

MATCH

Mobilising Advanced Technology for Care at Home



Theatre Study

Emerging Themes

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Introduction

A number of methods exist to gather user requirements from and about people who require care at home to inform the design of home care technologies. However, there are limits in the extent to which user requirements capture for future home care technologies can be determined by asking potential system users what functionalities or services they would like to see from these emerging technologies. Live theatre offers the possibility to demonstrate, using drama and props, a possible future home environment involving technologies for care at home that currently do not exist, and the interaction of people with such technologies. Live theatre has been successfully used for user requirements gathering, particularly to facilitate focus groups with technologically naïve people and for raising designers' awareness of the challenges of designing for older people. In the MATCH context, live theatre served as a communications mechanism allowing potential users to engage fully with a novel home environment scenario, and thus provide valuable design data for future home care systems.

Background

The School of Computing at Dundee University has experimented with the use of drama, both video and live theatre, for requirements gathering with older users for novel technologies [3-10]. Theatre, whether live or on video, has the ability to 'pretend' - so undeveloped technology can be presented as real and working. Theatre enables scientific concepts and novel technology, with their esoteric language and jargon, to be translated into everyday life, thus enabling the audience to apply them to their own situation. In addition stories, with 'real' characters, with whom the audience can identify, help the audience engage with problems and questions encountered.

The script writer initially discusses the research questions both with researchers and with potential older users of the technology. On the basis of these discussions, and a number of iterations with the researchers, a script is produced that addresses the issues that are important to the researchers. The structure of the script is in the form of a dramatised story including tension and conflict to achieve drama. Characters resisting or struggling with pieces of technology introduces tension and asks questions. The theatre creates the "story of an interface", where an audience can look at a piece of technology, its possible usefulness, design and usability, and how a human being interacts with it, the human being having attitudes, emotions, physical difficulties and needs.

The scripts are designed to encourage dialogue between users and designers, and are based on a genre specifically designed to encourage audience participation - Boal's "Forum Theatre" [11]. This has been modified by Morgan who has used these techniques extensively within professional training for communication skills (e.g. within palliative care, and the training of medical students) and in community consultation (including with seniors). More recently she has developed this technique further for requirements gathering and raising awareness amongst Information Technology designers of the characteristics of older people. Short plays, lasting from five to ten minutes, are enacted and this is followed by a discussion with the audience (the Forum) and between the audience and the actors (who stay in role). All discussion, debate and criticism are focussed on the story which enables both users and designers to discuss, argue, inform and share needs and experience in a very safe way. This very safely allows users and designers to draw on and share their experiences. This can be particularly useful in an area where individual needs and disabilities are subject to very wide variation.

The Dundee group have always worked with theatre professionals, script writers, directors, actors and facilitators, and believe that the use of professionals in these roles contributes greatly to the success of the venture [12,13]. The genre has been shown to be very powerful for facilitating dialogue about sensitive issues and has been shown to change the mind sets of the audience.

The use of Forum Theatre within the MATCH Project

Within the Match project it was decided to use Forum Theatre as part of a requirements gathering exercise. When considering requirements for technology to support care at home a range of stakeholders are involved. A typical range of stakeholders for a project such as MATCH could include health care professionals, social care professionals, informal carers, older people, disabled people, policy makers, decision makers, researchers and legal and ethical experts [1]. These stakeholders have different perspectives, and different, sometimes contradictory views of the way in which home technology might be used and would fit into the daily routine of users and both professional and informal carers [1]. This raises sensitive issues, and the response of any group of stakeholders may well depend upon the way that the group is constituted. Certain groups might dominate others in discussion sessions, for example, to the detriment of others. The theatre study was therefore designed not only to gather requirements to inform the work of the MATCH team, but also to empirically investigate ways of facilitating discussions with multiple stakeholders both in mixed and separate stakeholder groups. This was done using a qualitative approach to examining the responses and interactions of the different stakeholder groups across both days.

Three scenes were developed – these consisted of:

- Scene 1, showing a typical older couple (Fred and Shirley) with complex care needs living in their own home;
- Scene 2, after an acute event (Fred had a stroke) a case conference takes place between Fred and Shirley's daughter, their case manager and a technology provider, the aim of this being to try to see how home care technology might assist Fred and Shirley to remain independent;
- Scene 3, showing Fred and Shirley back in their own home with a variety of new technology and their varied experiences with it.

