Including Stakeholders in the Design of Home Care Systems: Identification and Categorisation of Complex User Requirements

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Abstract

Home Care Systems have not been taken up in people's homes as eagerly as might have first been anticipated. Yet with an increasing ageing population and an increased drive to support people living independently in their own homes, there is a continuing need for well designed, acceptable Home Care Systems. The complexity of the requirements of both individuals and the network of care surrounding people in their homes makes providing home care solutions a difficult task. In particular, what is known about, and expected of Home Care Systems is still unclear and can often differ between the various stakeholders involved. This paper is part of a project on Mobilising Advanced Technologies for Care at Home and presents the motivations for including stakeholders in both the design and ongoing configuration of homecare systems.

1 Introduction

An increasing number of people, coping with a variety of illnesses, impairments or disabilities, age related or otherwise, prefer to stay in their own homes to receive care. This is both socially beneficial - they can remain in a familiar environment, close to family and friends - and economically beneficial – it is costly and impractical to provide sufficient specialized care facilities given the increasing ageing population. Advanced technologies can support care at home, but this needs to be done appropriately in order to be accepted. Technologies can be used to monitor situations such as someone being immobile or incapable and therefore requiring outside intervention. Increased networking capabilities can increase the potential for users to send and receive important care information from the comfort of their own home. Such systems, by their very nature, involve a number of direct users and other stakeholders all of whom are interested in and potentially able to influence how the system should perform.

In addition to the person being cared for in their home, there are likely to be partners living in the same space, friends and family living elsewhere who are involved in care or interested in its status, visiting medical personnel such as community nurses and remotely

located medical staff, such as a consultant in a clinic that the patient visits. Each person involved in the system and its development is likely to have very different needs, perspectives, and accountabilities, all possibly changing over time as the condition of the person and the possible behaviours of the systems change. Consultants or GPs, hands on social care professionals, and friends and family involved with care, might all want or expect the system to behave in different ways according to their own personal goals for maintaining the health and social welfare of the person being cared for. This can result in conflict of interests and a system whose behaviour is bound to upset or surprise at least one of the stakeholder categories at any one time. Social and professional conflicts such as these are only examples of the many issues that arise given a complex Home Care System being used within a complex network of care.

In this paper we aim to examine some of these issues from the point of view of home care system design and implementation, considering how the nature of home care technology can help identify and, ultimately resolve, them. We begin by describing in more detail the homecare environment and its stakeholders. We then identify particular issues that can arise and consider ways in which inclusive system design and development methods can address the satisfactory resolution of some such issues.

2 Home Care Systems and their Stakeholders

We define home care as a potentially linked set of services of either social care, health care, or both, that provide, or support the provision, of care in the home. Our focus is on technologically supported home care, in particular those that involve specialised computer systems. Such home care support can range from simple stand-alone electro-mechanical alarms installed in a person's home, perhaps to indicate a bath overflowing or a door left ajar, to systems integrated into the home's physical infrastructure that monitor patient state, perform sophisticated analyses, deliver customised information to patients and clinicians and support communication among them.

We distinguish between

- the social and professional aspects of home care, including the people being cared for, the carers, and any external stakeholders playing a role in the care, their respective roles and interactions with one another, which we call the 'Network of Home Care', and

- the technology used to support and realise activities of the network of care, providing the means to collect, distribute, analyse and manage care related information. Such technology typically includes sensors, devices, displays, data, and networks, and computing infrastructures.

Together we call this the Home Care System.

Making this distinction allows the identification of homecare challenges arising due to technological issues or social issues alone and those that arise due to the complex interactions between the two. The following sections discuss each of these in more detail. We begin by identifying the participants in the network of care and then describe the types of technology that make up homecare systems.

2.1 The network of home care

There are potentially many different stakeholders involved in home care. We characterise these stakeholders into several different basic categories.

- The Cared

Clearly at the heart of a home care system is the person or persons whose health or social welfare is being managed (maintained or improved). It is possible that a single person is being cared with respect to more than one condition. Furthermore, there may be more than one cared person in the same home. For example, the husband may have a heart condition and the wife may be under care for diabetes.

