Using Lifelogging to Help Construct the Identity of People with Dementia

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ABSTRACT

While there is much interest and work around the topic of how technology shapes our lives, there is less work around how technology can record our lives and how we can use that recording to remember, in cases when our own memories fail. Our work explores the incorporation of lifelogging technology into a therapeutic approach to support people with dementia. SenseCam therapy aims to stimulate the cognition of a person with dementia, with maintenance of their personal identity as its primary goal. SenseCam images are used as cues to meaningful discussions about the person's recent memories, thus constructing a particular version of the participant's identity during the therapy sessions. The constructed identity was enriched by uncensored details from the day-to-day life of the SenseCam wearer and hugely influenced by the content of SenseCam images. This reflects how the identity of people with dementia transforms but continues despite the disease progression, thus illustrating how technology goes beyond just shaping the wearers' lives. This paper reports details of three case studies carried out as part of a qualitative study exploring the potential of lifelogging technology in supporting health care professionals and relatives to develop a more holistic version of the identity of people with dementia than during other therapies.

Author Keywords

SenseCam; Dementia; Identity; Lifelogging

ACM Classification Keywords

J.4, K.4.1, K.4.2

General Terms

Human Factors; Design

INTRODUCTION

It is difficult to think of an aspect of our lives, which is not now shaped by technology. Our communications, entertainment, education, healthcare, transport, even our art and culture are all increasingly availing of rapid developments in technology. There are still portions of populations to whom technology may not be as easily accessible including the elderly. Nevertheless, they are still surrounded by advances of the digital world. Deeply embedded in this inexorable embracing of technology that we are all part of, is the question of who we are, what is our identity, how can we control or even manage our own identities and what now defines our identities in this modern world. Nowadays much of our communications are not face-to-face but based on email, teleconferencing, or phone, many of our social interactions happen online with people we may rarely see, and much of the footprint we leave behind us, our digital estate, is created, captured and stored using technology. In such a world, what actually defines us and our identity is an almost philosophical point of discussion.

One of the things that technology is starting to do for us is to help us to get more access to our own identities. We can use various technologies to capture what we do, say, and present to others, and we can then look at that ourselves and see what others think of us. Lifelogging is an emerging phenomenon of recording ourselves digitally, for our own uses, much of which involves us interacting with our own identities.

We work with a special case of lifelogging, or perhaps an extreme example, where we help in shaping personal identity for people with dementia. While we can all use technology to get more access to our identity, for people with dementia or their carers lifelogging is a way of enriching the care relationship. The paper reports a study about how lifelogging can be used to shape identity, and literally not just to represent it but co-construct a strict new identity.

Dementia is an umbrella term for many different diseases, all of which have similar symptoms, but different aetiologies. The symptoms include a serious loss of cognitive abilities including: impairment in short term and episodic memory of recent events; deficiency in language skills due to decreased verbal fluency; and damage to the

visuospatial abilities. All impairments are beyond that which might be expected from normal aging affecting social activities, relationships or employment [1].

However, the most debilitating effect of dementia is diminishing identity, which usually occurs simultaneous with the disease progression [12]. Every person's identity is constructed based on their memory resources, their language and their social interactions with others, all of which are impaired even early on in dementia. The nature of identity and its relation to memory date back to the 18th century when Locke [9] described the memory theory of personal identity. According to Locke the present self is only the same as the self of the past if the present self remembers the events of the past self.

"As far as this consciousness can be extended backwards to any past or action or thought, so far reaches the identity of that person; it is the same self now it was then" [9].

In other words, a person's identity is composed of the accessible past memories and a person who has no memories of their past thus has no identity. The notion that identity has foundations in episodic memories has been supported by other research [2, 12]. Post [15] also states that the only way a person can experience a "full self-identity" is when their memory is intact so that it connects the past and the present together.