The process involved was that each scene was enacted, followed immediately by a period of facilitated discussion. This employed a number of special techniques. The thought bubble technique – with the facilitator asking questions such as “how would person A be feeling right now?”, “what do you think person B would do/say next?” proved to be very useful, the facilitator ensuring themes and issues to emerge without any particular bias caused by the specific characters in the play. There were also significant benefits to asking the actors to respond “in role” to questions from the audience. The actors were well briefed and were thus able to respond in such a way as to open up more debate or further explore the issues raised. This was found to be a particularly successful way of encouraging the audience to empathise with the characters in the play (and thus with future users of the technology which was being portrayed).

The study ran over two days. In order to investigate the effects of stakeholders being together or in separate groups, stakeholder participants saw all three scenes of the play in the theatre together on the first day. Each scene was followed by discussions, with a final plenary discussing the whole play. On the second day, however, participants (N=13) were separated into distinct stakeholder groups. From the potential stakeholders that the MATCH team had identified, three main groups were selected for this study. These groups were: older people; health and social care professionals; and home care technology researchers (including health policy research). The older people (potential service users) were the stakeholder group in the theatre. This group watched the play in the theatre, again with discussion after each scene. The other groups watched the same performance broadcast live from the theatre into their separate rooms. The groups only joined together as a mixed group for the final plenary discussion. Overall, 20 participants saw the play over the two days of the study.

Language barriers emerge when multidisciplinary groups are brought together and it is essential to be aware of any potential variations in language used across different disciplines. This is particularly important in home care technology where the area is already not well understood by its potential future users. For example, the term “technologist” was assigned by MATCH to describe those people who are involved in the design or building of technologies for care at home. However, social and health professionals used the term “technologist” to refer to those who are involved in the assessment of or the prescribing of home care technologies.

The study therefore revealed that there is a challenge in categorising stakeholders in that people may belong to more than one group (e.g. a carer may also be old and thus a partial user of home care equipment), and it is important that all the users are appropriately assigned. There is also a question as to whether the research team should assign people to stakeholder categories or should people assign themselves? MATCH decided on their

own stakeholder categorisations (e.g. McGee and Gray [1]) and gave a clear definition which allowed stakeholders to be clearly assigned to these MATCH pre-defined categories.

Theatre Data Analysis

The data collected consisted of:

- The script (text)
- The performance (video)
- Observation field notes (text)
- Dialogue/interaction (video/audio)

The approach to the qualitative data collected was to explore the different themes that emerged to

- identify issues and themes important to the various stakeholders (both within and between the different stakeholder groups) and
- to explore the effects of having stakeholders in single stakeholder groups vs. mixed stakeholder groups

Three researchers each took an independent set of structured observational notes during each of the theatre performances and the discussions that followed. Analysis of the data followed the framework analysis [14] approach. The three researchers developed descriptive codes from the observation notes and these were then validated by discussion. The following is a consolidated list of the agreed emerging themes that can inform the design of home care technologies. Full data analysis from the study based on the video recordings is underway and results will be presented in due course.

EMERGING THEMES/ISSUES

(1) Emotional / Feeling

FEAR	Fear that if help is asked for that one will be put into a home. People are often scared of the unknown, being separated from partners or loved ones or their independence being taken from them.
PRIDE	Pride can stop people from asking for help (technological or otherwise).
ANXIETY	Some frail elders may be prone to feelings of anxiety and therefore technologies that require response from the user may be less appropriate.
LOSS OF CONTROL	People don't want to feel controlled by the technology itself.
INDEPENDENCE	Users may not want technology to reduce their independence.
TRUST	Two way trust and respect must be established between care providers and other stakeholders and the clients/users. It is important that the client(s) have confidence in the people introducing the technology and the technology itself.
STRESS	Technology has the potential to relieve stress but also to add stress due to frustrations operating the devices.

