1   Leveraging everyday technology for people living with dementia: a case study

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5   word count (minus abstract) 5412

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10

11   Abstract

12   Purpose

13   To present the self-described 'journey' of a person with dementia (Brian; author 3) in his re-learning of

14   old technologies and learning of new ones and the impact this had on his life.

15

16   Design/methodology/approach

17   This is a single case study detailing the participant's experiences collaborating with a researcher to co-

18   create methods of facilitating this learning process, which he documented in the form of an online blog

19   and diary entries. These were analysed using NVivo to reveal the key themes.

20

21   Findings

22   Brian was able to relearn previously used technologies and learn two new ones. This lead to an

23   overarching theme of positive outlook on life supported by person-centredness, identity and

24   technology, which challenged negative perceptions about dementia.

25

26   Research limitations/implications

27   The paper provides an example of how learning and technology improved the life of one person with

28   dementia. By sharing our approach we hope to encourage others to embrace the challenge of designing

29   and developing innovative solutions for people with a dementia diagnosis by leveraging both current

30   mainstream technology and creating novel bespoke interventions for dementia.

31

32   Originality/value

33   The personal perspective of a person with dementia and his experiences of (re-) learning provide a

34   unique insight into the impact of technology on his life.

2

Introduction

Dementia is an umbrella term for symptoms that arise from a number of different underlying causes including Alzheimer's disease, vascular damage and Lewy bodies. The biggest risk factor for dementia is age although the numbers of younger people being diagnosed is increasing. Dementia is primarily a cognitive disorder (DSM-5, American Psychiatric Association, 2013) with the different causes resulting in different profiles of spared and impaired cognitive function, including memory, attention, planning and initiating activities. At this time none of the causes of dementia are reversible and people can expect to live with declining cognitive abilities over a number of years. While the profiles of cognitive impairment vary across the dementia subtypes, the effect is always to reduce a person's independence leading to reliance on one or more other people to fulfil their needs (Astell, In Press). Understandably dementia has a major impact on those who are diagnosed and their families World Health Organisation, 2012) and poses major challenges to maintaining quality of life (QOL; Topo, 2009). To date, the medical model of dementia has dominated, focusing on degeneration and loss of abilities (Gilliard, Means, Beattie & Daker-White, 2005; Innes, 2009; NICE, 2007). This view is both deterministic and pessimistic (Kitwood, 1990) and fostered widely held misconceptions that little or nothing can be done to help (Banerjee, 2010; Vernooij-Dassen et al, 2005). This has led to excessive disabling of people with dementia (Well & Dawson, 2000), where an individual with an acquired or congenital condition is disabled to a greater extent than is due to simply having the condition (Brody, 1971). This excessive disabling is due to environmental factors, which include the attitudes and behaviour of those around the person, who for a variety of reasons, take things away from or do not allow the individual to do a range of things for themselves.

However, it is possible to reframe dementia from a psychosocial perspective to provide a theoretical basis for a person-centred approach (Innes, 2009). Person-centredness involves valuing and treating each person living with dementia as an individual, appreciating their perspective and ensuring a positive social environment. This psychosocial approach focuses on retained cognitive and social

3

60 abilities, promoting their use to allow people with dementia to function to their full capacity (Kitwood,

61 1997; Robinson et al, 2010; Wells & Dawson, 2000) and live a relatively normal, enjoyable and active

62 life (Devlin, MacAskill & Stead, 2007).

63   Finding 'Non-drug interventions that make a real difference to people's lives and improve quality of

64 life' and 'enable people to maintain their dignity and independence for longer, reducing disability' is a

65 priority of the UK government (Department of Health, 2013b p.35). Technology is one such

66 intervention that could help improve the lives of individuals with dementia (Cash, 2003). Most

67 developments in this area have been in 'Assistive Technology' (AT), i.e. devices or systems that help

68 individuals to perform tasks and increase safety (Royal Commission on Long Term Care, 1999 as cited

69 in Cash, 2003), for example, automatic medication dispensers (Alzheimer's Society, 2012). Limited

70 technology has been developed specifically to support people living with dementia. Two such are

71 CIRCA (Computer Interactive Reminiscence and Conversation Aid; Astell, Alm, Gowans, Ellis, Dye &

72 Campbell, 2008) and LIM (Living in the Moment; Astell, Ellis, Alm. Dye, Gowans, & Vaughan,

73 2006), both of which highlight the applicability of ICT for people with dementia and particularly the

74 accessibility of touch screens.