The life narratives that we use in everyday storytelling and which are created by the use of language in communication are also viewed as foundations to the persons' identity [11]. Communication is a process of social interaction through which people make sense of themselves and of the world around them [8]. Thus, life narratives as representations of one's identity, cannot be discussed independently to memories and social interactions. Memory is essential to the ability to relate with others through communication about one's past [7]. Equally the ability to communicate is necessary to making sense of the reality by constructing narratives about one's memories [13]. This connotes that the combination of memory, narrative and social interaction is essential to individuals forming, reliving and creating meaning of their life experiences and to maintaining their identity [16]. Accordingly, maintaining the sense of identity by a person with dementia will be challenging as the disease impairs memory, communication and social interaction. This result in an inability to relive, form and share their life narratives, thus leading to identity loss in dementia, which is the problem we address.

Given that identity may be one of the early casualties of cognitive decline, we carried out a study, the focus of which was to explore an intervention aimed to provide resources for the person with dementia, which can be used in forming memories, in communication with others and in social interaction, with maintenance of the person's identity as the overarching goal.

Alike many other aspects of our lives, healthcare interventions are influenced by current developments in

technology. The practice of lifelogging, which is automatic and ambient digital capture of life experiences typically through mobile sensors or wearable devices, is one way the technology can be incorporated into memory interventions for people with dementia. Lifelogging results in personal, recent and meaningful prompts from our past, encouraging sharing of personal memories [5]. The lifelogging devices are usually wearable and the data capture happens automatically and ambiently in the background without requiring any action on the part of the wearer.

The device of particular interest to our research is the SenseCam. This is a small camera plus a number of other, simple sensors, worn around the neck by the use of lanyard at chest level and facing forward. It does not have a viewfinder and automatically captures images every 30 seconds, resulting in thousands of recorded images per day, each taken from a first person viewpoint, i.e. the images never include the wearer but capture the wearer's view of the world in front of them.

The potential of SenseCam technology as an aid to memory problems faced by people with dementia is increasingly being recognized [3]. Previous research reported many memory-related benefits showing that SenseCam images can act as effective cues to recall of episodic memory, as well as improving recall of an event reviewed using the SenseCam images [3]. Earlier research also suggested that SenseCam images mimic episodic memory in being: personal and meaningful to the individual; of recent past, captured from the first person's point of view, captured automatically without requiring mindful awareness [5].

However, there is limited reported research on using SenseCam directly to help maintain the identity of people with dementia. Massimi *et al.*, [10] used SenseCam images alongside music, narratives and movies to build ambient biographical displays aimed to improve quality of life for persons with dementia, including enhancing their sense of identity. The findings were positive, implying an improved sense of identity after using the display [10].

SENSECAM THERAPY

For the purpose of this study SenseCam was used within a therapeutic framework named "SenseCam therapy". The therapy involved the participants wearing SenseCam to collect images of events from their everyday lives and reviewing them with trained therapist. The therapist was a psychologist trained in dementia specific therapies including the well-known Cognitive Stimulation Therapy (CST). The main aim of the therapy was to stimulate the cognition of people with dementia in an implicit way. The therapist explored whether SenseCam images can cue the person's recent memories and encourages meaningful discussions about themselves during therapy sessions. This in turn, had an anticipated effect of supporting the construction of their identity, for people with dementia.

The SenseCam therapy adopted some aspects of CST framework, including the ground rules stating the focus should be on on opinion based discussions rather than

factual prompting. Moreover ensuring respect and inclusion of people with dementia and their beliefs and encouragement of implicit learning. The CST format of 14 sessions running over a seven-week period was also adopted for the delivery of SenseCam therapy [17]. For the period of these seven weeks, participants in our study each wore SenseCam every day while they went about their everyday life. Participants, who each had some form of dementia, decided with the help of their carers when they wished to wear the SenseCam and under what social conditions (e.g. when alone at home, during leisure-time activities, when socializing with others, etc.). Participants were also made aware of a privacy button on the camera allowing them to switch the SenseCam off at any time they wish.

