned, during the interview, no recordings were made because of confidentiality. However, during the session and immediately afterwards everything was written down as literally as possible. These notes were then entered in NVivo 11, a software tool to aid in the analysis of qualitative research methods. First, core concepts and themes were coded in vivo. These concepts and themes were then discussed with the moderator and a second researcher.

III. Results

The focus group interview started with an exploratory conversation about quality of life and wellbeing in relation to self-assessment scales.

A. Adoption of Self-Assessment

On the question of whether older participants would welcome such a self-assessment, four out of six participants thought that it was a good idea, yet two participants did not. Those open to such a self-assessment, would do this for their own interest and when they felt up to it, rather than because a health professional said so. Moreover, they mentioned they would like to fill out only those topics and items about which they felt were relevant for their situation. Those participants that were not in favour did not see the usefulness of it as they were still in good shape.

> P4: "I'm 79 years old. I still feel good, so I don't need such an evaluation. I am not thinking about these things"

Some of our participants would only fill out those questions of interest to them, they would skip the questions that they would not deem relevant.

> P6: "I would fill this in, in this way I get an overview about myself."

> P3: "If you don't want to fill it out, then you don't have to... You (cf. the researchers) can keep these questions in the questionnaire, but I would just skip them."

Our participants were triggered by this self-assessment. It did cause worry about their place in society and their risk of being patronized.

> P1: "We are a burden and they won't put any efforts in us."

B. Topics

The main items that seniors mentioned that such a self-assessment survey would need to entail were self-reliance, social contact, financial means, healthy diet and active leisure.

1) Self-Reliance: In the context of this focus group study, self-reliance meant that someone is able to do things his or herself, preventing becoming dependent on a third party.

> P1: "I still live at home alone and I hold it all together, but I experience that some things become more difficult as I get older. (...) You don't want it, but eventually you become dependent on others."

2) Social Contact: Our participants found it important to meet others, instead of being alone all day. Feelings of being unsafe outside, also provide an indirect reference to the importance of social contact. Because of unsafe feelings, our participants expressed being held back to visit places and becoming lonely.

> P1: "If you are always trapped between four walls, you become a fool."

> P3: "That's why I eat here (cf. cafeteria). We all eat together, so at least it isn't a dialogue with the deaf."

3) Financial Means: Our seniors talked at length about their precarious financial situation. It was - more than once - extensively linked to quality of life and wellbeing in this focus interview. It was found crucial for wellbeing that life and daily activities remain affordable.

> P1: "I think that we - seniors - have to pay too much. With only our pension, we can't afford much."

> P4: "You live alone, but whether you cook two or six potatoes, the electricity cost will remain the same." P3: "We have to pay even more, there is an extra fee because we consume too little."

4) Healthy diet: When talking about nutrition, they indicated that a healthy diet (e.g., eating fruits and vegetables) remained important when getting older. According to our seniors, there is a misconception about the eating habits of elderly people. As mentioned by person P6, older people eat too much meat and not enough vegetables. Since not everyone cooks for his or herself, it is important that the food that is served is healthy.

> P6: "Many people think that older people only like to eat meat. We get too much meat and not enough vegetables, there should be more fruit and vegetables."

> P5: "Maybe they should listen to what we want (cf. more vegetables and/or fruit), and take that into account."

5) Active Leisure: The participants acknowledged the importance of physical activity, and an additional feature for a personalised exercise scheme was suggested.

> P3: "You can follow up on yourself and your evolution. There might be suggested exercises so you can improve."

Besides exercising in order to stay fit, sports are also social activities where one can exercise together with friends.

> P5: "For example, I joined a walking club. I'm staying active, but I'm also among other people and you can make new friends. I like that."

C. Formulating Concerns by Using the GRiST Tool

As a second part of this focus group interview, we discussed the GRiST risk assessment tool [5]. Figure 2 shows the overview of all topics covered in GRiST. It depicts a tree of life on which all the different topics related to mental health and wellbeing are being displayed. Like many other related surveys that assess wellbeing there is an extensive set of items that ask for depression, physical and mental decline, social isolation, etc.

Next, We will discuss the concerns that came up by our participants.

1) Focus on Decline: When reviewing the topics and items, participants found some of the questions in the current version of GRiST to be rather depressing. They mentioned that the questions were heavy and focused on declining health status and associations with risks and death. Participants wondered whether items could be 'lighter' and less introspective. It gave a too negative view of a person's life.

> P4: "These questions are so heavy... 'feel vulnerable', 'not looking after yourself', 'feel like hurting yourself', 'feel like ending it all' - sigh. When I am feeling sad, I rather turn on a good movie than answering those questions...

