The Role of Assistive Technology in Supporting Formal Carers

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Abstract. In an increasingly ageing population, solutions are being sought to enable older people to live independently in their own homes. Assistive technology has the potential to develop supportive environments for older people through "ambient assisted living". This chapter is based on results from the implementation of an assistive technology project designed to provide formal carers with patient information to support them in their case management. The study followed the trial use of a telecare system, capturing the experiences of formal carers and documenting the impact of assistive technology. The findings identify that assisted living devices have the potential, once trust is established, to support formal carers to undertake their role more effectively. However, in accepting assistive technology as part of an integrated care solution, there are implications on the role and responsibilities of the formal carer, existing mechanisms for delivering community care and the quality of the relationship between the carer and the cared for. The paper concludes by considering the challenges for assistive technology if it is to be directly supportive of formal care-givers.

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1. Ambient Assisted Living, the Home and Formal Care

Global population ageing is pervasive, representing a significant health and social care burden to society [1] as increasingly more people require high intensity care and support to undertake activities of daily living [2]. An ageing population has raised pertinent questions about how we can best meet the needs of older people, through providing care and assistance that supports their independence, choice and quality of life. Effectively addressing these challenges has spawned a plethora of policy initatives, frameworks, and declarations emphasising the role of Information and Communcation Technologies (ICT) in helping to care for older people [3][4]. The challenge is to support older people to 'live independently', 'in a secure environment' with 'peace of mind', priorities identified in The Ambient Assistive Living Road Map [5]. This road map defined the need for a solution which supports ageing in the home, as "enjoying a healthier and higher quality of life for a longer time, assisted by technology, whilst maintaining a high degree of independence, autonomy and dignity." [5]. However, in delivering on these aims, assistive technology needs to be considered within the context of existing delivery mechanisms, and its potential impact upon formal methods of delivering care in the community.

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This overarching objective is supported by aging-in-place literature, which has identified the home as the preferred living environment for older people [6]. In a survey of 2000 people undertaken by Bayer and Harper [7], amongst those aged 45 and over, over 80 percent of respondents felt 'somewhat strongly' or 'very strongly' that they wish to remain in their own home as long as possible. Furthermore, when asked about where respondents would prefer to receive care, 82 percent stated that they would prefer to receive care at home, rather than move to a care facility. Other literature has established reasons for the home as a valued place in the lives of older people, identifying the importance of the home as a source of shared memories for the older person, constituting an important factor in sense of belonging and identity [8][9]. The home has been articulated as being central to the independence and autonomy of older people, representing an environment where notions of freedom and choice are exercised [10]. Moreover, research on restorative environments suggests that the home is a place of security, to recover from stressful life events and to maintain a well-being equilibrium between positive and negative effect [11]. The importance of the home has also been situated with the context of service delivery. Research examining the impact of health and social care provision has evidence that services delivered within the home environment can enable older people to retain higher perceived levels of independence and quality of life [12], whilst moving to a care facility brings about feelings of dependence and represents a downward trajectory in old age [13].

Given the importance of the home as a place to deliver care, a key priority is creating a domestic environment, and ICT solutions, that encourage and support health aging. In the areas of falls prevention, lifestyle and activity monitoring and alarm response systems, assistive technologies have been designed to support people living at home [14][15]. Here, research suggests that assistive technology can play a significant role in sustaining or enhancing levels of perceived safety, encouraging freedom of movement around the home and in the completion of activities of daily living [16][17]. Technology for older people has been considered as 'freeing' and a protection of individual privacy, as it enables older people to stay in their home longer, encouraging independent living and preventing the need for institutional care [18] [19]. Whilst technology might be considered supportive, other research has identified barriers to the long-term acceptability of assistive technology in the homes of older people, identifying ethical issues related to privacy, confidentiality and obtrusiveness [20] [21], which can potentially compromise or undermine personal identity [22].

In delivering care to older people within the home, existing evidence suggests that technology cannot work in isolation and must be part of a more integrated care solution [23]. This requires that the development of ICT solutions for independent and assisted living are designed to support and enhance the care delivered through existing informal (friends, family members, neighbours) and formal (doctors, nurses, healthcare professionals) pathways. Research suggests that formal carers can develop close relationships with older people, establishing a strong sense of trust and reciprocity in the process; such that formal carers assume an active role in the decision-making process concerning access and take-up of services [24] [25]. Given the central role of the formal carer in delivering care, they have a fundamental role to play in the ways in which older people interrelate with assistive technology and therefore in the overall acceptability and usability of healthcare technologies within the home. Moreover, as assistive technology is likely to be delivered through formal service mechanisms and providers, it needs to be supportive of the working practices of care providers and empower them to make better-informed decisions about care.