(2) Technology

SENSORS	What do sensors look like and where are they placed? How is the sensor data processed? Who can see the data from sensors? In what format? Who has control over who sees it and what can be done with it?
CAMERAS	Use of cameras requires consideration depending on the attitudes of the client(s) and the intended use of the images from the camera. In the right environment the reaction to cameras may be positive.
MONITORING	The advantages of monitoring have to be realised by those being monitored before they become acceptable. They are often required or requested by a spouse or friends or family rather than the client. This has to be negotiated with all concerned.
FEEDBACK	How should data that is collected about a person in the home be reported to the resident and the formal and informal carers? What information is useful to know? What information is appropriate to be viewed by the different parties involved in the dialogue of care?
MAIN CONTROL UNIT	If there is going to be a main control unit it needs to be accessible but non-obtrusive. Will this be purpose built or via an existing device such as the TV or phone?
REMOTE INTERCOM	A remote intercom system would allow communication between Fred and Shirley when they are not together.
REMINDER SYSTEMS	Can be very useful if tailored to one person's needs. This has to be balanced with the fact that it might annoy other people in a shared living space. One solution might be to provide a reminder system which adapts to multiple users and contexts.
MULTI-MODALITY	Sensory, cognitive, and physical impairments demand that several modalities of interaction be available. This also suits variation in preferences and context.
COGNITIVE SUPPORT	Systems should have memory/cognitive support where possible.
PERSONALISATION	– Technology/interfaces should be configurable to suit the users.
CONFIGURATION	The system should be configurable. This may be done at the design stage, at set up, or during run time. Who has control over the final configuration of a system? The user, the care providers, or the friends and family? Perhaps negotiated configuration should be supported. Appropriate methods for user configuration need to be explored.
HIDDEN FUNCTIONALITY	Don't assume that everyone requires reduced functionality. Sometimes the solution might be to hide certain features and reveal them incrementally.
PORTABILITY	Could there be a portable version that people can take away from the home?
SWITCHING OFF TECHNOLOGY	If the technology or service is unwanted or no longer needed it may be switched off.
DEPENDENCE	What happens if a client becomes reliant on a piece of technology or software that has to be removed for some reason?
LIMITATIONS	Clients should be visited after a period of use to determine any limitations of the technology in place.
TECHNOLOGY OVERLOAD	If too much technology is put into the home too early, it disables instead of enabling the user. For example, if an arthritic person does not have to leave her chair anymore in order to control objects around the home, she may lose a valuable opportunity to use her hands and legs, which results in the arthritis worsening.

(3) Care

CARE PLAN	It is important to have a care plan and even perhaps keep a diary to revisit as the care condition(s) evolve over time. Lifestyle data might be useful for this. Current assessment processes may well provide insufficient detail.
CARE TEAM	There needs to be a 'team' approach. It involves all those concerned making decisions together. However, in the long run, in order for technology to pay for itself, technology should enable care teams to be reduced or existing care teams to take on more cases.
FROM CARE TO SUPPORT	Technology can help to move away from providing care at home to giving support at home (enabling the resident).
HOLISTIC APPROACH	Technology is only part of the solution. It is important that technology is not substituting for activities that are people centred. It is a tool that can assist, not replace. The care plan and the clients progress has to be monitored in terms of both health and social care and well being.
MISINFORMATION	Common problem of true picture not being given to health and social care professionals when giving a care assessment. They are only able to get a "snapshot" of the person at that moment in time and also be given selected information by their client. Technology can be used to discretely monitor the actual day to day situation of their clients. Therefore, technology could also be used to alleviate the problems associated with misinformation or limited information to these professionals when providing a care assessment which could mean that care solutions offered will match the actual care needs.
OBSERVATION	It is crucial that the care providers observe the users/clients in action in their own home to determine what might be useful for them. How does the OT know what they were capable of before their first visit to assess fairly how much they are improved or worsening? A crucial part of observation is real, emphatic listening during assessment conversations.
REPRESENTATION	Need those who are going to be receiving care to be there at discussions about their care. Where possible the cared for should represent themselves and not have another family member/carer take this role as they may have not have compatible views about how care should be delivered.
DEMONSTRATION	Providing demonstrators or visualisations of technology in action increases positive attitude towards technology.
RISK ASSESSMENT	Health and social care objectives often involve assessing and minimising risk. This has to be balanced with maintaining client independence. What are the definitions of RISK? Fire Vs Breakdown of a relationship for example. Additionally, some technologies may be viewed as an infringement of social liberties. However, where placement of these technologies could mean that a person could stay at home for longer, intrusive technologies may be acceptable in this circumstance.
EARLY INTERVENTION	Need for introduction of technology into homes before crisis situations and the level of technology input can be increased as per additional care requirements.
INCREMENTAL APPROACH	Introduce only one piece of technology or one solution at a time. Support needs to be step by step – incremental. Not all at once. Technology should be introduced bit by bit.
SELF MANAGED CARE	It is important to support individuals to 'self manage' and help people care for each other (drive for informal care).
ELECTRONIC RECORDS	Since the stakeholders are distributed across many locations (call centre, GP practice, carers' home(s)), they need decentralised, secure access to the cared-for's health record so that they can help efficiently.

