

Photography and storytelling: Exploring the Experiences of People with Early Stage Dementia



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Executive summary

Introduction

I undertook a four-week Churchill Fellowship leading an exploratory photography and storytelling study to understand how people with dementia experience being a student at VUK (Voksenskolen for Undervisning og Kommunikation) school and to find out about creative activities and services which are being delivered in Denmark to support people with dementia.

Photography and storytelling project

The project aimed to develop an understanding of the work VUK undertake, directly from the students' perspective. Students with dementia were supported to explore, vocalise and show what attending VUK meant to them using photography and storytelling.

Ten students, with a diagnosis of dementia, took part in the project. Two groups were run weekly for four weeks. Students were provided with cameras to take pictures both at home and at school and required support to take and talk about the photographs. The students' images were used during each session as prompts for discussions and creative activities, with each group completing a poem and storyboard about being a student at VUK. The emergent themes from the sessions were:

What students do at VUK

Lessons are run in cognitive training, art and music therapy, woodwork, computing and history and the students are able to choose to attend lessons according to their interest. The school assess and monitor the students to ensure the classes to meet their needs.

How they feel about attending VUK

The students talked about attending the school as meeting new 'challenges' and 'tasks', which they looked forward to and welcomed. They also spoke of achieving and succeeding in their activities and it was observed that lessons are planned so the students are able to see progress or complete tasks successfully. The students experienced the school as a place for 'positive learning'.

Friendships with other students

The students have a very good relationship with each other. They spoke about enjoying spending time with each other, talking together and being with 'like-minded' people, who shared similar experiences of living with a dementia and who want to learn.

What it is like to live with dementia

Students used humour to explain the impact of their dementia and expressed frustration and anger at sometimes not being able to say what they wanted. They talked of the difficulties they face every day and how their sense of purpose can be stripped from them. The students discussed the importance of getting out of the house, of doing something positive, and how the school supports their sense of purpose.

Cultural differences

The differences between English and Danish cultures were often discussed and students became more comfortable with hearing and speaking English as the project progressed.

The value of using creative activities in research

The use of images prompted conversations, memories and discussions amongst the students. The students suggested the images helped them to tell their stories.

A wider Danish picture

Meetings were arranged with the Danish Dementia Research Centre, the Danish Alzheimer's Association, a music therapist from Aalborg University and Skelhuset (a day service for people with early stage dementia, who visit a cabin in the woods).

Skelhuset offers activities based on supporting daily living and functioning, such as gardening, cooking, washing and cleaning. Additionally, they offer creative activities such as sewing or music and encourage physical activity through daily walks in the wood.

Remembrance Dance sessions, set up by the Danish Alzheimer's Association, use dance and music to support memories, tap into emotions, support family/carers relationships and increase physical activity.

Conclusions and Recommendations

Creating a challenging environment

- Services were observed to provide welcoming, supportive yet challenging environments for people living with a dementia.
- The students at VUK talked about meeting new challenges at the school and how they look forward to taking these on and succeeding.
- The balance between making activities challenging and successful is an essential part of creating a stimulating environment.
- Encouraging people with dementia to take part in activities which support their everyday activities of daily living and give a sense of normalisation is important.
- The students talked of the value of being with 'like-minded' people who share and understand each other's experiences and diagnosis.

VUK within a UK context

- Recommendations for delivering a similar model to VUK in the UK would be:
 - Liaison with VUK.
 - Developing a strong ethos with clear aims and objectives.
 - Developing activities which support cognitive functioning, foster conversation, support memory, orientation and social engagement.
 - Developing clear lesson/activity plans.
 - Providing a variety of activities, with access to a range of activity materials.
 - Undertaking appropriate assessments and monitoring to ensure people with dementia are in classes suitable for their needs and interests.
 - Ensuring the venue/environments are appropriate for classroom activities.

Use of creative activities

- Creative activities can be used to engage the person with dementia, carers and family members. This inclusivity can increase understanding between the person with dementia and carer, strengthen relationships and encourage communication.
- Creative activities can foster feelings of purposefulness and worth and can have practical applications. Finding ways to share and use the outputs of creative activities can be as important as the act itself.
- Consideration should be given to the use of creative activities in supporting people with dementia to participate in research activities.

Enabling people with dementia to tell us their stories

- Photography and storytelling enabled the students with dementia to be creative and supported them share their thoughts, feelings and experiences.
- Giving people with dementia the space to discuss what it is like to live with dementia can be very important for them and for you as the carer/teacher/researcher.

1 Introduction

My four-week Churchill Fellowship was undertaken to lead an exploratory photography and storytelling study to understand how people with dementia experience being a student at VUK (Voksenskolen for Undervisning og Kommunikation) school and to find out about creative activities and services which are being delivered in Denmark to support people with dementia.

VUK, operating in Aalborg Municipality, Northern Denmark, is an adult school of education and communication, providing special education to adolescents and adults. Their philosophy is to match education at an individual level, focusing on the person rather than the diagnosis and ensuring that people have access to lifelong learning. Their service includes the provision of cognitive training and creative lessons for people with a diagnosis of dementia, who attend the school as students. Lessons are run in cognitive training, art and music therapy, woodworking, computing and history. These lessons are tailored to support the student's cognitive function, wellbeing, social activities and supporting daily living and decision making.

The school hosted a project to explore the students with dementia's experience of being a student at the school, giving them a voice to express how they experience the learning process. The project was co-led with a colleague from University College Northern Denmark (UCN). The aim of which was to develop an understanding of the work VUK undertake, directly from the students' perspective. Using visual and social prompts through this creative project, people with dementia were supported to explore, vocalise and show what attending VUK means to them.

In addition to visiting with VUK, I also had meetings with the Danish Dementia Research Centre, the Danish Alzheimer's Association, a music therapist from Aalborg University and Skelhuset (a day service for people with early stage dementia).

Figure 1: Enjoying Aalborg Harbour



2 Background

The work of VUK is based on the philosophy of person-centred care, offering individualised and tailored education for their students. The school seeks to identify 'what is possible instead of limitations' and so works with their students to help them grow and develop¹. This is indicative of Tom Kitwood's² (1997) philosophy of person centred care, which does not use labels such as 'patient', as these can be disempowering and reduce a person's sense of self-identity. Instead the aim of Kitwood's work is to provide a supportive and positive environment, in which the person with dementia is valued and is treated as an individual with individual needs and experiences^{2,3,4}.

