# ANNOTATED BIBLIOGRAPHY

# Literature Review | Long Dinh

# Citation

Bharucha, Ashok J., Vivek Anand, Jodi Forlizzi, Mary Amanda Dew, Charles F. Reynolds, Scott Stevens, and Howard Wactlar. "Intelligent assistive technology applications to dementia care: current capabilities, limitations, and future challenges." *The American journal of geriatric psychiatry* 17, no. 2 (2009): 88-104.

Topic: Ethical considerations of monitoring technologies **Quote:** 

"Ubiquitous health monitoring technologies also raise serious ethical considerations. The very systems that are designed to promote independence not uncommonly require varying degrees of privacy impingements to collect the data during both the developmental phase and the routine use. [...]

Successful implementation of assistive technologies for research and clinical purposes will require not only an analysis of stakeholder-specific ethical considerations but also setting specific issues (i.e., personal home versus nursing home)"

#### Notes:

Consider environment that we are designing for, such as nursing homes or the personal home. This can raise concerns if we are monitoring their health as it raises concerns on privacy of patients.

Topic: Research gaps in current engineering and comp sci domains

#### Quote:

"Beyond the complexity of designing devices that are commensurate with an individual's needs and preferences, critical research gaps also exist in the engineering and computer science domains. These include

- efficient collection and storage of voluminous real-time continuous data from multimodal sources (basic and advanced sensors, audio and video technologies, etc.) that lend themselves to user-friendly access and analysis;
- development of automated data reduction and mining techniques to point to clinically meaningful events and deviations from a prior baseline (i.e., finding the needle in a haystack);
- integration, analysis, and correlation of the data with clinical parameters;
- further advancements in wireless network technologies that are capable of transmitting real-time multimodal digital data confidentially to caregivers; and finally
- development of increasingly sophisticated computational and statistical techniques to model human activities and behaviors."

#### Notes:

When designing for caregivers or researchers, we may consider to design for access of collecting and analyzing data

## Citation

Fiß, T., Thyrian, J. R., Wucherer, D., Aßmann, G., Kilimann, I., Teipel, S. J., & Hoffmann, W. (2013). Medication management for people with dementia in *primary care: description of implementation in the DelpHi study*. BMC geriatrics,13(1), 121.

Topic: Lack of current detailed procedures for medication management

#### Quote:

"Maidment et al. concluded that "medication management in dementia is a broad concept that should encompass a complete review of medication, including assessment of indication, dosage, interactions and continued need"

#### Notes:

Review and assess current regimens of medications with patients. Account for their dosage, continued need, and interaction.

# Citation

Arlt, S., Lindner, R., Rösler, A., & von Renteln-Kruse, W. (2008). Adherence to medication in patients with dementia. *Drugs & aging*, 25(12), 1033-1047.

Topic: Facilitating medication adherence in patients **Quote:** 

"Strategies for facilitating medication adherence in patients with dementia include prescribing as few medicines as possible, tailoring dose regimens to personal habits, and coordinating all drug dosing schedules as much as possible. When providing medication organizers, it is important to observe the patient's ability to use devices appropriately. In addition, automated computer-based reminding aids, online medication monitoring and telemonitoring may be helpful for patients with mild dementia."

#### Notes:

Incorporate customizable options to tailoring regimens to users personal habits

Topic: General Factors with Non-adherence in patients **Quote:** 

"Numerous studies have identified factors associated with partial or poor medication adherence in older patients. Cognitive function is regarded as a key factor. Other factors include poor knowledge of the drug regimen and the purpose for which drugs are prescribed, type of prescriber, complexity of drug regimen schedules, occurrence of adverse drug effects, living alone, low income, low education, personal and cultural beliefs about medication, depressive symptoms and depression, current smoking, problem drinking, race (other than Caucasian) and drug cost sharing. Older age, in general, was found to be associated with both lower and higher levels of drug adherence, or to have no relationship at all."

#### Notes:

Further evidence of factors for non adherence including complexity of drug regimen schedules

Topic: Forgetfulness as a factor for medication non-adherence

Quote:

"Poor medication adherence has been related to elderly patients' impaired memory or impairment of other cognitive domains, and forgetfulness as a causative factor has been reported in 16-40% of elderly patients. In elderly patients with peripheral arterial disease, forgetting to take the medicine was the most common reason for self-reported non-adherence."

Notes:

How to address the problem of forgetfulness in taking medicine

Topic: Assessment of Medication Adherence Quote:

"How to assess medication adherence in patients with dementia depends on the stage of dementia and the patient's willingness and ability to cooperate. From a practical point of view, the challenge is to recognize patients at stages of cognitive impairment already adversely impacting on medication adherence before a negative outcome from non-adherence has occurred. For this purpose, a performance-based assessment tool might be useful for screening medication management ability, in addition to a careful drug history, inspection of all medicines used (in- cluding over-the-counter drugs) and evaluation of proxy information, if indicated."

#### Notes:

How can we monitor the patterns of each medicine regimen in our design to evaluate if a patient is non-adherent to the medicine

## Citation

O'Keeffe, J., Maier, J., & Freiman, M. P. (2010). Assistive technology for people with dementia and their caregivers at home: what might help. Final report prepared for *Administration on Aging (Massachusetts)*, 1-30.

Topic: Importance of Assessing an Individual's Deficits, Abilities, and Preferences

Quote:

"If an AT product is not matched to a person's needs, abilities, and preferences, it may be ineffective or may even cause distress. The features of dementia that can influence the acceptance, use, and effectiveness of assistive technology include, but are not limited to, a person's

- specific pattern of cognitive abilities and deficits,
- specific emotional and behavioral changes,
- personality characteristics and attitudes toward technology,
- attitude regarding assistive technology that appears to exert "external control," and
- physical and social environment.38

Any or all of these factors can result in an AT product not being used effectively or at all— even if it has been proven to be highly effective in a controlled setting. An individual must be both willing and able to use a product and comfortable with its use. Research has indicated that the use and acceptance of an AT product may also depend on individuals' personality, motivation, and insight into their deficits

An initial assessment may require a trial period with a specific AT product. Monitoring technology to ensure safety can be of enormous benefit to caregivers, but its use needs to be carefully introduced and implemented so that it is effective and does not cause distress to a person with dementia. For example, if a bracelet with a tracking device is uncomfortable to wear, a person with dementia may try to remove it. Similarly, the sound of an alarm when a person opens a door can be frightening."