The therapist who coordinated the study visited the wearers at pre-arranged appointments twice a week, for 45 minutes each time. During this time the therapist reviewed the images and engaged the participant in discussions about the images using software, which automatically structures the thousands of SenseCam images, captured each day, into discrete "events". The event-based browsing software developed in the CLARITY centre [6], allows huge amounts of SenseCam data to be navigated easily. The images were not reviewed prior to the sessions in order to ensure they were representative of recent events. The participants were encouraged to self-select images they wished to review from the events organised by calendar dates.

The participant, the carer and the therapist kept a journal each reflecting on observations throughout all sessions during the seven-week period. The therapist observed the participant engaging in the therapy, noting reflections in the journal regarding the process of administration, enjoyment and reflections on the construction of the person's identity.

METHOD

This research was conducted in an exploratory and descriptive approach using the multiple case study method. The case study is a method of empirical inquiry that enables investigation of a phenomenon within its own real life context [18]. Three individual case studies were conducted to collect in-depth data about the complex issue of SenseCam use as means to help in the construction of the identity of people with dementia thus exploring how technology can do more than just shape our lives, it can record it so we can remember it and thus help to define ourselves.

John, David and Dolores were the participants of the three cases. John was an 87-year-old frail man with a diagnosis of early stage Alzheimer's disease. He lived with his wife Mary who occasionally took part in the therapy sessions. David was a 57-year-old man with an early onset dementia following a myocardial infarction. Patricia – his wife sporadically participated in the therapy sessions. Dolores was an 87-year-old woman with a diagnosis of early stage

vascular dementia. She lived independently and coped with her memory impairments by using a written diary.

The case study methodology enabled collection and analysis of both qualitative and quantitative data. The qualitative data included medical and social history, collected during an audio recorded semi structured interview with the carer and the person with dementia before and after the course of the therapy and journals kept individually by the therapist, the carer and the person with dementia reflecting on observations throughout the sessions from the perspective of their author. The detailed field notes collected by the therapist reflecting on the processes of the therapy, type of discussions and interactions that took place. The content of the images was not considered as data informing the study, thus it was not analysed independently. However, the discussion matter cued by the images formed the data collected and analysed for the purpose of this study. Quantitative data included responses to psychometric measures on cognition, quality of life, depression, communication and anxiety collected before and after the therapy course. Non-parametric tests of repeated measures were used on the quantitative data with no significant differences recorded.

The data were analysed by placing the quantitative results in arrays with the qualitative data, which were grouped chronologically and thematically. Three individual case study reports were completed based on individual case study analysis. They provided clear and in-depth descriptions of the person, their context and the processes and their responses to SenseCam therapy. The data was further combined and recombined in several different ways across the three cases in order to get a thorough understanding of the nuances and the different points of view in each case. This process is known as cross case analysis. Taken together, the cases were instrumental to acquiring an understanding of how SenseCam therapy enabled the construction of a version of participant's identity.

CONSTRUCTING SENSECAM IDENTITY

Through the delivery of the therapy, a particular version of each of the three the participant's identity was created. This version was constructed by discussing SenseCam images of the participant's recent past within social interactions, directly with the therapist. The content of the images guided the discussions to be both recent and unveiling of different aspects of the participant's lives. This led the therapist to appreciate a more holistic version of the participants' identity than a version that may have been revealed without the use of prompts derived from SenseCam images. Thus, we named this version a "SenseCam identity". The SenseCam version is not the ultimate identity of people with dementia as predominantly it was created and enriched by the triggers derived from the content of SenseCam images. Additionally it was also confined to the timeframe within participants' lives during which the images were captured, and the narratives shared within the interactions

with the therapist. Thus the perceived identity could have been different depending on the means and processes used to unveil it. The process by which the content of SenseCam images guided the construction of SenseCam identity is divided by two main patterns discussed below.

