

Digital engagement in the balance – some case studies of older and disabled ICT users

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Executive Summary

The research reported here has been undertaken as a component part of the Sus-IT project, a 3-year collaborative research project funded by the New Dynamics of Ageing Programme (www.newdynamics.group.shef.ac.uk) to investigate the barriers and facilitators to sustained digital engagement for older people. Older people have much to gain from the use of digital technologies in particular computers and the internet, and conversely may face many disadvantages if they are not digitally engaged. Despite the fact that growing numbers of older people are becoming users of such technologies, they are still less likely than younger people to be digitally engaged. As public and commercial services are increasingly being offered online, it is crucial for policy makers, service providers and developers of ICT based products to understand the factors which can promote or prevent digital engagement by older people and the nature of potential solutions.

In the course of the project, Sus-IT researchers have engaged with over 1000 older people from a diversity of backgrounds across the UK, using a variety of research methods to gather evidence about the challenges and to explore their views about potential solutions. The findings/ outcomes of the component research activities which collectively comprise the Sus-IT project have resulted in 24 project-specific outputs. These outputs and related publications by members of the project team in conference proceedings and academic papers currently total over 65 publications. All are available in the public domain – some under a creative commons licence.

This short report presents the findings from five case studies of older people with activity-limiting disabilities who were also established computer users. The aim was to understand in some depth the factors that motivated these individuals to become digitally engaged, the particular challenges that they faced, and the consequences.

These case studies highlight the crucial empowering role that digital engagement can play in the lives of older people especially those who have activity-limiting disabilities. The evidence presented here has helped to inform the overall findings and conclusions from the research.

Further information about the Sus-IT project is available from: <http://sus-it.lboro.ac.uk/>

1. Introduction

This short report contributes to the Sus-IT project. Sus-IT is a collaborative research project, which is funded by the government's New Dynamics of Ageing (NDA) programme. The Sus-IT project investigated the actual and potential barriers to sustained and effective use of ICTs by older people, and explored a range of potential sociotechnical solutions to these barriers.

For older people, being digitally included can help them to maintain their independence, social connectedness and sense of worth in the face of declining health or limited capabilities, as well as also offering new opportunities to improve their quality of life. However older people are more likely to develop one or more physical disabilities that could limit or curtail their use of computers and the internet such as visual problems, motor problems or musculo-skeletal problems. To gain knowledge, understanding and insight into digital engagement of people with such disabilities, five case studies were conducted which are documented in this report. These studies explored the barriers and facilitators in the digital engagement process and the nature of the challenges which for some of the research participants had eventually become insurmountable. The potential triggers for disengagement were also investigated and are documented in this report.

2. Research Design

A case study comprises an in-depth investigation and a detailed and intensive analysis of a single case. The 'case' may be an individual, a group, an organisation, an event or situation, which may be relevant to the phenomenon under study. In this research, the phenomena under study are the barriers and facilitators to the digital engagement process for older people and in particular the challenges for sustaining ICT use.

2.1. The Sample

The five individuals recruited for this study were older people who have been long-term users of computers, and for whom computer usage had become an established part of their lives. The case participants were ICT users/former users with physical impairments of such severity that their ability to remain independent was compromised. Four of the five individuals were clients of Leicestershire CareOnline (LCOL)¹, and the fifth was recruited through personal contact. Four were female and one was male. Their ages ranged from 52-88. Two of the five research participants were actively using ICTs (with support from LCOL); the other three had ceased to use their digital technologies and had become digitally *disengaged*.

¹ * Leicestershire CareOnline is a local government agency run by Leicestershire County Council which helps vulnerable adults in the community, such as older people, people with disabilities and carers, to use computers and the Internet to enhance their quality of life, independence and well-being.

2.2. Data Collection tool and process

(1) Interviews

Interviews structured to meet the objectives described above were conducted in the homes of these participants, and for those clients of LCOL, in the presence of their ICT trainers. The interviews were conducted in a manner intended to put participants at ease (informed by the LCOL trainers) and to take account of the needs and characteristics of the participants. Every effort was made to ensure the interviews were as informal and undemanding as possible. The duration of the interviews was between one hour and one and a half hours.

A checklist was devised and used to guide the interviews and to elicit information from the participants. This included:

- how participants became aware of opportunities for learning to use ICTs;
- the process of acquisition of ICT skills and the drivers for doing so;
- on-going usage of ICTs and the benefits gained;
- the barriers and challenges to sustained ICT use;
- coping strategies and support available/sought.

Demographic information was also collected - including details of the disabilities of the participants, their social context/personal circumstances and indicators of digital disengagement where applicable.

(2) Ethical procedures

Prior to the interview taking place each participant was informed about the Sus-It project. Participant information sheets along with leaflets describing the Sus-IT project were distributed. The purpose of the interviews was explained and all the necessary assurances were given about confidentiality. Participants were assured that there was no pressure to answer questions quickly and reassurances were given that there were no right or wrong answers.

Participants were informed that they were free to end the interview at any point without the need for explanation. Consent to participate in the research and for the interviews to be written up as case studies and published was sought from each of the participants prior to the home visit taking place. For reasons of confidentiality, pseudonyms for each person are used in this report.

