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## **Introduction**

Dementia is a progressive, degenerative condition, with no cure (Caspi, 2017), however, there are ways of supporting people to adapt and cope with their diagnosis. Engagement in 'meaningful' activities may be one way of providing support to not just cope and adapt, but also to live as well and independently as possible, and to maintain control and quality of life (Genoe & Dupuis, 2014). Meaningful activities have been identified as those which encourage people with dementia to engage in everyday activities (Phinney, 2006), provide enjoyment, humour and group engagement (Stevens, 2011; Travers et al., 2015), provide purpose (Watson, 2015), enable the individual to develop and grow (Genoe & Dupuis, 2014) and are psychological and social in approach (Hamrer & Orrell, 2008). The value of such activities can foster greater social connections (Roland & Chappell, 2015), and increase confidence and self-esteem (Stevens, 2011). Targeted, or purposeful activities as Boyle et al. (2012) discuss, can have a positive impact on an individual's cognitive function, such as cognitive stimulation therapy, which has been evidenced to reduce depression, improve cognition (Stewart et al., 2017) and improve quality of life (Spector et al., 2003).

### *The School of Education and Communication (VUK)*

Working on the principles of meaningful engagement, a school in Aalborg Municipality, Northern Denmark has developed a programme of activities to provide meaningful and stimulating activities for people with early stage dementia. VUK (Voksenskolen for Undervisning og Kommunikation) provides compensatory special education for adolescents and young adults who have a learning disability. The school works on a person-centred ethos, focusing on the whole person, rather than the individual's diagnosis. In this way, the school states that they consider 'what is possible, instead of the limitations' (VUK, 2015). As part of this ethos, VUK provide lifelong learning for people with dementia (VUK, 2015). Through a unique collaboration between the departments for older people and education, people with dementia can receive part-time education on a range of

subjects, including cognitive stimulation therapy and training, music and art therapy, and woodcraft. Their principles are based on existing theories in dementia, neuropsychology and education (Hilling, 1998; Gardner, 1999, Spector et al., 2003). The aim of this education is to support the student's cognitive function, wellbeing, social and daily living activities, and decision-making. Classes are designed to meet the individual needs of the students with dementia, using a structured format to support memory (Ward, 2015; Thoft, 2017).

People with early stage dementia attend the school as students. In order to attend, they must have a formal diagnosis of dementia. Qualified teachers and health care professionals assess the students throughout their time at the school, this is formally through the Mini Mental State Examination test, and informally through observations. This assessment ensures the students attend classes at their appropriate level and interest. Early evidence from VUK suggests this training can benefit the students, supporting their cognition, decision-making and day-to-day activities. Furthermore, there is evidence that the students can develop and learn new skills (Thoft, 2017; Ward, Sorensen, Kousgaard, Thoft & Parkes, 2018).

#### *Giving voice to experience*

This study evaluates the service delivered by VUK, seen from the perspective of the students with dementia. It allows their voice to be heard by giving the students an opportunity to participate in a collaborative project to explore their experiences of attending VUK. This study was developed from earlier research at VUK, and from the students themselves who wanted to share their experiences of this unique service in order to support other people with dementia. Earlier research includes a project by the teachers at VUK, who tested the impact of lifelong learning for the students (Ward et al., 2018) and on Thoft's (2017) student-led study where the students' voiced the importance of meaningful services and what it means to live with dementia.

There is growing attention to the way researchers involve people with dementia as active participants and collaborators in research (Pratt & Wilkinson, 2003; Mckillop, 2004; Rivett, 2017). To date there has been limited research, which focuses on the experience of the person with dementia, which may be because of the symptoms of dementia and perceived complexities of enabling engagement in research (Hubbard, Downs & Tester, 2003; Dewing 2007; Dupuis, Gillies & Carson, 2012). Research has tended to marginalize the experiences of people with dementia focusing instead on the views of carers either in their own right or as proxy informants (Dupuis, Gillies & Carson, 2012). Newer studies show that people with dementia can make a valuable contribution to research and that they see