1. Discussing current identity as influenced by recentness of images

Firstly, recent content captured by SenseCam images guided the construction of the participant's identity to include aspects of their current life. The images reviewed, presented events from the preceding days of participant' lives, which mainly consisted of mundane details of daily routines. Thus, the narratives shared with the therapist during the therapy sessions were based on these recent memories about everyday life as cued by recollections from the images. This was unusual when compared to the narratives produced in the before-therapy interview, which predominantly consisted of details from distant rather than from recent past. The narratives collected during the beforetherapy interview, offered each participant a freedom of choice with regard to what details about their lives and identities they wanted to share. Typically the details they discussed concerned their distant past where they exemplified themselves by their achievements, occupation roles, enjoyments and fruitful stages of their life.

In the case of John, during his before- and after-therapy narratives, he described his love for travelling, his life career in accountancy and his love of sports.

"...I've travelled and seen around the world and when I think of it and I lived in J in Cape Town in South Africa I have been working for a company and ehm I lived in New York and ehm another famous city San Francisco... and ehm played golf and tennis and some rugby and ehm been keen on sport really..."

Without the cues from SenseCam images, John described himself as having been a very active man with love for international travel. The narratives cued by SenseCam images showed how this identity continued, but also transformed over the years. They portrayed a slightly different, more sedentary view of John. They showed John still enjoyed a lot of outings however these were now narrowed to the city he lived in. His love of sport was also represented in John viewing it on television or by an occasional game of golf.

Similarly, in his before-therapy narrative David focused on his love of wildlife, his various occupation roles and in general presented himself as a hardworking man.

"then I went to work I went to X and got a job in X for a few weeks and then I got out of that and I worked for a landscape gardener we used to do the maintenance of a lot of the hotels and we used to we had a contract in the airport and an awful lot of banks in Z like used to maintain all that stuff" Both the cues from the SenseCam images coupled with his wife's encouragement, helped David to discuss more recent details about his life, which, in turn conveyed a more complete picture of his identity and not just of his past. The narratives shared during the sessions showed that while he was no longer employed or had the ability to work on complex projects, he maintained other important but less demanding aspects of his identity. They included his passion for wildlife and healthy diet as displayed by seemingly endless SenseCam images from various nature trips and wholesome food dishes he would prepare and eat.

Yet again, Dolores narrated her life story in a beautiful manner giving the impression it was a very well rehearsed story. She concentrated on the years she spent in college and in training, which seems to have consisted of a vibrant social life. A major part of her narrative was also devoted to her occupation, and to her children. There was little focus on the present except for a statement at the end saying she is happy where she is.

"There was plenty of work and ehm I came back to X and worked all around the different hospitals and doing locums here and there"

"Great life it was in C they were all bachelors ... and they'd all go to the river and we'd do the sandwiches and the lunch and the thing for the meal and we'd take it out with us and we'd do that every week"

"I'm very happy here and I'm going to stay and that's where I am up to this day"

The discussions cued by SenseCam images portrayed Dolores' life as more relaxed, with her no longer working or having as exciting a social life as in the past. Nonetheless, the narratives shared during the sessions also revealed she sustained some aspects of her identity including her passion for knowledge represented by the great amount of time she still devoted to reading and writing.

Other aspects of identity continued but altered over time including replacing her professional occupation with voluntary work overseas.

Collected, these narratives enabled the therapist to perceive a more holistic version of participants' identity. In other approaches and interventions like reminiscence or life story, little attention is given to recent events, which in turn results in creation of a particular version of participant's identity from the past, very different to the one constructed within SenseCam therapy sessions. The narratives shared with the therapist as cued by SenseCam images, enriched the identity, which had been presented in the before-therapy interviews and revealed how it continued and transformed through the participants' lives.