- Carer(s)

We define 'carer' as the person or persons who provide front-line medical, nursing or social assistance. Often the primary carer is a spouse or family member and this care relationship becomes more complex when the carer also requires a certain level of care. In this scenario it is often more appropriate to define a symmetric relationship in which the role of carer and cared for is bidirectional yet potentially changing over time. This type of situation in particular requires that home care systems be configured to deal with different end users at different times and situations. If health or social care support is required, additional carers may be introduced into the network of care. Carers may also want to access information about the cared remotely from a distance.

- Visitors

Visitors include social workers, community nurses, paramedics etc. who may be called out for assistance. The distinction between a visitor and a non-residential carer is perhaps not clear-cut. We can perhaps make the distinction based on the nature of the visit. If the visits happen regularly and in a planned manner, we would classify the role as carer; if the visit is occasional and unplanned, arising from some unexpected circumstance, then we classify the role as a visitor. Visitors might also include those entering an area that incidentally makes them a potential 'user' of the home care system. An example might be a furniture delivery person or a salesman invited on to the premises.

- Remote Users

Some medical and social staff will make use of information from the homecare system or supply information to it even though they don't visit the home itself. It may be that a single person fulfils both the remote user and visitor role, such as a GP. Remote users may also be non-medical. Family members living elsewhere might use the system to maintain awareness of the condition of the cared or perhaps to keep in contact with them.

- Technology Provider(s)

The people designing, making and distributing the individual home care technology can directly impact how the system operates. They too have intentions and requirements of their own which may or may not agree with the various other stakeholder requirements.

- Institutional Stakeholders

Institutional stakeholders are those who are not direct users of the homecare system, but who may influence its form or content. For example, the management of a housing association might place constraints on the type of technology that can be used in their homes. A minister of health might generate an initiative to promote homecare systems for a particular purpose (e.g. emphysema) or for a particular area (e.g., Glasgow).

- Other Stakeholders

There may be others who have an interest in the nature of the system, even though they may never use it. This might include members of the family who live elsewhere but are concerned for the welfare of the cared or have a financial and/or moral obligation towards the cared. This category may also include neighbours who are worried about the potential effect of "special" technology on their own home.

2.2 Home Care Systems

There is a variety of technology that can support home- based care ranging from simple mechanical and electrical devices through to sophisticated ambient technology at the other. At one extreme are simple sensors and electrical alarms that might be found in typical sheltered housing or retirement homes. At the other extreme is an array of interconnected ubiquitous technologies to support healthcare.

The key features of home care systems, from the point of this work, are:

- Sensors provide data about the status of the cared person

These sensors may monitor various aspects of the condition of the cared person: physiological signs (temperature, blood pressure), their movement in the house, their use of appliances. This sensor data may be subject to more or less sophisticated interpretation. The sensors may be carried by the person, be embedded in the home (e.g., a wall-mounted camera) or be attached to the person (e.g., a body-area network).

- Homecare is multi-user

Most systems that exist or are the subject of research have multiple users (see section 2.1). The cared person is probably a data source, but they are often also a user of homecare services, such as personalised symptom management information, medical condition alerts, reminders, etc. Carers may or may not directly use the technology themselves but most likely will use the system to support their care role somehow. Generally speaking, anyone involved in the network of care around a person being cared for at home might be considered a potential user of that homecare system.

- Home care is distributed

Information from a variety of sensors can be correlated and used to build up a picture of the home environment (e.g. to detect an abnormal situation or to guide remote consultation). An important issue is to relate what is happening in the home to the outside world (e.g. to alert a responder or carer). Through the use of sophisticated networking and management software, a variety of care situations can be detected and reported to various users of the system in order that they can respond appropriately to that particular care scenario.