participation as a way of making a contribution to family, community and civic life (Tanner, 2012; Dupuis & Gillies, 2014; Littlechild, Tanner & Hall, 2015). The main motivation to participate can be the desire to help others with dementia even though it cannot help themselves (Tanner, 2012). There is also a move to a more user-centered and rights-based approach to dementia research and care (Rehling & Ward, 2014; Rivett, 2017). But there is a gap in understanding the experiences of people with dementia in a variety of areas, including how they adjust to a diagnosis of dementia and an understanding of what is meaningful and helpful for them on a daily basis in order for them to manage their illness and maintain quality of life (Pipon-Young, Lee, Jones & Guss, 2012). This study contributes to knowledge about how attending the classes designed for people with dementia at VUK are experienced from the perspective of existing students with dementia, and how to support participation in research. Furthermore, the paper develops knowledge of a unique service, which aims to provide meaningful activities and support for people with dementia.

One way to engage people with dementia in research can be through creative methods, such as photography and storytelling, which have been used successfully to hear the voice of the person with dementia, to help them become active members of the research and been found to be empowering, helping to develop a sense of identity through participation (Palibroda, Krieg, Murdock & Havelock, 2009; Basting, 2011; Wiersma, 2011). The use of photo-elicitation (Harper, 2002) and photovoice (Wang & Burris, 1997), as methodological techniques, are increasingly being used with people with dementia to support their inclusion in research (Parke, Hunter & Marck, 2015). This approach is regarded as a way of supporting the voice of those who are marginalised and often missing in research (Hodgetts, Chamberlain & Groot, 2011). The use of photography is also suggested as a way of supporting memory and aiding discussions, be these photographs taken by the participants or brought by the researcher, it is an approach which endorses an understanding from the person with dementia's personal experience (Palibroda et al., 2009; Genoe & Dupuis, 2013; Shell, 2014).

This project used the creative methods of photography and storytelling to understand the experiences of the students with dementia attending VUK, developing the knowledge of using these techniques with this cohort. The project aimed to evaluate the service provided by VUK by understanding people with dementia's experiences of being a student at VUK, as they were seen as the experts of the service they attended. The students with dementia were asked to capture, through photography, moments/objects/images, which reflected their experiences of living with dementia and/or being a student at VUK.

## Methods

In order to explore the students' experiences, a creative approach was adopted, using photo-elicitation and storytelling methods (Harper, 2002; Parke et al., 2015; Murphy, Jordan, Hunter, Cooney & Casey, 2015), see Table 2. This approach can be a way to support and prompt involvement, while acknowledging that people with dementia can experience challenges with their memory, attention and concentration (Shell, 2014).

### *Recruitment*

Recruitment took place following successful ethical approval from the Danish Data Protection Agency (Ref: DOK333923). A convenience sample of current students with dementia were recruited, who had been attending VUK on average 2-3 years. All The research project and the four associated creative sessions (see Table 2) were discussed with all the students with dementia attending VUK at that time (n=30), all of whom were provided with an opportunity to participate. An information sheet was provided to support these discussions. Assessments of capacity to participate and provide consent was initially made by the teachers, prior to recruitment, and were ongoing throughout the study, following Dewing's (2007) method of process consent.

The recruitment process was undertaken in the school, an environment in which the students were familiar and comfortable and where they were known to each other. This provided an opportunity for an open and collaborative start to the research process (Thoft, 2017). The inclusion criteria required the students to have a diagnosis of dementia, have capacity to consent (as assessed by the individual, teachers and researchers), and have an interest in research and sharing their experiences about being a student at VUK.

The project was explained to small groups of potential participants (individually or up to four people) and issues of consent to participate were discussed and agreed. Twelve students agreed to take part, however, due to health/personal reasons, two students dropped out prior to the photography stage of the project, leaving 10 participants who took part in the project. There was no further attrition.

Participant demographics are presented in Table 1. Five participants were male and five female, they varied in age, from 67-83, and in their diagnosis of dementia, although 70% had a diagnosis of Alzheimer's disease. Student names have been replaced with pseudonyms (see Table 2).