#### Notes:

Come up with designs that aids to promote comfort into having patients accept the product.

# Literature Review | Stephanie Grose

## Citation

Holbø, K., Bøthun, S., & Dahl, Y. (2013, October). Safe walking technology for people with dementia: what do they want?. *In Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility* (p. 21). ACM.

Topic: Important not to take patient out of the equation and focus only on caregivers

#### Quote:

"Despite the overall recognition of the importance of user participation throughout design processes we find that people with dementia often are excluded from design and evaluation of technology that potentially can affect their lives"

#### Notes:

It might be worth it to put more focus on interviews of actual patients since it seems like they get left out often.

# Topic: Patients want a sense of independence Quote:

TABLE 4. Level of access to computers by social and health characteristics

|   | Hierarchical level or category of access |                                     |                                       |                                       |              |             |
|---|--|-------------------------------------|---------------------------------------|---------------------------------------|--------------|-------------|
| Social or health characteristic   | Core<br>access<br>(%)                    | Peripheral<br>home<br>access<br>(%) | Peripheral<br>family<br>access<br>(%) | Peripheral<br>public<br>access<br>(%) | Excluded (%) | Sample size |
| Gender  |  |                                     |                                       |                                       |              |             |
| Male  | 9  | 24                                  | 40                                    | 15                                    | 12           | 154         |
| Female  | 5  | 11                                  | 42                                    | 22                                    | 20           | 198         |
| Age group (years)   |  |                                     |                                       |                                       |              |             |
| 61–70   | 9  | 27                                  | 43                                    | 15                                    | 6            | 141         |
| 71 or more  | 5  | 10                                  | 40                                    | 22                                    | 24           | 211         |
| Marital status Single/separated/widowed Married/living with long term partner | 3  | 5<br>28                             | 47<br>37                              | 27<br>12                              | 18<br>14     | 163<br>178  |
| Health status   |  |                                     |                                       |                                       |              |             |
| No long-term illness/disability   | 7  | 18                                  | 39                                    | 19                                    | 18           | 217         |
| Long-term illness/disability  | 6  | 13                                  | 47                                    | 19                                    | 15           | 129         |
| Education   |  |                                     |                                       |                                       |              |             |
| Continued after 16 years old  | 8  | 32                                  | 29                                    | 7                                     | 25           | 73          |
| Completed education at or<br>before 16 years of age                           | 7  | 13                                  | 44                                    | 22                                    | 14           | 279         |
| Total   | 7  | 17                                  | 41                                    | 19                                    | 17           | $35^{2}$    |

Note: Summed data may not add up to 100 per cent due to rounding.

Topic: Patients are willing to give up some freedoms to ease the mid of caregivers

#### Quote:

"Anna expressed her reluctance toward giving up parts of her privacy by being remotely monitored as she did not see the personal need given her current state of condition. However, she did say that she might permit family members to electronically track her in order to reduce their concerns about her wellbeing."

#### Notes:

Patients are concerned with how worried their caregivers are and are willing to give up some freedoms to ease the mind of their caregiver.

Topic: Patients want to be able to contact caregivers on their own initiative

#### Quote:

"This, in particular, included having the opportunity to contact their caregivers on their own initiative (e.g., phone call and alarm notifications), rather than leaving it up to the caregivers to take such decisions on their own, for example, on when to intervene. "

#### Notes:

Patients are aware that they will need help from their caregivers sometimes, but they want to have some control of when to worry them and have a choice of when they need help instead of the caregiver assuming they do.

# Citation

Selwyn, N., Gorard, S., Furlong, J., & Madden, L. (2003). Older adults' use of information and communications technology in everyday life. *Ageing and Society*, 23(05), 561-582.

Topic: Not scared of technology, just selective **Quote:** 

"Whilst employed adults aged 60 or more years do not avoid using new technology, they did report being less comfortable than younger adults when using it and were more selective of the applications that they used."

#### Notes:

Older adults report not having as much of a need for the different technologies available, and are not scared to use it, but instead just pick and choose the things that they find useful before they put the time into learning about it.

Topic: Older adults adopt technologies that are mass marketed to them, such as television.

Quote:

"Most accessible technologies to older adults were mass market broad case and communications technologies. As can be seen in Table I, the majority of older adults had access at home to fixed/landline telephones, terrestrial television, video recorders/players and radios."

#### Notes:

Television is a technology that older adults find useful and entertaining, and most of them have those in their home. But many don't have computers. This shows that they find TVs more worth their time than computers.

Topic: Most older adults that use computers use it for function instead of fun.

Quote:

TABLE 5. Use of computers and the Internet in the last 12 months

| Activity or use  | Fairly<br>Very often often Rarely Never |    |    |                |
|--|---|----|----|----------------|
| Playing games  | 8                                       | 5  | 7  | 59             |
| Writing and editing letters, reports and other documents   | 27                                      | 23 | 18 | 11             |
| Making films or animations on a computer   | I                                       | I  | 7  | 70             |
| Creating and manipulating images (e.g. photographs)  | 12                                      | 9  | 10 | 48             |
| Watching DVDS/videos on a computer   | 2                                       | 5  | 3  | 69             |
| Making music with a computer   | 2                                       | 2  | 4  | 71             |
| Listening to music on a computer (CDS, MP <sub>3</sub> S)  | 4                                       | 7  | 7  | 6 <sub>1</sub> |
| Fiddling around on a computer/explore different bits of the computer to develop your own knowledge | 16                                      | 19 | 13 | 31             |
| Organising the computer's files/memory   | 12                                      | 19 | II | 37             |
| Programming the computer   | 6                                       | 5  | 6  | 62             |
| Learn something when using a computer program (e.g. from a CD ROM, encyclopaedia or database)      | 13                                      | 19 | 6  | 41             |
| Send/read E-mails (via computer or digital TV)   | 27                                      | 12 | 9  | 31             |
| Making/maintaining your own website<br>product information   | 4                                       | 2  | I  | 72             |
| Look for products and services/gathering product information online                                | 8                                       | 13 | II | 47             |
| Buy goods and services on-line   | 4                                       | 5  | 9  | 61             |
| Online banking/management of personal finances   | 4                                       | 4  | 3  | 68             |
| Look for information related to work/business/study<br>on the world-wide web                       | 10                                      | 15 | 7  | 47             |
| Download software, music, films or images from<br>the Internet                                     | 7                                       | I  | 8  | 63             |
| Participate in educational courses/lessons on the world wide web                                   | I                                       | 4  | 4  | 70             |
| Use adult entertainment on the world-wide web  | O                                       | 3  | 3  | 73             |
| Browse/surf the world-wide web for no specific purpose   | 4                                       | II | 13 | 51             |
| Use Internet newsgroups, bulletin boards, chat rooms or instant messages                           | 2                                       | 3  | 3  | 71             |

*Note*: The reported data are numbers of computer-using respondents (n = 79).

