



Article

Preferences of Informal Carers on Technology Packages to Support Meal Production by People Living with Dementia, Elicited from Personalised AT and ICT Product Brochures

Maria Laura De Filippis 1,3, Michael P. Craven 2,3,* and Tom Dening 1,3

- Division of Psychiatry and Applied Psychology, School of Medicine, The University of Nottingham, Jubilee Campus, Nottingham NG7 2TU, UK; maria.de_filippis@nottingham.ac.uk (M.L.D.F.); tom.dening@nottingham.ac.uk (T.D.)
- Bioengineering Research Group, Faculty of Engineering, The University of Nottingham, University Park, Nottingham NG7 2RD, UK
- NIHR MindTech Healthcare Technology Co-operative, Institute of Mental Health, Jubilee Campus, University of Nottingham Innovation Park, Triumph Road, Nottingham NG7 2TU, UK
- * Correspondence: michael.craven@nottingham.ac.uk; Tel.: +44-115-748-4210

Academic Editor: Francisco Javier Falcone Lanas

Received: 15 July 2016; Accepted: 22 December 2016; Published: 5 January 2017

Abstract: Assistive technology (AT) can help support the continued independence of people living with dementia, supported by informal carers. Opinions and preferences of informal carers towards a range of assistive and digital information and communication technologies (ICT) to support food purchase and menu selection, including navigation and online shopping, and safe meal-making by individuals living with dementia were investigated. General attitudes and experiences with assistive technologies were first probed by means of a focus group with carers (n = 6), organised through the Alzheimer's Society in Nottingham, England. A series of AT/ICT product brochures were then produced, describing packages of technologies to enable meal production. Task-specific questions were asked of carers (n = 10) at local Memory Cafés as to the perceived capabilities of each individual for shopping and meal-making. Carers were asked to make pair-wise choices in order to select a personalised brochure and to complete a questionnaire to elicit the practicality, desirability and affordability of specific products and to probe for preferences amongst key features. Opinions on ease-of-use, aesthetics, expected safety-in-use, independence of use and stigma related to the technology packages were also collected. Results showed that carers are able to make detailed choices and express preferences about assistive and digital technologies for the individuals in their care, and customise their enabler package. Most believed that having an enabler package would improve safety. Greater exposure of carers to newer digital products would be beneficial. The brochure method could be employed on consumer websites and by AT assessors.

Keywords: smart health; ambient assisted living; healthcare technology assessment; dementia; assistive technology; healthcare ICT; safety

1. Introduction

Dementia is a clinical syndrome, linked with ageing, that is characterized by a progressive deterioration in cognitive function (most typically, memory problems) and additional physical difficulties (mobility, hearing) that greatly impact on individual independence and autonomy [1]. Specific impacts of dementia on an individual's daily living include difficulties with instrumental activities and basic self-care, as well as emotional control, social behaviour and motivation [2–4].

Worldwide, along with other common chronic diseases of older people, dementia prevalence has increased with life expectancy and represents one of the major causes of disability amongst people aged 65+, and it also affects a smaller proportion of younger people (often referred to as "working-age dementia"). The effect of dementia typically demands an increasing level of third party care over the course of its progression, which is provided either by informal carers/caregivers such as friends or family (who may live with or apart from the individual) or formal (professional) carers in health and social care systems, or both. A major cost of dementia is in continuing social care as well as the costs incurred and time spent by unpaid informal carers [5].

People who become informal carers will typically adjust their lifestyle and adapt to the individual's changing needs, which for some is associated with stress and burden [6–8]. They will also typically explore options to address these needs and make choices with or without the individual about how they provide support [9]. This support may include the selection of Assistive Technologies (ATs), defined as "any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed" [10]. A well-designed, well-selected AT can be considered an Assistive Solution (AS), which improves the quality of life of both carer and the individual living with dementia [11]. As such, an AS may empower the individual in their daily and social activities, thus increasing their autonomy, and concurrently, decreasing the burden on carers. On the other hand, poorly designed or badly matched technology risks its non-use or abandonment. Several studies on AT for users with disabilities have underlined that after one or more years from delivery about one third of the technologies provided are likely not to be used for several reasons, such as discomfort, safety, increasing disability, or changes in the people providing care. In addition to these factors, the opinions and attitudes of carers toward the technology are also likely to have a considerable influence [12–15]. Previous studies in the dementia field have explored carer aspects of AT use, expectations and attitudes [16–18].