2.3. Analysis

All interviews were recorded and transcribed verbatim and observation notes were written up for each of the five cases. Individual interview transcripts and observation notes were examined by the researchers. From a content analysis, data from all five interviews were categorised under the following nine headings: participant profile, disability, drivers for digital engagement, complexity of technology, acquisition of ICT skills, usage of the technology, role of support, social circumstances/isolation and benefits. The tenth and final category that emerged from the data differed: for the two cases where digital engagement was being sustained, this last category was 'Challenges and frustrations of ICT use'. For the three individuals who were digitally disengaged, the last category was 'indicators of

disengagement'. The data relating to each case was then documented as an individual case study. These are reported below - the first two relate to the individuals who are digitally engaged and the remaining three are of the individuals who had become digitally disengaged.

3. Case Study Reports

3.1 Case Study 1: Sharon (digitally engaged)

Profile

Sharon is in her early 50's, and lives on her own in southeast Leicestershire, supported by personal assistants. Sharon is an active and competent computer user, who uses her laptop almost every day, assisted by a screen reader. Sharon remarked that having access to all the information available on the Internet 'gives her a buzz'. LCOL provided a computer initially (she now has her own laptop, which she likes, because it is portable), one-to-one training, and technical support visits as required. LCOL has been supporting Sharon for 10 years.

Disability

Sharon has been blind since birth and has a hearing impairment.

Drivers for Digital Engagement

Sharon was keen to learn new skills and interested in 'discovering the world of information out there' – though she pointed out that not all sites are accessible to her (i.e. screen reader friendly).

Complexity of the technology

Other than the screen reader, Sharon manages well without any other assistive technology. She does not have a Braille keyboard because she feels it would be too expensive and she is now used to managing with a normal keyboard. She reported that it has taken her years of practice to type on a normal keyboard in the same way as a sighted person would touch type, and she is now quite fast.

Sharon seems to be quite open-minded about using other technologies. She has a mobile phone, which she uses almost every day, and she learnt how to text in 2006. She is hoping to upgrade to an Internet and Skype enabled mobile phone soon – when she can 'find the right phone in the right price range'. Sharon has BT Vision Freeview at home, with an audio description facility. If a TV programme is being audio-described, she usually records it if she is not in. However, someone has to do it for her, as she reported that the device is not easy to use for blind people. Although Sharon has an iPod, she has given up using it because she felt it was not easy to use.

Sharon says she sometimes struggles with 'the number of emails coming in'. She has signed up to e-newsletters and she feels she receives too many of them; she would like to unsubscribe but does not seem confident about how to do this. She has thought of

changing her email address to solve the problem, but again she does not seem clear about how to go about this.

Sharon currently reads electronic books on her computer, and does not have an e-book reader. However, she said that this is something she is considering, as she cannot bookmark where she stops reading on her computer. Sharon is also looking for a Satellite Navigation System, following advice from her rehabilitation office after getting lost in the local area. She is also interested in an RNIB MP3 player, and intends to look into this, so that she can download her music from the computer and listen to it from the MP3 player.

Acquisition of ICT skills

Sharon's experience with computers began in 1999, when she received funding to do various IT courses with the Open University. The OU had a scheme whereby computers could be loaned out to students, and Sharon had one of these computers. However, she recalled that she 'did not really get on very well with the computer from the OU', as it was old and even typing was quite laborious and slow. Sharon started using a computer again in December 2002, when she heard that LCOL was offering Internet training for older and disabled people and took up the opportunity.

Sharon prefers one-to-one training, as she finds it hard to learn in a group, because if there is too much noise she struggles to hear what the tutor says. She said LCOL has 'been very good', and described her 'brilliant tutor' who worked with her to learn about her current screen reader (Guide). Sharon remembers that she did not immediately take to the computer, saying she felt 'extremely frustrated at the beginning'. She recalled it was difficult to find the right screen reader for her (she finds some synthetic voices are more pleasant and satisfactory than others, especially in view of her hearing loss), and the computer was slow.

Usage of the technology

Sharon uses the computer nearly every day to access information on the Internet (she has organised her preferred websites into folders in her favourites), write presentations, send and receive emails (and use folders to file emails), download and listen to music, and shop online (if the site is accessible). Sharon is on Facebook but she is unable to use the chat function because her screen reader does not read chat; however, she is very confident about updating her status, finding someone's wall and writing on it, leaving a message or sending an email. Sharon is also aware of other social networking sites such as Twitter, but she has not signed up yet. Sharon has her own website about direct payments, and is currently looking for funding in order to manage it herself. In particular, she would like to send one of her personal assistants on a web management course, which she feels would enable her to keep the site up-to-date. In addition, Sharon uses her computer for campaigning work, to send letters and emails to MPs and newspapers (she has recently sent letters to the Leicester Mercury and the Harborough Mail). In the past, she has also written letters on behalf of her mother. Sharon has undertaken public speaking work for the local authority, and she usually writes her presentations in Word, and then 'brailles' them.