- Homecare System Interaction is multimodal

Home Care systems are often capable of providing implicit, multimodal, and non-standard means of interacting to facilitate a more natural user experience. This may include the use of speech and non speech audio, graphical output delivered via mobile devices or digital television, gesture input and tactile output. Allowing users the choice of various single or combined modalities for different interaction tasks in different contexts is important.

- Homecare system needs are dynamic

Each user within the network of care might have very different needs, perspectives, or accountabilities, all possibly changing over time. Different users within the same network

might want different views onto the same set of health related data and varying access to the input and output devices within the system. Responding to service users' requests on an individual basis may offer a much better route to high quality home care than applying a single definition of quality to all service users. A person-centred approach requires that information about what matters most to each client be systematically collected, kept up to date, and communicated to staff. Carers in general often feel they have a unique personal knowledge and understanding of the needs and preferences of the person they care for and therefore should also be able to influence the timing and nature of services, and be able to implement changes in response to changing needs or requirements.

Given the multi-user, multimodal, potentially collaborative and distributed nature of Home Care Systems, it is likely that the software and system solutions will produce conflicts and challenges that home care research must address.

3 Home Care System Challenges

In the case of the provision of care at home, there are many areas for potential conflict in the needs, preferences and expectations of the participants in the Network of Care both with respect to the care itself and with respect to the requirements for, and configuration of the Home Care System. When these conflicts derive from different stakeholder groups, then we say there is stakeholder conflict. In order to begin to understand some of these potential conflicts we are conducting an ongoing series of stakeholder interviews and focus groups. The following sections describe a non-exhaustive list of the possible sources and consequences of stakeholder conflict that we are examining.

3.1 Sources of Conflict

Conflicts might arise if the various user(s) of the system misinterpret (a) other user(s) intentions or interactions and/or (b) the systems intentions or interactions. In order for home care systems to minimize the damage these conflicts can potentially cause, they have to be identified and described in such a way that their structure and characteristics are revealed with respect to potential resolution. What follows is not intended as a comprehensive and complete analytic model of such conflict, but merely an initial attempt to examine some examples, to illustrate their likely structure and variety.

- Multiple care conditions

It is common in an ageing population that the people being cared for in their own home will have a cluster of conditions to manage, some of which might interact with each other. This means that a home care system must be capable of dealing with decisions on which rules to follow if health indicators from different conditions or symptoms are conflicting with each other. There is of course the added problem that conditions are not only multiple within one person but of course can be spread between the persons living within the home.

- Complexity of Care relationships

Politically and socially speaking it is likely that conflicts will arise from conflicting interests or at least differing priorities or goals from different people. There is the underlying problem of who the system should rank 'highest' if each places similar but competing demands on the system. These conflicts arise because of the variety of different goals, needs, expectations or perspectives of the various stakeholders.

- Shared Interaction Spaces

The home might include not only the cared but one or more others. The system's configuration may be acceptable for some but not for others. For example, the cared may wish to have care messages and alerts presented by speech, but this might be annoying and disruptive to the carer if delivered via speakers. Similarly, information provided on a television might either be disruptive of TV use by others in the household or it might allow private and potentially embarrassing health information to be read by others.

- Service vs. User Experience

This is fundamental source of conflict, where the demands of the provision of care interact badly with other aspects of the life of the cared or home carers. The user requirements generated on behalf of the user given their care conditions might for instance conflict with what the user believes he or she needs or wants. A balance between achieving clinical efficacy and providing an acceptable user experience must be sought.

- Control and ownership of data

It is important that peoples' privacy is not disrespected as this remains one of the fears of Home Care Systems. The question of who owns the different data input/output from the system needs to be clarified. If two users want access or control over the system's data at any time then there needs to be some negotiated rules in place regarding this issue.

- Accountability

The issue here is that, following on from some of the previous points, it may be unclear whose responsibility it is if there are issues with the correctness or completeness of the data or with control over devices and their configuration. Conflicts can arise particularly when there are both institutional and personal interests at stake.

- Multiple changing requirements

It is likely in the home care context that user requirements will change. This may be as a result of changes in the medical conditions, new devices, changes in family circumstances, or simply changes in what people believe or the way they behave.

