Chapter 28

'Keep Taking The Medication': Assistive Technologies For Medication Regimes in Care Settings.

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"Visions of what technology can do… are rarely based on any comprehensive understanding of needs". Tweed & Quigley (2000)

28.1 Introduction:

This paper presents some of the early design work of the 'Care in the Digital Community' research project - begun under the EPSRC IRC Network project EQUATOR. One objective of the project is to improve the quality of everyday life by building and adapting technologies for a range of user groups and application domains. Consequently, it is very much concerned with developing supporting technologies based on a comprehensive understanding of user needs. Meeting this objective will require us to address fundamental and long-term research challenges in how computing technologies and concepts relate and adapt to a range of everyday domestic environments, including those characterised as 'care' settings. The Digital Care project employs a multidisciplinary research team to facilitate the development of enabling technologies to assist care in the community for particular user groups with different support needs. The general aim is to examine how digital technology can be used to provide various kinds of support to sheltered housing residents and their staff. Although the project anticipates exploring the affordances of a variety of technological configurations, including the use of virtual environments replicating real world situations and the use of handheld and

wearable digital technology, the focus of this paper is on our early work on providing support for the medication regime.

Gaining a comprehensive understanding of needs or a perspicuous view on user requirements in this domain poses a number of interesting methodological challenges. It is not just that many of the important ethical and deployment issues concerning the development, deployment and evaluation of real systems remain unexplored, but that methods for eliciting needs in such a complex setting are relatively under-developed. Moreover, any system of determining needs must reflect the complexity of this multifaceted state (Sheaff 1996). There are issues concerning the translation of the identified needs into a realistic, practical solution that can enable the person within their daily routine.

Domestic environments in general and 'care' settings in particular are very different spaces from working environments and represent a very different set of challenges for those involved in the design of systems . Technology can benefit disabled and older people.

> *The benefits can be measured in terms of the extent to which they may be able to live more independently and, importantly, the extent to which they may be empoered and socially included though availability and use of such technologies.* (Fisk 2001(a): 119*)*

When technology is incorporated within the home, the people who live with the technology on a day-to-day basis have tended to be overlooked (Tweed & Quigley, 2000). It is also important to recognise that the imposition of technology must be undertaken in such a way that it does not remove choice and control from the user (Fisk 2001(b))These people not only include the occupants of the living space but the support workers and others who have regular access to the domestic space. Technology can be incorporated into the person's lfe, such that they come to depend on it as Lupton and Seymour (2000) suggest:

> *Any human body using any form of technology may be interpreted as in some way adopting prostheses to enhance its capacities. Nearly everyone in contemporary western societies has developed a close dependency on technologies to function in everyday life, such as using spectacles to see clearly or a car to achieve greater mobility. As this suggests, the category of `disability' is not fixed, but rather is fluid and shifting, a continuum rather than a dichotomy.*

The nature of the home, and the character of everyday homelife is evolving and undergoing constant change in definition and as such is required to become responsive to the needs of people throughout their whole lifetime, and in most circumstances. Any design process requires the designer to consider the home from a proactive and lifetime perspective:

> *The home as a fixed entity is unresponsive and unable to accommodate the new demands placed upon it. The social care/ housing sectors act as reactive bodies to situations such as this and provide mechanical aids to enable the individual to reside within the home, but here there are obvious limitations and constraints embedded in this process. The home, it is contended, should be considered as more than just a physical entity.* (Dewsbury and Edge 2001)

The Digital Care project has begun to explore some of the methodological options open to those working in the domestic domain, in particular, the translation

of research into design recommendations and the attempt to uncover, elicit or validate 'requirements'. The problem is that research in these contexts is often regarded as not merely difficult but often inappropriate and intrusive. The deeply personal nature of many social activities limits just *what* can be investigated, as well as *how* it can be investigated, and reporting the interactional elements in a range of activities and contexts is often difficult. These and other delicate issues represent potentially obdurate problems and methodological responses have taken a number of forms. At present the Digital Care project research method for technology development includes experimenting with combinations of ethnographic study, user-centred design and evaluation and the use of 'cultural probes' with both residents and staff.