The study described in this paper was developed to explore the potential for offering packages of assistive technologies (including digital devices such as smartphone/tablets and ICT resources) made up from items currently available on the market, aimed at daily living activities for a person with dementia with an informal carer relationship. Relevant activities were determined by eliciting informal carers' opinions after which a customisable enabler package was created as a whole solution for an identified daily living activity. Carer opinion was then elicited on the package contents and to determine acceptability. This study was one part of a nine-month (January–September 2014) project Connecting Assistive Solutions to Aspirations (CASA), funded by the Technology Strategy Board/Innovate UK via an industry-led Small Business Research Initiative (SBRI) grant, through a funding competition "Long-term care revolution", that aimed to develop a more packaged approach to offering AT in the domestic setting. (Please note: the idea of enabler packages/packs was jointly conceived within the wider CASA partnership.)

2. Methods and Materials

As seen in Figure 1, assistive technologies can be assessed for satisfaction and non-satisfaction resulting either in good or poor matches to needs and aspirations and may suggest alternative choices or the need for improved designs [19]. In this study, we concentrate on preferences for existing technologies by carers, for use by the people in their care. The study had two phases: phase one used a qualitative method to define a daily activity for further investigation and phase two used quantitative methods to explore a novel brochure-based approach to selecting packages of AT/ICT for that activity.

In phase one, general attitudes and experiences with assistive technologies were first probed by means of focus groups with carers that were organised through the Nottingham branch of the Alzheimer's Society. A semi-structured instrument was devised to elicit opinion about the following areas: current use of AT, if any, and other technologies used by the person in their care such as household appliances and ICT products; opinions about the utility and aesthetics of technologies in current use; utility of AT to support choice and safety of the person in their care and communication

Informatics 2017, 4, 1 3 of 12

of such choices; utility of AT to support autonomy and independence in household tasks and going out; and utility of AT to support personal relationships and participation in family activities. Focus group data was gathered through audio recording, then descriptive and frequency analysis was performed on the transcripts. The broader results of these focus groups were published in more detail elsewhere [19] but are briefly summarised later in this paper along with task relevant details, including respondent quotes.

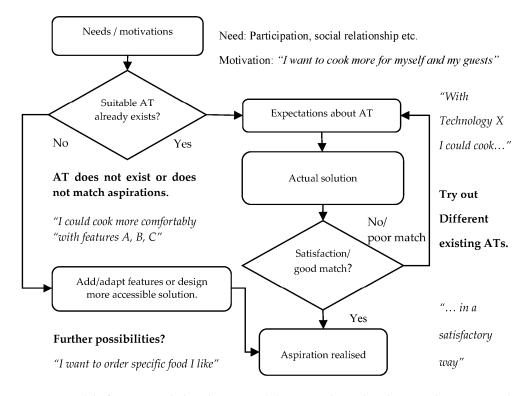


Figure 1. Model of aspiration-led evaluation and design, with meal-making used as an example.

During the period of the main CASA project (introduced above) a long list of technologies of 128 products available for purchase in the UK had been compiled based on common areas of consumer products for activities of daily living including both AT and general ICT products. The results from the focus group were intended to help the researcher choose a relevant daily living activity to focus on to be supported by a sub-set of the product list, aimed at supporting more independence in that activity.

For phase two, a series of AT/ICT product brochures were then produced to introduce relevant items from the list as a semi-customised package to support the activity. A set of questionnaires (with tick box answers, rating scales, ranking or scoring) were used to elicit carer opinion about the packages and product features. Carers, different from the carers in phase one, were recruited at local Memory Cafés (drop-in centres). First of all, carers were asked about the daily living abilities of the person in their care and prior use of specified technologies. Second, a basic description of each the 15 products was presented as a paper brochure. Each brochure showed a picture of the products, a description of their key features, and prices. Carers were then asked to rank the importance of the features for each product and to score the product overall in terms of its practicality, desirability and affordability. A system of pair-wise choice selection was devised to help the carer to customise the package brochure to reduce the number of product choices after an initial review of these. Opinions on perceived ease-of-use, aesthetics, expected safety-in-use, independence of use and stigma related to the technology package were collected. Finally, each carer was asked to make a judgment on enabler packages in general, categorized my modes of transport of the shopping stage. IBM [®]SPSS 22 was used to process the quantitative data.

Informatics 2017, 4, 1 4 of 12

A total of 16 informal carers were involved in the study. In phase one, taking place in March and April 2014, two focus groups of 3 carers each were organised with a convenience sample of six carers (50% female/male, aged: 52–83, average 68) who were caring for five individuals with various types and stages of dementia (3 males, 2 females) with an average age of 71. In phase two, taking place in August 2014, opinions were elicited from 10 informal carers recruited during three memory café sessions in the Nottingham area (50% female/male aged 57–81, average 70). These carers were caring for a total of 10 individuals (5 males, 5 females) with dementia of various types and stages, with an average age of 79.6. All studies were performed with ethical approval gained from the University of Nottingham Medical School Ethics Committee (reference No. R13022014 SoM PAPsych) and with an additional research agreement in place with the Alzheimer's Society. Participants were given information sheets and signed consent forms.