It should be noted that these sources of conflict are not mutually exclusive. For example, consider the case in which a cared wants to turn off an important medical alert when there are visitors in the house but the community nurse objects on the grounds that the alert is critical to the maintenance of the person's health. This example can be characterised as a service vs. user experience problem but also as a shared interaction space problem, since it's the fact that the alert is perceivable by visitors that bothers the cared. The solution might be to change the alert modality so that it's only perceivable by the cared, thus removing the shared interaction space and, indirectly, solving the user experience conflict.

3.2 Consequences of Conflict

We identify three basic consequences of conflict.

- System failure

The most important consequence is that both networks may fail to deliver the desired benefits or do so at an unacceptable cost. This cost may include a reduction in the quality of life of the participants. The resistance of participants to the introduction of certain technologies can threaten the delivery of health or social care.

- Poor Usability (and unintentional misuse)

Home Care systems should be capable of providing implicit, multimodal, and non-standard means of interacting to facilitate a more natural user experience. It should be possible for advanced custom technologies to be integrated with standard devices already in the home. In this way, users' existing knowledge, skills, and habits are not always replaced but instead supported or complemented. Depending on the nature of the task, and the current users, multiple ways of accessing certain functionality is needed. This will require modelling of all of the potential users and scenarios in order to offer them differing and suitable means of access as appropriate. All of this should lead to improved usability but is proving difficult to realise in the home care setting.

- Reluctance to use/accept the system

We distinguish this from poor usability as it refers to an effect on attitude or inclination, rather than actual performance. This remains a problem in the uptake of home care technologies and needs to be addressed at the stakeholder level.

4 Identification, Negotiation, and Resolution of Conflict

It should be clear from the previous section that complex user requirements and stakeholder conflict are a potential threat to the realisation of effective and usable home care systems. In this section, we present some initial ideas about how to resolve some of the potential conflicts arising in home care systems. These potential solutions, or partial solutions, to complex changing user requirements and stakeholder conflict, include technological solutions, socially or clinically negotiated solutions, and solutions implemented at a system design level (or some combination of these).

4.1 Enabling technology

These solutions require changing the technological resources that will be used to design and implement the actual homecare system. For example, adding a new sensing device may change the design possibilities for the system. Sometimes conflict may depend on assumed constraints on the technology choice. One potentially simple way of resolving conflict, in some circumstance, is to change, or develop different, input and output hardware and/or software. For example, consider the case in which the homecare system will track the movement of the cared in the house. The cared does not object, but the home-based carer does not want their movement to be tracked. The solution may be to refine the tracking system so that it only tracks the relevant person or, if both are tracked, data about the carer is filtered out and not communicated outside the home. Similarly, a problem with a cared preference to use speech output while the carer does not want to hear this could be solved by using suitably directional speakers or an earpiece.

4.2 People-oriented (Social & Clinical)

Issues can sometimes be removed without directly affecting the technology. For example, people may change their beliefs or attitude, perhaps through experience or, more formally, via training or education. The care regime could be modified to take into account the preferences of the cared or other carers, without unduly damaging health outcomes. Care arrangements might be able to be modified. For example, a cared person may be unhappy

about providing personal data about their movements in the house, data that may be needed in order to provide an accurate identification of situations when the cared is at risk. It may be sufficient to make the cared aware of the advantages of supplying the information in order to cause them to change their view and thus remove the conflict.

4.3 System Design

Some of the issues discussed might be best resolved during the design of the homecare system before the problem appears. The following are a non-exhaustive list of ways in which homecare system design could be enhanced to support this approach.