Assistive technology has the potential to support care providers, whilst delivering high quality care. Research has evidenced improvements in the effectiveness and efficiency of care delivery through providing formal carers with health and care information [26][27]. Remote monitoring facilitates the possibility that clinical decision-making can be undertaken by formal carers away from the home, or can be combined with home care visits, to better assess health and social conditions and deliver high quality care. The monitoring and interpretation of patient information can be reactive (action to a change in specific data) or proactive (to monitor long term trends and determine intervention) [15], enabling the prioritisation of care and better care management thus improving efficiency (better use of carers time and resources) and thereby reducing costs [28]. Assistive technology thus becomes an 'enabler' of care, acting as the interface between older person and formal carer and delaying the need for acute intervention.

Prioritising case management has prompted concerns regarding the quality of care, where technology is perceived as a replacement of patient-centred care, leading to the loss of the 'human factor' in care delivery [29]. Access to patient information is also an area of concern, ensuring that the caregiver has accurate, reliable and readable information to make better informed care decisions regarding the patient. Importantly, in introducing remote monitoring, such solutions potential redefine the role of the formal carer, thereby introducing cultural barriers associated with changes to working practices. Here, technology which is to be acceptable and usable in making decisions about the delivery of care, needs to be predicated upon an experiential understanding of the impact of ambient assisted living technology on the working practices of the formal carer and their relationship with the older person.

2. Formal Carers as Community Matrons

In this study we explored the impact of telecare technology in supporting the role of Community Matrons (CMs) in delivering care to older people. By definition, CMs are experienced and skilled nurses who deliver a personalized, case management approach to supporting older people within their homes. The emphasis of their role is upon addressing problems before they escalate and require high intensity, and more costly, service interventions. CMs are responsible for: reviewing and prescribing medication; needs assessment; providing health and social care interventions; co-ordinating input from other health and social care agencies and teaching and educating patients about their condition [30]. The Community Matron acts as the single point of contact for the provision and procurement of care for the older person, developing a relationship founded upon a degree of trust and reciprocity. CMs are required to monitor individuals care, providing one-to-one support to a caseload of vulnerable patients with long-term conditions. Appropriate interventions can be widespread and are based upon an in-depth knowledge of the client, but may include dietary, behavioural, lifestyle, medication aspects of health and well-being.

The role of the Community Matron emerged from the NHS Improvement plan [31], a key UK policy objective of which is to promote independence, well-being and choice amongst older people. This plan recommended a new clinical role for nurses, predicated upon the holistic management of individual cases i.e. case management. Case management is an extension of 'care in the community', adopted in the Community Care Act [32], which encourages the delivery of health and social care

within people's homes, providing people with services that meet their individual needs [33]. With case management there is an emphasis on the Community Matron to co-ordinate the delivery of the care, whilst encouraging the patient to self manage their condition, ensuring that older people are able to remain at home longer and preventing unplanned admission to hospital. The objective of the Community Matron is to increase choice, prevent unnecessary hospital admissions and improve outcomes, thereby enabling patients to live in their own homes independently. Research assessing the success of the case management approach, reveals mixed results regarding its impact on reducing unplanned hospital admissions and in alleviating the costs of care [34]. Others have highlighted the complexity of the role, identifying skills gaps, training requirements and the need for closer working with other healthcare professionals [35].

Whilst community care is well grounded in UK policy, the approach of providing services to older people within their own homes, through a healthcare professional, is widespread [36]. In the US, this operates within a framework of managed care aimed at frail older people with multiple problems. It is therefore intended that the results from this study have relevance across different domains.

3. The Project

This project evaluated the impact of assistive technology in helping to support CMs, as formal carers, to undertake their role more effectively. Assistive technology was trialed in the homes of older people, technology that integrated unobtrusive pervasive sensing in the homes of older people and linked to physiological/metabolic parameters and lifestyle patterns. Ambient sensing was used to capture information including activity monitoring, sleeping pattern, room occupancy, and gait and posture changes. The technology used a variety of non-invasive sensors throughout the home to provide continual activity and environmental monitoring of the individual.

The objective of the technology was to ensure CMs were provided with patient health and well-being information in a readable form, potentially providing a tool for improved well-being monitoring and early detection of changes in disease state. The data collected from the homes of patients, via ambient and body worn sensors, was transmitted via a home hub to a secure network platform, to the care provider systems for access by the formal carer. This raised the possibility of accessing patient information remotely or when stationed within their place of work, providing the means to make decisions regarding patients without the need to undertake a home visit. In addition to interpretation by CMs, the system provides the opportunity for older people themselves to access the information, through a specific television channel presenting their information. Here, the technology has the potential to empower older people themselves, through the ability to interpret and act upon any changes to their own condition.