2. Discussing unexpected details of participants' identity as exposed by SenseCam images.

The second manner in which the content of SenseCam images guided the construction of participants' identity was

when the technology didn't just shape our lives but also exposed unforeseen details of the participant's lives. The participants had full control of when they wore the device as they were advised to wear SenseCam only at times during which they were comfortable with what the camera might capture. However, even within the controlled periods of wear, at times the type of content SenseCam had captured was unexpected and surprising even to the participants themselves. The controlled wearing provided ethically safe boundaries ensuring private or intimate moments weren't captured. Yet, the power over the content of the images was still limited, due to the passive and automatic manner in which the camera captured the images. The SenseCam images exposed uncensored contents from the participants' recent pasts which differed significantly to the content normally presented in standard staged or posed photographs they might have been used to.

Furthermore, it seemed that if the participants had a chance to select the content captured by SenseCam images these unexpected details might have been excluded. However, using SenseCam within a therapeutic approach enabled an intimate but temporary partnership to be formed between the person with dementia and the therapist that allowed conversation of events that under normal interview circumstance may have been considered undesirable for discussion. Thus, it is assumed the particular version of identity constructed during the sessions is distinctive and unique to SenseCam images and trusting interactions as compared to depiction of one's identity during a standard interview or even via the use of common posed photographs.

For John and David these unexpected revelations included capturing and discussing certain practices that seemed to be considered as undesirable by their carers. John accurately recognised wine glasses in the images and commented on them with joy, despite having trouble recognising most other objects captured in the images. It was also observed that anytime John did mention wine, his wife tried to justify why he has done so. It seemed that at first she was a little self-conscious by John's positive reaction to wine being displayed in the images.

"...we must have been having some vino"

For David, this exposure consisted of SenseCam images capturing previously unmentioned David's pipe-smoking. In both cases the exposures were handled carefully and ethically and treated in a non-judgemental manner. The participants seemed at ease and comfortable discussing these revelations, despite their disclosure being so unforeseen. In the case of David and Patricia, they were even able to find humour in it. Mary opened up about some issues related to alcohol use in dementia, which highlighted this was a sensitive issue for them and may not have been discussed without the exposure which arose through SenseCam image review.

In the case of Dolores, there weren't as many particulars revealed by SenseCam that she may not have chosen to

discuss as one of her identity components. This was due to her being very selective about SenseCam wear. However, a strong theme about her came through when reviewing the images that may not otherwise have become evident. There were many images of Dolores' reflection in the mirrors throughout the images. Initially Dolores ignored them but as the therapy progressed and a friendly relationship was built up, she commented on them.

"oh yes that's me doing my make up, I always do my make up in the mirror in the room"

"I was probably checking how visible the thing (SenseCam) was, and it's not noticeable at all"

Without the use of SenseCam images, it is possible these details would never have been revealed during a standard interview or by using generic images. The content of the images unveiled some uncensored details that may have never been freely chosen as identity components. This further differentiates the version of identity constructed during the therapy sessions and displays how it was dependent on the content of SenseCam images. This SenseCam identity seemed more holistic and freed from the limits one may impose on their identity by the unforeseen content of images. This highlights the potential of SenseCam use as a tool to support construction of a current and more exposed version of the identity of a person with dementia.

While the SenseCam images guided the construction of a more holistic version of the participants' identity as perceived by the therapist, the people with dementia themselves didn't seem to fully associate with this version. In all three cases the participants seemed to have a stronger association only with the identity from their distant past, for example with that of their main occupation in earlier life. This varying perception of person's identity between the therapist and the person themselves is in line with the constructivism objection to the universal version of truth, and acceptance that truth is merely a subjective view, a more or less coherent way of understanding things as dependent on individual interpretations.