#### Notes:

Word-processing is the most popular activity amongst older adults. Others are "fiddling around on the computer", file and memory organization, and learning from computer software. Internet is low except for email. Advanced internet usage such as banking and shopping are not used.

Topic: Reasons for not using computers **Quote:** 

TABLE 8. Non-ICT users' main stated reason for not using ICT

|  | Frequency | Percentage |
|--|-----------|------------|
| No interest/motivation                                     | 67        | 25         |
| Too old  | 57        | 21         |
| No need  | 47        | 18         |
| No skills/inability to use computers                       | 34        | 13         |
| No access  | 18        | 7          |
| Too busy/life full outside of using computers              | 14        | 5          |
| Not clever enough/too lazy/too dull                        | 6         | 2          |
| No longer used in workplace (previous sole reason for use) | 5         | 2          |
| Ill health   | 5         | 2          |
| Frightened of computers/too technical                      | 4         | 2          |
| Financial cost   | 3         | I          |
| Computer is broken/given away/sold it                      | 3         | I          |
| Anti-computers   | 2         | I          |
| Family use it for me                                       | I         | 0.4        |

*Note*: Data are percentage of sample who had not made use of a computer in the past twelve months and who offered a reason (n = 266).

#### Notes:

Older adults that use computers are more likely to be male, married, 70 or less, and have continued their education after 16 years of age.

Topic: Older adults don't have use for technologies because they are not designed with older adults in mind.

Quote:

"The survey findings suggest that ICT at the moment is not attractive, interesting or useful for many older adults, and that those who do use ICT are predominantly male, younger, and well educated."

#### Notes:

It seems that technology is aimed at a very particular user, and that is not older adults. If the user is considered throughout the design process instead of the young, educated male, the technology may be more attractive to the older population.

# Literature Review | Megan Taylor

### Citation

Ansari, S. (2011). Designing interactive pill reminders for older adults: A formative study. *In Universal Access in Human-Computer Interaction. Users Diversity* (pp. 121-130). Springer Berlin Heidelberg.

Topic: Nonadherence as a health problem **Quote:** 

"Non-adherence among patients has been identified as a major public health problem that imposes a considerable financial burden upon modern health care systems. This burden includes 10% of hospital admissions, 23% of admissions to nursing homes and has been estimated to cost \$100 billion each year in the US." pg. 121

"Without intervention, adherence rates to long-term medication in high income countries are approximately 50% [18], while adherence in low and middle income countries may be even lower [23]. Millions of people don't take their medication correctly [15]. The consequence of mistaking medication can be very dangerous or even deadly." pg. 122

"In an extensive review of medication adherence research, it was found that approximately 50% of patients do not take prescribed medications in accordance with physicians' instruction [20]. Poor adherence is to be expected in 30-50% of all patients, irrespective of disease, prognosis or setting [14]."

#### Notes:

Nonadherence is a problem and is one reason why a medication management solution could be important. First quote offers statistic on financial burdens due to nonadherence. Second quote offers statistic about adherence rates in high income countries.

Topic: Design requirements for a pill dispenser system **Quote**:

"Context: Adherence among older adults should be increased. This can be applied by integrating an interactive design into a pocket size pill dispenser. Furthermore, pill dispensers should be secured (e.g., no access by children). Pill dispensers should also dispense only the pills that are required for a specific dose intake. An ideal interactive device should manage the reminder and the dispenser systems simultaneously.

Use: Interactive pill reminders should focus on this problem and offer a solution by dispensing medication to the elderly in a way that is secure, routine, and monitored by their physician or pharmacist. Considering the interaction tasks between the device and a physician or pharmacist, coupled with their work schedules, the device should also be designed so that it is simple enough for the industry to absorb it.

People: Primary users will be older adult patients that are required to take a long list of medications (e.g., complex diseases) for an extended period of time (e.g., chronic patients). Secondary users will be doctors and pharmacists who could upload and maintain the data necessary to continue the effectiveness of the device" pg. 122

"Patients frequently cite forgetfulness as the most common reason for not taking medication. Therefore, interventions that improve memory are likely to enhance patient adherence. Several cost-effective strategies are available that may help patients remember to take their medication. Patients should be encouraged to develop a home dosing routine for their medication use - a routine that enables a patient to take their medication at the same time each day and that involves cues that prompt medication taking rituals and enhance memory. Health care practitioners should encourage the use of medication adherence aids, such as calendars, pillboxes with built-in timer alarms, dosage counters, multi-alarm wrist watches, pagers with alarm and text reminders, medication diaries, phone reminders, computerized medication schedulers, and other adherence tools" [3]. pg. 124

"Medication Reminder Software: Although various factors have been related to adherence, patient understanding of the illness and influence of treatment on it can affect treatment adherence. If information provided to the patients is individually tailored, it has a greater impact on patient behavior than providing generic

information. In one such study on medication adherence in elderly patients with memory disorders, a Designing Interactive Pill Reminders for Older Adults: A Formative Study 125 PC-based software application to provide individually-tailored medication information was developed. Programmed in Visual Basic, the application automates a critical part of an intervention that includes assessment of patient health care literacy, preferred language, and information needs. The application provides printed output that includes the patient's name and answers to specific questions endorsed by the patient. Output is provided at one of two literacy levels and in Spanish as well as English. Patient adherence to cholinesterase inhibitor medications prescribed for memory problems was assessed longitudinally with an electronic recording device. Preliminary data collected from the research study showed that the device had a high degree of patient acceptability. The data also indicated that the use of the tailored information device was associated with high levels of sustained medication adherence [16]." pg. 124