The aim of this study was to examine the role of assistive technology in helping to support the role of the Community Matron in making informed decisions about the care of their patients. By presenting collected sensor data in a meaningful way for healthcare professionals, it was hoped that this would help them better manage their patient loads and make patient care more efficient.

The project aim was underpinned by a number of research questions:

1) To what extent can assistive technology better support the role of the formal carer in the decision-making process?
2) In what ways does assistive technology impact on the relationship between the carer and cared for?
3) What factors contribute to the acceptability and usability of assistive technology by formal carers?
4) What are the key factors influencing the acceptability and usability of assistive technology amongst formal carers?

In undertaking this role, CMs were recruited via the local NHS trust. CMs attended a number of recruitment days where the system was explained to them and they had the opportunity to ask any questions. CMs were asked to recruit patients to the trial, based upon who they felt would be most appropriate for the trial. Following recruitment, and the consent of the patients themselves, the equipment was installed in the home environment. A total number of eleven patients and four CMs were involved during the course of the trial.

4. Methods

For assistive technology to be directly supportive of the workload of the CMs, it was necessary to establish their expectations and requirements from the system, and to capture an understanding of the ways in which the system impacted on the ways in which they currently deliver care to their patients. The experiences of CMs and older people themselves were captured through a variety of methods. These included: An Older Adults Workshop, Live Forum Theatre, Trial and Case Conferences, Exit Interviews and a Dissemination session. Mixed methods were important for determining the requirements and expectations of the Community Matron pre-trial, to ensure ongoing issues were identified during the trial and to determine the overall impact and recommendations for the future post-trial. Older adults were involved at an early stage to ensure that the project was grounded in an experiential understanding of the needs of those receiving care.

This mixed methods approach was necessary to incorporate the views of both older people and CMs and to develop an in-depth understanding of the working practices, care delivery mechanisms and the development of the carer-cared for relationships. Given that the trial was six months and overall project length forty-two months, creative methods were used alongside more traditional research approaches in order to elicit a breadth and depth of information that a single method research could not achieve. Moreover, more creative approaches were perceived as an opportunity to alleviate participant fatigue, ensuring that they were engaged in varied ways across the course of the project. The application and development of the methods was underpinned by a participatory approach, ensuring that comments and feedback from each of the methods was incorporated into system re-design where possible. Incorporating the views of stakeholders in this way results in product development which is more reflective of the experiences of end users themselves; an inclusive approach advocated in the design and development of assistive technology for older people [37] [38].

4.1. Older Adults Workshop

An Older Adults Workshop was undertaken at an early stage of the work to determine the applicability of the technology within the lives of older people. It was felt important to elicit the feedback of older participants, and determine if the proposed ICT was fit for purpose within the home environment, before capturing the views of CMs. The workshop method was chosen as, if conducted effectively, it represents a participatory and inclusive way for older people to have their say in the design and development of technology [39].

A group of 13 older adults were invited to attend a workshop in the School of Computing at the University of Dundee. Members of the group had varying degrees of computing skills, some with little experience of using computers and some with everyday experience. They were of pensionable age, between the ages of 60-80 years old. The group all came from different educational and working backgrounds. There were three who had experience of working in a professional office environment, two who had worked in education, four manual workers and one ex-nurse. There were also several who hadn't worked. This gave the study a wide range of people from the target group. The health conditions of group members were not considered in the scope of this workshop, although many of the group referred to their health during discussions.

The workshop outlined the aims and objectives of the project, and presented the key features and specific aspects of the technology as the stimulus for discussion. The session incorporated both hands-on activities (interacting with system components) and information presentation (the visual representation of the information). Older people were asked for the comments on the system, identifying aspects of current care delivery, levels of acceptability concerning individual components of the system and likelihood of use within the home environment. All discussions were facilitated by a member of the research team with audio and video recorded for transcription.

4.2. Live Forum Theatre

After capturing the feedback of older people, it was necessary to elicit the opinions of the CMs themselves regarding the supportive role that the technology could play in their everyday working practices. To ensure that the technology was fit-for-purpose it was necessary to understand the working practices of healthcare professionals including the specific ways in which they delivered care to the older person and how technology can best support them. Live Forum Theatre is a method through which storytelling and the presentation of typical scenarios can be acted out to enable participants to reflect upon and engage with key aspects of the research [40].

Use case scenarios were developed as a result of earlier work conducted with CMs. These scenarios presented typical work examples confronting the matrons on a regular basis, incorporating the use of the technology. During the forum theatre event, scenarios were scripted and acted out by professional actors. The audience was given the opportunity to comment on what they have seen after each scene as a prompt for further discussion. This method was used as it gave the audience a chance to see how a telecare system could be used to support CMs in the delivery of care, and provided the platform for them to contribute their opinions. The Live Forum Theatre provided the opportunity to bring together the formal carers, technicians and academics, establishing a common ground, which is often difficult to establish when engaging end uses in research [41].