Role of support

Sharon's contact with LCOL is now for maintenance, as and when she encounters problems. She finds LCOL is very helpful to her, despite having limited time and

resources. She said they always try to help, 'but sometimes they cannot really follow it through ...Personally, I think they need to employ more staff'. Occasionally, she has had to wait for one of her Personal Assistants to arrive to help out with the computer instead. Sharon is also currently having problems with Skype, which she thinks may have been caused by a recent system update. Sharon belongs to several groups and is interested in setting up Skype calling, but she has not pursued this yet, as she feels Skype is quite inconsistent. She is a long-standing volunteer for a charity, *No Panic*, where she answers calls from anxious people; she thinks Skype would be ideal for this because it is free, but she feels that reliability is an issue. When Sharon encounters problems, she usually calls LCOL or asks her personal assistant to help (one of her personal assistants is computer-literate), but only 'after I've tried myself'. She is happy to call LCOL if she has problems, but she is also very mindful that they are sometimes 'snowed under'.

Social circumstances/Isolation

Although Sharon lives alone, she is supported by personal assistants she employs from her Personal Budget. She is an active volunteer and a member of several groups.

Benefits

Sharon feels she gains a great deal from being able to use a computer. In her own words:

'It thrills me to download music and listen to music. If I'm feeling low, music will lift me up ... it thrills me to write presentations attended by hundreds of people and get good feedback'.

She feels it has changed her outlook on life. She feels more confident about communicating with people and writing presentations and letters. Despite the problems she encounters with her screen readers, Sharon is not someone who gives up easily, saying 'I know there must be a solution somewhere'. She explained that her computer has 'helped immensely with keeping in touch with people' and that she would feel 'lost and isolated' if she had to give up using the computer. Sharon described how 'sometimes I get completely lost and confused [with the computer] ... but I gain a lot and therefore I won't give up easily'.

[Sharon did not mention it during the interview, but in Sharon's story on her website, it is clear that using a computer has played a part in opening up opportunities for her, including helping her move into her own flat in 2003.]

Challenges and Frustrations of ICT use

Sharon says that 'when everything is running smoothly' she feels 'pretty confident' using her computer. However, when a problem occurs (for example her email not downloading new messages) she quickly loses her confidence. She explained that she is not good with maintenance; it is difficult for her to sort things out if something goes wrong with the computer, although she will try. The main problem Sharon encounters with her computer is when the screen reader does not work as it should – she explained that screen readers do not cope well with boxes, images or adverts, and she sometimes finds that her screen reader freezes with certain combinations of keys, which is very difficult for her as she is unable to see what is happening. She described it as 'a waiting game'. Understandably, this is a source of great frustration for Sharon, and it also means that emails mount up in her inbox as she is unable to deal with them. Whilst she said that she would like someone

to come out and fix it, she appreciates that this is not always an easy thing to do – she explained that ‘even the RNIB people don’t always know how to fix screen readers’. Sharon is aware of alternative screen reading software, such as Jaws and Dolphin, but she explained that the alternatives are too expensive for her. Sharon explained that as long as websites are accessible, she feels confident about finding information.

3.2. Case Study 2: Katherine (digitally engaged)

Profile

Katherine is 54, and lives in central Leicestershire with her husband. Over the last two years, with the help of Leicestershire LCOL, Katherine has become an active and enthusiastic computer user. Access to information has transformed her life; she now has a confident, positive outlook, and feels able to cope with her physical symptoms. Katherine is now very much involved in the disability community locally and does ‘a lot of work for all kind of organisations’; she feels that using the computer has made it convenient and easy for her to do this work.

Katherine is currently the Vice-Chair of a local community group, which focuses on social inclusion for people with physical and sensory disabilities. Before joining this group Katherine explained that she had been in a cycle of disability and isolation for ten years, and was feeling very depressed and had lost her dignity and self-respect

Disability

As a wheelchair user and chronic pain sufferer, Katherine receives day-to-day help from a personal assistant.

Drivers for digital engagement

Katherine joined her local community group around three years ago, and started attending monthly meetings, where she slowly started collecting information about rights for disabled people, ‘bit by bit’ at first, because she felt her brain was no longer used to processing information. She learnt that she could claim certain benefits and have a personal budget with which to procure services, such as appointing a personal assistant. She thinks information and how it is passed on, (i.e. emails, Internet etc.) is the key to her improved life and well-being and she wants to share this message within the disabled community through her work, by spreading the message that ‘computers can help people who feel isolated and stuck in’.

As her participation grew and Katherine became increasingly involved in the group’s work, she needed to learn how to communicate by email (to mitigate the cost of phone calls and postal correspondence and to be able to communicate quickly and efficiently). She already had an Internet connection at home, as her son, who had left not long before, had used it and the contract was still running. It was through the project worker for the community group that Katherine was referred to LCOL.

Complexity of technology

She regularly uses emails, including attaching documents, and 'carbon copying' to multiple recipients. She also uses Open Office, Internet, Skype (which was installed on her computer on her request as it enables her to keep in touch with her son), Twitter (she has her own account and follows a certain number of people, mainly from the disability community), and photo editing software. Katherine is now equipped with a memory stick to back up her work folders, photos and music, and a portable hard drive for double back up (after having experienced a virus attack on her computer which resulted in the loss of folders and photographs).