Alongside this, is VUK's belief that learning should continue throughout a person's lifetime. Their provision of education for people with early stage dementia is unique, not only in comparison with the UK but also within Denmark itself. The importance of lifelong learning is to provide a way to adapt to change, to grow, to develop knowledge, to enrich our lives, be fulfilled and lead meaningful and less stressful lives⁵. Similar benefits of lifelong learning have been found with people with dementia where confidence and self-efficacy scores improved following participation in a 13 week education programme⁶. Furthermore, lifelong learning in older adults can be a way to support social activities, citizenship and a way to take greater control over one's life⁷.

Involving people with dementia in research and enabling them to voice their opinions and experiences is an area of research which has been developing over recent years, however they are often still absent in much research on dementia^{8,9,10}. The inclusion of people with dementia in research is a way of gaining an understanding of their experiences from their perspective and can help to tailor activities and services that are best suited to their needs. The movement for public and patient involvement in research^{11,12} and the work in person centred care² have helped to increase understanding about the need to involve different groups in research, including people with dementia. Studies have found that people with dementia can benefit from inclusion and that they want to be part of research studies^{13,14,15,16}. Benefits of such involvement can be increased self-confidence and knowledge, however these may be dependent on how valued their input or ideas are when used within the research process¹⁷. While care needs to be taken to ensure that people with dementia are appropriately supported to engage in research, there can be great value to them personally and for others in a similar situation in being active in research. One of the key drivers for engagement can be in wanting to help others¹⁶ and one area where this can be particularly valid is in understanding what services can help people with dementia to manage their illness, to live a good quality of life and to support their daily functioning¹⁸.

The use of creative methods of engagement with people with dementia is a growing area of interest and has shown some promising findings through improved communication, greater social interactions^{19,20}, improved memory²¹ and the development of humour and laughter^{22,23}. The use of photography and storytelling have also been used successfully to hear the voice of the person with dementia, to help them become active members of the research process and have been found to be an empowering process, helping to develop a sense of identity through participation^{24,25,26}. The use of photographs in research interviews²⁷, or photo elicitation, is thought to provide new insight to the interview process. Working on a different part of the brain to verbal communication, visual information can 'elicit' and 'evoke' information which is different in nature to a verbal interview alone²⁷. A photo elicitation project with people with dementia²⁸ found that photo elicitation prompted memories of past events and discussions around photographs can draw out greater details and information²⁹. The study at VUK therefore aimed to capture these creative methods of engaging people with dementia in research, and wanted to draw on their views and experiences in order to understand what the school offered and what value it had for them to attend.

3 Understanding the students' experience

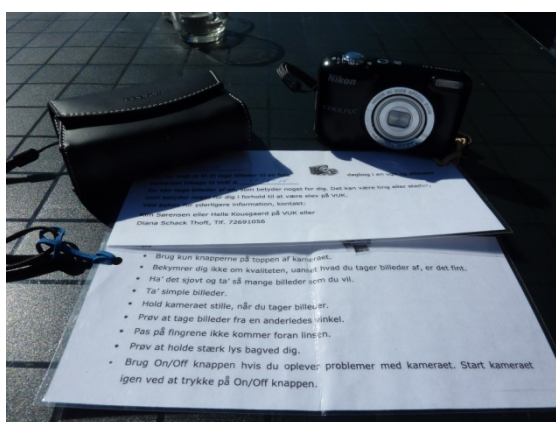
This section discusses the way that the photography and storytelling sessions were set up and run as well as looking at some of the outputs from those sessions, with a particular focus on the student's experiences of being a student and their thoughts on living with dementia.

3.1 Setting up the photography and storytelling project

Ten students took part in the photography and storytelling project (five male, five female), all of whom had a diagnosis of dementia. Most of the students had a form of Alzheimer's disease and all the students were aged over 65 years, with several in their early 80s. Two groups were run each week, with five students participating in each group.

Each student was provided with a digital camera with instructions on how to take photographs and what to take photographs of. The guidance prompted students to take images of 'objects, places or things which have meaning to you as a student at VUK'. The students were guided by the teachers at the school in this process and were taken on a walk around the school and outside in the local area. Students were initially given the cameras for one week, to take pictures both at home and at the school. Some students kept the cameras for longer and took additional images, as they became aware that some of the activities they were talking about were not properly represented by the images. An example of this was the music room, the woodcraft sessions and also some of the cognitive training activities.

Figure 2: Cameras and student instructions



The taking of the photographs and the use of images was not a simple process and the students required support to participate in this project, both from the school and from myself and my colleague. A great deal of thought and preparation was put into the development of this project. The choice of camera, for example, was carefully considered. Initial thoughts of using disposable cameras were dismissed due to the practicalities of getting the images printed in time for the sessions, with no 1-hour or 24-hour photo development services available in Aalborg. The quality of the image produced by disposable cameras

was also thought to make this option impractical. Therefore, digital cameras were used, with a simple model chosen which had few buttons and was large enough to be held securely but not so large as to become childish. The Nikon Coolpix was chosen as it fit the criteria best and overall this camera worked well for the students, who were all able to take several photographs after an initial instruction session given by the teachers.

The project at VUK was subject to proper ethical processes and conducted in agreement with the Danish Data Agency. McKillop and Wilkinson³⁰ (2004) make recommendations for making the research process more engaging for people with dementia and these suggestions were adopted in the project at VUK. Primarily, the students were given information about the study gradually and over several months. They were also asked to consent to participate in the project and give a choice as to whether they participated. The sessions took place within the school in a classroom with which the students were familiar. McKillop and Wilkinson also recommend that relationships are built between and within the group. Working alongside students at VUK meant they had an established

rapport and friendships amongst themselves. Additionally, the co-lead from UCN has worked extensively with VUK and knew a number of the students and staff very well. I also visited the school and met the students on several occasions prior to the study, initially at the design stage of the project and also when the students were recruited. This supported the development of and participation in the sessions and developed familiarity and understanding with all those involved.