Two Live Forum Theatre sessions were conducted focused on working through typical care delivery scenarios and discussing the way in which the technology could support them. Each Live Forum Theatre event lasted for between two and three hours with a rich level of discussion being produced during this time. In both sessions, the audience comprised healthcare professionals including CMs, telecare developers, technicians and academics. In line with the ethical submission of the project, potential service users could not take part in the Live Forum Theatre. However, on discussion with the formal carers prior to the events taking place, the research team was happy that the CMs and other healthcare professionals could represent the opinions and feelings of their patients.

The scenarios and discussions provided knowledge of the working practices of CMs and the specifics of delivering care within the home. The feedback also enabled a better understanding of the relationships that CMs have with their patients and the informal aspects of care delivery which technology needs to support. The Live Forum Theatre sessions were audio and video recorded and made available for analysis.

Seven healthcare professionals and six developers/technicians attended the first live forum theatre. This session introduced the notion of assistive technology to the audience and detailed the aims and objectives of the technology. The individual scenarios were scripted after detailed discussions with the script-writer and local community nurses. Each scenario was based upon typical situations confronting the CM when they are delivering care to the patient. Following presentation of the scenarios, CMs were asked about the processes for delivering care, their response to the needs of the situation and any additional support which could be provided to the formal carers to help them manage the delivery of care more effectively.

Having developed an understanding of the working practices of CMs, a further Live forum Theatre event was conducted. This event presented scenarios which included on 'A Day in the Life of a Community Matron Using a telecare system' and depicted the possible course of events and situations that may be encountered by CMs during a typical day using a telecare system. Responses were elicited from CMs, identifying the positive ways in which the technology could better support their decision-making without acting as a hindrance or barrier to the delivery of care. Eight healthcare professionals and twelve developers/technicians attended this event.

By re-enacting familiar scenarios, and asking CMs to respond to them, the control of the discussion was transferred to the formal carers themselves. This provided them with an environment where they felt more able to share their opinions, thoughts and feelings concerning the system. The Live Forum Theatre enabled deeper understandings to emerge of the issues impacting on the acceptability of assistive technology amongst CMs. Establishing their responses prior to the commencement of the trial, provided the opportunity to monitor these attitudinal changes as the trial commenced, monitoring expectations and identifying previously unconsidered benefits.

4.3. Trial and Case Conferences

CMs recruited to the project recommended a number of patients who they felt would benefit most from continuous monitoring in the home environment. Patients were approached in the first instance by CMs to determine their likelihood of being involved. The research team then contacted the older participants to explain the aims and objectives of the project, to introduce the key features of the system and to outline the anticipated benefits of their involvement. Where the older participant felt it was

desirable, informal carers were involved in the discussions. After acquiring informed consent, the equipment was installed in the homes of the participant for a duration of six months. Altogether, four CMs and eleven patients took part in the trial. During the trial, the CMs had access to the data produced from the sensors and devices of their patient's system through a secure online Community Ward website.

The Community Ward website gave the CM a three level display of the patients collected data. The top level displayed all of the patients that a single CM cared for. From here, the CM could choose to view the data of an individual patient. The next screen gave an overview of the statistics being collected for the selected patient. The third level of data gave a more detailed breakdown of a selected statistic in the form of a graph. The Community Ward website allowed the CM to view patient data at a level that was appropriate to the patient and the specific information that the CM required at the time of viewing. Screenshots of the Community Ward website can be seen in Figure 1.

At monthly intervals during the trial, case conferences were facilitated with the CMs as a group. Altogether, six case conferences were conducted. Each case conference lasted for between 2 and 3 hours in duration, were facilitated by two members of the research team and were recorded for purposes of transcribing. A group format was deemed most appropriate to facilitate shared dialogue and active discussion between CMs.

Figure 1. Community Ward Screenshots

The aim of the case conferences was to determine the impact of the technology on the working practices of CMs, identifying any aspects of the system that were/were not working well, any perceived changes in the relationship between the carer and cared for as a result of using the technology and issues relating to the usability and acceptability of the system over time. Capturing their perceptions over the duration of the trial, enabled the development of their attitudes towards the technology to be monitored over the course of the trial. Patients were discussed on a case-by-case basis, identifying examples of where technology had positively/negatively impacted on supporting/delivering care to the patient. It also provided the opportunity for CMs to relay any comments from their patients or informal carers about the system.

4.4. Exit Interviews

After completion of the 6 month trial, the equipment was removed from the homes of the older person. This was immediately followed by one-to-one exit interviews conducted with each of the CMs. All interview were conducted at a date, time and venue convenient to the Community Matron, lasted for between 45 and 90 minutes and were recorded for purposes of transcribing.