75 Everyday non-specialised technology, for example, television sets and telephones, also have utility and

76 significance in the lives of people with dementia (Nygård, 2008). Further exploration of this

77 mainstream functionality could go a long way to addressing the pressing needs of growing numbers of

78 people with dementia. However, technology in dementia care raises ethical issues relating to privacy

79 and control (Kinney, Kart, Murdoch & Conley, 2004) and the need to balance the rights and

80 responsibilities of people with dementia and care providers (e.g. use of electronic tagging – see Astell,

81 2006 for a discussion of this debate).

82 Currently, the potential of technology to help people with dementia is acknowledged, but not fully

83 realised (Cash, 2003; Robinson, Brittain, Lindsay, Jackson & Olivier, 2009). Specifically, there is a

84 need for more research with people living at home with the early stages of dementia, as most research

4

85   has been conducted in residential care when people's cognitive needs are typically more advanced

86   (Topo, 2009). Furthermore, many technology interventions have been designed to meet the needs of

87   caregivers (Astell, 2006; Schulz et al, 2003; Topo, 2009) rather than focusing on the individuals with

88   dementia (Orpwood et al, 2007).

89   The subjective experience of individuals with dementia is critical for improving the relevance and

90   quality of dementia care (Department of Health, 2013b; Phinney, 2008). While there are some high

91   profile examples of first person accounts of living with dementia (for example Christine Brydon, 2007,

92   2012; Thaddeus Raushi, 2001; and Richard Taylor, 2007) there has been limited investigation of the

93   subjective experiences of people with dementia using technology. This case study presents the

94   experiences of a person with dementia and a researcher, working together with currently available

95   mainstream technology. This study investigated the impact of technology use on Brian's life and how

96   this might translate to other people living with dementia.

97

98   Method

99   Participants

100   Research participant: Brian (living with dementia)

101   "I am 63 years of age and I was given a diagnosis of Mixed Lewy Body and Vascular Dementia when I

102   was 60. My background in brief: 1965-1974: Royal Navy; 1974-1982: Hospital porter; 1982-1988:

103   Care Assistant; 1988-1993: Social Care Officer; 1993-1997: Senior Care Officer; 1997-2003: Training

104   Officer. I had a stroke in 2001 and subsequent investigations and assessment in 2008 lead to my

105   dementia diagnosis in 2009. Before my diagnosis my experiences with technology were no different to

106   anyone else - Mobile phone, PC, TV and hoists in my work. Post-diagnosis I had problems with

107   anything with a plug: PC, TV remote control, talking books, microwave, cooker, landline phone and

108   any new technology. My dementia training at work had taught me that new learning was not possible in

109   dementia, which made me quite depressed. I was referred to the Dundee Alzheimer Scotland Resource

110   Centre where I met Dr Maggie Ellis."

111

112   Researcher: Maggie

113   "I was working as the Senior Research Fellow on the COBALT (Challenging Obstacles and Barriers to

114   Assistive Living Technologies; www.cobaltproject.org) project, developing tools for increasing

115   awareness, adoption and availability of technology to benefit older adults generally, not just those

116   living with dementia. Part of this work involved taking a novel application – NANA (Novel

117   Assessment of Nutrition and Ageing; Astell et al, 2012) - to an Alzheimer Scotland resource centre to

118   gather feedback from people with dementia. Brian was one of the attendees who agreed to try the

119   NANA system and during the subsequent interview he expressed his wider interest in technology. I

120   invited Brian to become involved in the COBALT project by co-developing strategies with me to help

121   him to re-learn old and learn new technologies. Brian agreed to write a blog for the project based on

122   these experiences as part of this process."

123

124   Co-developed learning sessions

125   Maggie visited Brian at home 26 times over approximately twelve months with the broad aim of

126   developing a methodology that would allow Brian to re-learn previously used technologies and learn

127   how to operate new technologies that interested him and to maintain the learning. Eighteen of the 26

128   sessions had a specific objective, of which four were general in focus, e.g. "To teach Brian the basics of

129   using an iPhone" and 14 were more specific, e.g. "To show Brian how to download an App and teach

130   him how to use it". The remaining eight sessions were designed to 're-cap' information/techniques/

131   tasks that had been previously covered. All 26 sessions involved the development of sets of either

132   written or typed instructions corresponding to each task. Brian and Maggie jointly agreed the order and

133   number of steps required for each task together (see Table 1 for example).