3. Results

A summary of the results of the focus groups is presented followed by the results of the carer interviews.

3.1. Phase One—Summary of Focus Group Results

The focus groups were facilitated by the authors (M.C. and M.De.F. with technology experience and T.D. old-age psychiatrist). The discussions about technology were wide-ranging. Transcripts from the focus groups were analysed by M.De.F. and consensus was obtained though discussion of all authors about the key themes within the data. The emergent themes were as follows.

- Selection and use—Informal carers were clearly aware that they strongly influence the selection
 of products. They also influence whether a product is abandoned. There are various reasons,
 for example: safety, complexity, the reluctance of the older generation to accept a new product or
 indeed any help at all. Carers found that they needed to provide frequent prompting if any AT
 was being used.
- Autonomy—Carers often mentioned how the person with dementia experienced loss of
 independence. This included impaired self-care and giving up self-directed social life and
 hobbies. Informal carers also recognised the effect of dementia on limiting their own social life
 and activities, and mentioned associated negative feelings about this. The need for autonomy
 and independence for both the carer and the individual in their care emerged as a central topic of
 discussion that AT could help to support.
- Safety—Carers were fearful of kitchen appliances that could cause injury. Food safety was
 also a concern. As such, respondents said they preferred to supervise cooking whilst having
 aspirations for more independence. For safety outside the home, carers were positive about
 tracking technologies such as bracelets and Global Positioning System (GPS) devices including
 satellite vehicle navigation (Satnav).
- Stigma—Carers were conscious of the possible stigma associated with dementia. In particular, not wishing to be identified as a person with a disease was a common cause of refusing to use wearable technologies, e.g., fall alarms. This reluctance to be labelled as a person with a disease means that there is a trade-off between privacy and the possible interests of safety. Self-imposed social isolation to avoid judgment and shame was also mentioned (and this also extended to avoiding situations where there could be financial benefit). All carers agreed that stigma was an important barrier to use of AT, but that aesthetic appearance could help, e.g., AT design that looks similar to other everyday technologies.
- Technology exposure—All the carers reported that individuals in their care were familiar with both low and high tech products in daily use. The most used products used (with or without involvement of the carer) were: telephone, TV, kitchen appliances, watches and alarms, paper and digital calendars, whiteboard, personal and tablet computers. All the carers recognised that

Informatics 2017, 4, 1 5 of 12

decline due to dementia affected the person's ability to use products that they could previously manage. Smartphones were judged to need supervision (problems with dialling or unlocking were cited), and for voice calls carers appreciated having phone dialler systems with pre-memorized numbers. Communication difficulties during calling were also mentioned. TV and radios were considered useful for "exercising memory" but decrease in ability to maintain attention was highlighted. Carers cited use of calendars and white boards as memory aids. Carers further suggested that smart appliances (real or imagined) could, for example, identify the user and assist them according to their need. For instance, the use of smart TVs, voice control systems and webcams were proposed.

From the focus groups, meal-making emerged as a particularly important theme. One respondent (T) suggested that tablet PCs and associated apps could, in principle, be useful to "manage daily routine with reduced text and powerful graphical presentations [...], for instance to organise a menu for the day or a shopping list." Among the common domestic technologies, all the carers agreed that the use of kitchen appliances was the most problematic for several reasons, including safety associated with the use of water boiling tools and the use of gas hobs. Another respondent (W) said, "The use of a gas hob could be dangerous" since a person with dementia could forget the appliance was hot or to turn off the gas after cooking. Carers therefore usually cooked for the person in their care. Cooking ready-meals (pre-assembled food) in a microwave was offered as the safest solution for independent cooking. Overall, though, the opinion of carers was that a person with dementia cannot easily cook autonomously. Respondent T suggested, "They could experience issues with following instructions or they may not be fully aware of cooking time. Often they eat raw or overcooked meals. In the light of that, devices that can help them to handle the cooking procedure could be very useful."

3.2. Phase Two—Product Brochure Study

The focus on a creating meal-making package was justified by the focus group results. Backing up this choice, others have previously noted that kitchen tasks may benefit from technology support for people with dementia living at home [20]. On the basis of the focus groups' indications, two of us (M.De.F. and M.C.) selected 15 available products from the initial long list of 128 ICT and AT items, as mentioned above, that could work together to support meal-making activities for a person with dementia. From the 15 products, a semi-customisable enabler package was created, called "Making the meals I want". The idea of the packages was to support a person with dementia though the entire activity, i.e., shopping, selecting food, safely preparing and cooking the food, with a focus on helping them perform the task more autonomously. To achieve an element of customisation and choice, amongst the 15 tools there were some pairs of products with similar or overlapping functions, e.g., Emergency GPS pendant vs. GPS soles or Electric hob security system vs. Gas hob security system. Therefore, each carer was first asked to select their preference within each pair before being given an enabler package brochure customised with their product choices to support the whole meal-making activity. The variants of the customisable enabler package containing these products are shown in Table 1.