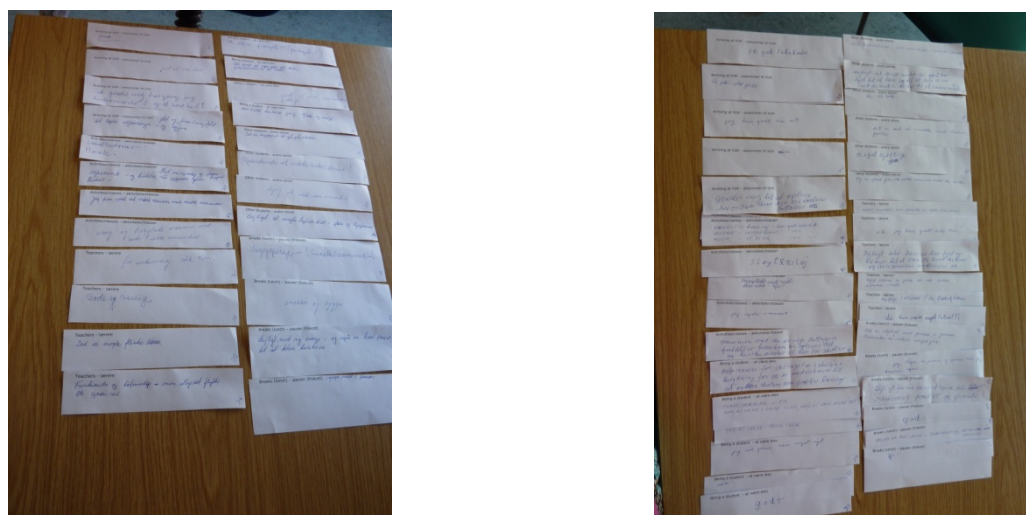
3.2 Using photographs with people with dementia

The images taken by the students were used during sessions with the students as prompts for discussions and creative activities. In one session, students were guided to write a group poem about school life (see Appendix for full poems). Each student was provided with pieces of paper with prompts about different aspects of being a student (Being a student, Arriving at VUK, Other students, Teachers, Breaks and Activities). They were then supported to write a few words or sentences under each prompt to create their group poem, a technique adapted from Collective Encounters³¹. See figure 3 for the two finished group poems.

The groups also used the images to create a storyboard of a 'typical day' at VUK, choosing images which would best represent the activities they did during a day at school, then using these to talk about how they felt about being a student, the activities they do and about their friendships (see Appendix for full storyboards). The students were prompted to talk about what the images they had chosen showed, and questions focused on how it made the students feel rather than focusing solely on questions which were reliant on memory or facts.

Most of the students had also taken photographs from home and these were used during one of the sessions as a way for people to share some stories about their home life and their family.

Figure 3: Student poems about VUK



The students were very keen to discuss the images taken from home, with some commenting in earlier sessions that these images had not been used and asking when they would be. A number of the students also recalled which images they had taken. When presenting their pictures during each session we began by handing out all of the images and had a general talk about them. These were then laid down on the table for everyone to look at. On a number of occasions the students would point to a picture and ask 'this is one I took, isn't it?'. The students were always correct in being able to identify their own images, even though it had been a week or more since they had seen the pictures and there were a number of images taken by students which were similar.

Students also identified pictures they had not taken, asking where the location on the photo was or who had taken the picture (this was particularly the case for the home pictures). I had taken some pictures of the school, the classrooms and corridors to add more choices to the initial selection. As mentioned, the school had taken the students on a field trip to take the images rather than taking images only of the school and everyday school activities, therefore some of the activities had not been captured. The students identified less with the images I had taken than with the ones they or their fellow students had taken, finding it harder to recognise the rooms and feeling a sense of disconnect with these. This was interesting to see and supports the need for, and value of, people with dementia taking their own images and having ownership and engagement with their own pictures.

Harper²⁷ wrote: 'I believe photo elicitation mines deeper shafts into a different part of human consciousness than do words-alone interviews' and Shell²⁹ experienced this, finding the dual process of looking and talking about the photos drew out reflections about the images. For Shell, this enhanced 'the development of meaning and insight' and was an aspect of the work at VUK which was also evident. The use of images prompted conversations and memories and generated often lively discussions amongst the students. The students themselves talked about the way the pictures had sparked memories and that they felt they had enhanced the discussions. One student called the process 'a gift' that they had been given the opportunity to think and talk about what they think and feel and that the process had been very 'positive'. While another student said 'you can put a lot without having to use many words', suggesting that the images themselves also help to tell the story.

3.3 Experience of attending VUK

3.3.1 *The activities*

Students are assessed and offered a place in a class which is most suitable to their needs. Students can attend the school for a whole day (6hrs) or for a class (1½-2hrs), as is most suitable for them and as assessed by the school. They can also choose which activities they take part in, according to their own interests. Students are continually assessed and monitored to ensure that the activities are tailored to their cognitive function and interests. The classes are run as they would be in a traditional school, i.e. in a structured format. The classes are built upon repetition of activities so that students have a structure they recognise and which supports their memory. The school is clear about how the activities may help a person with dementia but are also clear that this is not a cure.

The cognitive training sessions are the main classes run by the school, and during these sessions students are given the opportunity to work as a whole class, one on one with a teacher, on their own or in smaller groups. The day usually starts by reading a local free newspaper, looking at some of the news stories, the weather, TV guide and horoscopes (as one of the students commented, this helps them to remember when their birthdays are). This can be followed with the class choosing an old Danish song to sing. This activity is usually done with the whole class.

After a break, students start to work on different activities. The school have developed their own puzzles and games for the students to play, such as a list of animal names and images which the students have to match, or a map of Denmark with a list of the major towns and cities which students locate. The students also play games on the computer or iPad, work to develop their own life story on the computer, play board or card games, do jigsaw puzzles and crosswords.

Students are regularly tested by the teachers to complete tasks, for example in one of the sessions during the visit, a student talked about being timed to complete a jigsaw puzzle and had expressed his pride at getting faster and faster doing the puzzle, but also that he had developed a strategy to help complete the task by putting in the four corner pieces first to help the process.

Singing and music were an important part of school and home life for a number of the students. Not only those who attended the music classes, as singing has also started to be used in the cognitive classes. Students also sang songs during the photography and storytelling session. It was observed as a way to bond with other students, bringing out fond memories and was discussed as being important to life. As one student said, 'it is joy and life'.