Insert Table 1

*Methods: Photography and storytelling sessions*

Each participating student was provided with a basic digital camera. Careful consideration was given to the type of camera supplied to ensure that it would be easy to use, without complex and multiple instructions/options/buttons and that it was easy to hold (Rose, 2016; Thoft & Ward, 2016). The taking of the photographs in the school was overseen by the teachers at VUK, who provided instruction to the students on how to use the cameras and assisted the students in taking photographs of the school. A5 laminated instructions on how to use the camera and guidance on taking pictures was attached to each camera.

The researchers briefed the teachers, verbally and with an information sheet, on how to undertake this stage, providing guidance on how to support the participating students in taking photographs during their normal classes/activities, and helping the students to become familiar with the cameras (Evans, Robertson & Candy, 2016). The students were issued with new memory cards in the cameras and took these home, so they could also take photographs of their family/home life. All the photographs were reviewed by the researchers and images were selected and printed in readiness for the four storytelling sessions which followed.

The process of selecting the photographs taken by the students, to use in the discussion sessions, was initially undertaken by the researchers. While photo-elicitation recommends the images are chosen by participants (Rose, 2016), this is not mandatory. This decision was informed by both practical considerations and concerns not to overburden the students, who had taken 381 photographs between them (Jakob & Collier, 2015; Branco, Quental & Ribeiro, 2015). Images were not excluded if they were blurry or under-exposed (Radely, 2011; Photovoice, 2014), rather the choice to include an image was related to the range of activities depicted. Where duplicate images had been taken, only one image was included, for example students had taken multiple photographs of the school's entrance sign. In this instance only one photograph of the sign was used. Images were printed onto A4 paper and no changes or corrections were made. When viewing the photographs, the research team identified that a number of activities and areas of the school had not been captured. During the first session, the participating students made the same assessment and felt the photographs did not capture their full student experience. Three of the students requested to retain their cameras so that they could take further photographs of the school to adequately capture the school's activities. This option was available to all the participating students, however, no one else requested to take additional photographs.

Four weekly storytelling/creative writing sessions were developed and delivered with the participating students, in order to discuss the photographs taken, see Table 2. A process integral to the photo-elicitation approach, whereby meaning of the photographs is explored and experience is exemplified (Banks and Zeitlyn, 2015; Rose, 2016). The students were divided into two groups (Monday and Tuesday group), and sessions were set up to allow the students to discuss the photographs with each other and the researchers. Two groups were chosen to allow everyone a voice in the group, as larger groups can be challenging to participate in for people with dementia (Thoft, 2017). These sessions were delivered over two-hours, during the normal time/day students attend the school. Each session was jointly run by two researchers. A different creative activity was used each week to provide a structure to the sessions. The photographs were used to form the basis of discussions with the students, as inspiration for the creative writing, to support memory and provide added meaning to participant's experiences (Harper, 2002) (see Table 2 for session activity). Different photographs were taken to the sessions, with 12-16 images used each week. Photographs were chosen according to the focus of the session activity with photographs of the school taken to weeks 1 and 2, and family/home life photographs taken to week 3.

Insert Table 2

A visual methods approach guided the discussions, using open-ended questions to prompt discussions, such as 'what do you think of the pictures', 'what do they mean to you' (Wang, 1999; Wiersma, 2011). Questions were formulated to focus on emotional and personal experiences (Stevens, 2011), rather than on memory.

The sessions were video recorded by two cameras and audio recorded, with permission from all participants. This provided a total of 16 hours of video and audio-recorded data (two groups, each with 8 hours data). This allowed the researcher to capture both verbal and non-verbal signals from the students within the sessions (Ridder, 2007). Furthermore, data was captured from the photographs taken by the students and researchers (n=143 of the school; n=238 of family/home life), and from the creative methods used in the sessions (n=2 poems; n=2 storyboards, n=2 storybooks).

### *Data analysis*

The findings from this study were derived from the transcripts of the video recordings. The video recordings were uploaded to Nvivo v.10, where a full translation was undertaken into English. This was conducted by the researchers from Denmark and England. Thematic

analysis was undertaken on the English transcripts using Braun and Clarke's (2006) six stages of analysis. This involved using an inductive process of analysis. The transcripts were read by each researcher for familiarity and from this patterns and codes were identified both within each session transcript and across the sessions. Broader themes were then drawn from this initial analysis and a written report developed.