(4) Social/attitudinal

JARGON	Need to get rid of the jargon and language that often surrounds technology.
PESSIMISIM	Worry of providing/receiving care in a new way, i.e. with technology.
ENGAGING USERS	What do people actually want? Need better ways of identifying and capturing this information. Presentations and demos to potential groups of clients would be very useful. The benefits and potential positive changes to the clients should be emphasised.
ACCEPTABILITY	Getting an older couple to move into the world of technology requires them accepting the technology and what it can do for them.
CONFIDENTIALITY	Certain data and certain files would need to be kept confidential. This has to be communicated and accepted by all stakeholders.
WORD OF MOUTH	Word of mouth recommendations from friends or family increase the likelihood of acceptability of new technology.
MOTIVATION	Find out what the clients/users are/will be motivated to do – and support this. This can be different for different people. It is wrong to make assumptions about what the client ‘should’ be doing. This is not always the same as what the client wants to be able to do.
SELF PRESERVATION	A person may hold back in giving information about their care needs and additionally subtly make their carers feel unable to reveal the true situation for fear of the consequences.
LEARNABILITY	It can be more difficult to learn some new things when you are older. As one ages, does one’s desire to learn new things diminish? Memory problems are a particular problem. Some things are still easy to do if they have become automatic or habitual. Maybe solutions should be introduced earlier. It isn’t necessarily the technology that is the hurdle – sometimes it is the nature of the tasks or interaction required that are difficult to learn.
NEGATIVE VIEWS OF TECHNOLOGY	Previous experiences of technology (for example, it is expensive to run a mobile phone) may act as a barrier to those who hold this view accepting these technologies.
PERSERVERANCE	Following on from a negative experience using technology, will users continue to persevere?
INTERDEPENDENCE	Where a couple have varying disabilities they can work together to complete the tasks that they previously would have been able to both complete independently.
SHARED INTERACTION SPACE	Shirley interacts with the technology in one way – Fred interacts with the technology in another and then together there also must be a way for them to interact with the technology as a couple.
PERSONALISATION	Technology needs to be tailored to the carer and cared for’s lives. Minimal interventions need to be chosen that provide maximum leverage.

(5) Practical

TECHNOLOGY MAINTENANCE	Who is responsible for technology and software maintenance?
TECHNOLOGY FAILURE	What back up would be in place if there was a technology failure? Who is responsible?
ENERGY CONSUMPTION	Clients need to be informed of any power/energy consumption effects of the technologies. This might influence their acceptability.
CALL CENTRES	Desire for these to be a 'very' local service where the users may even meet with the call centre team so that they can put a face to a name. Are there enough staff to cope with the number of call centre enquiries that may arise from installing home care technologies? What should the qualification level of the staff be? Trained nurses?
TRAINING/SUPPORT	Who would provide training for the technology? How and when? Would it be one-to-one training? There would need to be some sort of follow up to see how they are getting on and to see how the technology was being used in practice. Training and support need to extend to many stakeholders: carers, cared-for, health and social care professionals who perform assessments, engineers who interact with end-users, and call centre workers who deal with users' calls.
MEASURING SUCCESS	How can we measure if the technology has 'worked'? Not good enough to test if it is operational or being used. Need to measure the social and health impact of using the technology/system. Technology isn't the answer to everything. Sometimes human intervention is the answer.
POLITICAL INFLUENCE	Alzheimer's is a big current concern. The issue of supporting an ageing population is important. Memory problems should therefore be supported with these technologies.
UNIVERSAL DESIGN	Experience of products that are designed for disability and are then adopted by the mainstream public.
COST	There are three important parts to this, cost of technology, cost of assessment, and cost of maintenance/support. In particular, the technology needs to be backed up by call centres who can be effective in troubleshooting and helping users. This requires not only an understanding of the technology, but also an understanding of the users' specific care needs.

Conclusions

The breadth and depth of the issues which arose clearly showed the value of theatre as a way of facilitating discussions of the potential of yet to be developed home care technology. Initial results from the continuing video analysis are providing valuable insights and useful design data. There are clear indications that the groups in rooms other than the theatre were able to engage with the drama even though they were not in the theatre itself. In addition there is evidence that the groups expressed more domain-specific interests when they were separated, rather than on the first day, when they were all together and the researchers/policy group tended to dominate the discussion. Further analysis of the video data will enable us to obtain more detailed information and take full advantage of the protocol used in the study, to determine whether the separate groups produced different data to the combined groups.

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