6

134

135 Materials

136 Brian wrote a blog for the COBALT project outlining his experiences and feelings about re-learning to

137 use old technology and learning new ones and how these experiences impacted on his life. He posted

138 32 blogs between September 2012 and May 2013, which provided a personal representation of the

139 impact of technology use on a daily basis. Table 1 contains an example of the diary entries provided by

140 both Brian and Maggie outlining the content and purpose of each visit.

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142 Insert Table 1 about here

143

144 Data analysis

145 Brian's blogs were analysed using NVivo 9 (NVivo), a Computer Assisted Qualitative Data Analysis

146 Software (CAQDAS) by QSR International, to facilitate analysis and reinforce methodological rigour

147 (Sinkovics & Alfoldi, 2012). NVivo formalises the way data are analysed and creates an 'auditable

148 footprint', thereby increasing reliability, transparency and credibility (Sinkovics & Alfoldi, 2012 p.827;

149 Sinkovics & Ghauri, 2008). It helps balance the nonlinearity and fluidity of qualitative research, with

150 detailed documentation of the process and ensures that researchers are self-reflective in the analytical

151 process, thinking critically and justifying their decisions (Sinkovics & Alfoldi, 2012).

152 After carefully reviewing different approaches, a method of analysis based on O'Neill's (2013) four

153 stages of analysis, which was adapted from Edhlund (2011) and Sinkovics and Alfoldi's (2012)

154 method, was selected (see Table 2).

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156 Insert Table 2 about here

157

158   Procedure

159   Brian's blog entries were transcribed manually and imported into NVivo. The sources were analysed

160   and an initial model created. The results were reviewed again and condensed into higher order themes.

161

162   Results

163   Brian was able to relearn to use his desktop computer, for the first time in years, and learn to use a

164   smart phone and a laptop. He re-acquired a number of lost skills, including emailing and also learnt a

165   number of new ones, including downloading and using a variety of apps on his smart phone. Over the

166   sessions he learnt to plan and carry out independent travel, to use PowerPoint and had the opportunity

167   to give a number of talks about his experience in the COBALT project.

168   The qualitative analysis revealed an overarching theme of 'Positive Outlook on Life, which was

169   supported by three main themes; 'Person-centredness', 'Identity' and 'Technology'. A number of sub-

170   themes contributed to Brian's overall positive outlook on life.

171

172   1. Positive outlook on life

173   As a result of using technology Brian realised that he could live well with dementia.

174   "I was just thinking to myself this evening. I have every reason to be positive about my

175   Dementia and how every time I find a square peg, I can nearly always find a square hole to fit it

176   into." (14/10/2012)

177   He began to have a more positive outlook on his dementia diagnosis and life generally.

178   "I realised that recently, some very positive things had happened to me. I was successfully

179   relearning my pre- diagnosis ability to use the computer. " (14/11/2013)

180   After his diagnosis Brian had been depressed and negative about his future. He gave up many activities

181   and was particularly disappointed to have stopped using his computer. His mood improved as he re-

182   engaged with technology.

8

183   "I very strongly feel that any fear or despondency I had previously has been put aside and

184   replaced by a new me. There are so many good things happening in my life, I can face each day

185   with a completely different outlook. (24/02/2013)

186 Through his blogs Brian documented all of his experiences, including the setbacks and periods when he

187 was unwell. In spite of these, he felt that his life was much improved.

188   "So at this time I am well and looking forward to future challenges and have to say, the

189   positives are easily outnumbering the negatives through this part of my Journey through

190   Dementia." (19/11/2012)

191

192 2. Person-Centredness

193 Brian's family and Maggie created a social environment that supported Brian's psychological needs.

194 Maggie used Brian's interests to individualise the intervention for him, recognising his uniqueness,

195 experiences and perspective. Maggie continually assessed the level of support Brian needed and

196 facilitated, enabled, encouraged and empowered him.

197   "Originally when I first met Dr Maggie she had to go back to the very beginning with me and

198   start with very easy to understand tasks on my computer." (11/05/2013)

199 Brian's wife, 'S' and daughter 'J' supported him strongly throughout the project and he described how

200 his wife's approach benefitted him.