## **Findings**

The project aimed to explore what it means to be a student at VUK, and the data was analysed drawing on the students' experience of being a student as identified in the storytelling workshops. HERE you could move the above section on how you did this then this would flow into the emergent themes NEXT. Emergent themes focused on school activities, knowledge and skills, the value of friendship, and what it means to live with dementia. An important findings included the way that creative methods could be used to support participation in research, enabling the students to tell their stories through the visual. These initial findings are discussed alongside the themes on the student experience.

### *Varied and supported classes*

The students described the variety of classes they attend at VUK, and of the structured approach to their day. Cognitive training classes form the majority of the day, and start with reading a local newspaper: reading articles; horoscopes (which helped the students to recall their birthday); the weather; and television programmes. These classes are designed to support student's memory and cognition, maintain interest in the local and national news and form opinions about current events. The morning session ended with a group song, chosen by one of the students from a list of traditional Danish songs and students often debate one of the news articles, to consider different aspects of the story and end the class by voting on a topic.

*And after we have read the articles then we talk about the day, these things we have seen and heard on the radio and TV and so on... (Johan)*

Cognitive classes continue with individual work, working in pairs or small groups to do puzzles, games, life story work etc. This can include the use of the computer, iPad or materials developed by the teachers. These materials include tasks to match the main cities to the map of Denmark, or the pictures of animals to the correct name.

*This reminds us of a game we play where we have to match the area with the city names (Kurt)*

The students discussed the structured process of the classes, how these support their learning, enhance meaning, and ensure successful completion of any tasks. The students reflected that attending the school could be challenging, but expressed satisfaction about being able to complete tasks, as Emma says it is a 'relief when the task succeed[s]'. The importance of challenge and success in delivering meaningful activities is highlighted by the students who found pride in their achievements.

Students discussed the music therapy classes, which many students attend, enjoying learning about composers, playing instruments and singing. Helena talked about the value of attending these, saying of singing that it is 'life and joy' and that 'the music stays with you when you go home and it can make you happy to sing'. The connection with music was an important aspect of the school experience, and was brought into several of the storytelling sessions where the students, on their own initiative, would start to sing. Singing was something to be enjoyed and was a way to bond members of the group. Even for those who did not join in the singing, it created a discussion point, for example leading to reminiscences about singing at home, and the cultural significance of music in Danish life.

Students also discussed the woodwork class, saying it had a 'cosy' atmosphere and a 'workplace humour'. The woodwork classroom is well equipped, see Image 1, enabling students to make a variety of objects including birdhouses, chopping boards, rolling pins, and restoring wooden benches at the school. There was a more masculine atmosphere with the woodwork classes and although women are welcomed, it tends to be the male students who chose to attend these classes. As with the music class, the woodwork class provides a creative outlet, and a space for personal expression, enjoyment, and to give back to the wider school community, e.g. renovating the school benches.

Insert Image 1

When discussing the benefits of attending VUK more generally, Emma realised that by being at VUK, there were no limits to what she or the other students could do. VUK provide opportunities to engage in a number of activities, and Emma's belief was supported by Johan and Kurt discussing how they had helped the teachers to develop computer and history classes following requests from the students. . Emma's comment (below) suggests that their experiences at the school were versatile and stimulating, with opportunities to engage in classes which were of interest and which enabled them to reach beyond normal expectations.



*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! (Emma)*

#### *Developing knowledge and skills through challenge and success*

Discussion of the practical nature of the classes developed into exploration of what the students learned and how they felt the classes were supporting their skills and knowledge. The photo-elicitation method, through their choice of photographs, supported the students to direct the course of the research discussion. One photograph prompted a discussion exploring how they, as students with dementia, fitted into the ethos of VUK. The photograph depicted a school bus with a slogan 'spring ud i livet' which translates as 'run into life' or as the students suggested, 'jump into life' (see Image 2). This generated a conversation about the challenges students face coming to VUK and of not knowing what each day will bring, but of wanting to meet the challenge ahead. The slogan was thought to represent the activities the younger students might do at the school, such as paragliding – as represented in the silhouetted image on the bus. However, the students with dementia saw the relevance to their experience through the meeting of and succeeding in challenges when participating in the school activities.