"A mobile application 'UbiMeds' has been developed to improve accessibility and support medication adherence for aging and disabled population [19]. In another pilot research study, customized messages were programmed into the user's mobile phones before they left their doctor's offices. As a result, a simulated SMS would arrive on the patient's phone when it's time to take the medication. The application on the phone also allowed them to anchor a medication event to a lifestyle event, i.e. always taken with lunch, so if your lunch schedule changes the medication reminder can, too. When it was time for a medication event the patient's phone would ring, a message would appear on the screen. When answered it asks the patient to touch the mobile phone to the medication bottle. The bottle had an embedded RFID chip, which can transfer information to the phone. The phone would then ask the patient if "X" is the medication they were taking and once confirmed, proceeds to instruct the patient on how to take the medicine. Every time the patient interacts with the application it records the event and confirms each event for clinicians to review from a Web portal in real-time or at a later date. This process resulted in an increase in 96 percent adherence in the pilot study [7]." pg. 125

"Medication Event Monitoring System (MEMS): The MEMS monitors are drug packages with integral electronic micro circuitry designed to compile the dosing 126 S. Ansari histories of ambulatory patients' prescribed medications. Each monitor consists of a conventional medicine bottle fitted with a special closure that records the time and date of each opening and closing of the container through integrated microcircuitry. Monitors are designed to be used by one patient with one drug. A reader transfers the dosing history data from the MEMS monitor to a MS-Windows based computer [1]." pg. 126

#### Notes:

Provides design requirements that can be used for our medication management system

To increase adherence in older adults, a dispenser should:

- be secure (no access by children, etc)
- dispense only the pills needed for the desired dose
- manage the reminder and the dispenser system simultaneously
- create a sense of routine
- be able to be monitored by a physician or pharmacist
- present information to physicians and pharmacists in a way that fits into their work schedules
  - o utilizes systems such as barcodes that are already used
- be simple enough for industry adoption
- be able to manage a long list of medications
- be able to manage medications over a long period of time
- help improve memory (through routine) to enhance adherence
- be cost effective
- provide individually tailored information
  - o responds to individual's name and requirements
  - o responds to unique user questions
  - o output in various literacy levels
  - output in various languages
- Be capable of anchoring a medication event to a lifestyle event (i.e always taken with lunch if your lunch schedule changes, the medication reminder changes too)
- Be capable of identifying medications
- Be capable of providing instructions for how to take the identified medication
- keep a record of medication use

- record time and date of each opening and closing of a container
- keep track of refills

Topic: Usability and user experience guidelines for pill reminder design

Quote:

"Usability and Experience Goals of the Users Based on the general requirements of small screen devices and design principles for older adults the following primary usability goals for users of the interactive pill reminder are developed:

#### Usability

- Effective The Interactive pill reminder should aid the user by helping them load and consume the medications in exact amounts at consistent times each day. It will also have a calendar to help organize medications.
- Efficient Loading medications should be simplified
- Easy to Learn Using a touch screen, buttons must be clearly defined and intuitive. Appropriate feedback should be given for each action.
- Options/Flexibility Color scheme, time, and the calendar should all be customizable to suit each user's preferences
- Safety-The user's personal and medical information should be stored in such a way that it is accessible only by the user (though with some exception to their primary health care physician, i.e. new/old prescription data, etc). And their medication must be kept safe in a secure sterilized compartment

#### Experience

- Enjoyability The user will be able to be more independent and have a greater quality of life
- Helpful The personal calendar will allow the user to take command of not only their medications but personal life as well.
- Motivating The Interactive pill reminder will inspire users to take their medications correctly

 Inviting – The Interactive pill reminder should be aesthetically pleasing, inviting the user to pick it up and interact with it through clear and clean menus, as well as right-brained icons and pictures."

#### Notes:

Potential list of guidelines for evaluating the usability and user experience of our product.

# Topic: Distinction between adherence and compliance **Quote:**

"The word "adherence" is preferred to compliance by many healthcare providers, because "compliance" suggests that the patient is passively following the doctor's orders and that the treatment plan is not based on a therapeutic alliance or contract established between the patient and the physician [15]. Indeed, adherence is a more Designing Interactive Pill Reminders for Older Adults: A Formative Study 123 neutral term than compliance, which can be construed as being judgmental. Despite these differences, both terms are commonly used as descriptions of medication-taking behavior [15].

Winnick (2005) defines adherence as: "the extent to which a person's behavior coincides with medical or health advice" ([22], p. e718). The term compliance, defined as 'to consent' or 'to do as asked', has been used instead of adherence for many years [6]. Other definitions of adherence add components such as knowledge of medication, timely filling of prescriptions, exact dosage, accurate timing of the doses, approximate sequence of taking the drug, correct length of therapy, and on-time attendance for follow-up appointments [20]." pg. 123

#### Notes:

We could use either term in our design requirements, but "adherence" is prefered to "compliance" in the healthcare community.

# Topic: adherence especially low among older adults **Quote:**

"Treatment adherence rates are typically lower among older adults, mental disorders, and patients with chronic conditions as compared to

those with acute conditions [11]. Persistence with medical treatment regimens among patients with chronic conditions and elderly is also disappointingly low [12]."

#### Notes:

Quote supports the importance of a tool for increasing adherence and justifies our targeting of the elderly and those with medical disorders.

# Citation

McGee-Lennon, M. R., Wolters, M. K., & Brewster, S. (2011, May).

User-centred multimodal reminders for assistive living. *In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 2105-2114). ACM.

Topic: design requirements for reminder systems **Quote**:

"We suggest that developers of home care reminder systems should design for diversity, context, priorities, autonomy, shared spaces, and optimal care." pg.1

"In order to increase adoption and ensure successful implementation of assistive living technology, we need to provide users with effective, accessible solutions that are enjoyable to use. These solutions need to be adaptable to a set of devices and interaction modalities that will depend on user needs, abilities and preferences as well as on available services and budgets." pg.1

"A home is a very personal space for everybody who lives there, not just for the intended user of the system but also for a spouse, children or even visitors. This means that we need to design reminders that are both usable and acceptable to a range of direct end users, i.e. the intended recipients of reminders, and indirect users, i.e. people who can perceive the reminder message despite not being the intended recipients. Reminders need to be adapted to multiple, sometimes conflicting, stakeholder needs [17], they need to be appropriate in a variety of changing contexts and they need to accommodate a wide range of ability levels [22]." pg.1

"We advocate a person-centred approach to care similar to [4] where needs and preferences are regularly reviewed and stored in a format such that they can be easily communicated to relevant stakeholders including end users. To accommodate this approach, reminder systems need to be highly modular, flexible and easy to configure."

