

# *Participatory Design-based Requirements Elicitation Involving People Living with Dementia*

## *Towards a Home-based Platform to Monitor Emotional Wellbeing*

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**Abstract**— We are living in an ageing population with an escalation in chronic illnesses including dementia and other age related diseases. People living with dementia often continue to live at home and are supported by caregivers and next of kin. It is often important to monitor the wellbeing of people living with dementia in order to measure their level of independence and to provide proper support at the time of need as well as supporting their quality of life. Some researchers have focused on monitoring physical wellbeing and activities of daily living (ADL). However, there has been a paucity of research focussed on monitoring mood, affect and the emotional wellbeing of people living with dementia, despite these people experiencing frustration, agitation, depression and social isolation to name but a few known effects. As a result, the SenseCare project aims to build an affective computing platform that uses sensors placed in the home environment to monitor moods, affect and the emotional wellbeing of people living with dementia. This platform is being iteratively designed and will likely use plug-n-play sensors such as passive infrared, wearables and camera technologies to infer emotions from facial expressions, voice intonations and physical behaviour and other modalities. However, it is important to interact iteratively with people living with dementia and their caregivers in order to understand their profound needs. In this study, we report on two focus groups that were conducted to elicit user stories and eventual requirements for the SenseCare platform. Since participatory design involving people living with dementia could bring about unique challenges, we adopted a dyad approach where a caregiver and the person living with dementia participate together in the focus group. This ensures that their needs are fully represented and that consent is fully transparent. In this paper, we report the personal stories elicited during these discussions which will ultimately inform the implementation of the SenseCare platform.

**Keywords**—*affective computing; people living with dementia; emotional wellbeing; participatory design*

### I. INTRODUCTION

The world's ageing population is increasing and statistics show that 17.8% of the UK population is 65 years and over [1]. Ageing brings with it different chronic diseases that effect people's cardiovascular and cognitive health. Dementia is a chronic condition mostly associated with the older population (65 years >) and is related to the decline of cognitive function.

Symptoms of dementia include memory loss, problems with understanding and judgement and can also have an impact of individual's emotions and their ability to express emotion [2]. People living with dementia may become withdrawn from daily living activities and have difficulty controlling emotions. People living with dementia can elicit agitation and frustration due to the effects of cognitive decline. Furthermore, they may also suffer from other debilitating conditions such as depression which could further affect their quality of life. Therefore, monitoring emotional wellbeing and not just physical wellbeing is important. Emotional wellbeing can also act as a proxy to a plethora of needs allowing a machine, a caregiver and others to intervene when the emotional wellbeing of a person living with dementia is in decline [3]. As a result of these observations, the SenseCare project was formed to build a home-based platform to monitor the emotional wellbeing of people living with dementia.

SenseCare stands for 'Sensor Enabled Affective Computing for Enhancing Medical Care'. The ambition is to use non-intrusive sensors such as passive infrared, camera-based technologies and wearables to monitor the emotional wellbeing of people living with dementia [4]. These signals would be streamed into a feature extraction and machine learning module to infer moods, affective states and emotions to trend key changes leading to a decline in emotional wellbeing. Emotional wellbeing will preferably be derived using a validated index score and visualised to caregivers and next of kin. The context of the occupant's emotional wellbeing will also be visualised allowing caregivers and other dashboard users to provide appropriate interventions such as entertainment (e.g. music) and social activities. In this project, it is important that family members and caregivers know that their 'loved ones' are happy and when they are 'not happy', allowing them to intervene at the right moment with the right method. However, before building this system, it is important that we iteratively interact with people living with dementia.

This study aims to elicit accurate real-life stories and requirements from people living with dementia by using a participatory design approach in the form of two focus groups in the community. Ethical approval was sought and gained for the project in 2016.

## II. METHODS

This study involved the organisation of two field meetings which took the form of two focus groups. These focus groups were held at Carrick Activity Oakfield Community Centre, Carrickfergus, Northern Ireland, UK. The first meeting was held on the 3 November 2016 and the second meeting took place on 19 January 2017. These focus group meetings were facilitated by Lisa Hendley from Alzheimer's Society UK and the SenseCare consortium. Participants received out of pocket travel expenses where necessary and all participants received a sandwich lunch at the meeting.