Insert Image 2

Another example of how the photographs acted as prompts to support the student's memory, as well as being springboards for individual and group discussions, was an image of a bookcase of games, situated in the classroom (see Image 3). This image started a discussion about being assessed and the importance of success. Kurt explained the students had participated in various tests, one of which involved completing a nine-piece jigsaw puzzle. This test was repeated and the times recorded by a teacher (Ward et al., 2018). Kurt proudly revealed that he had developed a strategy to complete the puzzle by first placing the corner pieces, leaving only five pieces to place, which made the challenge manageable. He reported that his time improved over the testing period, from over to under one minute.

Another student, Gudrun, added that the puzzle task had taken place over several weeks with different puzzles, suggesting that Kurt's strategy was not just learned for one puzzle but was adapted for different puzzles. Here Kurt evidences a learned strategy, which he implemented into a novel situation, transferring his knowledge from the completion of one

puzzle to another. Gudrun suggested this was related to practice – ‘practice does master’, saying that they ‘got faster and faster’ at the task. This not only exemplifies the skills the student’s gain from being a student but also the sense of accomplishment, enjoyment and pride they take from engaging in tasks that may be complicated, but with practice and support, they can ‘master’ and succeed in completing. This also illustrates the ethos of the school and how they create opportunities for lifelong learning with people with dementia.

Insert Image 3

Although classes were considered challenging and required attention and concentration, students benefited through re-learning things that they had forgotten. This was experienced as helpful and constructive. Theresa highlights the dual nature of being at the school, that it offers opportunities to re-engage with skills and knowledge that may have been forgotten, but that it does so in an environment of support and friendship with the other students.

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

Theresa’s comment was supported by other students who felt that their knowledge was being ‘renewed and refreshed’, that being at the school was about having ‘positive learning’ and that it helped to ‘keep the thoughts going, gives new energy’. This learning could be challenging, as discussed, but this was welcomed as the students felt they were using their brains in a way that supported their cognitive function, helping to maintain current skills and knowledge and develop new skills.

*We get some input, we get some introduction so we can talk about and use the brain and say if there is something we know about. I feel myself that I get myself confirmed in many ways (Helena)*

*To have friends who understand*

The students spoke of the positive relationships they have with each other the importance of being with ‘likeminded people’ with similar experiences and knowledge of what it means to live with dementia, describing the experience as ‘positive and rewarding’. A key aspect of being at VUK was therefore being with the other students and the special friendships they formed at the school. During the sessions, it was observed that students had a good camaraderie with each other, were seen to laugh and joke together and support each other.

*I would say that it is special friends you have here and that way I have something special with you, something in common with you that I do not have with others.  
(Theresa)*

In the second session, the students were asked to create a storyboard of a typical day at VUK, choosing photographs which represented different aspects of their day to discuss. A photograph depicting an educational banner from Aalborg municipality, with the title 'Alle hare en ven i skolen', translated as 'All have a friend at school', was chosen. From this image, the students created an explanation of what friendship meant to them:

*We understand each other.*

*We are each other's friends.*

*There is also a friendship with the girls!*

*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 (Tuesday group)*

All five members of the session contributed to this multi-layered understanding of friendship, depicting friendship as talking together and being there for each other. Their understanding is nuanced, drawing out how to behave with others, referencing the need for patience, not only as one person to another but in being patient with each other's dementia. Students felt safe in each other's company and were not worried about making mistakes or behaving differently. For instance, waiting while another student tried to recall a word, or showing interest when they heard a story for a second time. Furthermore, they understood the different levels of friendship, those they have with each other and those they have with teachers. Bent commented that they do not have support teachers in the classrooms and Theresa replied saying that 'we are all support teachers, everyone', meaning that they help and support each other and that this is an important part of their experience of being students at VUK. Finally, Katherine talks of the different ways we express our friendships and that personality is central to our experience of friendship and how we engage with others.