201   "Since the day of my diagnosis, this is how she coped with it. Never questioning, never angry

202   and never lying down to my Dementia. She deals with it face on. She has led by example and

203   this is why I can be so positive about my Dementia." (13/12/2012)

204 Encouraged by his successes with Maggie, Brian and S started to work on household technology that

205 he had previously stopped using.

206   "This week I am being re-trained in our kitchen. S has been concentrating on my use of our

207   Microwave Cooker...With a lot of patience, S is doing a great job and I am slowly getting the

208   idea of safety in the kitchen." (02/04/2013)

209   Brian acknowledged the importance of having the support and encouragement of other people in

210   helping him to move forward.

211   'With Maggie's help and my wife and daughter supporting me, I can be so much more positive

212   in the coming weeks and months.' (10/10/2012)

213

214   3. Identity

215   Brian's view of himself as a person with dementia changed over the time period as his technology use

216   increased and his confidence grew.

217   "I only have to think back six months and recall that I could barely use a Television Remote

218   Control. The changes in me are incredible." (04/02/2013)

219   Important in changing his view of what people with dementia are expected to achieve was his

220   experience of (re)learning.

221

222   3.1 (Re)Learning

223   Based on his previous training and experience working in health and social care. Brian thought that

224   people with dementia could not (re)learn

225   "Before I was asked to take part in COBALT I had very little interest in re-learning or in fact

226   learning something new. I thought those days had passed me by." (11/10/2013)

227   The use of technology allowed Brian to (re)learn and use skills he had not used since his diagnosis.

228   "When I reflect on the last ten weeks I am amazed at how much I have learned and re-learned."

229   (26/11/2012)

230 This was incredibly important to Brian as it enabled him to carry out tasks again and prove to himself

231 that he could move forward and there was hope despite a dementia diagnosis.

232   "I sometimes find it unbelievable that I have been able to understand, sometimes complex

233   Instructions, and retain at least some of them." (14/10/2012)

234

235 3.2 Self-image

236 Brian's self-worth, -belief and -esteem increased dramatically. He was previously self-conscious about

237 not being able to do things, but technology showed that he could (re)learn and do things independently.

238   "I am now using modern technology in my everyday living. I can safely operate the Microwave,

239   the digital TV remote control and the door exit alarm system. Things, which I found so simple

240   in the past, are now a great mystery to me. That is until I met Dr. Maggie and I started the re-

241   learning process." (13/12/2012)

242 Furthermore, technology allowed Brian to participate and contribute to society through the blog.

243   "As long as I am doing the blog and know that others are interested, it gives me that extra

244   strength and confidence. Thank you all." (14/11/2012)

245

246 3.3 Confidence

247 Technology brought back and increased Brian's confidence both in technology and in life more

248 generally.

249   "The more I use my new phone seems to further increase my confidence." (13/10/2012)

250 As part of being involved in the COBALT project, Brian had several opportunities to give presentations

251 to a number of audiences, which also boosted his self-confidence.

252   "Other things have happened recently as a result of meeting Maggie such as delivering

253   presentations and public speaking with a new found confidence." (14/11/2012)

254

255 3.4 Independence

256 Technology use allowed Brian to be more independent, for example, travelling independently, carrying

257 out tasks, and being less reliant on others.

258 'My work with the Scottish Dementia Working Group requires me to travel out of Dundee

259 fairly often. My phone carries all my files and information so I can travel lightly. It is also a

260 great comfort to me as I can keep in touch with everyone I need to.' (13/12/2012)

261

262 3.5 Control

263 Technology use gave Brian back a sense of control and empowered him.

264 "Today I was on my own at home and decided to watch a D.V.D. "Problem" I had not actually

265 carried out this task for more than 2 years. I have come to rely on other people doing it for me.

266 What used to be a comparatively simple task for me has gone. Before I was involved with the

267 COBALT Project I would have decided to wait until someone would do this for me. Not

268 now!!!" (14/02/2013)

269 It also gave him the tools, for example, the Internet, to find out and understand information.

270 "I soon got to grips with entering information and realised I was managing to work a bit faster. I

271 put in at least fifty names and numbers and felt really pleased with myself." (12/10.2012)

272

273 4. Technology

274 Technology itself positively impacted Brian's life. For instance Brian's iPhone became an essential part

275 of daily living and he downloaded a number of apps, for example, a daily journal to help keep a record

276 and record daily happenings.