Ethnographic studies (Hughes et al 1994) claim to provide a ‘sensitising’ to the 'real world', 'real time' character and context of everyday life and the facilitation of what Anderson (1994) calls ‘the play of possibilities for design’. As part of this project we are undertaking long term ethnographic, observational studies of the work of the staff as well as more 'lightweight' ethnographic studies with residents. However, the precise nature and value of the ethnographic input into design is controversial especially since much of our experience comes from ethnographic investigation of the workplace. It may be that we require significant shifts in our investigative techniques as well as in our understanding of design, to consider how technology relates to domestic, specifically 'care' settings and the requirement to support everyday living rather than productivity. One way in which we have attempted to increase the repetoire of available techniques is through the employment and adaption of 'cultural probes'. 'Cultural Probes' (Gaver et al 1999), originating in the traditions of artist–designers rather than science and engineering, and deployed in a number of innovative design projects (e.g. the Presence project) may prove a way of supplementing ethnographic investigations. We use 'cultural probes' (cameras, diaries, maps, dictaphones, photo-albums, postcards etc) in the Digital Care project, as a way of uncovering information from a group that is difficult to research by other means and as a way of prompting responses to users emotional, aesthetic, and social values and habits. The probes furthermore provide an engaging and effective way to open an interesting dialogue with users.

The eclectic approach adopted by this project attempts to meet some of the ethical and moral dilemmas through careful involvement and acknowledgement of users in the design process. One particular technical concern, perhaps a dominant if unusual concern for a research project, is that of dependability and associated issues of diversity, responsibility and timeliness (see the DIRC project). Given the care setting it is imperative that technologies designed for the setting are reliable and dependable. Sidsel Bjorneby (2000, 37) notes that the reliability of the technology is essential. Just as technology can enable it can equally be the cause of disablement and low self-concept. In amongst the technical challenges are other issues concerning the location of the interface, the generalisability of design solutions, the transfer of skills to real world situations, and support for independent living in the community. These challenges highlight some of the moral and ethical components of the design enterprise, in particular the need to carefully think through and balance issues of 'empowerment' and 'dependence'. As Gitlin (1995) argues:

> *The use of technology appears to present dramatic compromises in social activities, role definition, and identity.*

The challenge for the project is to provide support for individuals in the move towards independent living, rather than create new, technological, forms of dependence. This requires a certain ethical awareness and recognition of the various ways that technology can impinge on individual care pathways and a sensitivity towards the social implications of any technological intervention as well as an awareness that technology is not a static imposition but combines a range of ideologies in its imposition as Feenberg (1996) suggests:

> *Technology is a medium in which instrumental action coordination replaces communicative understanding through interest-biased designs. Simply put, sometimes technology is overextended, sometimes it is politically biased, sometimes it is both. Several different critical approaches are needed, depending on the case.*

Embodying a philosophy of care into design necessitates considering issues of empowerment and dependence and then thinking how these might usefully become incorporated into design guidelines.

28.2 Background and Setting: Hostel and Semi-independent living.

The setting for the project is a hostel and nearby and associated semi-independent living accommodation, managed by a charitable trust, for former psychiatric patients in a large Northern town. The hostel is the first step for patients leaving the psychiatric wards of local hospitals that are currently being closed down. In the hostel residents are provided with a room and are monitored and helped to develop independent living skills by a number of staff. Residents can then move on to the other, semi-independent living site of sheltered housing consisting of a number of flats and bed-sits, prior to moving out to flats in the local area, or, if they are deemed to need further and continuing support, back to the hostel. The overall aim of these facilities is to gradually introduce the patients back into the community and allow them to support themselves. Emphasis is on the learning of daily living routine and skills. As a general principle any technology introduced into the setting should contribute to this goal. A technology that merely completes a task for residents does little in producing independence but merely shifts reliance onto the technology.

28.3 Supporting Medication: Fieldwork

Although our research is at an early stage, a number of issues and requirements have already arisen. Initial introductory and debriefing meetings at the hostel and the semi-independent living accommodation and the early ethnographic fieldwork and return of cultural probes currently indicate some major preoccupations of both residents and care workers. One important concern of both residents and staff

focuses on issues surrounding the routine taking of daily medication. Many of the residents are on daily medication regimes and at the initial meetings as well as in interview a number of residents expressed concern about the possible grave consequences of them forgetting to take their medication. Observation and interview confirm the role of the medication regime in the maintenance of normal everyday life and residents emphasised their, often graphic, fears and anxieties over the likely consequences of forgetting their medication.