For phase two of the study, carers' opinions were elicited at local drop-in Memory Cafés. To avoid burdening café visitors with an interview format with no prior arrangement, a quantitative study was designed in advance (using tick box questionnaires, rating scales, ranking or scoring), to enable data collection in an efficient manner whilst using knowledge gained from the focus groups. For the analysis of phase two, since we had quantitative results, we chose to combine responses as percentages across the 10 respondents. These were either summarised across the extremes and centre of the five-point scales (Strongly/Agree, Neutral or Disagree/Strongly disagree), or as an average rating of features, or as percentages of respondents who gave particular feature ranking, e.g., 1 (top), which we then placed in rank order to provide clarity, or as percentage agreeing.

As a prelude to brochure presentation, to probe their prior knowledge and any preconceptions, carers were asked to rate their agreement (from 1, strongly disagree to 5, strongly agree) about the

ability of the person in their care to currently perform elements of meal-making activity, including experience with technology. As shown in the summary Table 2, for many elements related to a meal-making activity, the majority of the carers indicated that the abilities of person in their care were limited. The exceptions were choosing what to eat and storage. Furthermore, only one of the 10 people with dementia being considered by these carers had used a computer or smartphone or had experience with online shopping.

Table 1. Enabler package variants and their associated product mixes.

Selector	Product	Package Number																
			1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
D ' 4	1.	Emergency Watch	/	/	/	1	1	1	/	/								
Pair 1	2.	Smart Watch									1	1	1	1	1	1	1	/
	3.	GPS Pendant	/	/	/	/					/	/	/	/				
Pair 2	4.	GPS Soles					1	/	/	1					1	1	/	/
Pair 3	5.	Grocery App 1: specific shop online	1	1				1				✓			1	1		
	6.	Grocery App 2: compare different shops			1	1			1	1			1	1			/	1
D	7.	Safety device: electric cooker	/		/		1		/		1		/		1		/	
Pair 4	8.	Safety device: gas cooker		1		1		1		1		1		1		1		1
	9.	Smartphone																
	10.	Cooking App																
Common	11.	Satnav App	All variants															
Common	12.	Reminder task and support app							А	iii va	ıııaıı							
	13.	Motion decoder system																
	14.	Smoke & CO Alarm																
	15.	Flood sensor system																

Table 2. Carer assessment of the everyday abilities of the person in their care (n = 10).

Statements	Agree/Strongly Agree	Disagree/Strongly Disagree	Neutral
The person I am caring for is able to go to shopping alone	20%	70%	10%
They have no problem reaching the shops and returning home	20%	80%	-
They are still able to drive	10%	80%	10%
They are able to move around their neighbourhood	20%	60%	20%
They are able to contact someone when they need help	40%	50%	10%
They are able to use public transport	20%	70%	10%
They are have used a smartphone	10%	90%	-
They are have used a tablet or personal computer	10%	90%	-
They are used to online shopping	10%	90%	-
They have problems storing purchases in the correct place	50%	40%	10%
They have problems to remembering when to eat	20%	50%	30%
They are able to choose what they wants to eat	30%	30%	40%
They have no problems in the use of kitchen appliances	-	80%	20%
They are able to cook in a safe way for themselves and others	10%	90%	-

Informatics 2017, 4, 1 7 of 12

Each of the 15 products was assessed by carers in terms of importance of its interactive features, and in overall terms of practicability, desirability and affordability as perceived by the carers. Each product had different manufacturer stated features, or in the case of the two safety cookers these were not broken down further but the respondent was able to choose gas or electric. These features were used to probe the carers' priorities for the assistive products in the enabler package and also acted to help them think in detail about the use of the AT. Table 3 shows the carers' overall assessments of the 15 products. Table 4 shows the percentage of the 10 respondents preferences for product features where pair-wise selections were made whereas Table 5 shows the same for the remaining products. Features are ordered by frequency of preference in both tables.

Product	Usefulness of Product						
	Practicality	Desirability	Affordability	Overall Score			
Emergency Watch	56%	60%	43%	53%			
Smart Watch	44%	41%	46%	44%			
GPS Pendant	71%	55%	91%	72%			
GPS Soles	63%	58%	58%	60%			
Grocery App 1 (specific shop)	55%	49%	81%	62%			
Grocery App 2	43%	40%	69%	51%			
Safety electric cooker	77%	72%	40%	63%			
Safety gas cooker	89%	83%	66%	79%			
Smartphone	30%	36%	45%	37%			
Cooking App	48%	43%	64%	52%			
Satnav App	49%	46%	50%	48%			
Reminder task & support App	62%	54%	67%	61%			

72%

67%

63%

63%

67%

54%

71%

66%

63%

77%

64%

71%

Smoke & CO Alarm

Motion decoder system

Flood sensor system

Table 3. Carer assessment (scores out of 100%) of the 15 technology products (n = 10).