Acquisition of ICT skills

Katherine had never used a computer before she got in touch with LCOL when she was given a recycled laptop free of charge. LCOL took care of setting it up and showing her the basics of email, the Internet and a few other applications, such as word processing and Skype.

After having one-to-one sessions with staff from LCOL to get to grips with the basics, she 'played around' with the computer and learnt to use other applications by herself, such as using Windows Media Player for listening to music, and Twitter to follow Cabinet members and disability officers. At the outset, she found that the formal training 'wasn't going in', but with time and by practising herself, she made good progress. She also knows how to replay TV programs on her computer via BBC's iPlayer. In short, she said she feels 'very confident in the use of the computer now'.

In the early days of using a computer, LCOL helped Katherine to communicate by email and look for information on the Internet. Once she 'got to grips with the basics', she started 'playing around' and working out how the different applications work. Katherine felt that it was 'doing it' that made her remember how to use an application. She struggled to remember the sequences at first, and in 'engaging the brain to work with the hands ...getting to click'. It was by practising that she got over the eye-brain-hand coordination challenges – as she expressed it, 'doing it made me remember'. She explained that she is from an older generation and her brain has never been used to working with computers, so she feels it is more difficult for her than it would be for younger generations who are used to new technologies and the way they work.

Usage of the technology

Katherine demonstrated how she organises the information she finds on Internet with the use of bookmarks, and folders and sub-folders in her bookmarks. Katherine is also confident in how to make display changes to suit her, by going into the control panel application from her desktop. She reported that she discovered these features after a while, when she was getting more confident with using the computer and was happy to explore it on her own. She also knows how to use the 'enlarge text' function when she has trouble reading on screen.

She pointed out that the help of LCOL goes beyond providing the basics. For Katherine 'they're a constant help in the sense that they're always there at the point of need'. She said that if there is a problem with the computer she feels able to phone them, and they will assess and fix the problem, or, if she cannot manage to work out how to use an application, she knows she can rely on them to help and guide her. For instance, when

she received a digital camera as a Christmas gift, a member of the LCOL team came to set it up, and show her how to use it and how to upload the photos onto her computer. In Katherine's words LCOL helps her 'to get more confident in the use of the computer'.

Role of Support

Katherine explained that she had felt 'terrified to start' when LCOL set up the computer and began to teach her how to use it. She had, at that point, very little confidence in herself and had suffered from years of social exclusion. She was 'extremely worried about breaking it', but the LCOL team provided a lot of technical and emotional support (on the phone or in person if needed), and reassured her – 'they said I couldn't break anything. And even if I did, they would come out and fix it!' With time, Katherine became 'more and more confident', and realised that 'there is always a way to undo it' if she encountered problems. This realisation, combined with reassurance from LCOL that she would not break the equipment, seemed to play an important role in her willingness to 'play about' and teach herself some elements. She is now a confident user of email – including sending attachments,

Speaking about LCOL, Katherine said that that 'it would be very easy to give up if you didn't have that support', especially when encountering difficulties, and 'you need the confidence to keep using it'. She explained how she had encountered a problem with indecent content, but someone from LCOL had come out to sort it out. She felt that a lot of people are afraid to ask for help when they're not sure how to use the computer or an application. From her experience, 'it's very difficult to ask for help when you're a disabled person because you're in a cycle of disability and isolation'. Katherine feels that LCOL is essential in keeping her using her computer. Although she said she would persevere if she encountered problems and there was no support available, she said 'if it kept happening I would probably give up'. In addition, she thought she would not be able to afford the cost of buying a new computer herself, or the cost (and time) of getting it fixed if anything went wrong. She said it would be like 'cutting her arm off' if she no longer had a computer - 'I would feel as if I'd lost a lot'.

Social circumstances/isolation

After a serious accident 14 years ago when Katherine broke her back she felt she had lost everything (her job, mobility, respect, dignity etc.) and ended up very isolated. One of the losses she identified was that of a normal husband/wife relationship, because her husband had to be her carer (in addition to his full-time job). Before becoming part of her community group and LCOL, she described how she was in a constant cycle of pain, morphine, loss of dignity and self-respect. In her words, she describes that time as 'like being in prison', when she was terrified of agency care and felt failed by the system. She perceived that 'people were ashamed of her disability'.

She now feels she got her life back. She also feels she has regained her self-respect. She is more able and wants to manage her own life, even with the pain she experiences. She described her current state of mind as 'my brain is waking up' and said that 'all this is connected to computers and information'.

She also commented that she is better off now, financially and emotionally, by virtue of all the information she got from the Internet, which enabled her to apply for disability grants, and not feel 'like you're separate from your community'. Information and access to a

computer has really changed her life – ‘Before, I had lost me, lost everything ...now, I feel quite normal again. I’m doing something I would do if I wasn’t disabled’.

Benefits

Katherine enjoys using the computer for her hobbies, such as finding craft patterns, shopping on the Internet, and finding information about health and medical equipment.

Boosted by her experience with computers, Katherine has just recently learnt to send text messages. This was more ‘out of necessity’ than a desire to learn a new technology, since text messaging is her personal assistant’s preferred way to communicate. Katherine is now thinking of the next step for her, which she says will be doing her grocery shopping online (her personal assistant currently takes her to do this). Katherine has used the internet to do some shopping, but has some concerns about payment security, choosing to use a prepaid card instead of a standard credit card in order ‘to avoid getting into trouble’ – she reported that she had recently bought a garden table on eBay with the help of her personal assistant.