The aim of the exit interviews was to establish the overall impact of the technology in the context of their initial expectations. Both anticipated outcomes and unanticipated benefits and drawbacks of the technology were discussed and their implications for the adoption of monitoring technology commented on. The exit interviews provided the opportunity for CMs to evaluate their own experience of being involved in the trial, as well as the perceived advantages and disadvantages of assisted technology for the older participants themselves. Additionally, they proposed recommendations for the successful integration of such technology in the future, and identified potential practical and political barriers to adoption.

4.5. Dissemination Session

A final dissemination session was held 4 weeks after the trial was completed. The aim of the dissemination session was to engage CMs in workshop to feedback on the key findings from the trial and to determine if the findings were an accurate portrayal of their experiences. The emerging results provided the stimulus for further discussion with CMs and retrospective reflection on their engagement in the trial. Importantly, it identified any instances and examples of where the system may have been useful in supporting them to deliver care, and progress of the individual patients during the trial.

All CMs attended the dissemination session, alongside 5 members of the research team. This was a further opportunity to bring together formal carers, technicians and academics within a process of shared working to further refine the issues raised in the project. The dissemination session lasted for a duration of 3 hours and was tape recorded for transcription purposes.

4.6. Analysis

Throughout each of the activities outlined above, researcher field notes and audio and/or visual recordings were taken.

Thematic analysis [42] was applied to this content and the main themes were extracted. The thematic analysis followed the key principles outlined by Braun (i) familiarisation with the data (ii) generating initial codes (iii) searching for themes (iv) reviewing themes (v) defining and naming themes (vi) producing the reports.

Key themes and findings were mapped across the course of the work and synthesized across the Adult Workshops, Live Forum Theatre, Case Conferences, Exit Interviews and Dissemination Event.

5. Key Findings

The CMs (CMs), as providers of health and social care to the older person, identified a number of key issues in the application and development of assistive technology with the homes of older people. They relate to the acceptability of the technology within the homes of the patients, the impact of the technology on the relationship that they have with their patients and also identify ways in which assistive technology needs to be supportive of the everyday needs of CMs. These issues emerged and developed in different ways throughout the project, as CMs and patients became more familiar with the technology.

5.1. Role of the Formal Carer in Integrating Assistive Technology

Research into patient privacy has revealed that assistive technology within the home can lead to perceptions of being monitored, heightening levels of anxiety and feelings of being watched. [13][15]. The findings from this project suggested that CMs, by placing them in a position of control, can alleviate concerns related to monitoring and privacy, thereby increasing levels of acceptability of technology amongst older people

Issues relating to patient privacy were first reported by CMs during the forum theatre sessions, and was a theme raised in the early discussions with older people. The older adults in the workshop session were the first to question how telecare systems, through being visible within the older person's home, would compromise an individual's privacy. They felt that having telecare devices visible to family members, friends and other visitors could increase the stigma associated with having a telecare system in the home i.e. visitors would know the patient is being monitored and would perceive them as being 'ill' or in need of assistance.

Similarly, the CMs felt that privacy would be a significant issue if the system and its features were not adequately explained to the patient, thereby increasing levels of anxiety and concern if the older person does not understand the purpose of the individual sensors. CMs felt that there was the potential of some sensors to be intrusive as they closely resembled a camera, for example, particularly the Passive Infra Red (PIR) sensors which had integrated flashing lights when activated. During the initial theatre session, the CMs commented that with the introduction of a telecare system, the patient may feel like:

> *"everyone is watching their every move"* [CM FT1]

CMs felt issues relating to privacy and monitoring could have a specific impact on the adoption and acceptability of the technology amongst older people. The CMs felt that patients would feel as if they are being watched, potentially restricting their behaviours within the home and increasing anxiety levels/tension as a result of having the system within the home. In the early case conferences, the issue of privacy and intrusiveness was again raised by CMs, within the context of informal carers acceptability of the system. A Community Matron relayed the story of the wife of one patient who felt that the system was watching her movements and activities within different rooms and actively intervened to turn the sensors off.

However, the Community Matron, being responsible for making care-related decisions, played an active role in minimizing concerns over privacy and increasing levels of acceptability. CMs revealed that they were often in a position of trust; patients relying upon the formal carer to make the most appropriate decisions to benefit them.

CMs therefore acted as the mediator, allaying the everyday concerns of older people and informal carers regarding privacy and behavioral monitoring. The Community Matron were also available to explain and regularly reinforce the potential benefits of the system to the patient, resulting in increased levels of acceptability amongst patients. However, this requires that CMs understand how the technology operates and that they 'buy-in' to the anticipated benefits of the system. Given this, the Community Matron may still feel uncomfortable promoting a system that has not yet become an integral part of their care provision.