Medication issues - dosage, delivery of 'medi-pacs', reminders, re-assuring residents about delivery and so on also feature heavily in the everyday work of the staff. At the hostel medication is kept in a locked drug cabinet, distributed by the staff when required with records kept in a written log. At the semi-independent living site patients must manage their own medication and, as stated, it is a source of continuing anxiety. Although provided with a week's supply of packaged daily doses by the pharmacy - 'medi-pacs' - there is some concern that they may either forget to take their medication or accidentally overdose. Technical devices that may prove useful in these circumstances are various medication reminders that help patients manage their own medication, i.e. when to take it, record acknowledgements of reminders and so on allied with a system to automate the recording of drug information. But the functionality of any technology provided must be carefully considered and sensitively deployed. The devices are intended to act as 'reminders' to residents to take their medication and are not indicators that any medication has been taken and obviously such devices must be dependable as failure of the technology could have potentially disastrous consequences.

Where residents are responsible for taking their own medication, this fact has significant implications for the way in which medication is monitored and tracked. For example, the use of a bar-code scanning approach would place an inappropriate burden on the resident. One possible approach we have considered for the hostel has been to use RFID-based smart labels in order to ascertain whether a resident has taken their medication from the medication store - as used in the ‘Magic Medicine Cabinet’ system (Dadong 1999). Another possibility we have explored is building certain reminder and recording features into the 'medi-packs' themselves. While this will not control the medication regime to prevent deliberate overdosing, it may contribute to the prevention of accidental overdosing. Some instances from the early fieldwork - coincidentally occurring on the same day - illustrate this point. In one case the care worker, following a phone call from the resident's doctor was concerned to intercept the delivery of a 'medi-packs' in order to replace one dosage of tablets with another. In another incident there was some concern that an elderly resident was accidentally overdosing as a consequence of the design and delivery system for the 'medi-packs'. As the 'medi-packs' are delivered from the pharmacy at about 6:30pm the resident was required to take only the evening dose for that day, leaving the two earlier doses to be taken the next week. Problems were arising both because the resident, used to emptying each daily dose, was accidentally overdosing by taking all the medication for the delivery day, but also was being left with no morning or afternoon medication for the same day on the following week. Finally, one of the residents deliberately overdosed by taking all the medication in the newly delivered 'medi-pack'. This incident also highlighted other issues to do with medication and the recording of,

access to and integration of information as the care worker gave information on the resident and the medication to the ambulance service.

28.4 Requirements

The initial studies have identified a range of requirements regarding the resident's medication and the design of technologies to support the medication regime (Cheverst et al 2001). In the semi-independent living area residents are expected to manage their own medication and weekly supplies are provided by the pharmacy packaged into individual doses within a plastic container known as a 'medipack'(*figure 1)*. This arrangement causes anxiety and inconvenience for both staff and residents. Residents, who have previously relied on the staff to provide their medication at the correct time, must now depend on their selves to remember what to take and when, leading to worries about missed medication, taking pills at the wrong time or even accidental overdoses. This in turn, leads to residents relying on staff to provide reassurance about the medication and in some cases reminders of when and what to take. This kind of reliance is of course, detrimental to the aims of the semi-independent unit and a solution that bridges the two stages was thought to be desirable.

In order to achieve this intermediary stage residents primarily need a system that will reassure them that they are following the correct regimen, whilst leaving the task of managing their medication in their own hands. It is important that the system does not take over the task for them completely as many commercial products attempt to do by fully automating the dispensing of drugs at the correct time. The aim here is not to automate a task and remove a cognitive load, but to encourage self-reliance and allay any fears of getting it wrong. In addition to these requirements it would also be desirable to provide some form of unobtrusive feedback, accessible by the staff for monitoring the residents progress. This function of the system may be also be used to alert the staff to possible problems such as a deliberate overdose.

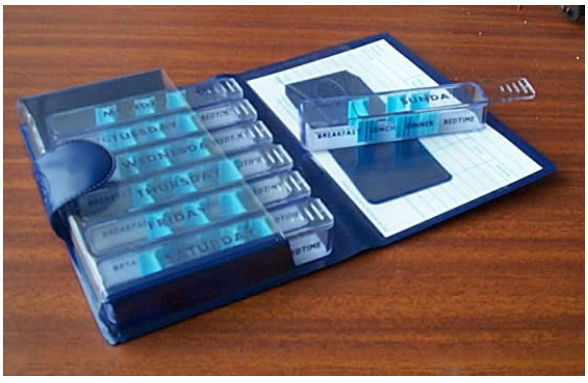

Figure 28.1. A 'medipack'.