277 "I am also able to refresh my memory about what has happened recently at the touch of a

278 button…"I make use of the alert mode to help me with my medication times and to remind me

279 of meetings and appointments." (13/12/2012)

280   Brian's computer allowed him to make PowerPoint presentations and enabled him to book transport

281   and hotel accommodation and make online purchases.

282   "…here I am all ready to use the Internet on the comfort of the couch." (13/10/2012)

283

284   4.1 Engaged

285   As a result of using technology Brian became more engaged and experienced a renewed interest in life.

286   This started with the iPhone, which 'captivated' him and extended to other technologies and life in

287   general, from television programs to his Grandson's schooling and sports.

288   "Out today to a family gathering. I could not wait to let them see the latest challenge, which I

289   had started to overcome. They were very impressed (especially my nieces and nephews and my

290   grand-son). I was tired by the end of the day trying to explain "COBALT" to them. So much

291   has happened to me in the past few weeks." (14/10/2012)

292

293   4.2 Social

294   Socially, technology allowed Brian to re-engage and become an active part of the family again, which

295   also improved his relationships. Social media enabled Brian to keep in touch with relatives and friends

296   all over the world. Such activity was important for tackling the stigma of Brian's dementia as people

297   could see he was living well and were less wary to get in touch. Brian realised he was not alone and

298   that other people with dementia felt the same.

299   "I decided to go on to the computer just to see how much work I would be able to carry out. I

300   started by sending out 3 E-Mails to friends and asked them to send me a reply when they

301   received them. Within 1 hour I had 3 replies. I marked that up as another success. I then spent 2

302   hours on the Internet and did some Family research. I had some good results and was able to

303   link up with people from Ireland, Australia, U.S.A. and England." (05/10/2012)

13

304   Through his blog Brian was included and connected to society and able to help people understand

305   dementia.

306   "I feel encouraged with so many good people around me to help in my hour of need. I include

307   in this the people who actually read the blog." (14/11/2012)

308

309   4.3 Purpose

310   Technology use brought meaning back into Brian's life giving him a purpose, something to look

311   forward to and keep him busy.

312   "It is my intention to keep posting my blogs. They have become part of my life." (19/11/2012)

313   Brian also felt that he was contributing to society, being a voice for people who have dementia and

314   helping other people, particularly through describing his life with dementia.

315   "My Vascular Dementia appears to be on hold at the moment but my Dementia with Lewy

316   Bodies has been erratic to say the least…I am currently ticking all the boxes for my Dementia

317   with Lewy Bodies. It has been explained to me the unpredictable nature of this Dementia and

318   this is the bit I have problems fully understanding" (04/02/2013)

319

320   4.4 Pleasure

321   Technology also brought Brian pleasure, from using his iPhone to look at photos to reading via the

322   Kindle, which his wife gave him for Christmas. Brian was excited to learn anything new on his iPhone.

323   He was enjoying life, was a lot happier and brighter.

324   "…I spent hours basically enjoying using the phone." (25/10/2012)

325

326   4.5 Opportunities

327   In addition, to these benefits Brian had other opportunities, which he believed not have had if he had

328   not joined COBALT and started using technology.

329   "I thought those days had passed me by. It also took me into a completely new place. I was

330   transferring my new technology skills into writing presentations and going on to actually

331   deliver them to some well attended Conferences. This was down to Dr Maggie and the

332   confidence she had in me." (11/05/2013)

333 Two main opportunities were public speaking and being on the National Committee of the Scottish

334 Dementia Working Group (SDWG).

335   "I have been elected on to the National Committee of The Scottish Dementia Working Group.

336   This organisation is run by people who have Dementia. The committee represents others who

337   have Dementia and their carers. The S.D.W.G. are funded by Alzheimer Scotland. The

338   committee has a keen interest in the political departments who have any interest in Dementia

339   Strategies. Being a newly elected member I will have to give a presentation to the rest of the

340   existing Committee." (19/11/2012)

341 Brian was able to participate because of his positive outlook gained from technology use. These

342 opportunities further increased his positive outlook by increasing his confidence, sense of achievement,

343 pride, value and self-worth.

344   "These days I am been made to feel so included that my self-worth has increased greatly."