"In the home care reminder context, we define users as people who choose (or in some cases are selected) to receive reminders. Direct end users can include the person with care needs, family, friends and formal carers. For example, a system might remind all members of the household of an appointment, or it might remind the formal carer of tasks such as checking the medicine cabinet." pg. 2

"Speech output in particular should be configurable. Individual reactions to gender, politeness, accent and length of message were very strong and varied." pg. 7

"The family home tour revealed clear generational effects. The middle-aged mother discussed solutions that could exploit her mobile phone, the young children were very positive towards wearable devices and the grandmother was keen to exploit mainstream technologies such as their TVs. The youngest participant summarized the need for personalisation as follows. "I would want it to like a hair band or a watch ... you know telling me to remember my school stuff ... but then mum could get her reminder to her phone cos she is always on that..." (Tour 7, Male, 9)."

Seamless Integration into Life and Home Users wanted a reminder system to be easily integrated into their daily life and their physical surroundings. "Maybe like a digital photo frame or something ... but it would have to look okay wouldn't it – you wouldn't want some big box in your living room..."

"Successful reminder systems need to strike a delicate balance between being prominent enough to attract users' attention, but subtle enough not to be perceived as intrusive or distracting. Audio reminders, in particular, can startle or scare users if played unexpectedly." "Screens should be placed where users are most likely to see them, such as in the living room or kitchen. Many people favoured the idea of a controllable panel in the hallway. Users also liked the idea of more ambient display technologies (such as a coloured light) that act as generic reminders. "Sometimes I just need reminding that I have to remember something you know ... so I wouldn't even need to hear 'take your pill' I would just know if I heard the bleep that I have to take my pill." (FG3, female, 85+). People were concerned that they might not be able to get to a landline phone in time or that they might not be able to hear mobile phone reminders because they did not know where their mobile was. A final aspect relevant to the theme of seamless integration was robustness. Quite a few users doubted the reliability of technology, and they were wary of the disruption that a malfunctioning reminder system was likely to cause."

Many users raised concerns about usability issues such as the font size of visual reminders and intelligibility of audio reminders. However, this does not mean that people with a visual or auditory impairment would not use visual or auditory reminders, In our focus groups with people with severe hearing impaired people (including Deafness), one person said "Some speech is okay with my hearing aid ... I mean it would depend on the volume and quality [of the speech] wouldn't it..."

"Some users wanted to be able to remove reminders once the associated task had been completed while others would like a view of the history of reminders they have attended to. Participants reacted positively to the idea of smell and tactile reminders but this may have been due to the novelty of these delivery methods."

"Designing for Shared Interaction Spaces As soon as other people share the home with the intended recipient of the home care reminders, issues of privacy and obtrusiveness arise. Reminders that cannot be easily interpreted by visitors provide privacy, especially if users do not want to be seen as needing care. For example, while spoken reminders are explicit, clear indicators of care needs, the meaning of non-speech sounds such as Earcons is opaque unless explained [16]. At the same time, reminders should not unduly disrupt other people living in the home."

"Designing for Diversity Reminders need to be highly personalizable, because one size does not fit all."

"Designing for Context Contextualization figures heavily in the successful reminder strategies that emerged from the data. Reminders are most effective when delivered at the right location, at the right time and through the right device. Systems should be configurable based on the devices that are acceptable and available to the user. There are strong synergies between location and device. For example, many people favored reminder screens at the hub of the home, which is often the kitchen [11]"

"Designing for Priorities Reminders should reflect the urgency of the task"

"Designing for Autonomy Autonomy is a fundamental issue in the design of pervasive technology for healthy ageing [10]. Reminder systems should support users as autonomous agents who are in control of the system, not the other way around."

#### Notes:

Synthesized, these quotes describe design criteria for reminder systems. The end users in this article include "the person with care needs, family, friends and formal carers." We can use these specs as considerations for our own design.

A reminder system should:

- be designed using a person-centered approach
- Be designed for
  - Diversity
  - Context
  - Priorities
  - Autonomy
  - shared spaces
  - o optimal care
- provide users with solutions that are
  - effective
  - accessible
  - enjoyable to use

- adapt to multiple, sometimes conflicting stakeholder needs
- be appropriate in a in a variety of changing contexts
- accommodate a wide range of ability levels
- be highly modular, flexible and easy to configure
  - Speech output in particular should be configurable
  - Individual reactions to gender, politeness, accent and length of message were very strong and varied
- Seamlessly integrate into life and home
- Successfully strike a delicate balance between being prominent enough to attract users' attention, but subtle enough not to be perceived as intrusive or distracting.
  - Audio reminders, in particular, can startle or scare users if played unexpectedly.
  - Screens should be placed where users are most likely to see them, such as in the living room or kitchen
- Provide privacy
  - especially if users do not want to be seen as needing care
  - Use reminders that cannot be easily interpreted by visitors
- Be reliable
  - Some people doubted the reliability of technology, and they were wary of the disruption that a malfunctioning reminder system was likely to cause
- Be usable
  - Readable font sizes
  - Understandable audio reminders
- Be highly personalizable
- Have customizable reviewability
  - Some users wanted to be able to remove reminders once the associated task had been completed while
  - Others would like a view of the history of reminders they have attended to.
- Provide reminders that reflect the urgency of the task
- Support users as autonomous agents who are in control of the system, not the other way around.