The participants' association with distant past was apparent through direct references to aspects of their past identity and indirect displeasure in certain more up-to-date aspects captured by SenseCam images. John often seemed a little confused by the SenseCam images, however it is difficult to argue this was due to him dissociating with his current identity. John's episodic memory of recent events was so severely impaired he had very little insight to his current life. Although, in the perception of people in John's life the recent events continued to create a version of John's identity, they had little impact on John's awareness of this current version. John mainly associated himself with his identity of the past. There were occasions when John recognised the images and had the understanding they were of his recent past, but he purposefully avoided discussing them by distracting the therapist with other items in his house. These avoided images often included sedentary

behaviour like watching television. John often remarked that they were very uninteresting and used items like the world atlas as distraction and hint to discuss his history of his travels from his distant past.

In the case of David the idea of associating with distant identity was called upon by his wife and carer more often than by David himself. This could be due to David's denial about memory problems. Patricia, his wife and his carer often referred to David in conversation as "The way David used to be" "Before this all [David's diagnosis] started". Additionally when asked if SenseCam portrayed a version of David's identity to the therapist, Patricia answered that it did but only partly. When probed further she explained:

"well I suppose she would have picked up that he's not out he's not in big crowds or he's quite alone he's quite a reserved guy compared to before but he is very calm he's very quiet and he's a very gentle person ... I hope she picked up his whole love of nature that's all really and lots of quietness..."

The idea of SenseCam portraying Dolores's identity was explored directly with her, initially by asking if there was anything in her life that helped her or re-enforced her identity. After giving it some thought she answered, saying that when she looks at photographs she had collected over the years they remind her of all different stages of her life and of who she became. Dolores was then asked if the SenseCam images represent her identity in a similar way to her collection of personal images. She revealed that the SenseCam images portray a different part of her – which is only the present one. She reflected that her identity is represented more accurately by the collection of photographs from her life. She further stated that SenseCam images represent what she does now as oppose to who she is as a whole. She also revealed that viewing SenseCam images alone without the interaction and discussions about her present and past doesn't hold as much meaning.

"They are different in that they show more of what I do now as opposed to what I have worked hard to achieve/become... they make me realize that I am a lot less active and I don't do as much volunteering or walk that much anymore ... I don't get up that early as I feel tired then whereas I used to be up very early"

Similarly as in the case of John, it was also observed that Dolores showed reluctance reviewing images of sedentary behaviours. Frequently she remarked about the time she wasted during any activity she thought of as insignificant. For example if the images showing her eating her breakfast were reviewed for too long she would comment: "Am I still at it?"

These observations suggest that participants associate with their past identity. They also appear displeased by certain aspects of the more current version of their own identity, being classed as elderly, inactive or with memory impairments. It is important to be aware that differing versions of identity can be constructed and that people with

dementia tend to see their past identity as more preferable even though it might be outdated and misrepresent their current status. Consequently, if people are asked directly about their identity they may present a particular version that may be misguiding to the interviewer. This further highlights the usefulness of SenseCam to enrich the version of identity that may be presented using the standard interview methods.

DISCUSSION

SenseCam therapy helped to construct more holistic versions of the identity of the participants. It included references to both distant past as well as the recent past. Unforeseen details of participants lives were exposed via SenseCam images, even though they may not have been revealed by choice. The constructed identities do not represent a chronological life story or a static account of the person. They were based on SenseCam images and the associated narrations and are a mere version created by the interaction of the person with dementia and the therapist. This SenseCam identity is open to change and alteration with each additional image captured and reviewed.