345   (4/02/2013)

346

347 5. Setbacks

348 Like most people Brian sometimes found technology difficult and frustrating and he experienced a

349 number of setbacks, which detracted from his positive outlook. His dementia also affected him at times,

350 which he wrote about with great clarity.

351   "I do still have very dark days when I do not retain much information and I can become very

352   confused sometimes." (12/10/2012)

353 After one period of three or four days when it was difficult to remember things, Brian found that when

354 he next worked with Maggie he was able to pick it back up.

355   "I am thankful that I am able to use the computer and the phone, so obviously most of my

356   newly learned skills have been retained. This is very important to me, as it is the opposite of

357   what has been happening to me in the past. I see this as a positive experience. "(02/10/2012)

358 Brian was able to overcome the setbacks and persevere through the support he received, the realisation

359 that he could (re)learn and his attitude.

360   "…occasionally I will have these "temporary blips" but when they happen now I know help is

361   at hand." (02/02/2013)

362

363 In addition to the themes relating to Brian's experience, the analysis identified one further theme of

364 importance for making technology more widely available to other people living with dementia, that of

365 the low expectations and negative beliefs held by other people.

366

367 6. Challenging negative perceptions

368 Brian reported several examples of other people being surprised or amazed at this regained abilities and

369 the way he was able to learn new technologies.

370   "I spoke with my Consultant last week and he was delighted to hear how successful Dr Maggie

371   has been in such a short time. To be honest, he looked astonished when I demonstrated the use

372   of my IPhone." (11/05/2013)

373 His experiences confirm that the people around individuals with dementia often have very low

374 expectations about what they can do.

375   "Friends, relatives and even some carers have said that they were sure that a diagnosis of

376   dementia would leave me without these skills forever. Some of them have been shocked to see

377   me use me use an iPhone. Especially, when I know when they cannot use one." (13/12/12)

16

378

379   Discussion

380   This study aimed to investigate the impact of an individual with dementia working

381   collaboratively to re-engage with technology and examine the impact of this on his life. The first

382   finding was that Brian was able to relearn to use technology he had previously used, particularly his

383   desktop computer. In addition, he became a confident user of a smart phone and a laptop. Qualitative

384   analysis of his blog posts during the project revealed that technology use produced an overall 'Positive

385   Outlook on Life' for Brian, comprising three main themes: 'Person-Centredness', 'Identity' and

386   'Technology'. This study contributes to the currently limited research on the subjective experiences of

387   people with dementia using technology. It highlights the potential of technology to improve subjective

388   quality of life and make a real difference to the people living with dementia.

389   Person-Centredness was very important in contributing to the positive impacts of technology use in

390   Brian's life. This illustrates the importance of a psychosocial approach (Brooker, 2007; Kitwood, 1997)

391   and highlights that interventions may be most effective when implemented in the context of Person-

392   Centredness. Furthermore, Person-Centredness provides a way of managing ethical issues by focusing

393   technology use on the needs of the individual and not on motives such as filling (Alm, et al., 2005)

394   gaps or priorities of care providers, which may conflict with those of the individual (Astell, 2006).

395   Person-Centredness has been criticised as an overused and 'woolly' term, which 'is often so difficult to

396   achieve in practise' (Brooker, 2004 p.221). There are only a few empirically rigorous studies looking at

397   Person-Centred interventions and the subsequent impacts on people with dementia (Edvardsson,

398   Winblad & Sandman, 2008). The current study provides a working example of Person-Centredness by

399   working collaboratively with a person with dementia at every step of the process.

400   Individualising the support offered to Brian was central in this study. Therefore, when applying

401   technology use to other people with dementia and deciding what, if any, technology is most

402   appropriate, it is important to consider the individuality of each person (Nygård, 2008), recognise their

17

403 retained abilities (Gillard et al, 2005; Wells & Dawson, 2000) and ensure that they are central in

404 making decisions (Alzheimer's Society, 2012). In Brian's case, this was evident in the co-development

405 of the learning sessions and the structure of steps agreed by both parties. Other people with dementia

406 may be less interested and committed than Brian and will have different needs and views and as with

407 the population at large, technology might not be suitable for everyone (Alzheimer's Society, 2012).

408 Future research into the subjective experiences of people with dementia using technology, including

409 other dementia subtypes, should inform how technology could be most effectively used.