Topic: importance of reminder systems

Quote:

"Home care and assistive living solutions are crucial for enabling this user group to stay active and independent for longer in their own homes [6]." pg. 1

"Existing approaches to reminder design only partly address these complex issues. There is a clear need for guidelines that allow designers and developers (and where appropriate end users) to create configurable and multimodal reminder systems which can rise to the challenges of home care." pg.1

"While it is tempting to use only those modalities for reminders where acuity is relatively well-preserved, it is in fact important to make reminders in all modalities as accessible as possible to people with varying abilities. For example, even though touch can function as an alert to take medication, users might not remember which medication they need to take or how many of each pill are required. This information might need to be presented graphically or sonically. Designers need to work with care professionals to devise a strategy for accommodating different levels of sensory impairment. An example for such a strategy for tasks that require dexterity can be found in [27]." pg. 2

"Making reminders multimodal is particularly important given that the acuity of all sensory modalities declines with age [1], often as a consequence of the condition that caused the original care needs. For example, diabetes may lead to impaired vision and, due to peripheral neuropathy [7], to an impaired sense of touch. The number of people with both significant vision and hearing impairment is set to increase dramatically in the future, partly as a consequence of the ageing population [25]. Alerts that are based on touch and smell are particularly important for these users." pg. 2

#### Notes:

Reminder systems are important because they help promote independence. Designers should strongly consider accessibility in design. A large portion of our population is aging and losing sensory functions.

Topic: Design challenges for reminder systems Quote:

"Home care and assisted living pose very specific challenges for design. The key issues can be clustered around three main themes; complexity of care needs, the multi-user and multi-stakeholder nature of home care, and the need for well-defined pathways and accountability [17]." pg. 2

"Many potential conflicts regarding reminder delivery can arise between users and other stakeholders. For example, a user may prefer auditory reminders, but due to a hearing impairment, these reminders need to be so loud that the neighbours can hear. A formal carer may have decided to use a loud beep to remind a user to lock the doors at night because this has been identified as a safety threat, but the user perceives this sound to be highly disruptive and disturbing. These conflicts need to be resolved so that the reminders remain effective while still being acceptable to the user and those sharing the home interaction space." pg. 2

"Since reminder systems are multi-stakeholder, it is particularly important to identify clear pathways for resolving any conflicts. These pathways need to include explicit mechanisms for seeking user input and validating the selected options. The different goals and needs that underpin each conflict need to be identified [8]. In resolving conflicts, clinical efficacy needs to be balanced with an acceptable user experience and institutional requirements." pg. 2

"Why do Reminders Fail?Reminder strategies are only effective if people can adhere to them. Adherence can be affected by health problems. For example, a person with depression may choose not to act on reminders when feeling low. A few users argued that their needs were so complex that they could not be met by a reminder system alone. For example, one older male respondent was a diabetic who sometimes forgot his insulin. Since double doses of insulin can result in complications, what this person needed was not simply a reminder to take his insulin, but also a way of monitoring that he had already taken it."

"Designing for Shared Interaction Spaces As soon as other people share the home with the intended recipient of the home care reminders, issues of privacy and obtrusiveness arise. Reminders that cannot be easily interpreted by visitors provide privacy, especially if users do not want to be seen as needing care. For example, while spoken reminders are explicit, clear indicators of care needs, the meaning of non-speech sounds such as Earcons is opaque unless explained [16]. At the same time, reminders should not unduly disrupt other people living in the home."

"Designing for Optimal Care guidelines may need to be violated for important tasks, such as taking vital medication."

#### Notes:

The challenges of designing for assistive living fall into three main categories that we should keep in mind throughout our project:

- 1. complexity of care needs
- 2. multi-user and multi-stakeholder nature of home care
- 3. need for well-defined pathways of accountability

Additionally, design guidelines may need to be violated for important tasks such as taking a vital medication

Topic: What people forget and why Quote:

"41% of older respondents in the questionnaire said that they forgot to do certain things in and around the home often or all the time, as opposed to 32% of middle-aged and 17% of younger respondents. However, when specifying what tasks they forget, older people ticked fewer boxes than younger or middle-aged people. In particular, they were less likely to report that they forget daily chores (older: 4%, middleaged: 14%, younger: 22%) and paying bills (10%; 32%; 42%). All age groups were equally likely to forget medications and appointments." pg. 4

"The things that cause people to forget tasks were similar across all methods used. Memory problems, failing to use reminder strategies, and distractions, e.g. by phone calls or more important events, were all mentioned. People also stated that they tended to forget tasks that

were not important or urgent. The only significant difference between age groups in the survey was that middle-aged people were more likely to say they were too busy (67%) than younger (48%) or older (34%) people (p<0.0001)." pg. 5

"Stress, tiredness, and low mood were cited as further reasons for forgetting. Some respondents mentioned that physical problems prevented them from remembering or completing tasks. These problems were not just caused by ill health, but also by the medications people were taking." pg. 5

#### Notes:

All people were equally likely to forget appointments and medications, so our product could be useful beyond our target user group. Low urgency of task, stress and tiredness also decreased memorability. Older people were less likely to forget doing chores or paying bills.

Topic: Tools people use to remember **Quote:** 

"The highly varied strategies people claim to use can be grouped into five categories: paper-based (e.g., calendars), technological and specialized (e.g., mobile phone reminders and pill boxes), temporal (e.g., integration into routines), people-based (e.g. phone calls from friends) and physical (e.g., placing books to be returned near front door)." pg. 5

"Paper-based methods Calendars and diaries were the most popular, followed by to-do lists and sticky notes. In the questionnaire sample, older people were more likely to use diaries and calendars, and were less likely to set alarms or use an electronic personal organizer (see Figure 1). While the survey revealed the central role of paper-based reminders, the home tours allowed us to fully document the complexity of such systems. Many people had multiple calendars, diaries and notebooks and complex systems for annotating them and working between them

People-based reminders Several respondents mentioned people-based strategies, such as relying on friends and family to remind them of important tasks. Several people in the survey also

described serving as the main personal reminder system for a family member with dementia.

Temporal reminders Temporal reminder strategies emerged as central throughout our research. A common strategy was to integrate tasks that would otherwise be forgotten into routines, e.g. "I never leave the bathroom without looking at taps" (male, 46-60, survey). This plays to older people's strengths, because this age group found it particularly easy to remember daily chores. Temporal cues could be external, such as radio programs that served as indicators of the time."