To ensure that the views of people with dementia and their lifestyles are fully represented, we adopted a 'dyad' approach. This involves recruiting both the caregiver (informal or otherwise) as well as the person living with dementia. The first focus group involved 10 participants (5 dyads, 1 dyad=1 caregiver + 1 person living with dementia). The second focus group comprised of 12 participants (6 dyads).

It can be arguably more challenging to carry out participatory design with people living with dementia due to short term memory loss as well as the fact that older people may not have exhibit a high degree of technology literacy. Thus, it was important to elicit requirements through normal social interactions and storytelling before introducing any form of digital technology and sensors.

## III. RESULTS

Initial examination of transcripts from the first focus group indicate key findings:

- People became upset when others do not understand that someone has dementia.
- When diagnosed with dementia, people often become very emotional and can feel depressed. For some, this is just a transition to a period of acceptance. For others, it is more prolonged. This was called 'a personal journey'.
- Caregivers reflect that the personality of the person living with dementia can change and that this can be the most significant change, e.g. "he used to be an extrovert, but suddenly I have this man sitting in a wheelchair crying his eyes out, not him at all."
- On discussions regarding technology, participants were intrigued as to how a system could understand when someone was very emotional, or detect mood changes.
- Sometimes, the circle of friends shrinks where one person is living with dementia. Friends do not know how to cope so they visit less frequently. Consequently, the home can become a lonely place, especially for the caregiver living with someone whose 'personality' has changed.
- Technology may help to let people cope, and manage frustration in situations around the home.

- Several caregivers commented on the data that SenseCare could gather and who would have access to it, e.g. in the family.
- There were several examples of how this cohort already use technology effectively. One example was the Pebbell Mini GPS tracker<sup>1</sup> which was used by one caregiver to locate her husband if he left her side. Another example cited by several participants was a door stop alarm which offered a simple alert when a front door was opened. This was used by people when on holiday to ensure that they could know when their partner was leaving the room. It was also used by several people in their homes in multiple locations; for example, to alert when the person living with dementia sought to use a room other than the bathroom at night when going to the toilet. There was a useful comment from a caregiver: "*Learn methods and techniques from people caring for those with dementia at home instead of from social workers or anybody else.*"

Examination of transcripts from the second focus group indicate several key findings:

- Caregivers themselves experience feelings of isolation and loneliness.
- Changing family lifestyles as a result of dementia can cause anger and frustration. Some family members can be in denial which causes issues.
- Caregivers feel guilty when seeking respite/holidays.
- There are changing behaviours of people with dementia, becoming angry and for example swearing.
- Caregivers are at times depressed, related to feelings of guilt and frustration.
- Using gardening, music and dancing have been used lift moods and bring back old memories.
- Music rapidly triggers positive mood changes whether individuals or in groups.
- Feeling happy when 'purple patches' of personality of person living with dementia re-appear.

The two focus groups have informed the requirements and design of the SenseCare platform. Fig. 1 illustrates use cases that emerged from the focus groups. Table I provides an elaboration of these use cases. Tables II, III, IV, V and VI provide an enumeration of the real-life stories.

Thematic analysis of the focus group stories resulted in the identification of five key themes: 1) *Communication* (issues related to communication barriers between the carer and the person living with dementia), 2) *Isolation* (e.g. loneliness), 3) *Frustration* (emotions related to anger, annoyance, confusion and aggression), 4) *Carer challenges* (key lifestyle challenges faced by carers, e.g. issues associated with guilt) and 5) *Interventions* (interventions that induce positive emotions such music, dancing and humour).

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<sup>1</sup> <http://www.pebbell-gps.com>

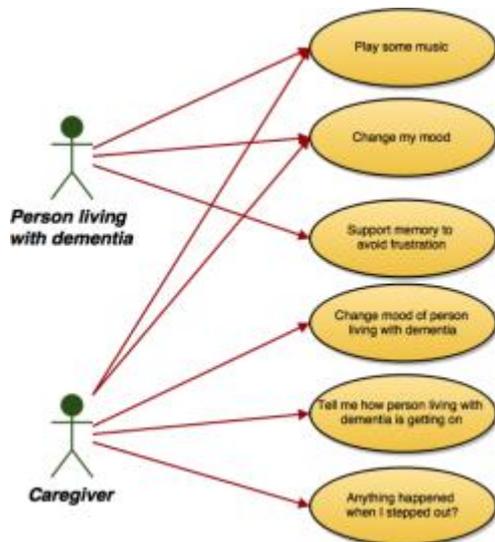


Fig. 1 - Use cases for people living with dementia and their caregivers.