410 The findings also demonstrate that people with dementia can (re)learn if appropriate techniques are

411 used, supporting previous findings (Bier et al, 2008; de Werd, et al, 2013). Additionally, the process of

412 (re)learning was an important part of technology use that contributed to the positive impacts. Previous

413 studies have highlighted the desire to learn and the meaning and positive impact of (re)learning in

414 people with dementia (Beard, Knauss & Moyer, 2009; de Werd et al, 2013). However, as shown in this

415 study, a high level of support was needed, which must be balanced against the benefits. Other research

416 also highlights that training and on-going technical support is vital (Kinney et al, 2004). Therefore, a

417 key recommendation is that, if possible, other people with dementia should try and be encouraged to

418 (re)learn, using appropriate teaching methods and support, such as the approach developed here. As

419 Brian's experience highlights, the benefits of (re)learning are not restricted to technology use. Future

420 research into the most effective learning techniques in people with dementia should identify how these

421 can be applied most successfully to a whole range of interventions to enable people to live well with

422 dementia.

423 The present study confirmed that technology can have an impact in dementia care beyond safety and

424 security and improve subjective QOL, helping people with dementia to enjoy life, remain active and

425 involved (Marshall, 2001; Orpwood et al, 2007; Topo et al, 2004). Furthermore, the potential for

426 everyday non-specialised technology to have positive impacts was highlighted, supporting the results

427 of Nygård (2008).

428   Brian's example will hopefully provide hope and encouragement for people currently living with

429   dementia and their families that it is possible to influence life after a diagnosis of dementia. Brian is

430   just one individual and as such, his experiences with technology, both before and after his diagnosis are

431   unique. However, we hope that by sharing his experiences with technology both here and on the

432   COBALT blog, other people will start to challenge the low expectations and negative perceptions of

433   what is possible once someone has a dementia diagnosis.

434   Excess disability was first described in the 1970's but its relevance and appropriateness in describing

435   the experience of people diagnosed with dementia is just as important today, as indicated by the

436   negative reactions Brian encountered during the project. With the current political drive to reduce costs

437   and demands on health and social care services by people living with dementia, tackling excess

438   disability is now essential. Intervening to maintain people with dementia to function as well as possible

439   will delay demands on families to provide care and also reduce demands on formal care services.

440   Harnessing the functionality and capacity of technology is a key part of achieving this and the first

441   prong of our call for more researchers to turn their talents and scientific skills to developing solutions

442   for people living with dementia.

443   In making this argument we are not proposing that technology is a panacea for all of the challenges

444   faced by people living with dementia. Rather, we suggest that technology should be an increasingly

445   important part of equipping people to live as well as possible after receiving a dementia diagnosis. At

446   its most basic technology can provide prompts and reminders to assist people with their daily activities.

447   As Brian's example demonstrates, technology can also support the maintenance of independence, i.e.

448   doing things for himself rather than having to rely on someone else, for example booking travel and

449   travelling independently.

450   Additionally, digital technologies can support people living with dementia to meet their higher-level

451   needs for autonomy, pleasure and fun (Astell, 2013), for example through engaging and meaningful

452   activities (Astell, Alm, Dye, Gowans, Vaughan & Ellis, 2014). The technological functions that support

453 social interaction for the wider population, including email, FaceBook™, and Skype™, can also be of

454 major benefit to people living with dementia, as is starting to be recognised elsewhere (Hori, Furuya

455 Kubota, Koike, & Kinoshita, 2011).

456 In future we can expect technology to be much more involved in delivery of care and supporting self-

457 management, due to generational effects and the increasing numbers of people, like Brian, being

458 diagnosed at a younger age (Levine, 2013). Cognitive prostheses were originally proposed to enhance

459 the cognitive abilities of everyone, although their potential application to people with cognitive

460 impairment is possibly even more appropriate (Astell, et al., 2008). Unfortunately there are very few

461 digital activities designed specifically to meet the needs of people with dementia and this is the second

462 area where we would encourage other researchers to bring their creativity and innovation to bear.

463 Combining current and future digital functionality and hardware with understanding of the cognitive

464 profiles of the different dementia subtypes opens up a whole new world of opportunity to enable people

465 to live a good life with dementia.