#### Notes:

People use four primary types of reminder systems:

- 1. paper-based (e.g., calendars),
- 2. technological and specialized (e.g., mobile phone reminders and pill boxes)
- 3. temporal (e.g., integration into routines)
- 4. people-based (e.g. phone calls from friends)
- 5. physical (e.g., placing books to be returned near front door)

Our design should fit into to these mental models. People-based reminders are especially prominent for those with dementia.

# Topic: How People Would Like To Receive Reminders Quote:

- "46% expressed a preference for one modality [21% had no preference]"
- "older people were less likely to favour visual reminders"
- "Interestingly, the self reported impairment of a particular sensory modality did not affect whether the user would like to receive reminders using that modality."
- "The main difference in device-related preferences between age groups concerned phones. 40% of our older sample wanted reminders to be delivered by landline phones, whereas fewer than 5% of younger and 8% middle-aged users favoured this mode of delivery (p<0.001)."</li>

#### Notes:

Things to keep in mind when designing our medication reminder system: According to this study, people prefer multimodal reminders.

Older people were less likely to prefer visual reminders, but a sensory impairment does not necessary keep an individual from wanting a reminder sent through that mode. In other words, someone people with hearing loss still want auditory reminders. Don't make assumptions about physical limitations.

# Literature Review | Gail Thynes

## Citation

Cotrell, Victoria, Katherine Wild, and Theresa Bader. "Medication management and adherence among cognitively impaired older adults." *Journal of gerontological social work* 47.3-4 (2006): 31-46.

Topic: major causes of non-adherence Quote:

"Little is known about the medication management behaviors of individuals with dementing illness, although it is known that forgetfulness and confusion are major causes of unintentional nonadherence."

#### Notes:

These may be the two problems we focus on solving: eliminating forgetfulness and confusion

Topic: contextual cues

#### Quote:

"The literature suggests that older adults often rely on contextual clues (e.g., taking medications with a meal) and automatic or ritualized behavior to remember to administer their medications."

#### Notes:

Ask patients what contextual cues they most often employ. We could also create a design that utilizes patients habits and creates reminders

Topic: role of adherence aids

#### Quote:

"Barat, Anderson, and Damsgaard (2001) suggest that adherence aids such as pill dispensers may reduce the likelihood of drug errors in individuals with probable dementia."

#### Notes:

Incorporating a device that separates the pills could reduce errors and confusion.

Topic: Role of deficit awareness in mitigation strategies Quote:

"Further, Branin (2001) found that older adults who expressed greater concern about their memory were more likely to rely on external props (e.g., a pill box.). Therefore, the role of deficit awareness may be a key element in the choice and utilization of appropriate strategies."

#### Notes:

Could help with interviewing patients, who aware are they of their memory deficit.

# Topic: AD patient perception of intelligence Quote:

"Empirical studies have not only confirmed that awareness deficits occur frequently in individuals with Alzheimer's disease (McGlynn & Kasniak, 1991; Schacter, 1991), but that respondents often rate themselves as having above average memory when compared to non-impaired controls (Duke et al., 2002; Feher et al., 1991)."

#### Notes:

Design consideration, this reinforces that patients may not be the most reliable source of information in this case.

Topic: importance of awareness in use of external aides **Quote**:

"Brustrom and Ober (1998) report that AD patients who reported a greater awareness of deficits made more fre- quent use of compensatory mechanisms than those who did not. They were also more likely to report that the memory strategies used were ineffective. For those who self medicate and rely on external aides, awareness may be more important than cognitive status in achieving good adherence."

#### Notes:

Design consideration

Topic: effect on caregivers' medication **Quote:** 

"Further, it has been suggested that the stress of caring for a loved one may compromise the caregiver's adherence to his or her own medication routine, again questioning the effectiveness with which families manage their relatives' drug regimen."

#### Notes:

Area of inquiry with caregivers in interviews

Topic: Medication Complexity Index

Quote:

"The Medication Complexity Index (MCI) (Conn et al., 1991) evaluates each medication according to the number of medications, frequency of doses, additional directions to be followed, and mechanical actions necessary to administer the dosage."

#### Notes:

I wasn't even aware of this, and it may be something we should refer to once we know what medications are prescribed for Alzheimer's and TBI.

Topic: DRUGS - Drug Regimen Unassisted Grading Scale and User Testing tasks

#### Quote:

"The Drug Regimen Unassisted Grading Scale (DRUGS) (Edelberg, Shallenberger, & Wei, 1999) uses an ecological approach to examine performance on tasks designed to simulate drug adherence behavior. The following tasks were measured for each prescription medication: (1) identify medications correctly, (2) specify the correct dosage, and (3) specify the correct timing of dosage. A fourth task, accessing the containers, was omitted for this study. "

#### Notes:

Three tasks to test in user testing and effectiveness of design

Topic: Dementia deficits scale

Quote:

"Awareness of deficits was measured using 3 subscales of the Dementia Deficits Scale (DDS), 28 items that measure awareness of cognitive and functional deficits and general loss of awareness (Snow et al., 2004). "

#### Notes:

Awareness that there are tests to measure deficits. This could be a question for doctors to address in interviews, and how how design could help assess cognitive function.

Topic: Importance of in-home visits

Quote:

"In-home inspection of medications has been found to result in more accurate assessment of medications being taken when compared to clinic visits (Yang, Tomlinson, & Naglie, 2001)."

Notes:

We should make a point of conducting our patient caregiver interviews in-home.

Topic: How important are caregivers in medication management

Quote:

"Eighty-five percent of the AD group informants reported providing assistance in managing their relatives' medications."

"It is important for an informal caregiver to accurately assess the care recipient's ability to manage medications in order to assure that a safe level of adherence is achieved. Informants of both AD participants and non-impaired individuals were able to accurately predict their relatives' performance levels on the DRUGS tasks. AD informants also accurately predicted the actual adherence rates of their relatives, while the informants of non-impaired participants over-predicted adherence."

"Both groups achieved 84% adherence, with 70% of AD respondents and 65% of non-impaired individuals scoring 80% or higher. This

acceptable range of adherence for the majority of AD participants is likely due to the support provided by informal caregivers, who appeared to play an important role in assuring adherence rates that were comparable to those of non-impaired older adults."

#### Notes:

Important consideration for role caregivers play in medication adherence

Topic: types of help from caregivers

Quote:

"...qualitative descriptions of assistance were content analyzed and categorized into 5 types:

- none,
- minimal (very occasional reminders or check of pill box),
- verbal/visual (regular reminders and/or frequent pill box check and/or sets up lists),
- physical (sets up pill box),
- and complete (dispenses dosage)."