In empowering CMs, it was important they felt a sense of ownership in accessing the data. Here, CMs were asked to make the decisions concerning how and when they chose to act upon the data and also had the freedom to halt the trial and ask for a removal of the system if they felt it was not working. Moreover, through the regular case conferences they were provided with the forum for voicing their concerns which where possible resulted in changes to the equipment. Transferring control to the CMs provided participants with feelings of safety, as they were aware that the formal carer themselves were representing the needs and wants of the patient. Older people felt more secure in the knowledge that CMs were the individuals monitoring their data and responding to changes. The fact that the CM were the ones undertaking the 'watching' and being in control of the technology was seen as fundamental to patients accepting being monitored:

> *"there was nobody [in the end] that felt threatened or paranoid in any way that we were watching at all… but I think that's to do with your relationship with the patient… they were very very happy that they knew that I was watching and that I was proactive in it all and I think that's what gave them a bit more confidence really knowing that I was watching."* [CM1 End of Trial Interview]

CMs, in acting as the mediator to the system, provided the everyday support to older people to become familiar with the system, minimising any concerns or worries and educating the patient about the system to minimise perceptions of 'being watched' and suspicions about what the system is designed to achieve. Here, CMs can play a significant role in smoothing the integration of technology within people's home. Additionally, the CMs were in the best position (as the main point of contact with the older person) to relay any issues with operability and reliability of the equipment. As well as feedback through the case conferences, CMs were encouraged to provide daily or weekly feedback on their experiences via e-mail or telephone. This provided formal carers with a channel for raising and discussing queries and issues, and was beneficial to the development of the technology as it allowed for re-design.

5.2. Assistive Technology and Impact Upon Role of the Formal Carer

CMs identified the importance of trust and reciprocity in the relationship that they developed with their patients and often spoke about a 'partnership approach to care'. This was a theme that was evident from a very early point in the research from the first forum theatre session. The CMs felt that such trust took a considerable time to develop with the client, predicated upon a continuity of care with the client and maintained by regular personal contact and communication. Indeed, this close relationship gave rise to early suspicions regarding the intention of the technology. CMs reported that patients felt that the system was designed to replace the role of the Community Matron:

"one patient thought the system was a replacement for me." [CM 2 CC4]

The CMs felt that maintaining this trust was fundamental to patients talking openly about their condition, ensuring their compliance with recommended treatments and their concordance with decisions made by the CMs. Prior to the trial, CMs reported that the involvement of the patients in the trial was dependent on the involvement of the CMs:

> *"they know that you have made a difference in the past, if they can see the difference before where you've improved things then they're more willing to have a go at something new."* [CM FT1]

This was evidenced in later case conferences where CMs explained how a number of the trial participants were engaging in the study as they thought that it might 'help out' the CM and therefore accepting the system as it supported their own health and well-being.

Indeed, CMs reported the continued involvement of the participants being dependent on the relationship with the older person. During the second forum theatre session, and the first case conference, CMs stressed the importance that any system should not compromise this relationship and the levels of trust that they had developed with their patients. In particular, it was highlighted that any false positives that led to the CM questioning the patient based on the data could result in the patient not wanting to be as open to discuss issues with the CM.

During the trial, the issue of trust continued to be raised on a number of occasions. In some instances the system was used by CMs to directly challenge the perceptions of the patient. For example, on one occasion the patient informed the CM that they had not been the toilet but the system suggested otherwise. Assistive technology thus provided the source of tension, challenging the CM/patient relationship. The CM was keen to ensure that they system did not compromise the CM/patient relationship and the knowledge of the client and the monitoring of the CM were prioritised over reliance upon the system. CMs consistently reported that they did not substitute patient visits as a result of what they interpreted from the system data, although the data was often used as a prompt for a visit or telephone call, but was not seen as a replacement.

The issue of trust was again raised in the post-trial interview stage with CMs. They felt that being involved in the trial brought additional responsibilities, through increased patient expectations (that the CM were continuously monitoring and interpreting the data). If such a system was to be adopted in the long-term, CMs felt that this would bring a mental burden (stress and worry) in meeting patient expectations:

> *"if you'd been on annual leave it worried me that nobody had been monitoring… when you're away for two weeks holiday, what's happening in the meantime... how do you reassure the patients... I'm going on holiday now, who's looking at the data?"* [CM1 End of Trial Interview]

This raises the question that if CMs are to be seen as mediators in the implementation and management of such a system, how can this be best facilitated without compromising the CM/patient relationship. CMs recommended the possibility of an alternative person monitoring and identifying patterns in the data, a person with clinical experience who could raise any concerns with the CM. They felt that this

would alleviate the resource burden of interpreting such technology, whilst ensuring continuous monitoring of the data.