The woodwork sessions were only attended by a couple of the students who took part in this project and only by the men. In the class the students have the opportunity to make rolling pins, chopping boards, bird houses and are also renovating benches at the school. This is a very practical session which results in objects which the students can keep and use or which have use for the school. One of the students told an amusing story of making a rolling pin, only to find that his kept cracking and had to be re-done, sending the teacher's hair grey! There was a very strong sense of achievement from this student when he had made his rolling pin, but also was a shared joke with some of the other students given the number of attempts that had been made to make the rolling pin. This also showed the sense of camaraderie that was part of this class, as one of the students described it, it is a very 'working place humour'.

The students expressed that being at the school was about meeting new 'challenges' and 'tasks', which they look forward to and welcomed. One student wrote in the poem that they were 'looking forward to hearing and seeing what is being told at school', while another wrote they were 'happy and expectant' of the day's activities. While the students welcomed being challenged by the activities, they were also pleased to succeed at them. They spoke with pride about getting faster at the puzzle test and spoke about the 'relief when the task succeeds'. Making the lessons so that the students are able to see progress or complete the tasks successfully is an important and integral part of the school's ethos.

One of the students said that being at the school was 'interesting... is important for us, is contributing, is experiencing the school as positive learning'. This sentiment is echoed by another student who said that attending the school was 'to be renewed, repeated'. The lessons that they attend help them to not only feel as though they are doing something positive, making a contribution to the school and to their lives, but also the lessons help to renew/refresh skills through repetition and practice. The students told us 'it keeps the thoughts going' and 'you are fed with things that you have forgotten'.

The school was called 'unique' by one student, and through this Fellowship, I have seen the uniqueness and the positive impact this is having on the students who attend. This is a very special school, which fosters a positive attitude about dementia and for those living with a dementia.

'It is nice to come to a place where you can do so many things – only fantasy has limits and some students have no limits!'

3.3.2 The camaraderie

The students have a very good relationship with each other and with the teachers. There were clearly strong friendship bonds between some of the students, these were observed during the time spent at the school, but also was expressed by the students. They spoke about enjoying spending time with each other, talking together and meeting new people.

One of the key elements of this was that they were meeting with 'like-minded' people, people who shared the similar experience of living with a dementia and who want to learn at the school.

'Nice that there are others who also have the desire to learn and to share this with others, who feel the same way.'

The students who engaged in the photography project expressed a lot of humour with each other, sharing jokes and laughing together. Takeda *et al.*³² (2010) reported that laughter was a way to show positive emotions which show that a person is relaxed and happy. This was true of the way the students were observed at the school, however, humour was not only a way of sharing experiences but was also used as a way to cope with dementia. One student used jokes as a way to deflect from any difficulties in understanding a question. The other students accepted this and were observed to continue the joke or to incorporate it into the activity or discussion that was taking place.

There was also a great deal of support and understanding shown between students, especially those who may not have understood an instruction or could not recall a word or event. The students helped each other a great deal, prompting recall, asking questions or helping each other with instructions. This was observed in one of the photography and storytelling sessions where two students worked together to write their lines of poetry as one student had not understood the instructions. They were also very respectful of each other's level of dementia, they did not express any frustration when stories were repeated, and often joined in and asked questions to draw more out of the story, or if a joke was repeated they would laugh or comment on this.

While there were some individual differences of opinion and the groups were not always cohesive, the overall feeling from the school was that the students were there for each other and wanted to be supportive towards each other. As some of the students commented:

'... getting together becomes positive and rewarding'.

'There are special friends here, we have something in common. We help and support each other'.

3.4 Experiences of dementia

While the project had not focused on what it means to live with dementia, this was something which came out of the discussions naturally and was not a topic which had been prompted. One way this was talked about was through joking about the impact of the dementia when a person could not recall something – for example one student liked to joke that 'it's because of the kidneys' (pointing at her head). While at other times frustration and anger were expressed at not being able to say what they wanted or not being able to remember a word.

They also spoke about what it actually means to live with dementia, that it is difficult to get out of the house sometimes and that every day is a challenge, as one student said:

'It can also be a challenge just to come here and get out of the door, the door step can get higher and higher to get over there if you don't get out much.'

One lady spoke about the difficulties of using the telephone and how you can forget which numbers you have already dialled, making it impossible sometimes to finish dialling. This individual had started to write down the telephone number so that she could cross out the numbers as they were dialled, so helping her to remember.

Another student talked about what it meant to have a diagnosis of dementia and the level of protection that you experience – saying that sometimes it can be a ‘misunderstanding of protection’. They talked about being feeling ‘totally alone’ and having their sense of purpose stripped from them, being told to *‘just sit down and clean the house then mow the lawn and the day goes with that. And the ones that are staying at home are just waiting for the husband or wife to get home and tell a little bit about what is happening....’*. The students discussed the importance of getting out of the house, of doing something positive, and the school is one of the ways of doing this. It gives a reason to leave the house and when they get home you have something to talk about. One student finished by saying that *‘now you are having a good time when you are here and you are feel good when you go home, but it can happen that some problems occur when you go home but you have had some good experiences’*.

This openness to discuss their dementia is perhaps supported by the philosophy of VUK, in that they do not try to hide or protect their students from their diagnosis of dementia but to work with them and with their diagnosis. In this way they are focusing on the resources to enable people to live their lives and manage their condition rather than on the fact that there are challenges with dementia.

3.5 A cross cultural project

The work at VUK was a cross cultural collaboration which generated some interesting results. As a non-Danish speaker, I relied heavily on the translation skills of my colleague from UCN. Some of the students spoke English and were happy to speak with me in English, while others could only speak Danish. What transpired was a growing interest in the cultural differences between our countries, which were discussed in each country’s tea and coffee drinking habits, in English politeness vs a more direct Danish nature and in how best to translate a joke from Danish to English. The language difference also started to break down during the four weeks of the project, as I became more familiar with Danish words and the students became more comfortable with hearing English. What was interesting to see was that more students started to speak English with me and by the final sessions the back and forth between English and Danish had become quite frequent. Also the students started to respond (both in English and Danish) to questions asked in English, even before the question had been translated, suggesting that they became more comfortable with hearing English. On several occasions my UCN colleague was also admonished when she started to translate a question, being told ‘I understood!’. One student explained in the last session that *‘I have found it interesting and difficult with the English Danish language, I have understood most of what has been said, but has found it difficult to pronounce it’*.