This phenomenon of SenseCam therapy helping to construct more holistic versions of the identity of people with dementia implicates three main discussion points. Firstly it suggests a potential to use SenseCam as a tool to learn and discover the identity of persons with dementia. The people surrounding the person with dementia are often disinterested, and forget to acknowledge the person within the disease. Medical professionals often depersonalize the individual in light of the symptoms and their medical interventions. As a form of digital technology SenseCam offers a way of bringing the person back the surface within the circle of people around them and is an example of how the interaction between humans and technology can be used to enhance how a person is viewed by others. One way to achieve this is to use the SenseCam similar to the methodology used in this study. By reviewing and discussing images of recent past, healthcare professionals as well as people with dementia themselves learn about their identity in the present. Additionally, another possibility is to use SenseCam in order to collect life logs before an identity of a person with dementia diminishes. These life logs can then be used to feed back or curate identity once it starts to erode alongside the disease progression [4]. In later stages, once the identity is much weakened and the ability to express it is minimal, the life log can be used to enable the direct carers to get to know who the person is. Thus we could have technology not only shaping. But preserving our lives. There are some ethical concerns with SenseCam enabling the construction and perception of this more current version of identity to the researchers. People with dementia focus on distant past whereas SenseCam encourages a focus on the recent past and it also unveils unexpected details which may not have been discussed had they not been exposed. Regardless of people with dementia making the choice not to, or being simply incapable of remembering certain events, their forgetfulness or their age should be respected.

Secondly clear recommendations on how to use SenseCam with people with dementia needs to be developed for professionals as well as for the informal carers and loved ones. We have found that identity exposure can be involuntary to the research aims and happens by the proxy of using SenseCam with the participant. The types of details revealed by the images are not always the ones participants would want to share voluntarily. Thus, professionals using SenseCam as a therapy with people with dementia need to be prepared for such exposures and how to handle them sensitively. This highlights the need for consideration of the strong ethical implications of SenseCam use with people with dementia. The study reported in this paper was guided by the principles of CST in order to ensure there was always an ethical review of SenseCam images. They include rules like showing respect to the person with dementia and making him/her feel of equal importance and never exposing their difficulties [17]. Similar ethical guidelines need to be developed specifically for SenseCam use by people with dementia.

The overall findings from this study identified a number of issues, which should be considered when using SenseCam with people with dementia, which can be summarised as follows:

- Consider the contextual factors of the person with dementia including the level of cognitive impairment, existing coping mechanisms to memory impairments that they may have developed and the presence and existing interaction patterns with the carer;
- Tailor the therapy to suit the individual needs of the persons with dementia and their carer;
- Use SenseCam within a therapeutic framework;
- Develop a trusting therapeutic relationship with the participants;
- Anticipate discussing intimate and unexpected details from the person's life;
- Ensure that personal details revealed by SenseCam are dealt with sensitively and ethically;
- Appreciate the version of the person's identity as constructed during the therapy but respect their perception of identity.

Finally the last point to note in this discussion is the need for developing a study protocol for a randomized controlled trial (RCT) to test the success or failure of the SenseCam therapy. The development of such a protocol should be guided by similar protocols developed previously to evaluate home-based psychosocial interventions for people with dementia, mainly the study protocol developed to evaluate the individual cognitive stimulation therapy for dementia (iCST)[14]. Issues of treatment adherence are the main concern when delivering therapy like SenseCam at the scale of an RCT — with participant numbers reaching the

hundreds. It is necessary to ensure that the therapy delivered to the people with dementia is in fact the therapy intended to be delivered [14]. In order to ensure the treatment was implemented as intended the treatment integrity model was followed in the RCT of iCST and should also be followed when designing the protocol for SenseCam therapy. The treatment implementation model sets out that specific components of an intervention including delivery, receipt and enactment are a requirement to assessing whether a valid clinical trial of a therapeutic intervention has been conducted [14]. If a RCT on SenseCam therapy for people with dementia would indicate that the therapy is beneficial, a recommendation for its use could then be issued.

CONCLUSION

SenseCam therapy enriches the details participants share about their identity in a standard interview. It exposes a more holistic identity version, which includes aspects of both the distant and the recent past. Using SenseCam to help in construction of the identity of people with dementia is an important discovery in the use of lifelogging technology for dementia interventions, and possibly for other applications also. It offers a potential to use SenseCam to inform healthcare professionals and family carers about who the person really is. It also highlights the need for strong ethical implications of SenseCam use with people with dementia. The choice of the type of details revealed about each participant is greatly reduced when using SenseCam, and the professionals using this technology with people with dementia need to be aware of unexpected exposures about participants' lives. Lastly with clear recommendations of how to use SenseCam with people with dementia, a need for protocol development to test its success has been identified.