5.3. Assistive Technology as a Supportive Tool in Delivering Care

In the discussions held during the first Live Forum Theatre, the CMs expressed concerns in relying on technology for making care-related decisions. The CMs felt that they needed to develop trust in the system, through ensuring (i) that the equipment was consistently reliable and (ii) that the data generated was timely and accurate.

During the first forum theatre session, CMs were asked about the potential of the technology to increase efficiency through more effective case management. This might include using assistive technology and the patient information to better prioritise visits or to reduce the number of unnecessary calls. CMs were wary of replacing or re-prioritising visits based upon what the assistive technology was telling them. This was partly attributable to their lack of trust in the system but also to their uncertainty of the role of the technology in replacing established working practices. One CM reported:

> *"I wouldn't particularly think about swapping appointments just by judging what's on the screen"* [CM FT2]

At this point, CMs revealed that their patients typically experienced multiple problems and that making a decision based on the datasets within the system would be problematic. CMs often combined their intimate knowledge of the client, with specific medical information, and observed behaviours to arrive at a decision. The assistive technology itself could not combine the tacit knowledge which the CM possesses. In the initial stages, CMs felt that the system would actually decrease levels of efficiency, as it represented another responsibility i.e. monitoring the data, which they would need to undertake in addition to a patient visit:

> *"if the patient says they aren't feeling well then we have to visit no matter what the data says."* [CM FT2]

Additionally, CMs felt that there was a limit to the intelligence that the system could possess. Whilst the sensors yielded information around the home, it did not provide the CMs with in-depth knowledge of the patient within the home. Everyday patterns and intentions for patients movement around the home were more complex and could not be integrated into the system. For example, door sensors provided them with data relating to room usage, but provided little contextual information about the activities of the person within the room. For example, "entering the toilet does not tell us that they used the toilet", "opening the fridge, does not provide us with evidence that they have consumed solids and liquids". In being supportive of the role of the CMs, there was a requirement for data that expressed a finer level of granularity.

However, there was a notable change in CM attitudes and perceptions during the second Live Forum Theatre session, as they began to perceive the system in a supportive role, as opposed to something designed to replace the care they were received. Here CMs began to articulate assistive technology as part of an integrated care solution, where the information generated by the assistive technology might provide the prompt or the stimulus for action on behalf of the carer. At this stage, benefits in terms of patient management, were still not being articulated, yet the potential assistive role of the technology was being expressed:

"If the system wasn't showing things, I wouldn't take it as definitive, but if it was showing things, it would prompt me to make a visit." [CM FT2]

Evidence of improved case management were further hampered with reliability issues with the equipment. Here, there was some disparity in the readings taken by the CM and those relayed by the system. This difference caused some early anxiety for CMs, prompting unnecessary visits to corroborate the data and undermining trust in the system. This had the effect of decreasing frequency of use in the early stages of the trial. Moreover, by placing CMs in control of the system, the CM becomes the conduit for reporting problems with the reliability of the equipment. This represented an extra burden for the Community Matron, who had to manage the integration of the system with their own everyday workload, directing time and efforts away from caring towards the integration of the technology.

However, CM feedback was used constructively to facilitate the re-design of the technology. Comments were fedback into the technicians who made subsequent improvements to the technology and to the presentation and readability of the data. Alterations mainly focused on the graphs to allow a CM to view exact data at a particular point as well as removing any outliers that were clearly not part of the patient data to make the graph easier to view. Also, changes were made to the design and implementation of the sensors used in the system to better fit the way in which the patients were using them. As the trial progressed, CMs re-engaged with the system, as they began to see that the changes that they had proposed were used for meaningful system change and development.

5.4. Assistive Technology as a Tool for Improved Case Management

As the trial progressed, CMs began to identify specific examples of where the technology helped support the CMs to undertake their role i.e. patient management. Here, the data from the system assisted the CMs in making specific interventions that may not have arisen without the trial equipment. It was when the CMs shared these benefits that a change in perception towards the technology was noted and the CMs began talking about the system as assistive and supportive technology for them rather than as a direct replacement of what they do. A movement from using the system reflectively, as noted in early case conferences, to using it proactively for early intervention was seen during the later case conferences. The CMs began to see the system as enabling them to monitor long-term trends in the condition of their patients. Here, CMs began to make changes to lifestyle and diet as a result of trends in the data. This prevented crisis situations from occurring through making necessary interventions based upon patterns in the data. Importantly, where there were inconsistencies in the data, CMs through their knowledge of the client, felt able to establish that they were outliers and removed them from the interpretation of the data in some cases where automated monitoring of the data or a third person analyzing the information may have yielded false alarms or incorrect inferences, the Community Matron was able to interpret the results within the context and circumstance of the individual, for example, where changes in medication resulted in higher or lower rates of blood pressure or where room activity could be linked to friends of relative visiting.