The growing ease at hearing English spoken and at understanding the process which was put in place for the translation (I asked a question, which was translated) and the increased use of English from the students suggests that this form of cross cultural project can work well. Not only did it inspire conversations and interest in a different culture but it provided memories of learning a different language, travelling abroad and, for some students, use of a different language. This was an unexpected outcome of the project and one which seemed to have some positive results.

3.6 A fond farewell

In the final session with the students at VUK, we presented them with a storybook of all the images and stories/poems which each group had created. We used this as a final discussion point to draw on their experiences and to confirm that what had been reported was correct. We also celebrated with some traditional Danish pastries, coffee and a chance for a chat and social occasion.

This approach to ending a project is supported by current thinking^{19,24,30}, as it provides an ending to the work, is a way of leaving people with a sense of achievement and is a way to say thank you for participation and celebrating the work undertaken. This approach was appreciated by the students, one of whom said she was glad to show her family what she had been doing as they want to know what she does at school, while another was later seen by a teacher to be showing the book to his woodwork class.

Figure 4: The final session – their project photobooks and a Danish celebration



4 A wider Danish context

This section presents a discussion about other services and projects being undertaken in Denmark to support people with dementia which I visited through the Fellowship.

During my Fellowship, I was able to visit some very interesting services and projects which are being run in Denmark. In addition, I also found out about some other services, which it was not possible to visit on this occasion, but which provide an interesting insight into the way Denmark is being creative in their care for people with dementia. One service in particular was a care home where they have created a street scene in their home, with shops, a bus stop etc., where the residents can go and buy goods. Another care home has painted the doors in resident's rooms so that they blend into the walls, as a way to ease resident's stress and support wandering behaviour. The use of ball pits and Jacuzzi baths are also being used as sensory stimulus and stress reduction. While the ethics of some of these different approaches may be a cause for discussion, I felt that they were worth a mention as it shows the range of activities which are being used and that there is more to learn from these approaches.

4.1 A cabin in the woods day service

Visiting Skelhuset was a particular highlight of my Fellowship. This is a cabin, set amongst a very picturesque woodland, providing day care for younger people with early stage dementia. People can attend during the week day and they have approximately three to seven people attending each day. The cabin is run by Aalborg municipality and offers activities based on supporting daily living and functioning, such as gardening, cooking, washing and cleaning. Additionally, they offer creative activities such as sewing or music and encourage physical activity through daily walks in the wood – there was a stress placed on the importance of physical exercise and its benefits for the mind and body. The cabin is an actual house, with a living room, kitchen and bedrooms (which offer respite for anyone needing a break or personal space).

Figure 5: Images of the Skelhuset



The work is tailored towards a younger age group (up to 70 years) to take into account their levels of activity and interest. Other activities are also supported, such as going to dementia cafes, museums, music trips and social activities. The manager at Skelhuset felt strongly that social aspects of cabin life were as important as the other activities and thought the cabin should be somewhere where people could meet, talk and interact with other people.

What was interesting to hear was that a new centre is planned in Aalborg which will provide similar services for people in the more advanced stages of dementia. What had become apparent at the Skelhuset was that the people with dementia attending did not want to see the future progress of dementia by being with people who were in the later

stages of the disease. Not only because activities need to be tailored to their abilities and functioning but also because it was thought to be difficult to see others who are in a more severe stage and hence what might lie ahead.

What resonated most about the Skelhuset were the peaceful surroundings and the opportunities that it presented for people with dementia. It showed what can be achieved and just looking at the garden and the veranda, all of which had been tended or built by people with dementia, was inspirational. The house itself was very cosy and decorated in a homely and time appropriate décor for the age of people who were attending. The house provided a place where people could attend to spend their time doing everyday, normal activities in a very natural environment.

I had a wonderful moment with one of the service users, who had very little verbal ability but was determined to show me his drum kit and pick out CDs of his favourite music. With a few words of broken Danish and English and a lot of non-verbal communication we connected and they were able to show me something important about the house and their life.

4.2 Physical activity and dancing

Physical activity and dementia has a lot of importance in Denmark, this was discussed with the manager of the Skelhøst and during meetings with the Danish Dementia Research Centre and Danish Alzheimer's Association. Findings from the Danish Alzheimer's Intervention Study (DAISY) have shown a positive impact in potentially delaying the 'progression of functional decline' in early stage Alzheimer's disease³³ and initial positive effects on behaviour are being found in the ADEX study which has been looking at the quality of life through physical activity in Alzheimer's disease. This study is being finalised and the results of this will be interesting to follow-up³⁴.

While on the Fellowship, I was fortunate to visit one care home that is running a project, set up by the Danish Alzheimer's Association, called Remembrance Dance. This model is based on the use of dance and music to support memories, tap into emotions, support family/carer relationships and increase physical activity. The Danish Alzheimer's Association say that it is a way for 'the body to remember what the mind has forgotten'.

It is very traditional in Denmark for people to learn to ballroom dance in their childhood and this model taps into this knowledge of dance by running dance sessions in care homes. The model is quite simple, with people (residents, carers and family members) being invited to take part in an hour long dance session. Chairs are placed around a room, traditional Danish music is played and people are invited to dance. The people with dementia are supported to dance by volunteers/carers. In the session I attended, I saw the joy that the music and dancing brought to the residents, who sang and moved along to the music. The staff would support any residents who were not physically able to stand and dance, to move to their own abilities, and only if they wanted to. Some of the residents had dressed up specially for the session, wearing 'sparkly' tops and makeup, having made an effort to look good for the dancing. The session I observed was opened by a semi-professional dance couple who danced a couple of demonstration dances and then danced with different residents for the rest of the session.

A short break was held in the middle where canapés and drinks were served, giving the chance for people to have a rest and some refreshments, and also to show that this was something special and was to be a celebratory event.

Sessions are run weekly for 8 weeks. The idea at the end of these sessions is to hold a 'ball' or special event where everyone dresses up to attend. It is a way to mark the end of the sessions and say thank you to everyone who has taken part. Staff are invited to

be creative at this event, decorating the room or cooking something special to eat so that it really feels like a unique and celebratory event.