28.5 Medication manager or 'MediPic'

Initial design proposals looked at augmenting the medipack, but observation showed that residents did not tend to carry the medipack with them and therefore a mobile system was not required. The current system consists of a simple box divided into compartments separating individual doses. This compact form-factor can be easily restocked and delivered to the resident's accommodation and is therefore a positive point to carry over into the new design. The box itself would not be augmented but exist as a replaceable 'cartridge' for a separate housing containing the medication management device. *Figure 2* illustrates the design for the initial prototype device.

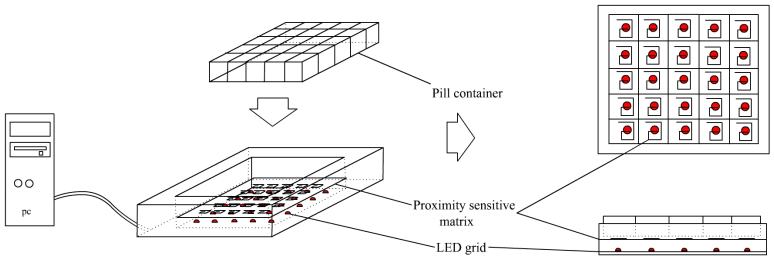

Figure 28.2. Prototype medication manager.

The transparent pill container sits on top of a layer containing a grid of coloured light emitting diodes. Looking from above, each compartment has two lights to indicate which pills can be taken and which not. In this case red and green lights are used, red for stop, green for go as it is a familiar colour combination. However, it should be noted that these colours may pose a problem for some people with colour blindness and can be easily replaced with another combination. Once a pill is taken or has been missed the lights go out indicating that the compartment is no longer 'live', and should be ignored. An initial prototype (*figure 3)* has been constructed using this design.

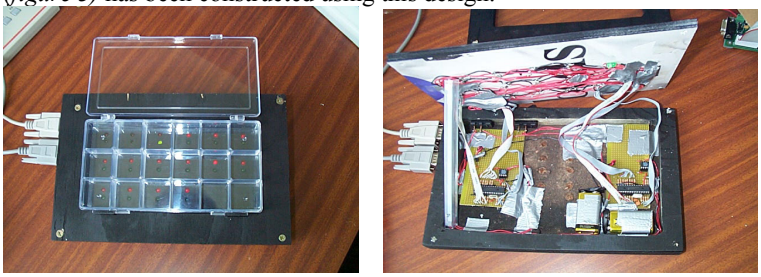

Figure 28.3. Version 1 of the medication manager. Internal view shows two circuits controlling two banks of LEDs.

Control of the lights is through a simple micro controller circuit (*figure 4*), which receives commands via a serial connection from a PC. The use of a PC as

the controlling system for the medication manager, simplifies development and future prototypes will consist of an entirely embedded system. At the moment software on the controlling PC provides a calendar function controlling the lights directly (*figure 5*). This design provides residents with visual reminders of when to take medication and provides reassurance that the correct medication is being taken. Omitting the use of audio reminders or other more tangible reminders, forces the resident to actively check on the current state of the lights thus reinforcing the routine.

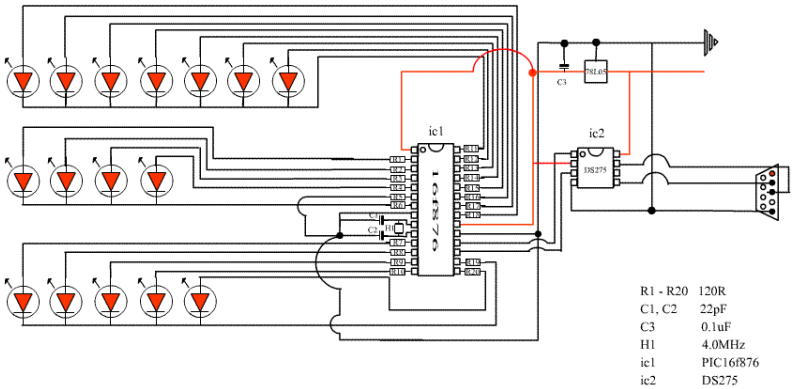

Figure 28.4. Basic circuit for serial light control in the medication manager.

