



Sheffield Dementia Involvement Group

June 2024

'Influencing a virtual reality training tool'

Summary

- Most attendees had some understanding of virtual reality.
- Although people had mixed views about technology the majority could see the potential of using Virtual reality as a training tool.
- People felt it would be possible to show how Dementia can affect sensory experiences.
- Virtual reality would not be able to show how people living with Dementia think or feel.
- This type of training tool would be a good way to initiate conversations about Dementia and care.
- People were interested in other potential uses for Virtual Reality for example 'training the brain'.
- People acknowledged that things would get worse as Dementia progresses, some have prepared for this.
- The future does concern people particularly the prospect of going into care or hospital admission.
- Slowing down and doing things step by step can keep people active and involved.
- Not everyone was aware of the Herbert Protocol.
- One couple advised that when worrying about changes that may occur due to Dementia, ask yourself does it matter?

Background

Earlier this year SHINDIG was approached by University Technical College known as UTC Sheffield. Students had been set a challenge by Anchor Care. Their task was to create a virtual reality training tool to teach staff about what it is like to live with Dementia. We invited four students to attend our Tea and Talk planning meeting in June. They brought with them questions which the group answered and adapted.

Our June SHINDIG was attended by 8 people living with Dementia and 8 carers/supporters. Due to decreased mobility two attendees were provided with taxis by Sheffield Health and Social Care. Facilitators were allocated to escort them on arrival and departure. This was hugely appreciated by both individuals as it will enable their continued attendance. We had 2 new attendees and 4 referrals. Our 2 observers were from Primary care and Sheffield Hallam University. The 3 students who brought the topic this quarter were invited to assist the lead facilitators in each group to ask questions.

Main Report

Question 1: What is your understanding of virtual reality?

Most attendees had some understanding of virtual reality and were able to offer examples and differing opinions.

“It’s like a box on your head, the granddaughter has one, but we don’t want to try it”.

“It would be frightening for someone with Dementia”.

“A great education tool, it would help staff to experience something they can’t get out of a book”.

“It’s brilliant because you are in the situation”.

Amongst attendees there were people who really embraced technology and those who fear it.

“Medical use of VR is very positive, there is lots of potential”.

“If it was kept to gaming, I’d be happy but the future of these scares me, I would never use one”.

As conversations progressed people did begin to consider the potential for Virtual Reality.

“I’m a technology dinosaur, I need everything explaining but I do like to try things”.

“I’ve tried it before, bit scary, I’m a down to earth person, but I do see the potential”.

A carer in one group asked the student, how can you know how Dementia feels?

The student acknowledged that there were limitations with using Virtual Reality. Stating that it could show how people see things and experience sound but not how they feel or think.

Question 2: What is your opinion of using Virtual Reality to train/educate people?

The group felt it important for the students to know that everyone living with Dementia is a unique individual with their own strengths and limitations.

“It is difficult to pinpoint symptoms into a single training package. Everyone has their own unique set of symptoms. Therefore, could the training be tweaked and personalised?”

Someone suggested this kind of tool could form part of a larger training package.

“Restricted, it can't show everything but could be one of a number of tools used to educate people”.

The group did feel that the tool could capture experiences of the following.

“Symptoms such as the effects of noise, for some people increased sensitivity to noise can trigger anxiety and isolate them. Black mats can be confusing and too much or too little stimulation”.

It was felt that the training should not be a one off, it should be repeated to check staffs understanding. Some people reflected on poor experiences of being in hospital.

“A good target group would be hospital staff. Hospitals are not a good experience for people living with Dementia. Don’t give enough time and structure, overload with information”.

It was suggested that this form or training could get people talking.

“It’s a good way of initiating conversations about care and giving people knowledge in a realistic way”.

A carer asked if the tool could be adapted for a person living with Dementia to re-train the brain.

“Training the brain with repetitive experiences has been talked about before”.

This led to a student clarifying the purpose of the project.

“This isn’t linked to finding a cure or even solutions it is to give a lived experience”.

In another group this was echoed.

“The tool would not be used to teach people about the diagnosis or types of Dementia rather the reality of living with Dementia. Through the eyes of people with Dementia”.

Question 3: What are your most difficult experiences of living with dementia?

How does this impact on your daily life?

People living with Dementia spoke openly about losing the ability to do certain things, sharing how this frustrated them. There was awareness that things were going to get worse.

“Confusion, losing things and jumping to the wrong conclusion. It is important to keep things visible for the person living with Dementia”.

“I’ve lost my numbers, I used to be good at arithmetic but it’s a struggle now and that really frustrates me”.