- Enhance network policy languages for networks being built for homecare systems
- Develop configuration/monitoring tools based on patterns of care and system models
- Develop or augment system models to enable conflicts to be identified and dealt with effectively
- Identify and categorise patterns of care at home within these networks and develop a pattern language to support this
- Participatory design
- Allow for (dynamic) system configuration

Ultimately we believe that appropriate solutions will involve improving the identification, description and resolution of stakeholder requirements and potential conflicts between them. This process should include stakeholders at the design stage to elicit requirements and identify possible conflict. It should also involve ongoing negotiation and resolution between both the stakeholders themselves and the stakeholders and the system. This is likely to include the ability of the system to dynamically evolve with the (negotiated) changing requirements of the stakeholders where possible. It is for this reason that our research involves an ongoing investigation into the inclusion of stakeholders throughout the design and evolution of Home Care Systems.

5 An Initial Exploratory Study of Stakeholder Attitudes and Beliefs

Based on the argument that we believe participatory design and dynamic configuration to be potential solutions to some of the issues of Home Care Systems, we are currently conducting a series of standard user requirements techniques with the various stakeholders of Home Care Systems to inform the design of these systems. These include attitudinal questionnaires, semi-structured interviews, focus groups, and live theatre, all aimed at finding out different perceptions and attitudes towards Home Care Technologies and Systems. Including the various categories of stakeholders of homecare systems should allow us to gain a much richer understanding of the interactions between the various attitudes and expectations of all those likely to influence or be influenced by such systems. This might also highlight the causes and consequences of conflict arising and allow us to examine the possible solutions to any such emerging conflicts.

An initial interview case study has been carried out in order to explore the attitudes towards and expectations of current standard home care technology - the pull cord alarm.

Some initial results will be presented here and the interviews will be discussed in more detail at the conference.

The objectives of this initial case study were (1) to explore the attitudes, understanding and expectations that exist of current simple home care technology, and (2) to explore the suitability of our conceptual framework as a way of organising stakeholder issues, in particular the degree to which our concepts correspond to those of the key stakeholders.

We wanted to explore the following issues:

- Awareness of device(s)/service(s)

- Quality of Service(s)

- Interaction with Device(s)/Service(s)

- Control/Influence over Device(s)/Service(s)

We hypothesised that the stakeholder interviews will confirm that
- Conflicts exist
- Conflicts can be best identified through use of technology by various stakeholders over time and space.

The results from the initial case study revealed that although all stakeholders interviewed everyone had a good understanding of how the pull cord system works, and how the response unit handle the alarms, the concerns and priorities of the different users of the system varied. Another observation was the perceived data flow from when the alarm is pulled until the contact is notified. When asked about the importance of the system to them, each person also had varying perspectives.

Further results from the study are being processed and additional interviews within this case study are still being carried out. This type of study elicits very rich information regarding people's perceptions of how such technologies and systems work which are often not revealed through conventional questionnaires or even single person interviews. Including even a small section of the 'Network of Homecare' can tell us more about both how different people view current homecare technology and what they might want from future homecare systems.

6 Conclusions and Future Work

In the home care setting, there exists a case for systems that provide configuration and adaptation services to its users to support system evolution addressing the effects of the ever-changing care plan and the changing needs of the complex network of people involved in care. The problem exists then as to how such systems might evolve and how this evolution can be facilitated. Given the number of potential users of a home care system - from the people being cared for to the people directly involved in care, and those requiring access to the system in some way, this becomes a complex research issue both socially and technologically.

We believe that the problems of stakeholder conflict present a significant research challenge for traditional automatically configured homecare systems. First, it is clear that the configuration system must be able to express the full range of possible configurations necessary to address potential stakeholder conflicts. Second, during design these conflicts must be identified so that suitable automatic configuration solutions can be implemented. A more significant challenge for automatic configuration is the likely situation in which conflicts only emerge as the system is used. In this case, there must be a cost-effective way to find suitable configuration(s) that enable the conflicts to be resolved, if possible. A solution is required that exploits the notion of including stakeholders at both design time and during the ongoing configuration and evolution of a Home Care System. This will require a dynamically reconfigurable system in a framework capable of supporting complex and changing user requirements. We also need a methodology that enables non-specialists – the network of care itself – to manage this system evolution.

Acknowledgements

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