TABLE I. Use Cases

Use case	Relates to	Notes
Play some music	Person living with dementia, caregiver	The 'power' of music to interrupt negative moods and change emotional state was described several times in the workshops. This use case would offer the opportunity to change the mood of people living at home by playing some preferred music.
Change my mood	Person living with dementia, caregiver	A person living with dementia could use the SenseCare platform to 'cheer me up', perhaps by waving arms or some similar notification.
Support memory (to avoid frustration)	Person living with dementia	Several participants in the workshops noted that people living with dementia became frustrated if everyday actions and habitual events were forgotten (e.g., watch news at 6pm). This use case could use a calendar to provide some smart home functionality such as, e.g. switching on TV at 6.
Change mood of person living with dementia	Caregiver	In this use case, the caregiver can instruct the platform to carry out a key operation such as changing the mood of the person living with dementia. The SenseCare platform could use context awareness to determine how this use case plays out.
Tell me how person living with dementia is getting on	Caregiver	In this use case, the caregiver can ask the SenseCare platform for some information on how the person living with dementia is 'getting on'. This could be in terms of physical activity around the house, inferred emotional status, etc.
Anything happened when I stepped out?	Caregiver	In this use case, the caregiver can ask the SenseCare platform for some information on how the person living with dementia coped, when the caregiver stepped out to the shops or went to the garden for ½ hour.

TABLE II. Dyad Stories Theme: Intervention

Theme: Intervention
<b>In response to researcher's question "what makes you happy at home?"</b> <i>"... my dad still has a very good sense of humour and everybody just enjoys him telling a joke. Fair enough if they might be back to front but he was always a great storyteller so I mean that's good to laugh at."</i>
<b>In regards to happiness;</b> <i>"...we've taken up ballroom dancing again. Turn on the radio, pick a good piece of music, play music that you like and we just burn up a bit of energy on the middle of the lounge floor."</i>
<i>"...[dancing] brings back old memories."</i>
<i>"Dare I say he's like a very obedient child [laughs], he never speaks back but if he looks... a bit lonely.... I would put on ... music ... I sent away for DVDs... The minute they go on his toes start going and then he sings along."</i>
<i>"...he sings along and I sing along and I feel it cheers us both up.."</i>
<i>"the daughter-in-law, she's a music teacher and she would go into the piano and start playing and she'll say Daddy what will we sing? and she'll give him maybe a choice of two, any more than that then he's confused. And we'll all sing, whoever's there, and that cheers us all up."</i>
<i>"when the music comes on [group says it changes them, they come alive again?]?... one woman, I've never seen her other than walking ... [with her head down], she's suddenly dancing and ... singing. So it's just amazing."</i>
<i>"My Mum, there's no conversation with her but once you put the music on, she knew the words and sang. It's really, I can see a trigger..."</i>

TABLE III. Dyad Stories Theme: Communication

Theme: Communication
<i>"He doesn't really talk any more."</i>
<i>"He never admitted his eye was sore, even though it was cut and if he had a cold or a sorehead or anything. ... he never says anything is wrong."</i>
<i>"Devise a machine, tell you where pain was or suffering from pain. That would be brilliant."</i>
<i>"Maybe the craic [slang for humour, social interaction or 'good times'] isn't as good now..."</i>