The Danish Alzheimer's Association runs a two-day instructor course for staff to deliver the dance sessions. This is proving to be a very popular and effective training course, with over 18 municipalities engaging in the programme and approximately 180 nursing homes having trained staff.

This project is currently being evaluated, however initial findings suggest that this programme can decrease problem behaviours, improve social interactions, enhance mood and communication. Residents with dementia have been reported to talk about the session hours later and ask when the next session is going to be. People who have problems with verbal communication have been seen singing along to the music and relatives are reporting positive reconnections with family members, enjoying the physical contact with their partners through the dance. These initial findings suggest that Remembrance Dance is having a positive effect, and this was certainly observed at my time in the care home where residents were smiling, singing and dancing to the music.

5 Conclusions and Recommendations

The aim of this report has been to share the experiences and learning points from the Travelling Fellowship to Denmark. There were many things to take away from the time spent in Denmark, however, there are four key messages which summarise the learning from this visit and show ways in which people with dementia can be better supported.

5.1 Creating a challenging environment

Both VUK and the Skelhuset provided a welcoming yet challenging environment for people living with a dementia. Both these services work to support people with dementia to retain their skills, be they skills for activities of daily living, cognitive function or social interactions. However, neither was seen to shy away from challenging the people they work with. The students at VUK themselves talked about meeting new challenges when they come to the school and how they look forward to taking these on and succeeding. This balance between making activities or tasks challenging yet achievable can be difficult and may require supporting an individual, telling them when something is not right and helping them back onto the right path, but it is an essential part of creating a challenging environment. Being able to achieve your goal is important in working with people with dementia, even if that task has to be completed several times before it is achieved, as was experienced by the student who re-made his rolling pin until it was right. I think this is a good example of both the student's positive attitude in wanting to make the rolling pin properly but also of the school's ethos in offering support, in challenging the student and in ensuring they achieved what they set out to achieve.

The photography and storytelling project was also a challenge for the students to take part in. While it was managed in a very supportive way, it asked the students to take part in new activities and to work with a new person visiting from England. The nature of the dual language approach was at first a cause for concern for a number of the students. In the first session, they expressed concern that they could not understand English, however by the end of the four weeks more than half of the students were speaking partly in English and all but two admitted to understanding the English spoken, if not feeling able to speak it themselves. The process of translation was carefully managed during the sessions and reassurances and explanations given throughout the sessions as to how the sessions would be run and how the Danish/English would be translated. Given the right support, the students were able to meet the challenge of taking part in a cross cultural project and embraced the opportunity this presented them, using it to practice their English, to compare cultures and to joke about the very polite lady who had come from England to work with them!

Two important aspects of the services which I visited during my Fellowship was their emphasis on providing everyday activities and social activities for people with dementia. It was clear that being given the opportunity to go out and take part in normal activities was very important, whether it was going out to play mini golf with a day care centre, baking bread at the Skelhuset, tending the garden or visiting a museum. Alongside the actual activities was also the importance of doing these with 'like-minded' people, people who shared and understood each other's experiences and diagnosis. These views were expressed very strongly by the students at VUK and were observed at the visits to other services.

During my Fellowship it was very clear that, as with the UK, service provision for people with dementia is not universal across Denmark. The work of VUK or the Skelhuset are not available to everyone and this is something that both countries need to develop - the provision of good quality, inspiring and challenging yet supportive services which anyone with dementia can access regardless of where they live.

5.2 VUK within a UK context

The students were keen for the message of VUK to be shared with a wider audience and for people to hear what it is like for the students to attend the school. They spoke very positively of their time at the school, of their friendships and of their identity as students. The school provides a flexible and tailored provision in a range of activities (social, creative and physical) and the students, taking part in the photography and storytelling project, wanted others to hear about the work they are doing so that more people with dementia can benefit from a similar approach and ethos. Part of this is in the development of lifelong learning for people with dementia and providing them with purpose and a sense of self-worth and self-identity.

One of the questions which I find myself considering is how a service such as VUK could work within an English context? In talking about the project with a colleague we discussed that the activities which are carried out at VUK are not significantly different from those used by day care services or care homes in the UK but that it is the structure of these activities and the ethos by which they are being carried out which is unique.

VUK have a very structured approach to their day and lessons. The school starts at the same time every day with classes running for 1½-2hrs with a 15 minute break. The cognitive training classes use a consistent format and so routine and structure become part of the support mechanism for the students. Similarly the ethos of lifelong learning, seeing the person not the diagnosis and working with students at their level combine to create an atmosphere of learning and development.

To develop this on a par with VUK would require significant funding, the sourcing of an appropriate venue and recruitment of staff to teach. This may be too great a risk for one funder to take on and would probably require the input of several organisations to undertake. It may be more realistic to suggest piloting this on a smaller scale, for example with an organisation that already provides day care services for people with dementia, such as Alzheimer's Society, Age Concern or similar charity. The delivery of a similar service to VUK, would most likely be delivered in the UK by a charitable organisation, given they currently run most dementia cafes and day care services.

My recommendation to develop such a service would be through liaison with VUK, to consider running this service one day a week, initially, adopting VUK's structured approach and taking into consideration the following points:

- Assessment of the people with dementia to ensure they are working in classes at a similar cognitive functional level and are in the earlier stages of dementia;
- Identify ways in which to monitor the progress of the people with dementia: their enjoyment of activities; level of engagement; support required; cognitive decline.
- Use a venue which allows for a classroom setting. VUK work around a large table which enables the group to work as a whole and then for students to work individually, with access to a computer. Work created by students is also displayed around VUK.
- Develop the ethos behind the sessions: why is this format being adopted, what are the benefits for people with dementia? A clear ethos, such as that of VUK will help to define the aims and objectives of adopting this format.
- Develop activities which support cognitive functioning, foster conversation, support memory, orientation and social engagement.
- Develop lesson or activity plans with clear learning points, how to support people with dementia to achieve the activities and how to provide challenging activities.
- Consider the variety of activities available, so that people can engage with more than just cognitive training, such as working with computers, history lessons, music or art therapy, woodwork, gardening, cooking etc. Access to a range of materials is important, such as games, IPads, computers etc. so that students have a choice of activities suitable for their needs and interests.