“I Struggle with hallucinations, acute anxiety, distinguishing reality from hallucinations is difficult”.

One person described specific experiences which caused them distress. Suggesting the tool could be used to show people different scenarios to help them gain a better understanding.

“One thing that has happened to me since diagnosis is that I have dark dreams trying to find a person then come to a dark wall and there is a struggle. Slow, frustration dark thoughts. You could create a series of situations to navigate using Virtual reality”.

Another attendee recalled the SHINDIG meeting in April, during which our discussions incorporated images of rooms with different patterns, colours, and layout.

“At a previous meeting we looked at images and they were problematic This is a big subject, seeing is a very different experience for people living with Dementia”.

People spoke about their vision “playing tricks” and how things like a dressing gown hung on a door could look like a person.

One carer shared that the Dementia Stars training she attended really helped her to understand visual perception.

Another person living with Dementia recalled getting lost in the rain while volunteering and there being no-one nearby to ask for help.

“It was frightening I just sat down and cried, I haven’t got a strategy for this”.

This led to a conversation about smart phone apps and trackers. This individual had negative experience of a supported living facility where she felt tenants were monitored intrusively. This led to suspicion around certain technology. She then held up an old style Nokia phone.

Laughing “You can’t get apps on this”.

One couple really value having a tracker as it enables the person living with a diagnosis to continue enjoying his daily walks independently.

The group were made aware of The Herbert Protocol.

Navigating public places was also mentioned.

“Lived experiences such as it being impossible to find a toilet, this makes going out and about very difficult. Needs to be your first job to find out where the toilets are. No toilets in town now. Make sure you are equipped when you go out and you will feel better”.

Difficulties regarding use of public toilets is an ongoing issue for attendees. The Coordinator of SHINDIG recently bumped into two attendees at a café in town. One showed her a small slip of paper with six digits in small writing. To use the toilet, he needed to locate it then negotiate a ‘baffle’ lock by pressing six buttons, then quickly turn a knob to gain entry. I spoke to staff who although helpful could only suggest that people ask them for help to access the toilet. The three of us discussed this afterwards agreeing it would be humiliating for some people. The locked doors have resulted from other members of the public misusing these spaces.

The future worries some people. Changes in environment and perceptions of reduced choice and control were recognised as factors that could progress symptoms of Dementia.

“I’m worried about being cared for in a home and constantly being told to sit down with a television on constantly. I worry I would become anxious and become aggressive out of frustration”.

“I am worried about having to go into hospital and being put in bed and losing the ability to walk. People with Dementia must cope with different staff and attitudes at every shift change”.

An attendee shared how having no family necessitated her pragmatic approach to dealing with what the future may bring.

“A lot of people still avoid those tricky conversations. I have made plans, easier to do now as I have insight, I’m prepared for moving into a care home, so it doesn't worry me”.

How couples spent their time together has changed and previously enjoyed activities like baking, embroidery and travel had either stopped or had to be adapted.

“I’ve noticed myself getting slower, still getting it done but slowing down, not frustrated by this yet. I know it will get worse”.

“We had to give up the camper van as the anxiety of maintaining the vehicle became too much. We still do the gardening and cooking together. We just have need to break it down and do things one step at a time”.

One carer reflected on how her partner would put on sad pieces of music and have a cry. She felt this may be a coping strategy to manage feelings of loss.

Carers within the group listed the following as problematic aspects of Dementia.

“Being asked questions repeatedly, being followed by my spouse all the time and him forgetting that we have spent a lovely day with family as soon as we get home”.

“I’m frightened that this will happen to me”.

The group agreed that it was important to live as well as you can and adapt to what you are being faced with.

One couple shared how being realistic and having some perspective is helping them adapt.

“I give myself more time to do things, knowing things will decline is hard. With Dementia choices narrow”

“We live a smaller life now and have adopted a new phrase, does it matter?”

Conclusion

Virtual Reality is a box used to transport you to another reality managed by a computer.

June's SHINDIG gave people living with Dementia the opportunity to discuss the potential of using Virtual Reality to educate people about their lived experiences. This topic led to animated conversations and attendees were keen to learn from the students as well as offer opinion. We have invited the students to re-visit SHINDIG once their project is complete so that attendees can see how their input has been used.

Other information

The Herbert Protocol is a national scheme that encourages people living with Dementia, carers, supporters to provide and put together useful information, which can then be used in the event of a vulnerable person going missing.

Herbert Protocol forms can be accessed and completed online and printed off for use in an emergency.

The number for the **Dementia Advice Service, DAS is: 0114 2502875**

For further information please do not hesitate to make contact.

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