TABLE IV. Dyad Stories Theme: Carer Challenges

Theme: Carer challenges
<i>"... this is just my opinion; carers are not well enough appreciated as far as I'm concerned. Because you look at what they're actually saving in all the work they do."</i>
<i>"I think, guilt is an awful thing too if you're a carer, as you say, you feel as though you can't have your holidays the way you used to. Sometimes it can make you feel guilty about leaving them."</i>
<i>"I had quite a lot of that because if I wanted to do anything it was 'Oh you're going out to leave me...'"</i>
<i>"... I think that's where I found it more difficult because he was always very</i>

independent. He was driving up to he was 91. He sold his house when he was 90..."
"I asked for respite after two years and I was more or less told, well we'll put you on a list. I said well it's just like this, I'm going on holidays because if I don't I'll not be fit to look after him."
"it's a big, big learning curve from the carer's point of view. You know some of your reactions have the opposite to what you would normally do and you have to probably learn by experience more often because you just don't know the reaction to the various incidents, so you've got to take all of this in. I find, luckily up to now, you don't have much time to get depressed because you're kept busy."

TABLE V. Dyad Stories Theme: Frustration

<b>Theme: Frustration</b>
"That was a real mood change, he was a real outgoing person and she just changed completely. She couldn't cope with everyday things, things annoyed her. She would get agitated."
"Biggest emotion. Frustration. The emotion 'I am frustrated'. Sometimes very difficult. Coping on a 24/7 basis. Trying to do the thing right, Managing the situation, frustration. I can see your piece of technology working quite well in regards to frustration on both sides."
"...watching the news at 6 o'clock. ... 6:05 every night he would become very annoyed and you don't know why, but with this [SenseCare] technology, by 6 o'clock it could be something to do with music for 6 o'clock news to trigger something and you could see the response" - <b>Comment relating to the non use of technology/sensors for monitoring.</b>
"But we are discussing emotions and that would annoy me. I wouldn't like that. Somebody watching me and telling me not to do something. However, if I asked for help or needed help. Not interfering with day to day tasks... I would be emotional about it." - <b>Comment relating to technology/sensor use for monitoring.</b>
"...you're torn, because especially if you've a young family at home. Sometimes you just don't know what to do..."
"...other traits change. My father was a very, very quiet man, he became very aggressive, he became very verbal and I was called all the names under the sun from a man that never cursed or swore in his life. I found that very, very difficult."
"... It depends the part of the brain that's affected, you know, it affects their aggression and their moods."
"Oh anger, depression, I suffered a lot from depression at that time. Frustration and guilt for putting him in somewhere. Although at the end my father was quite happy to go in somewhere because he was scared, he was falling... I wasn't fit to lift him, I felt fragile myself and he was happy just to be in."
"Yeah, anger can come out." <b>In reply to the researcher question "So if you were feeling depressed and down, do you think you act differently?"</b>
"... she has these awful wee panic turns where she can't find something."

TABLE VI. Dyad Stories Theme: Isolation

<b>Theme: Isolation</b>
"Not as many people would call in."

"They don't know what to do, they talk around the person and he is excluded, and we were out for dinner and he was sitting there and everybody was talking and not to him. People don't really know what to say."
"I think for some people that I've visited, there's a feeling of isolation."
"loneliness in so far as there can be other people there but inside their head they still feel alone and they are not engaging."
"... once your family and friends' circle know of the circumstances, they're inclined to stay away. They don't seem to call as often as they used to and this sort of accentuates the loneliness part of it too, I think mainly, I suppose for both people concerned, but mainly the carer would maybe notice it."
"Yes, sort of cut you off, you know?"
"It's like any sort of illness, if you meet a friend or something who has been diagnosed say with cancer or something, you find it hard to have a conversation"

#### IV. CONCLUSION

Researchers along with Alzheimer's UK recruited several dyads involving people living with dementia and their caregivers to participate in two focus groups to gather requirements and views on the use of technology to monitor emotions in the home. Several key use cases were identified to inform the development of the SenseCare platform. Real life stories were elicited which provide key insights into the profound challenges related to emotional wellbeing and stability. Thematic analysis of user stories resulted in five key themes: 1) *Communication* (communication barriers between the carer and the person living with dementia), 2) *Isolation* (e.g. loneliness), 3) *Frustration* (anger, annoyance, confusion and aggression), 4) *Carer challenges* (disruptive lifestyle challenges faced by carers), and 5) *Interventions* (inducing positive emotions via music, dancing and humour).

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<sup>2</sup> [www.sensecare.eu](http://www.sensecare.eu)

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