*Awareness of the living with dementia*

During the sessions, it became obvious that the students experienced challenges when living with dementia. These were especially related to their cognitive function, memory and language problems. Students found it difficult to recall words or details of their past/current lives, for example the age of a daughter. The students dealt with their dementia in a very open and honest way, showing their frustrations in different ways, for example with anger at not being able to recall a word, or by finding other ways to explain what they meant. There was recognition of the impact of their dementia and they would comment that they would say something more, 'if we can remember'. As Kurt stated, 'that is what we have trouble with, remembering'. VUK seemed to enable this open dialogue by being a safe place for people with dementia where they benefit from being with likeminded friends. The methodology in the study likewise made it possible to address complex and sensitive topics, such as living with dementia, as it allowed the participants to share their thoughts and experiences without restrictions from the researchers and in a way that focused on the photographs or the creative medium rather than directly with the individual.

Humour was also used as a way to cope with their frustration, acting as a way to deflect a question, ease tension or mask when a word could not be recalled. One student had a habit of touching her head and saying 'it's all in the kidneys!', while another student would say that we (the group) can just take a fight over an issue – 'And we have not been fighting yet'. These were said with a smile and a laugh and acted as a way to reduce feelings of stress or uncertainty when not knowing how to respond to a question or to how to take part in the group discussions.

The students also shared insights into what it meant to live with dementia. Johan talked of the sense of 'misplaced protection' that many health/social care professionals and family members have following a diagnosis and how this can result in fewer opportunities to engage in activities for the person with dementia. Johan explained that the longer you do not leave the house, the harder it can be to do so. Here VUK is seen as an opportunity to get contact with the outside world, being a doorway to the wider society. Students have to attend in person, so taking them out of their houses, giving purpose and meaning to daily life, which often is not present with a diagnosis of dementia, as Johan experienced. Johan expresses the importance of not being isolated at home, consequentially it becomes harder to get out. His use of metaphor to explain the feelings of fear and challenge to engage with the outside world is poignant and expressive.

*It can also be a challenge just to come here and get out of the door, the doorstep can get higher and higher to get over ... if you don't get out much (Johan)*

Johan explains that it is important to engage with other people, so that you are not constrained and can feel a part of society. Attending VUK is, therefore, an important part of engaging in the wider society as it offers the opportunity to meet other people, maintain and learn new skills, stay connected to current events, and gives a reason to get out of the house.

## **Discussion**

Until fairly recently, the narrative of dementia research has been more commonly conveyed from the perspective of the caregiver, rather than the person with dementia (Beard, 2012). While this is gradually changing, Rivett (2017) argues there should be greater focus on supporting people with a diagnosis to engage in research by using methods which enable them to contribute to the growing knowledge base about dementia from their unique perspective.

Over the past decade in the UK, there has been a growing culture of involving the 'voices' of people with dementia and their carers in policy developments and initiatives (National Dementia Declaration, 2018; DoH, 2015) which appears to be encouraging more researchers to contemplate involving people with dementia in research (Hubbard, Downs & Tester, 2003; Pratt & Wilkinson, 2003; Mckillop, 2004; Dewing, 2007; Dupuis, Gillies & Carson, 2012; Rivett, 2017). In April 2017, over 80 people with dementia and carers, through 15 different groups were involved in the review of the National Dementia Declaration 2010 (DAA, 2012). A major outcome of this review was the revision of the nine 'I' statements to five 'We statements', heralding a significant shift in thinking. These new dementia statements encapsulate what is important for people with dementia and their carers. They state that they want to be seen for who they are and not defined by their diagnosis; able to maintain normal day-to-day living and remain socially connected; respected and valued as equal partners in care; and supported to actively participate in research. People with dementia no longer just want to know about and contribute to research (DoH, 2015) they want to actively participate (DAA, 2017) and should be empowered to do so if they wish to be involved (Nuffield Council of Bioethics, 2009).