Key results from the enabler package selections were as follows. Ninety percent of the respondents chose the emergency watch over the smartwatch (Pair 1), 60% preferred the GPS pendant versus the GPS soles (Pair 2), 70% chose the specific store grocery App 1 over the grocery App 2 (Pair 3), and 70% preferred the safety gas hob instead of the safety electric hob (Pair 4). The most popular enabler package (see Table 1) was number 4, which included the following products: Emergency watch, GPS Pendant, Specific Grocery App 1 and the safety gas hob. The other package variants chosen were 2, 5, 6, 7, 8 and 9. We can also note that the digital/smart products had the lowest overall ratings except for the task reminder App. Amongst the top-rated features of products, continuous monitoring, alarms and aids to avoid memorizing (phone numbers, locations, shopping list,) and use of pictures or video featured highly across the products. Some other design features were preferred.

Finally, respondents were asked to comment in the usefulness of enabler packages in general, assuming they could support shopping by car, public transport or online and could help prepare meals. The questions were chosen to reflect areas highlighted by the phase one focus group such as stigma and safety. Table 6 shows the responses given. Seventy percent of respondents also believed that enabler packages would increase safety overall although 30% still thought the person in their care would have problems understanding alarms.

Table 4. Paired product features ordered by frequency of top-rating by the carers (n = 10).

Product	Most Top-Rated				Least Top-Rated
Emergency Watch	Trigger alarm: single button press for assistance	Splash resistant	Contact call: sequence of numbers for emergencies	Organise help: microphone and speaker for direct calling	-
	40%	20%=	20%=	20%=	
Smart Watch	Tablet and smartphone compatibility	Voice control: answer/reject calls, turn music up/down etc.	Seamless Communication: make and receive calls and read large display	Instant Notification: notifications from phone apps plus on-screen apps	Dust & Water Resistant
	30%=	30%=	20%=	20%=	0%
GPS Pendant	Simple design: no confusing lights or buttons.	Locations update: find last known location online, updated every 4 min	Accurate localisation: satellite accuracy to about 10 m when outside	Battery alert: email sent when down to 10% of capacity.	-
	40%	20%=	20%=	20%=	
GPS Soles	Real-time syncing: continuous monitoring of the location	Email and SMS alerts: if person leaves/enter defined areas on a map	Battery: lasts for a week during normal use	Detailed reporting: shows past locations/activity history	-
	60%	30%	10%	0%	
Grocery App 1 (specific shop)	Picture of products with descriptions: see what is available to buy	Instant shopping: create a typical order based on previous deliveries	Products separated by storage location: different colour bags with labels	Search for entire shopping list: select more than one product at a time	-
	50%	40%	10%	0%	
Grocery App 2	Create/manage shopping lists at home	Set price alerts to avoid overpaying on common items	Discover Savvy Buys (cut price items)	Saving suggestions and cashback vouchers	-
	70%	20%	10%	0%	

Table 5. Non-paired product features ordered by frequency of top-rating by the carers (n = 10).

Product	Most Top-Rated				Least Top-Rated
Smartphone	Pen: stylus may be used to tap screen, alternative to fingers	Internet connection: data and Wi-Fi connections	Voice control: turn off alarm, answer/reject calls, music volume etc.	Smart watch Compatibility: leave phone/tablet untouched	-
	40%	30%=	30%=	0%	
Cooking App	Video recipe: video explanations step-by-step	Step by step explanation: each recipe explained in pictorial steps	Weekly menu: weekly suggestions of complete menus	Nutritional information: 10% = Tools: weight converter, glossaries	Shopping list: save ingredient lists of the selected recipes
	50%	30%	10%=	10%=	0%
Satnav App	Navigate to contacts: saved destinations of existing contacts	ns of voice instructions stored o		Real time traffic information: pinpoints traffic delays	-
	60%	20%	10%=	10%=	
Reminder task and support app	Imported third-party apps: remind users of tasks while using apps	Persistent Cues: grab attention at start, encourage completion	Task warnings and "floating" time tasks	Contacts/messages linked to tasks	-
	40%	30%	20%	10%	
Smoke & Carbon Monoxide Alarm	Heads-up and Emergency alarm: early warning of rising smoke or CO levels are rising using light/sound	Remote monitoring: check the battery by smartphone/tablet. Reports levels and alarms	Light ring: colour display dependent on what is happening in the room	-	-
	50%=	50%=	0%		

Informatics 2017, 4, 1 9 of 12

Table 5. Cont.