5.3 Use of creative activities

This Fellowship reaffirmed that there are many different ways in which we can work with people with dementia to take part in creative activities, and that these need to be tailored to the individual's interests and abilities. The use of creative activities, be it photography, signing, baking or woodwork, can be incredibly rewarding for a person with dementia. This was observed at VUK, the Skelhuset and at the Remembrance Dance session. Music, in particular, has a great resonance with people with dementia. The students at VUK called music 'joy and life' and it has a way of reconnecting us with our memories, fostering communication and reducing problematic behaviour. The use of music with people with dementia is not unique to Denmark, and the Remembrance Dance sessions had a number of similarities with Singing for the Brain, run by Alzheimer's Society in the UK. Similar benefits have been reported for both of these models for people with dementia and their carers^{35,36}. One of the main strengths of both these models is the way that they engage both people with dementia and carers/family members in the activity. This approach is one which could be developed further in the UK by arts organisations and organisations running dementia services. This inclusivity can increase understanding between the person with dementia and carer, strengthen relationships and encourage communication.

What the visit also highlighted was that creative activities can foster feelings of purposefulness and worth. For example, at VUK the woodwork class were making practical tools for people to use, they were also restoring benches that would be used by the school so that the students could see the impact of their efforts. At the Skelhuset, the students worked to create and maintain the house, looking after the garden or baking bread for lunch. Even the storybook which was given to the students at the end of the project at VUK was a way of celebrating their work and was something to show other people what had been achieved. This practical aspect of the creative arts is something which could be explored further. In considering the outputs of creative arts as not just something that can be aesthetic but which also has a practical application, such as baking a cake to share with a group or creating a book of stories to share with residence, staff and family members. In considering what I gained from my time in Denmark and what learning could be developed in the UK context, I would suggest that finding ways to share and use the outputs of creative activities can be as important as the act itself and we need to explore how to do this more often as a way of showing the value of using creative arts with people with dementia.

Finally, consideration should be given to the use of creative activities in supporting people with dementia to participate in research activities. The use of photography and storytelling in this project supported the students to choose what they told us about being a student at VUK, it supported their memories and recall of student and home life and helped to foster discussions across the group. A similar format could be adopted by UK organisation to evaluate or review their service offer as a way to involve the people with dementia or carers more actively in the research process.

5.4 Enabling people with dementia to tell us their stories

People with dementia have many stories still to tell and the use of photography is one way they can be supported to tell us about their experiences now and from the past.

The photography and storytelling not only enabled the students with dementia to be creative but also supported them to have a voice to share their thoughts, feelings and experiences. The students showed pride in the photographs they had taken, they wanted to tell the story behind the picture and it prompted memories of stories which may not otherwise have been shared. While the students were supported in both the taking of the

pictures and in the telling the stories about the pictures, it was a very positive experience for everyone involved in the project.

One final lesson which the students at VUK gave me was that allowing someone to talk about their dementia, rather than trying to ignore or pretend that it is not there, can be rewarding. Giving people with dementia the space to actually discuss what it is like to live with dementia, hearing them joking about it or just listening and being respectful of what is being told to you can be very important for them and for you as the carer/teacher/researcher. Sometimes we can be afraid to be open and be honest about this disease and while there are times when it is not appropriate or when too much information or disclosure could have a negative impact on an individual, it was also evident that for the students who I met at VUK, talking about their dementia was a way of coping with it and it was also a part of who they are now and a part of their story.

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Appendices

Index of organisations visited

- Voksenskolen For Undervisning Og Kommunikation (VUK)
<http://vuk-aalborg.skoleporten.dk/sp>
- Danish Dementia Research Centre
<http://www.videnscenterfordemens.dk/english/>
- Danish Alzheimer's Association
<http://www.alzheimer.dk/>
- Skelhuset
<http://referater.aalborgkommune.dk/Pdf.aspx?pdfnavn=17675951.PDF&type=bilag&id=16710>
- Aalborg University <http://www.en.aau.dk/>
- University College Northern Denmark <http://www.ucnorth.dk/>

Poems about VUK

Group 1

Arriving at VUK

Good
Nice to be here
We are delighted every time we arrive and to be here!
Happy and expectant for today's challenges and tasks

Activities/classes

Local stories
Music
Talk about the news and the day's tasks
Challenging and relief when the task succeeds
History
We like to be together with other people
Singing and joy. Together with other nice people

Teachers

Nice teaching. Sweet teachers
Sweet and friendly
They are some nice teachers
Patience and understanding - but nevertheless moving the boundaries

Being a student

To be renewed! Repeated!
It's good to be a student at the school
Good people here on the site
Good to meet nice people
Not being home
It keeps the thoughts going. Gives new energy

Other students

It's cosy to attend the school
Exciting to meet other students!
Great to meet nice people
Great to socialize like-minded - joy and forthright

Group 2

Arriving at VUK

A good feeling
We feel good
We do like it
Nice
Looking forward to hearing and seeing what is being told at school

Activities/classes

Cognitive training – really like it
History - interesting – really like it
Music - It is ok
Woodworking
Cosy with games
Reading newspaper – so so!
We enjoy togetherness
Along with the other students, telling how we experience it, what wishes we have for the school

Being a student

Interesting, for participation in the school is important for us, is contributing, is experiencing the school as positive learning
Bicycle training - ok
Like being in school again, if we can remember it!
We want to learn something new
Nice

Other students

New people - new talks - happy being together
Nice that there are others who also have the desire to learn and to share this with others, who feel the same way
Ok – most of them
It's nice to talk with fellow sufferers
Very cosy
We are happy to be with others

Teachers

Very happy with the teachers and their helpers
OK, I like them!
Nice when the teachers have desire and ability to teach us what they can and thus motivate us
Both teachers are good to be together with
Skilled, knowledgeable - most of them
They can be very sensible

Breaks (lunch)

Cosy! Talk together!

Chatting and having a cosy time

Lovely with new energy - and also a short break to clear the thoughts.

Sing much during breaks.

Breaks (lunch)

It's great with lunch in the break. Lunch is always very good.

I take a pear and eat when I get home

Great besides eating then getting together becomes positive and rewarding

Good

Breaks are too long - the lunch is ok. The Salmon sandwich.