In order to support people with dementia to be active in research, consideration must be given as to how best to do this. Involving people with dementia in research brings its challenges, particularly as people can experience difficulties with memory and language, as illustrated by this study; but given the right amount of support and the correct tools, such as photo-elicitation and storytelling, all students involved in the project have been able to actively contribute to the evaluation of the school as well as sharing their daily experiences of living with dementia. The VUK study shows that using photographs and

creative methods can provide a unique insight into life with dementia, as seen from the perspective of those living with the condition.

This study also highlights the importance of providing services which people with dementia experience as joyful, rewarding, and meaningful; and which support opportunities to develop trusting and supporting friendships with like-minded people. It reinforces the findings from previous studies which highlight the benefits of meaningful engagement in activities, which have been specifically designed for people with early stage dementia (Spector et al., 2003; Woods, Aguirre, Spector & Orrell, 2012), albeit in this case, in a school which has a core philosophy of lifelong learning.

Besides offering a stimulating and interesting learning environment, VUK have created a space and context where it was possible for people with early stage dementia to meet people and develop new friendships. This is a very important part of attending the school, indicating it is not enough just to provide services which focus on creative activities and cognitive stimulation. It is important to create a positive and safe environment where people with dementia are supported in developing constructive friendships with other people who share the same experience. Very often people with dementia can experience challenges with socialising with friends and family, as they no longer feel part of an equal relationship (Clare & Woods, 2008; Wawrziczny, Antonie, Ducharme, Kergoat & Pasquier, 2014; Thoft, 2017), becoming increasingly isolated (Tanner, 2012; Swane, 2014; Thoft, 2017). At VUK, the students experience opportunities to relax and enjoy the company of people who understand their situation.

The study has also highlighted how people with dementia can often use humour as an accepted coping mechanism. It can help to create a relaxed atmosphere during classes, where students feel comfortable being able to make mistakes without the fear of judgment. This may be in contrast to when they are with family, friends, and professionals when they can feel they are frequently being corrected for making mistakes or their diminishing competencies are constantly being highlighted. Such experiences can leave them experiencing poor quality of life and low self-esteem (Clare & Woods, 2008; Tanner, 2012). The findings from this study therefore suggest that more opportunities need to be created for people with dementia to engage in activities which promote positive social engagement.

The students at VUK appreciated the opportunity to attend the school, even though they occasionally found it challenging. VUK strongly promotes that people with dementia can be given challenging tasks to complete as long as there is tailored support and a successful

outcome. The role of supported success ensures the students experience positive and meaningful learning. People with dementia want to be involved in meaningful activities, which can positively impact on their quality of life, sense of wellbeing, and can improve confidence and social engagement (Richeson, Boyne & Brady, 2007; Pison-Young et al., 2012; Roland & Chappell, 2015; Thoft, 2017). These findings are congruent with similar studies which found improvements in quality of life, memory and decision making after engaging in meaningful activities (Spector et al., 2003; Woods, Aguirre, Spector & Orrell, 2012; Genoe & Dupuis, 2014; Travers et al., 2015), and which are a source of enjoyment and foster friendships (Stewart et al., 2017). What VUK offers is a tailored service which provides an opportunity for lifelong learning, in an educational setting, engaging in activities which test and challenge, but ultimately provide benefits for the students. The uniqueness of VUK lies in both the experience of being a person not defined by dementia, but a student who attends a school to engage in lifelong learning, which is offered over several years, not just weeks. It is an environment that the students have evaluated as being joyful, rewarding, challenging, but ultimately beneficial for them.

## **Conclusions**

The students reported value in attending VUK and engaging in lifelong learning. It was important to them to engage cognitively and socially. Engaging in cognitive activities has helped to maintain their skills and knowledge, although the impact of dementia is evidenced through their loss of memory and grappling to find the right word. Moreover, the school enables the formation of new friendships with people who also have dementia. This provides a level of understanding and support, which they do not necessarily experience with other friends and family at home.

According to the students in this study, attending VUK means: to be challenged; to engage in personal growth; to succeed; and to find new friendships. The activities the school offer may not be unique in themselves, being based on existing theories, however, it is perhaps the way that these activities are presented and by whom which is unique. This is done in a natural educational setting with qualified teachers and health care professionals whose ethos is one of tailored support and learning, over a long period of time and as such offers a new way of working with people with dementia.

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