Product	Most Top-Rated				Least Top-Rated
Motion decoder system	Smart control: app control of the whole system, timed schedules, check sockets	Movement detector: up to 10ft away long cord for positioning, wireless signal	Modular kit: control as many house areas as required using extension switches	-	-
	50%	30%	20%		
Flood sensor system	Alarm siren: built in alarm for flood, rapid temperature change, or tampering	Automatic water control: closing water supply to prevent damage	Tilt sensor: detection up to 15 degrees, alerts if device is moved	Temperature sensor: built in temperature sensor for fire	-
	60%	30%	10%	0%	

Table 6. Overall opinions on enabler packages (n = 10).

Statements		ness to Buy reeing (n =	Usefulness to Prepare Meals	
	Car	Public	Online	% Agreeing (<i>n</i> = 10)
The person I am caring for would find an enabler package very useful	100%	60%	20%	60%
They would be more independent by using an enabler package	50%	40%	10%	40%
They would increase their self-worth by using an enabler package	50%	10%	20%	50%
They would easily use an enabler package alone	100%	50%	10%	20%
They would use an enabler package without being concerned about what the other people think	50%	50%	20%	40%
They would use an enabler package safely	100%	40%	20%	40%
They would find an enabler package attractive	100%	40%	30%	20%
If they used an enabler package my life will be made easier	100%	30%	30%	40%
Total	81%	40%	20%	39%

4. Discussion

From the phase one focus groups it was found that carers saw a positive role for AT/ICT products in supporting meal-making whilst expressing doubts about potential for more independence for the person in their care, on the grounds of cooking and food safety. This led us to choose to design an enabler package as a whole solution for meal-making, from shopping to cooking. From phase two of the study, similar to phase one, carers were seen to be mostly quite negative about the capabilities of the person in their care to conduct the different tasks to fulfil shopping and meal-making activities independently. On the other hand, they were able to engage well with the AT/ICT product questioning with no prior notice and made detailed assessments of their design features, based on information given about these on the day. From both the product assessment (Table 3) and analysis of features (Tables 4 and 5) it was seen that digital/smart products had the lowest overall ratings with the exception of the task App. Carers showed preferences for functions such as monitoring, alarms and memory aids and use of pictures/video for prompting (Tables 4 and 5).

There was a range of package variants chosen, which justifies the inclusion of choice in the offering, albeit from a limited selection. In general, enabler packages were seen by the majority of

Informatics 2017, 4, 1 10 of 12

carers as increasing safety although with a concern about how well alarms would be responded to. It was seen that very few of the carers in our study were familiar with digital products (only 1 in 10 for questions in phase two). However, carers expressed preferences about specific aspects of online shopping, for example, even if they were less positive about smartphones, smartwatches and Apps in general. It is important not to confuse lack of experience with lack of interest and in the phase one interviews [19] it was notable that one carer was positive about the potential of Smart TV, which is a very new technology.

It can be deduced from the enabler pack questionnaire (Table 6) that users would ideally like support for modes of shopping that they are familiar with, with a high preference for support of shopping by car. Therefore, it is interesting to notice (Table 2) that few of the individuals being cared for were considered able to drive at present and most were considered unable to go out and shop and return home unsupported. So, whilst we might have expected a better perception of relative usefulness of online tools that would allow a person to shop from home if they had limited ability to go out, we did not see this in our study. This suggests that greater exposure to ICT products would be useful to increase familiarity and highlight their potential. On the other hand, the result could be interpreted as an unmet need for technologies to assist with driving (to be fulfilled in the near future by self-driving/driverless cars, perhaps?).

The strengths of this study are that we have worked with groups of carers actively engaged in that role, in a range of different circumstances, and caring for dementia of varied severity and different types. We have successfully used our focus groups to identify a priority area for potential development of enabler packages and we have tested these with a new sample of carers. The package approach is potentially helpful in a market where there are many similar alternative products, since it can guide end users through what would otherwise be a mass of product detail. Our study is limited by the use of a pragmatic convenience sample, especially in phase two due to recruitment having taken place on the days of the Memory Café sessions with no prior arrangement with individuals. In particular, we did not collect details of primary or co-morbid medical conditions of the persons in care apart from a diagnosis of dementia indicated by the carer, nor the stage of severity of the dementia. The time available with participants was used to concentrate on the product assessments, to probe the benefits of enabler packages, to probe perceptions of capabilities to use them, and other aspects of user acceptance. Our sample was quite small so it is important not to overgeneralise (for example, in a different sample we could have found more prior experience with digital products). Furthermore, choice of products was limited to items identified in the earlier part of the CASA project by the wider partnership. This does constrict the degree of personalisation in the study. Given more time, we could have repeated and broadened the product search following the focus groups but this was not feasible in a short project. Therefore, future package designs could be more personalised than used here. Another limitation is the use of quantitative methods which were selected to best fit in with the setting of phase two where the data collection needed to happen efficiently so as not to burden respondents who were being engaged on the day at the Memory Cafés, unlike the phase one focus groups that were prearranged. Use of overall descriptive statistics on quantitative data will not provide the richness of a qualitative study that would reveal detailed individual needs. Furthermore, we decided not to expose carers to physical technologies due to time and budget constraints in the project as a whole, as well as for the same reason that it would not have been practical in the Memory Café setting in addition to the multiple questionnaires, although this could be done separately in the future.