#### Notes:

Important design considerations for types of help AD patients need for medication adherence.

Topic: Highest adherence rates in AD patients Quote:

"Interestingly, AD participants receiving only minimal assistance with their medications and those receiving physical help had the highest mean objective adherence rates, 96.7% and 92.3%, respectively."

#### Notes:

Design consideration that total pill management may be the best option to consider for highest adherence rate.

Topic: Lowest adherence rates

Quote:

"Those receiving no assistance and those receiving verbal/visual assistance reported the lowest mean objective adherence rates."

#### Notes:

Design consideration: verbal/visual assistance alone is insufficient intervention

Topic: Ability of AD patients to assess their awareness and performance

Quote:

"There was a positive relationship between scores on the dosing and timing tasks and prediction of performance of these tasks, which could be related to the tendency of older adults to rely on their memory of previous functioning rather than assessment of their current abilities. Non-impaired individuals may have predicted their performance more accurately because their abilities to perform had not deteriorated to lower levels, thus there was little or no discrepancy in their past and current performances. AD respondents may have perceived their current performance as matching their pre-illness competencies, especially since most were relying on their informant/caregivers to manage their medications. Thus, they may have lacked adequate feedback of their current management skills."

#### Notes:

Design consideration of user assessment of effectiveness.

# Topic: Two successful intervention techniques **Quote:**

"Informants of AD participants who chose a management strategy that included all aspects of their relatives' regimen, including dispensing each dosage, were caring for individuals with much lower MMSE scores and lower levels of awareness than were those of all other strategic approaches. This suggests an informant/caregiver approach consistent with the care receiver's level of cognitive decline."

"Another group using an appropriate strategy, those providing only minimal or occasional assistance, reported consistently high adherence rates. This group had the highest MMSE scores and, with the exception of one individual, the AD respondents were able to predict their DRUGS skill levels perfectly, suggesting that early stage

individuals may be capable of managing their medications with very little assistance."

"Adherence rates were lowest among individuals receiving the strategy of regular reminders without set-up or dispensing assistance, while those receiving set-up assistance reported much higher adherence rates, despite their lower mean MMSE scores and more complex regimens."

#### Notes:

Identifying user groups and design requirements

# Citation

Henriques, Maria A., Maria A. Costa, and José Cabrita. "Adherence and medication management by the elderly." *Journal of clinical nursing* 21.21-22 (2012): 3096-3105.

# Topic: Adherence Interventions Quote:

"Adherence increases for interventions applying special medication packaging, dose modification, participant monitoring of medication effects and side effects, succinct written instructions and standardized (not tailored) interventions (Conn et al. 2009). Interventions that improve medication adherence for people with chronic condition are essential. Psychosocial interventions engaging people in self-management of medication offer potential for improved patient outcomes in complex diseases (Williams et al. 2008)."

#### Notes:

Design requirements and scope of medication management system. Packaging and medication side effects are beyond the scope of our project, but information management could be improved and part of our design.

Topic: Consideration of long-term illness adherence **Quote:** 

"Some interventions can be effective in increasing adherence and health outcomes (Banning 2004, 2008, 2009, Connor et al. 2004, Higgins & Regan 2004, Hughes 2004, Haynes et al. 2009); however, in long-term treatments, it is important to simplify the treatment regimen and consider a set of complex interventions ensuring interaction with the patient, and in complex regimens in the elderly, there is no evidence that the interventions have an impact on increasing adherence (Krueger et al. 2005, Haynes et al. 2009)."

#### Notes:

This contradicts the findings in the previous article about complexity with AD patients and may be worth looking into further.

Topic: Three factors of medication adherence interventions **Quote:** 

"We took as a framework a priori conceptual model of medication adherence interventions by Ruppar et al. (2008, p. 133), 'A conceptual model of medication adherence interventions ... The factors that are involved:

- (1) patient-centred factors (knowledge, skills and attitudes about medication,
- (2) Factors of medication and
- (3) Factors of administration of medication'."

#### Notes:

Design requirements for consideration. We can likely only address the third, but it may help consider the other two.

Topic: Results of qualitative research and strategies used to manage medication by elderly patients

Quote:

"The content of discussion was analysed, and categories and subcategories identified. Of data analysis, four categories emerged, which describe the interpretation and strategies of people aged 65 years or more and with chronic illness, managing their medication: to live with drugs, taking medication, belief about drugs and relationship with health professionals (Table 1)."

Table 1 Categories and sub-categories of the medication and strategies used for management of medications by older people who manage their medication

| Categories                                | Sub-categories  |
|---|---|
| Living with drugs                         | Benefits of drugs Adaptation to adverse effects Lifestyle Past experience of illness Medication adherence Help family |
| Take medicine/Consumer<br>multiple drugs  | Age and medication Habits Case Find Change Information Thoughts and unanswered questions                              |
| Beliefs about medicines                   | Attitude towards drugs<br>Acceptance  |
| Relationship with health<br>professionals | Relationship with the doctor<br>Relationship with the nurse<br>Trust<br>Professional help                             |

#### Notes:

These are design considerations to review during ideation. The subcategories are helpful like lifestyle )could include travel), habits, information needed.

## Citation

Hayes, Tamara L., et al. "Medication adherence in healthy elders: small cognitive changes make a big difference." *Journal of aging and health* (2009).

Topic: Statistics

Quote:

"More than 75% of people aged 65 and older take prescription medication, and on average they take 3 or more medications a day (Helling et al., 1987; Ostrom, Hammarlund, Christensen, Plein, &

Kethley, 1985). Unfortunately, more than 50% of these individuals are nonadherent to their medication regimen (Botelho & Dudrak, 1992; Kendrick & Bayne, 1982), which can have tremendous impact on their health."

"In a study of 2169 community-dwelling older people, Yee and colleagues found that drug-related visits accounted for 12.6% of all emergency room visits, at a cost of \$1.5 million over a 12-week period (Yee, Hasson, & Schreiber, 2005). Of these visits, 19% were directly related to medication nonadherence."

#### Notes:

Important to have statistics to back up claims and justify design decisions.