A few years ago, Katherine applied to the local Borough Council for a rent rebate and she was told she did not qualify. She was also told she did not qualify for a disability facilities grant. Determined to persevere, Katherine searched the Web and found out that she was, in fact, entitled to a rent rebate (£10 rent rebate and 50% council tax rebate) and to a disability facilities grant, which she has now received. As a result, she has been able to install a ramp outside her house, and is in the process of converting her garden into an outside space suitable for her needs as an electric wheelchair user. The whole process took about 16 months; she feels this is an illustration of how much having access to a computer (and with it, extended access to information) has changed her life ‘for the better’.

Katherine sees information as key to her life:

‘The difference that changed everything was information ...it’s been a fair old journey but it’s changed my whole life. I feel valued, and I feel confident compared to what I was ... it’s improved my life so much’.

Katherine now feels valued, and observed that it is very important to her to feel valued. She now has the confidence to go out and talk to people about Personal Budgets, and feels that progress has been made in this area since she has been representing people. She observed ‘I can get information for people out there with the computer’. Katherine is now very much involved in the disability community. She goes to activity groups and feels she is ‘being part of something’. She talks about her disability to other people and likes to present herself as a success story, and tries to encourage other disabled/older people to engage with computers and information in order to get out of the isolation and disengagement vicious circle (‘they don’t know what they can get’). She feels that she now has a sense of purpose. She is in the process of setting up a forum on Skype to help other people in similar situations.

Learning to use a computer, and the resultant access to information and communication channels, have dramatically improved Katherine’s life.

Challenges and frustrations of ICT usage

Katherine described how she sometimes struggles with searching for information, specifically, finding the right words to find the information she requires when she does a

Google search. She said that LCOL provided the first clues on how to use Google and she expanded from there. When she is unable to think of the suitable words to retrieve the information she is looking for, she uses a dictionary and persists in her search. However, she does feel that terminology is changing all the time, and sometimes she finds it difficult keeping up to date and to keep track of abbreviations. Katherine also expressed concern about information overload – ‘sometimes there’s too much information’. However, she finds that refining her search terms helps with this.

3.3 Case Study 3: Terry (digitally disengaged)

Profile

Terry is an 88 year old former RAF officer. He left school with a school leaving certificate to join the RAF as an Officer Cadet at age 17, rising to the rank of Wing Commander at the end of his career. His technical background was in electrical engineering but he spent time in Special Operations and in the Diplomatic Service. Terry was widowed in 1999. He now lives on his own in his own bungalow, but one of his two daughters lives nearby. His RAF pension makes him financially ‘comfortable’.

Disability

Although otherwise generally in good health, Terry began to suffer from macular degeneration in his 70’s. His eyesight gradually deteriorated until, around age 83, he was registered as partially sighted and had to stop driving. His hearing has grown poor and he wears two hearing aids.

Drivers for Digital Engagement

Terry’s wife Gillian was an ‘early adopter’ of technology and they bought their first computer in the mid 1990s. Gillian was initially interested in using it to manage their finances and administration, and then became interested in emailing and finding information on the internet. Initially, Terry and Gillian bought a computer and printer. It did not have a built-in modem, but when Gillian expressed an interest in using email, her daughters bought a modem as a present for her 70th birthday and they took out a subscription with a broadband provider. Terry was keen on researching his family history and they subsequently bought a scanner to scan in family documents.

Complexity of the Technology

Generally Terry and Gillian were able to do what they wanted to do with the computer, and as a former electrical engineer Terry felt he was sufficiently ‘practical’ to work out how to set up and use their equipment. However they did encounter a few problems that he was not able to resolve himself. He told us that while Gillian was still alive, they had at one point decided to back up the information on their computer, but that whatever they had done resulted in text only displaying in a column one letter wide. Both his daughters and their families were living quite far away at the time, so they had sought support from various other people with expertise – a nephew who was quite ‘tech savvy’ had come over for the day, and the son of a friend who had a company building pcs had also come over to help, but they had not been able to resolve this problem. In the end, he and Gillian had

decided simply to go and buy another computer (fortunately they were well enough off to be able to do this).

After Gillian died, Terry invested in another new computer with a flat screen monitor, built-in modem, a better printer so he could print photos from his digital camera, and better quality speakers so that he could listen to music. He also decided to change his broadband provider which required setting up a new email account, passwords etc. and a bit later, on an occasion when his son-in-law was visiting, they set up a wireless network so his family members could use their laptops when they visited. However by this time Terry had really stopped using the computer independently. When family members were visiting they would encourage and help him to log in and look at his emails. However they would sometimes have to abandon the exercise because Terry could not remember his log-in details and password for his new broadband service and couldn't locate the piece of paper he had written them on.

Acquisition of ICT skills

Gillian had secretarial skills and with Terry's technical background they managed to '*teach themselves the basics*'. However Gillian was keen to use more advanced features such as spread-sheets and labels. Because she had a mobility disability, she '*sent*' Terry to the local college to undertake formal training courses on spread sheets and word processing, and he in turn taught these skills to Gillian. After that, they were content to develop their skills and learning through trial and error.