Cudd et al. have previously developed a framework for user-centred design (UCD) of single technologies or whole solutions for people with dementia [18] which includes the technology/solution itself and the user dyad of carer and person living with dementia. Focusing on the carer in this study, we have conducted one iteration of the first four steps in this framework: (1) Establish the desired activity of activities; (2) Establish a process model of the activity/activities; (3) Produce the best 'test-bed' and an experimental protocol to explore acceptability, usability and scenario-based functionality with end-users; and (4) Conduct the exploration. The framework recommends multiple

iterations of these steps before moving on and this will need to happen here also, in particular to include people with dementia as end-users in addition to carers before finalising package offerings.

5. Conclusions

The design and acceptability of an enabler package, a personalised (or at least semi-customisable) AT/ICT whole solution for supporting an activity of daily living, has been explored using qualitative and quantitative methods in a two-part study. Overall, the results showed that carers are able to make choices and have preferences about assistive and digital products for the individuals in their care, albeit whilst expressing some doubts about their utility.

There does appear to be a need for greater exposure to digital/ICT products to help people see their potential benefits. We would of course expect that attitudes in this area may change with younger cohorts having much greater familiarity with these devices. Having introduced the concept of enabler packages and explored one area of daily living, further work is needed to establish validity after presenting physical products to households, including people living with dementia, to determine their actual utility and value, according to the later steps of a UCD framework such as that suggested in the literature. Since this study was completed, one of the partner organisations in the overall CASA project has founded a new company to exploit knowledge gained to support provision of personalised care supported by technology (http://www.youralcove.com/).

By presenting the products integrated into a brochure format we can note that the AskSARA website http://asksara.dlf.org.uk, (see also AT Guide at http://www.atdementia.org.uk) currently presents advice about products linked to self- or carer-assessed need. A brochure approach could be a way of outputting the results from such a website. Customisable packages are already commonplace in some industries such as telecommunications, e.g., broadband/phone/TV packages, and product variants are typically used as filters on price-comparison websites, so familiarity of personalisation is increasing in the population as a whole. As well as for direct use by consumers, the brochure method employed in this research could also be used in a care setting or in other professional practice to expose users to choices of assistive technologies. In particular, AT assessors, who may be occupational therapists or other trusted personnel, may find the method useful in making needs assessment a more meaningful and pleasurable activity. Finally, we can note that the approach to package design that we have used for meal-making could be repeated for other areas of daily living, e.g. a set of products for looking after a garden or indoor plants. In general, the brochure method suits an approach to needs assessment that aims to support a desired activity as its goal, rather than focussing on impairment or deficit.

Acknowledgments: The research reported in this paper was supported by the NIHR MindTech Healthcare Technology Co-operative. The views represented are the views of the authors alone and do not necessarily represent the views of the Department of Health in England, NHS, or the National Institute for Health Research. The authors acknowledge funding support for the research through the Connecting Assistive Solutions to Aspirations (CASA) project, provided by the Technology Strategy Board (Innovate UK) Long Term Care Revolution initiative by means of a Small Business Research Initiative grant. The CASA project was a collaborative venture led by commercial partner Leone Services Ltd., in partnership with Sensixa Ltd. The University of Nottingham, University of the West of England, Bristol and Swiss Cottage School, Development & Research Centre. The authors would also like to thank the Nottingham branch of the Alzheimer's Society, for organising the recruitment of carers and for hosting the focus groups, and all of the carer volunteers.

Author Contributions: All authors conceived the study. M.D.L.F. designed the experiments. All authors performed the experiments. M.D.L.F. and M.P.C. analysed the data. All authors wrote the paper and M.P.C. prepared the manuscript for publication, with input from the other authors including its revision following peer review.

Conflicts of Interest: The authors declare no conflict of interest. The funding sponsors had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript, and in the decision to publish the results. M.P.C. and T.D. are trustees of the charity Trent Dementia Services Development Centre which has a licence for AskSARA to use it in the web-based AT Guide mentioned in the conclusions.

References

1. World Health Organization. Dementia Fact Sheet. Available online: http://www.who.int/mediacentre/factsheets/fs362/en/ (accessed on 12 July 2016).