So so!

Picture stories of VUK

Group 1 Picture Story

1 - Front sign of VUK

This is the first thing you see, the first time you come to VUK – then you don't notice it anymore.

It is about being together and new experiences. The unique thing is that you are fed with things that you have forgotten.

It is about friendship.

This place is unique.



2 – Students entering the building

Coming into VUK, it is exciting, looking forward to what we are going to do today.

Who are we going to be with, how 'cosy' will it be?

It is positive coming here, we do not feel anxious coming here.

3 – Entrance to the class room

The entrance to the classroom, (the teacher) has arrived – he is here.



4 – Teacher in the classroom (showing cameras)

These show the classroom but not the normal activities.

5 – Students and teacher in the classroom

We get input, but it is difficult to say.

Normally, we start by reading the newspaper. After we talk about the day and what is happening around us.

After there are smaller tasks – puzzles, Sudoku, crosswords using pictures.

Some use the iPad and the computer.

6 – Student using a camera

It depends where you go, it could be creative, or woodwork. Here you can make a rolling pin, and other things such as a bird house or chopping boards.

7 – Woodwork benches (replaced with student photo)

It is 'cosy' to be at the woodcraft class, there is a special humour there, which is a working place humour.



8 – On the way to the music room (replaced with student photo)

It is some of the best things you can do. It is life and joy.

You can't sing if you are in a bad mood, you need to be happy to sing.

The music stays with you when you go home and it can make you happy to sing.

We sing and have some movement in the music class.

9 – Heading out of the door

Some students go out in the break to enjoy the fresh air.

10 – Students sitting outside

Others sit in the classroom having a 'cosy' time. Talking, talking, talking, with good stories.

We also drink coffee, which is very important! "A good cup of coffee is easy to get". A lot of Danes like coffee, it is our national drink.

11 and 12 - Friendship photo of two students hugging, two students helping to use cameras

It is different to have private friends and those here.

There are special friends here, we have something in common.

We help and support each other.

13 – Vans with ‘Jump into life’ slogan

“Jump into life” is the slogan – this shows the challenges we face, the new experiences and the new challenges we have at the school.

It can also be a challenge just to come here and get out of the door, the door step can get higher and higher to get over there if you don’t get out much.

It is nice to meet new people. Also it is nice to bring your new experiences home.



14 and 15 – Students leaving the school and the yellow bus

We go on the bus home.

We appreciate that we are picked up and dropped to the school and then taken home, it is a treat.

There’s a safety in being picked up and being taken home – we don’t have to worry.



Group 2 Picture Story

1 – Picture of the front of VUK

Its super good, we get a good day again.
We look forward to getting here and we like it.

2 – White bus at front of VUK

It's good, it's a nice bus.
Four of us come on the bus and it comes to collect us.
One student drives a car – which is almost as big as the bus!
It is nice to come to a place where you can do so many things –
only fantasy has limits and some students have not limits!
We are among like-minded people.

3 – Newspaper

The first thing we do is read the newspaper and discuss what is in the newspaper.
We get some good discussions and different opinions, there can sometimes be a vote on a discussion and we vote for one opinion.
It does not have the most in-depth news.
We read the weather forecast, TV programmes and horoscopes –
used to help us remember our birthday.
It takes nearly 2 hours.

4 – Student and teacher outside

This makes us think of the breaks – to get some fresh air or to smoke!
We were walking to the church and that was a good day.
We relax during the breaks and talk.

5 – Student completing a jigsaw puzzle

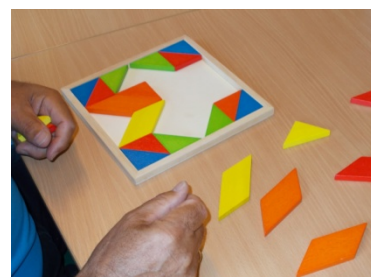
We do puzzles.
We had a test with nine different pieces that was timed. One found a structure to work out how to put the four corner pieces in first and then he only had five more! We became faster and faster.
We play other games and Find the First is fun.

6 - Games

This reminds us of a game we play where we have to match the area with the city names. Not everyone has played this game but it is played after lunch, when some students are not here.
Trivial Pursuits has been brought in by one, one of the first editions and we have played this.
Some are funny, it is interesting to be introduced to new games, it is fine when you are used to them and it keeps the brain going – it can be amusing to play them.
Some games can be boring.
Some like the crosswords – looking up answers in the encyclopaedia.

7 – On the way to the music room (replaced with student photo)

In music we sing and one plays the harmonica.
It reminds us that we also sing in the morning – One of the teachers has introduced this before the summer holiday.
It is nice to sing, good old tunes.
We choose different songs and everyone has a turn to choose and later we will find some Old Danish songs to sing – One of students is looking into this.



8 – (Missing picture of history class – replaced with student photo of history and computer class)

It is a small class. We would like to have more people.

There is a new class being made about computers and iPad, where two students and one teacher participate.

9 – (Missing picture of outdoor activities – use one of a view out of the window)

One of the teachers sometimes has good ideas for outdoor activities, e.g. golf, walking to the church.

We also have a football tournament (where one student looks at one corner and kicks to the other corner, to cheat the goalkeeper!), bowling, golf and sports activities.

10 – Aalborg municipality school banner

This reminds us of a noticeboard in the classroom.

Friendships:

We understand each other.

We are each other's friends.

There is also a friendship with the ladies!

We love to talk to each other.

It is easy to make friends.

Friendship is behaving well to each other.

We talk to each other and are equals, we are patient.

Also the teachers can be a friend.

Not everyone has a friend. It depends on your personality how you make friends; we don't all hug each other.



11 – Students leaving the school

This could be the end of the day.

There are 10 buses to pick everyone up. One drives by himself.

We can feel tired – one is not so old to feel tired!

On a Tuesday some come in from 8am-2pm, which is nice, the 6 hour day is ok. But the history class is only 2 hours, which is too small.

You can volunteer to which activities you take part in.

We have a good mood.

We come here to have joy and laughter but also talk about more serious things – we understand each other.

(NB: the images shown in this report were taken by Alison Ward or given by permission of the students to use in this report. By request of the students, no images of the students have been used.)