Usage of the technology

Although Gillian used the computer more often than Terry, they were both regular users. After Gillian died, Terry carried on using most of the same features – some word processing to write letters and documents, sending some emails, downloading and printing out digital photographs, and browsing the internet, although he stopped using the spread-sheets. Frequency of usage was probably a few times per week in the early years after Gillian's death, though it declined steadily as his eyesight worsened.

Role of support

As Terry's eyesight deteriorated, he found it more difficult to use the computer without assistance and would wait until one of his family members were there to help, or would ask them to do tasks on his behalf. The main problems that Terry experienced were primarily to do with not being able to see well enough to either read or enter information on the screen, despite his daughter having set the font size as large as she could (he explained that the eyesight problems caused by macular degeneration affect vision in the centre of the visual field which is blurred and distorted, so that reading glasses and even high power magnification does not help). His daughter was keen to try to find ways of helping Terry to continue using the computer, and did some research on the internet to look for assistive technology devices, but they were not sure whether these would help with Terry's visual problems. When Terry became registered as partially sighted, he was referred to a Low Vision Unit at the local hospital, where he and his daughter had a chance to look at a number of different accessibility aids such as keyboard overlays as well as screen magnifiers. However some of them were very expensive (e.g. some of the screen magnifying equipment cost several hundred pounds) and although he could have afforded them, Terry was still not sure how useful they would be for his condition, so did not buy any.

Social Isolation

Although Terry found it more difficult to sustain some of his social activities as his eyesight deteriorated, and especially when he had to stop driving, he maintained good social connections. In addition to regular contact with his family and neighbours, he was a member of the local church, a member of several bridge groups, attended weekly French conversation and exercise classes, and participated in social and cultural outings. Often family and friends would provide transport, but he also continued to travel independently on public transport (bus, train) when he was familiar with the routes, and by taxi. When he was a regular computer user, he often used his computer to look up travel-related information, to make bookings for the events and classes he attended, as well as to send occasional emails or write letters to friends and family members.

Benefits

Terry is strongly independent and it is important to him to try to manage his own affairs without calling on his family or others for support. He found using the computer/internet useful in allowing him to book travel and holidays, to complete online forms e.g. for a railcard application, to communicate with family members living abroad, and particularly to store and print his digital photos (mainly because this allowed him to enlarge them to A4 size so he could see them better). These activities helped him to feel independent and self-reliant.

Indicators of disengagement

Although his daughter had changed the font size on his computer to make it easier for him to see, as Terry's eyesight continued to deteriorate, he relied more and more on asking his family members to do word processing and online tasks on his behalf. For some time he did use the computer independently on occasions to print his digital photos although he only took photos during visits to family or holidays. However a few bouts of health problems meant he was not going away so often, and he was also finding his digital camera harder to operate because of his impaired eyesight. Then on one occasion in 2009 he wanted to print some digital photographs and discovered that his computer was no longer working. A few months later, his daughter bought him a refurbished hard drive, but it had no operating system installed. She planned to reinstall his copy of Windows, but they could not find the original disk with the software key. In early 2010, on a shopping trip with his other daughter, he decided to buy a new processor. On the same visit his family connected the computer and got it all working. However since then Terry himself has never used it.

3.4. Case Study 4: Mary (digitally disengaged)

Profile

Mary, a widow aged 88 years, was a teacher for many years. She remains an active volunteer and continues to seek the satisfaction of helping others to develop skills and acquire new knowledge. She writes poetry and composes songs.

Disability

Mary suffers from a hearing impairment, from macular degeneration and from a 'frozen shoulder' following a car accident. Her eyesight required her to strain to get close to the computer screen when she used it. Her tutor from LCOL felt that Mary was tense during their sessions, which seemed to cause aching arms and discomfort at the keyboard. Mary also experienced memory loss (see example below) which made it hard for her to remember how to carry out actions on her laptop.

Drivers for Digital Engagement

Mary first bought a computer when she was in her late 70s because she '*got weary of people talking about it*' and wanted to know '*what it was all about*'. '*I felt I wasn't in the 21st Century*'. This motivated her to learn how to use a computer and she remarked that '*I've spent my whole life learning, and I'm happy when I'm learning*'. However when classes ceased for the summer, she felt unable to continue without support and gave up using her computer for a number of years. Subsequently, when Mary was in her mid-eighties, she had a bad fall after which she suffered periods of confusion and pain and was ill for some time. In November 2010, to assist her recovery process, Mary was referred to LCOL to help her learn to use a computer so that she could transfer the many poems and songs she has written to an electronic format.