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REFERENCES

- [1] American Psychological Association 2001. Statistical Manual of Mental Disorders, 5th edn, American Psychological Association, Washington, DC.
- [2] Beike, D.R., Lampinen, J.M. & Behrend, D.A. 2004. The self and memory, Psychology Press, New York; Hove. East Susssex.
- [3] Berry, E., Kapur, N., Williams, L., Hodges, S., Watson, P., Smyth, G., Srinivasan, J., Smith, R., Wilson, B. & Wood, K. 2007. The use of a wearable camera, SenseCam, as a pictorial diary to improve autobiographical memory in patient with limbic encephalitis: A preliminary report, Neuropsychological Rehabilitation. 17, 4-5, (2007), 582-601.
- [4] Crichton, J. & Koch, T. 2007. Living with dementia: curating self-identity, DEMENTIA-LONDON. 6, 3, (2007), 365.

- [5] Doherty, A.R., Pauly-Takacs, K., Caprani, N., Gurrin, C., Moulin, C., O'Connor, N.E. and Smeaton, A.F. 2012. Experiences of aiding autobiographical memory using the SenseCam. *Human-Computer Interaction*, 27
- [6] Doherty, A.R. and Smeaton, A.F. 2008. Automatically segmenting LifeLog data into events. *IN:* Automatically segmenting LifeLog data into events. *WIAMIS 2008 9th International Workshop on Image Analysis for Multimedia Interactive Services.* Klagenfurt, Austria: WIAMIS. 20-23.
- [7] Holstein, J.A. & Gubrium, J.F. 2000. The self we live by: Narrative identity in a postmodern world. Oxford University Press.
- [8] Killick, J. & Allan, K. 2001. Communication and the care of people with dementia, Open University Press, Buckingham; Philadelphia, Pa.
- [9] Locke, J. 1847. An essay concerning human understanding, Troutman & Hayes.
- [10] Massimi, M., Berry, E., Browne, G., Smyth, G., Watson, P. & Baecker, R.M. 2008. An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease, Neuropsychological Rehabilitation. 18, 5-6, (2008), 742-765
- [11] McAdams, D.P. 1996. Personality, modernity, and the storied self: A contemporary framework for studying persons, Psychological Inquiry. 7, 4, (1996) 295-321.

- [12] Mills, M.A. 1997. Narrative identity and dementia: a study of emotion and narrative in older people with dementia, Ageing and Society. 17, 6, (1997), 673-698.
- [13] Naylor, E. & Clare, L. 2008. Awareness of memory functioning, autobiographical memory and identity in early-stage dementia, Neuropsychological Rehabilitation. 18, 6, (2008), 590-606.
- [14] Orrell, M., Yates, L.A., Burns, A., Russell, I., Woods, R.T., Hoare, Z., Moniz-Cook, E., Henderson, C., Knapp, M. & Spector, A. 2012. Individual Cognitive Stimulation Therapy for dementia (iCST): study protocol for a randomized controlled trial, Trials. 13, 1, (2012), 172.
- [15] Post, S.G. 2000. The moral challenge of Alzheimer Disease: Ethical issues from diagnosis to dying, Johns Hopkins Univ Pr.
- [16] Small, J.A., Geldart, K., Gutman, G. & Clarke Scott,M. 1998. The discourse of self in dementia, Ageing and Society. 18, (1998), 291-316.
- [17] Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M. & Orrell, M. 2003. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia, British Journal of Psychiatry. 183, 3, (2003), 248-254.
- [18] Yin, R.K. 2009. Case Study Research: Design and Methods, 4th edn, Sage Publications, Thousand Oaks, Calif.