466

467 Limitations

468 Generalisation of findings from a case study is difficult in terms of other people with dementia, who

469 may have different types and stages of dementia and of course each person and their experience is

470 unique. However, key findings and principles from this study can be a starting point for working with

471 other people with dementia. In future studies, a combination of qualitative and quantitative measures

472 could be used, for example, QOL measures at the start and end of the study.

473

474 Conclusion

475 To conclude, this study has demonstrated that technology use is not only possible but can be

476 meaningful and beneficial to a person with dementia. The experience of re-engaging with technology

477 had a positive impact on the life of an individual with dementia and contributed to an overall 'positive

478 outlook on life'. Other people with dementia might also benefit from a similar approach that is

479 individualised, in a person-centred context with appropriate teaching methods and support.

480

481 Acknowledgements

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605 Table 1. Example of a co-developed learning session from the perspective of both Brian and Maggie

Visit number	Date	Brian's perspective	Maggie's perspective
2	26/09/12	We worked on my Desk Top computer after you had shown me how to switch it on then assisted me to log on. At this early stage I had forgotten the very basics. You worked very slowly when explaining the skills I would need to operate the computer. You also suggested to me that perhaps it would help if everything you taught me should be also written down so that I could refer to it when I was alone. You taught me that day how to send E-mails and also how to send work attached to E-mails. It took me some time to understand this but I did send you an E-mail while	Objective: To introduce Brian to the idea of writing a blog.

The COBALT team had decided that we might ask Brian to write a blog for us detailing his experiences of using technology. Brian agreed in principle and we decided that the first thing we would do would be to reintroduce Brian to using his PC. Brian had mentioned that he had lost confidence in using his desktop PC. For example, he used to make personalised greetings cards and has recently given this up as he doesn't feel able to do it anymore. I started slowly with Brian, showing him how to get started with switching the PC on and signing in, etc. He mentioned that he had forgotten how to send emails so I started by |

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you were standing beside me and I did manage this successfully. I then sent you an attachment. You demonstrated to me how I might send photographs and blogs.   BLOGS?????? So you then explained what a blog was. As I said previously you wrote everything down so that I may refer to it when you were not there with me. I was very eager to get started and decided that night to write and send my very first Blog for Cobalt.

reminding him how to do this. It became clear that Brian would benefit from having a set of instructions available to him each time he went to use his PC. He could refer to these when I had gone and this would allow him to work independently and to rehearse the procedures involved.

Method:
I wrote a set of set-by-step instructions down on his notepad as we worked through them, e.g.
Switch PC on
Logon using your password
Double click on the 'mail' icon, etc.
Brian and I decided that it would be good practice for him if I sent him an email from my iPhone, there and then. As he had agreed to write a blog for COBALT I asked if I could take a photo of him on my iPhone so that we could use it on the

			website. Brian agreed and I took a photo of him sitting at his PC and then emailed it to him. I then showed him how he could save the photo to his PC and send it as an attachment to an email. Brian and I did this together and he sent me a further email later that evening by himself with another photograph attached.

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609 Table 2. Data Analysis Stages based on O'Neill's (2013) Method

Stage	Steps
1: Descriptive	Project details were entered into NVivo. Data sources were imported into NVivo and attributes, values and classifications were assigned to the data (O'Neill, 2013).
2: Topic	The research question guided the analysis. Coding involved grouping related concepts and organising them into nodes, with initial nodes seen as ideas or topics (O'Neill, 2013). Models and graphs of the nodes were created outside NVivo. These allowed reflection on developing aspects and helped identify emerging higher order themes (O'Neill, 2013). Whilst technology may have had an impact, other variables, known as rivals, could also have contributed. Therefore, topics and nodes were created for potential rivals. Yin (2009) describes a number of different types of rivals, for example, craft rivals that include the null hypothesis, threats to validity and investigator bias and real-life rivals including direct, commingled and implementation rivals.
3: Analytic	Nodes were merged into hierarchies, sets, models and relationships to create higher order themes (O'Neill, 2013). This was firstly done in NVivo. The results were then transferred into MW, reviewed again and condensed into higher order themes. The tool 'memos' was used in NVivo, which allows interpretations to be documented separately but linked to the material being analysed (O'Neill, 2013).

4:Conclusions	Theories and models were developed from the analysis.
	Diagrams were useful to illustrate the findings.

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611

612   Figure legends

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614   Figure 1a, CIRCA interface

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616   Figure 1b, LIM interface – musical chimes

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