Complexity of the technology

Mary initially had a PC but disposed of it when she 'down-sized' her home. She replaced it with a laptop (a 'Notebook' - with a small screen and keyboard, and a track pad) chosen by her son. She experienced visual problems with this – especially finding it difficult to see the position of the cursor (mouse pointer). Subsequently on the basis of their assessment of her needs, an additional keyboard, and a mouse, monitor and printer were supplied by LCOL. The larger screen made it easier for Mary to see the icons and cursors. The mouse was provided as Mary had major difficulty using the touch pad on her notebook. However, she still struggled with using the mouse as she found it difficult to follow the cursor on screen as it moved too quickly for her to control it. Memory loss added to Mary's difficulties in finding her way in her computer use ('*remembering where to go*'), and remembering where she has got to. She explained that when she does something on the computer she can't quite remember how she got there and how to go back, and she feels she '*ends up in a big mess*'.

Acquisition of ICT skills

In her late 70's, Mary attended computer classes at the local Technical College and felt she got on reasonably well with learning how to use the computer. She enjoyed the classes and subsequently joined a computer club for 'silver surfers' at a local church. (However shortly after the club closed for the summer, Mary gave up using her computer for the first time). As indicated above, in her mid-80s Mary resumed use of a computer through use of the services of LCOL which delivered a bespoke nine week one-to one training course for Mary in her home, based on her interests.

Usage of the technology

At the time of the interview with her in the autumn of 2011, Mary was typing up all her poems and songs and scanning her many performance photographs into the computer to create a picture gallery to view and to enable her to find and to print out poems and

images. She used her computer for word processing, file management (for storing separately her poems, memoirs, pictures in a picture gallery) and for printing.

Role of support

Regarding family support to cope with her digital technologies, Mary explained that her son and daughter do not really have sufficient time to show her how to use the computer, or, more importantly to her, to spend some time on the computer *with* her. Although one of Mary's grandsons has offered to help her to use the computer (she described him as a 'child born with computers' who is very at ease with new technologies), she felt she could not really follow what he showed her because he did not show her 'for long enough to hold it'. She explained that she '*started with goodwill, but felt too slow and that I was a nuisance*'. Not only was the pace too fast but she also prefers to learn by doing something herself, and then repeating it, rather than simply watching somebody showing her how it is done. Mary feels that her family would like her to use the computer and other new technologies (such as a Nintendo DS and a graphics tablet they gave her), but she does not feel that they have adequately explained to her how to use them, or what she can do with them.

Social isolation

Mary lives alone and has done so since her husband died. After his death she moved into the small ground floor flat where she currently lives. She regrets that she meets fewer people now and observed that the '*feeling of being useless and sitting here all day does sting you*'. She would like to be useful again would like to help older people with computers, passing on what she has learnt (how to get started, typing etc.) and feels this would make her feel less isolated.

Benefits

Mary had valued the support and opportunities for social interaction at computer classes she had been attending and missed these when the summer break came. More important to Mary than the skills she learned with LCOL was the social interaction she enjoyed while learning with her tutor: '*Dorothy made me feel worth something*'. She liked the fact that Dorothy was interested in her and reduced her anxiety about '*doing something wrong*'. However, once Mary had received a certificate '*to say I'd learnt the basics*' and had achieved her objective of typing up and printing out all of her poems, she lost a sense of purpose regarding use of the computer. She knew Dorothy had other people to help and was concerned not to take up Dorothy's time. She did not use the computer in between Dorothy's visits (though she was happy to turn it on during the interview and demonstrate what she could do). She thinks she '*needs an impetus, some reason to continue using the computer*'. Mary is not really interested in technology for its own sake, such as her Nintendo DS or her computer, when she is on her own - she really wants something to share with other people.

Indicators of Disengagement

Mary contacted LCOL in late 2011 and arranged for them to collect their computer equipment. The latest news of her is that she has handed on her own laptop to a recently-bereaved friend and hopes to pursue her passion for teaching and helping others by assisting her friend to make use of the computer.

3.5 Case study 5: Sarah (digitally disengaged)

Profile

Sarah is an 85 year old widow who lives alone. She is retired having previously worked as a District Council Officer. She has no formal educational qualifications and '*learned on the job*'. She owns her own home and relies on friends/family members to accompany her when she goes out.

Disability

Sarah no longer feels able to go out on her own since a major operation in 2009, although she is mobile and independent at home. She explained that she got so '*low*' during her illness that she felt there was no point trying to use the computer again.

Drivers for Digital Engagement

Sarah's brother provided the stimulus for her to seek equipment and training from LCOL in mid-2002. Being able to maintain frequent contact with him was a primary motivation for her to use the computer initially. Sarah described how her brother was '*very good at using computers*' and was very enthusiastic.

Complexity of the technology

LCOL provided a desktop computer, printer, desk and computer chair, which Sarah thought were '*very good*'.

Acquisition of ICT skills

Sarah had never used a computer before approaching LCOL, and described how she was '*a bit apprehensive at first*', saying she '*didn't really know what to do with the computer*'. She received 15 training sessions of one and a half hours duration each on file management, settings and troubleshooting, use of the Internet, email and word processing.

Overall, Sarah felt '*very pleased*' with the progress she made learning to use the computer. However, when she was on her own she described how she was sometimes '*afraid of doing something I shouldn't do*'. She gradually overcame this feeling by becoming more familiar with the computer and used it more frequently.