- 2. Buijssen, H. *The Simplicity of Dementia: A Guide for Family and Carers*; Jessica Kingsley Publishers: London, UK, 2005.
- 3. Huang, H.-L.; Shyu, Y.-I.L.; Chen, M.-C.; Huang, C.-C.; Kuo, H.-C.; Chen, S.-T.; Hsu, W.-C. Family caregivers' role implementation at different stages of dementia. *Clin. Interv. Aging* **2015**, *10*, 135. [CrossRef] [PubMed]
- 4. Wolfson, C.; Wolfson, D.B.; Asgharian, M.; M'Lan, C.E.; Østbye, T.; Rockwood, K.; Hogan, D.F. A reevaluation of the duration of survival after the onset of dementia. *N. Engl. J. Med.* **2001**, *344*, 1111–1116. [CrossRef] [PubMed]
- 5. Animal Defenders International World Alzheimer Report 2010. The Global Economic Impact of Dementia. Available online: https://www.alz.co.uk/research/files/WorldAlzheimerReport2010.pdf (accessed on 12 July 2016).
- 6. Blieszner, R.; Roberto, K.A. Care partner responses to the onset of mild cognitive impairment. *Gerontologist* **2010**, *50*, 11–22. [CrossRef] [PubMed]
- 7. Brodaty, H.; Donkin, M. Family caregivers of people with dementia. *Dialogues Clin. Neurosci.* **2009**, 11, 217–228. [PubMed]
- 8. De Vugt, M.E.; Stevens, F.; Aalten, P.; Lousberg, R.; Jaspers, N.; Winkens, I.; Jolles, J.; Verhey, F.R. Do caregiver management strategies influence patient behaviour in dementia? *Int. J. Geriatr. Psychiatry* **2004**, *19*, 85–92. [CrossRef] [PubMed]
- 9. Wolfs, C.A.; de Vugt, M.E.; Verkaaik, M.; Haufe, M.; Verkade, P.-J.; Verhey, F.R.; Stevens, F. Rational decision-making about treatment and care in dementia: A contradiction in terms? *Patient Educ. Couns.* **2012**, 87, 43–48. [CrossRef] [PubMed]
- 10. World Health Organization. A Glossary of Terms for Community Health Care and Services for Older Persons. Available online: http://www.who.int/kobe_centre/ageing/ahp_vol5_glossary.pdf (accessed on 12 July 2016).
- 11. Federici, S.; Scherer, M. Assistive Technology Assessment Handbook; CRC Press: Boca Raton, USA, 2012.
- 12. Phillips, B.; Zhao, H. Predictors of assistive technology abandonment. *Assist. Technol.* **1993**, *5*, 36–45. [CrossRef] [PubMed]
- 13. Kittel, A.; Di Marco, A.; Stewart, H. Factors influencing the decision to abondon manual wheelchairs for three individuals with a spinal cord injury. *Disabil. Rehabil.* **2002**, *24*, 106–114. [CrossRef] [PubMed]
- 14. Federici, S.; Borsci, S. The use and non-use of assistive technology in italy: Preliminary data. In *Assistive Technology Research Series*; IOS Press: Amsterdam, The Netherlands, 2011; Volume 29, pp. 979–986.
- 15. Scherer, M.J. Outcomes of assistive technology use on quality of life. *Disabil. Rehabil.* **1996**, *18*, 439–448. [CrossRef] [PubMed]
- 16. Fleming, R.; Sum, S. Empirical studies on the effectiveness of assistive technology in the care of people with dementia: A systematic review. *J. Assist. Technol.* **2014**, *8*, 14–34. [CrossRef]
- 17. Gibson, G.; Dickinson, C.; Brittain, K.; Robinson, L. The everyday use of assistive technology by people with dementia and their family carers: A qualitative study. *BMC Geriatr.* **2015**, *15*, 89. [CrossRef] [PubMed]
- 18. Cudd, P.; Bolton, E.; Gallant, Z.; Greasley, P. The person living with dementia, their carer and their digital technology. In *Assistive Technology: From Research to Practice*; IOS Press: Amsterdam, The Netherlands, 2013; pp. 610–615.
- 19. De Filippis, M.L.; Craven, M.P.; Dening, T. Informal carer role in the personalisation of assistive solutions connected to aspirations of people with dementia. In *Ambient Assisted Living and Daily Activities*; Springer: Cham, Switzerland, 2014; pp. 236–243.
- 20. Wherton, J.P.; Monk, A.F. Problems people with dementia have with kitchen tasks: The challenge for pervasive computing. *Interact. Comput.* **2010**, 22, 253–266. [CrossRef]



© 2017 by the authors; licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC-BY) license (http://creativecommons.org/licenses/by/4.0/).