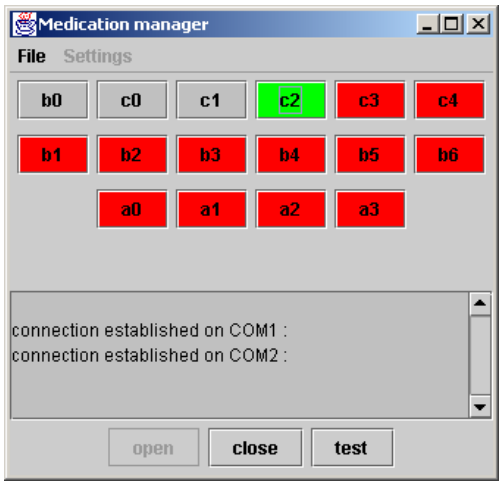

Figure 28.5. Screenshot of medication management software.

28.6 Conclusion: Further work and research challenges.

The next version of the medication manager will be larger to allow the management of a week's supply of medication. This will involve the use of a more complex micro controller with a larger number of bi-directional I/O ports. The PIC16f876 (Microchip 2001) currently being used, has a simple 35-word instruction set and is relatively easy to program, however, this chip has support for only 16 lights (= 4 days). The initial prototype design also includes support for feedback to the staff, though this has yet to be implemented. The design incorporates a layer of 'charge transfer' touch sensors, which can be activated through the pill container, registering a touch on the bottom surface of the container as a pill is removed. Version 2 of the prototype will incorporate this technology and will allow staff to gather data on a resident's progress in this area. This may also be of help in an emergency situation where a deliberate overdose has occurred. Information on what has been taken will be available and an early warning may be possible.

Further work is also needed to address dependability and feedback issues. It is extremely important the system function in a dependable manner before any thought of field tests is considered. We must remember that this application domain requires high standards of reliability as any failure of the system could affect the residents in an extremely adverse manner. Clearly much of the potential of assistive devices relies upon the successful operation of a range of new technologies as well as the readiness of users to accept and embrace a new technology. Just as we should not allow ourselves to rely upon overly negative stereotyping of these particular users, so too must we avoid the temptation to make exaggerated claims as to their technological adeptness. Instead we make the case that special thought needs to be given to the design of technological artefacts, that takes into account such factors as a different learning curve and a different place for the artefact within the lifestyle of the user.

Over the coming months we will be deploying the chosen solutions within the setting. This deployment process will itself raise a whole series of important and necessary issues for research into assistive technologies. Following deployment a period of evaluation will commence which (in addition to raising further issues) will no doubt lead to refinements in our initial set of requirements and therefore modifications to our adopted approach. In particular we anticipate the emergence of design challenges in matching generic and specific requirements with available technology; in addressing the 'tailorability' of COTS systems and devices; and in ensuring the delivery of genuinely mobile and dependable devices.

At present we envisage a prolonged period of extensive continuous testing to determine the systems performance, before deployment in the setting. In addition a number of design workshops have been scheduled both for user evaluation and feedback and for considering the integration of the medication manager with other devices - such as interactive picture displays or digital family portraits (Mynatt et al 2001) - that may be incorporated into the resident's home, as well as consideration of training and tailoring issues. The medication manager is thus part

of an iterative design process (Clarkson and Keates 2001), in which problem specification, matching the system to the real world and evaluation should be a continuous process. In this view design issues do not cease with the initial deployment of the device or initial evaluation, with everything occuring after this being given the status of 'maintenance'. Instead deployment is regarded as yet another opportunity for design considerations to be highlighted, challenged and reassessed.

This paper has presented our early work on a project investigating the role of computing technologies in supporting a community housing project. The driving aim of the project is to explore the extent to which the requirements of a community care trust can be met by technology whilst staying within the political and ethical boundaries imposed by the given application domain. In devising a medication manager, an assistive technology supporting aspects of everyday life seldom addressed by conventional computers, we are also faced with the research challenge of investigating new aesthetics and new functionality in support of a wider range of personal and social values.The challenge is to understand how best to integrate devices into our surrounding environment and how these may be used as part of everyday life (see Dewsbury 2001). We need to ask whether current approaches to design are appropriate in such complex care settings. The preliminary research of the Equator project suggests that new conceptual models, theories and guidelines are needed for explaining and informing the design of these emerging technologies. It also requires a shift in our thinking about research, towards using and developing theories, practices and techniques that are interdisciplinary.

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The DIRC Project - go to http://www.dirc.org.uk/

The Equator Project - go to http://www.equator.ac.uk/ For greater detail on the construction of the medication manager go to http://www.equator.ac.uk/digicare/

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