Usage of the technology

Sarah explained that she used the computer to '*converse with people*' (presumably by email) and sent messages to her brother and close family. She reported playing games, such as Patience. However, her tutor indicated that Sarah made more extensive and richer use than Sarah appeared to recall herself: "(Sarah) used the LCOL website to find information, for example on local groups, health and various interests. As her confidence grew she explored other websites she successfully searched for details of a project her son had been involved with – restoring a WW2 bomber at a local aerodrome and erecting a model of it in the nearby town.... She also explored the website for the restaurant run by a member of her family and the venue where she was to hold her 80th birthday celebrations. She used to enjoy surprising her family members with e-Cards for birthdays, Christmas and other special occasions."

Role of Support

Sarah described learning how to use the computer at home with Wilma from LCOL as '*brilliant*'. In particular, she explained how she felt she did not need to worry too much if she had done something wrong on the computer as she was sure Wilma would know how to put it right.

Social isolation

Sarah has lived on her own since she was widowed some years ago. She said that she did not know many people to communicate with through the computer and that people of her age do not usually have a computer. Sarah explained several times that she did not have many people to send messages to during the day, as members of her family were at work. (It was not really clear whether she thought that they needed to be at the computer to receive the message, whether she was deterred by the lack of immediate response, or whether she thought her family should not be disturbed during work hours).

Benefits

For Sarah, one of the benefits of using a computer was that it made her feel she '*wasn't alone*' because she could get in touch with people and felt that the computer '*was here for me*'. Sarah does not think she would ever use a computer again – although she recognised that it would probably be good to have a computer at home now that she is no longer able to go out by herself, and she spends a lot of time at home. However, she does not really feel able or willing to use a computer again. Although she is interested in family history she does not think she would want to use a computer for this purpose.

Indicators of Disengagement

Sarah's brother, who first put her in touch with LCOL, used his computer a lot – this encouraged her to use her own computer to keep in touch with him. However, erosion of her brother's support appears to have begun when he remarried and moved away. These changes in his domestic situation, and the implications for his relationship with his sister, followed by his death in 2007 meant that Sarah lost the primary motivation to keep using it. Ill-health undoubtedly was another factor which contributed to Sarah's decline in interest in using her computer. She has experienced several periods of ill-health in the last few years, including hospitalisation for a considerable period of time, and these seem to have affected her motivation to use the computer, such that, in October 2011 she contacted LCOL to ask them to collect her computer.

4. Discussion

These case studies are testimony to the strong motivation and determination which all five research participants demonstrated in their efforts to engage in the digital world. They reveal the enormous satisfactions and rewards all five individuals had enjoyed from their digital engagement. However, it is very clear that these rewards are exceptionally hard-won and come about as a result of great personal courage and commitment of the ICT users – and of similarly great investment, expertise and effort by the dedicated trainers involved and by supportive family members to make ICT usage possible for these individuals. These personal accounts all convey the immense frustration, obstacles and

financial barriers associated with computer usage and difficulties of gaining 'trouble-shooting' assistance. The availability of excellent support emerges as a critical success factor in providing psychological support and encouragement as well as technical competence in resolving problems in a timely way and at point of need.

For those who had been unable to sustain their use of ICTs – except by proxy - the case studies also reveal the complex, subtle and multi-faceted nature of disengagement, and highlight the difficulties of finding indicators by which the phenomenon could easily and reliably be measured. In the cases of Mary and Sarah, where equipment had been donated to them by a charitable agency, their full disengagement could be said to be marked by returning their computers – though in a sense Mary has continued to be 'digitally engaged' through helping her friend to become a user. In the case of Terry, he kept his equipment and his broadband connection, but had become an occasional user 'by proxy' rather than a regular user of the computer and internet by himself. In these three cases, disengagement is also clearly a process which takes place over a period of time, rather than a sudden event – though of course disengagement could occur because of a 'catastrophic' event such as a stroke which might make continued usage impossible.

While disability/ill-health and difficulties in dealing with the technology are mentioned in all five cases, it is notable that the three participants who eventually gave up using their computers had persisted with their usage for some time in the face of these difficulties. The cases also reveal the crucial importance of social support both for sustaining as well as initiating use. In all three cases of 'disengagement' it is possible to hypothesise that without either the support from LCOL (in the cases of Mary and Sarah) or from family members (in Terry's case), computer usage could have been discontinued much earlier than it was. However each of the three individuals finally seems to have reached a point where the costs of persevering in terms of the frustration, effort and demands associated with ICT use outweighed the benefits they had previously enjoyed, resulting in disengagement from the digital world.

A new insight to emerge from these case studies is that while a single risk factor on its own did not trigger disengagement, it seems that there are complex cumulative factors which result in a 'last straw' effect. For instance, a physical problem such as poor eyesight or arthritic hands may make using the computer a frustrating struggle, but subsequent problems with the technology (examples which have been collected through both survey findings and case study findings include hard disk failure, problems with a software upgrade, and difficulties in making a printer work) may have meant that the user loses motivation to persevere, or simply finds the physical or cognitive effort required is too demanding. This can be further exacerbated by a lack of social support, encouragement, or information and help towards finding potential solutions.

In conclusion, these five case studies have made an important contribution to knowledge about the role of ICTs in the lives of severely disabled older people and this will inform policy and practice relating to the design and delivery of ICT learning and support and to the design of ICT devices and systems.

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