Answering these questions is making it worse."

P3: "I would complete all the questions except those about death and depression."

2) Snapshots of Life: Participants also noted that filling out a one-time assessment takes only a snapshot of their lives. This underlines the importance of the more dynamic aspects of using GRiST, including how a sequence of assessments can be viewed over time with graphs of changing status, which was not covered in the focus group.

P4: "All these items are so negative. If the question was 'Do you sometimes feel sad?', I would answer 'yes', but now 'Are you sad?' 'no', that's a snapshot. It is not because I am sad today, that I will be sad tomorrow."

Participants were concerned that some questions were unclear and difficult to understand, and sometimes even impossible to answer. They expressed a need for a social worker to help understand and fill out the items. They also acknowledged that the advantage of a self-assessment is that people probably will be more honest when answering questions.

P3: "I don't think that everyone is capable of filling out these questions. Aged persons don't always know what they read. Or they don't understand the question. Usually there is a social worker who is helping to fill out the questions."

P4: "Yes, but are you going to tell everything to such a social assistant? You might say: 'Fill in yes, please', while you actually know that the real answer is 'no'..."

3) Sharing Data with Others: Keeping this in mind, our seniors mentioned that they felt it was acceptable that data would be shared with physicians or medical staff, but – to our surprise – they did not like sharing this information with family or friends. The participants did not want to burden their relatives and feared they might get too worried.

P3: "I would give the data to a confidential adviser: a social worker or a nurse for example."

P4: "If I would send these data to my daughter, she would immediately be worried. Of course, I don't always feel that good, but she doesn't have to know that."

IV. Discussion

A. Evaluation of Self-Assessment Questionnaires

While the economic benefit of self-assessment in health may be obvious, the direct advantages to those that need to complete the self-assessments are less clear. To some extent, there might even be disadvantages, i.e. less face-to-face contact, exposure to decline that lies ahead. Although this study did not involve participants using the online self-assessment and they were unable to explore the full interactive functionality, it did highlight some important issues and provided guidelines for future designs.

B. Suggestions and Improvements

Our participants like the positive and optimistic aspects of their lives emphasized and not just the problems. Efforts should be made to focus on their capabilities and not on their failings, which tends to be the focus of clinicians. Balancing scale items so that risks are measured via positively phrased items can be a good idea, e.g., 'Do you feel sad?' could be complemented by 'Do you feel happy?'. Assessments should be viewed within the context of their time series rather than being disconnected discrete episodes. More concrete questions are preferred over abstract 'introspective' questions that are more tuned to clinicians. Topics could focus on, for example, specific activities of daily life – ADL – that inform these more abstract concepts. Such activities are also easier to fill out, e.g., note the difference between a grand concept 'My dexterity is still good' versus 'I can still tie my shoe laces'. Finally, outputs that provide information and tips tailored to the individual on how to stay in good shape and keep safe are likely to be welcomed.

C. Limitations of the Study

We acknowledge that this study involved only six seniors, who were not able to use the actual self-assessment scale and could not explore the

full interactive tool. Rather we relied on screen-shots of GRiST. Hence, it is our aim to extend this study to more participants and a longer, hands-on use of the tool. Currently, this is ongoing and more focus groups are held.

V. Conclusion

If older adults can monitor and assess their own health and wellbeing, this can improve the quality of care. This can also be an improvement for physicians by reducing health care costs. Physicians could focus more on those patients who are in need.

However, it is not clear to what extent older adults are open to such an online self-assessment tool. During this focus group – with six participants – we explored the perspective of older adults towards mental health and wellbeing in general and an online self-assessment tool.

We found that not all participants were in favour, and even those who were in favour of such a self-assessment, mentioned that they would skip some items. In particular, the seniors in this focus group indicated that they would not want to fill in too 'sensitive' or 'heavy' questions. Moreover, it was remarked that having to fill out too many items that measure decline could actually result in the opposite, namely becoming more depressed. More emphasis can be put on preventive aspects, rather than solely using the GRiST tool for detecting risks.

Our participants also were not keen on sharing this information with the next of kin, in particular, they did not want to burden them. They felt more at ease sharing this information with health professionals.

Finally, we also suggest that not only big negative concepts such as suicide or harming someone should be covered, but rather we have to look into more specific activities of daily living (ADL) and smaller topics. Such activities are also easier to fill out.

It is the objective of our current research project to improve GRiST further and to tailor it for self-assessment by older adults. It will build on these exploratory findings and, in addition, explore how sensors can automate input of data and reduce both manual and cognitive load.

Acknowledgment

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