"I did most of the time, I didn't initially because there were a few blood pressure checks that I had to make that didn't seem to ring true and there was a bit

of a difference in the beginning but over the month it ironed out, could see that a few different readings didn't matter over the long term" [CM 2 End of Trial Interview]

Moreover, CMs were in the best position to interpret the multiple problems of the patient and bring about an intervention that would best support the older person. Whereas the data itself might have suggested one intervention, the knowledge of the CM, and there ability to undertake a visit when necessary resulted in the optimum intervention. CMs cited examples where they needed to synthesis a number of datasets for a particular patient in order to make a recommendation i.e. a patient living with high blood pressure, low weight, and abnormal sleeping patterns. Whilst the system presented this data to the Community Matron, this needed to be interpreted meaningfully for an appropriate intervention to be initiated:

"it [the system] picked up that she'd had no sleep, she hadn't gone to bed at all and it picked up that her blood pressure was low and picked up that she hadn't eaten, that she'd lost weight… it actually helped her pain control because she wasn't taking her long acting pain relief in the right way… it also it got her back into a routine basically, it made her put her alarm on and not spend all day in bed at the weekends." [CM2 CC 3]

The requirement of assistive technology if it is to function as an efficient clinical decision-making tool is to be supportive to the formal carers, supplying information for the appropriate decision to be made. It is unlikely to function successfully in isolation, as technology cannot incorporate the knowledge that the Community Matron possesses. The CM has knowledge of: personal histories, backgrounds, family situations, home and environmental circumstances, daily routines which are all drawn upon to arrive at an accurate clinical decision. Whilst technology may not be able to incorporate these facets of individual well-being, there is a need to ensure that assistive technologies are tailored to the requirements of the individual. Moreover, that there is a recognition of the 'softer' elements of care delivered by the formal carer.

In the early stages of the study, CMs were initially skeptical about the impact of the technology on their roles and work responsibilities. CMs raised early concerns about the aims and objectives of the system, frequently discussing the technology versus person debate. The CMs defined their role more broadly than the delivery of task-oriented, health-based care, and identified components of social, psychological and emotional well-being, as well as mediating with other carers and healthcare professionals. The CMs identified a limitation in the assistive technology which presented information to the carer through monitoring and sensor information.

The CMs felt that their role constituted more of what was described as the 'softer' elements of care, such as prompting, encouraging and supporting. This form of care was seen as important for assisting patients to self manage their own condition and thus fundamental to their independence. These 'softer' elements of care operated *alongside* the collection of diagnostic information.

5.5. Patients Viewing their Healthcare Data and Self-Management of Health

The system provided the opportunity for older people to visualize their own data through their television. Patient data could be relayed to the older person through a series of graphs available through a television channel. From the outset of the project, this was seen as important in ensuring that users had a sense of control over the system.

Moreover, a key responsibility of the role of the CM is to encourage self management amongst patients and patients viewing their own data was seen as a potential tool to support the self-identification of health and well-being issues.

When this aspect of the system was raised in the early workshops, older people felt that this could be empowering, enabling older people to be more directly involved in analyzing their own condition and promoting self management:

> *"A patient would feel confident using such visualisations to help with the self-management of health."* [OA2 during OA Workshop]

In enabling older people to have control of their data, it placed the older person more central to the decision-making process, shifting from their role as the 'passive recipient' of care:

> *"They share information with the carer rather than just listen and be dictated to."* [OA5 during OA Workshop]

Others felt that viewing their own data might be alarming for the older person. Here, there was the possibility that the patients could become obsessed with the readings generated by the system, leading to stress, worry and hyper-tension:

> *"Maybe the user/patient is better not to know because they might get obsessive about whether they slept or not and this would mean that they suffer a greater lack of sleep as they worry more about the readings"* [OA2 during OA Workshop]

These concerns were echoed by CMs themselves. When the CMs were asked during the second forum theatre session about patients viewing their own data, the initial response was that it could be potentially inappropriate. They felt that some patients may not want to be confronted by information regarding their own health:

> *"Any new information will be alarming to a patient and could cause them concern"* [CM during FT2]

CMs felt that there was an assumption that older people would know how to interpret the data. Whilst a key responsibility for CMs is educating patients about their own condition, they still had patients who were less confident when interpreting their own health and well-being data. This resulted in increased workload for the CM:

> *"…half the time I was going out for reassurance, they had been looking at particular data such as blood pressure rather than looking at the whole thing and saying about how they felt in themselves so yes it was a downfall from that point of view… you would be there for ages because there is always something else they remember."* [CM4 End of Trial Interview]

At the end of trial interview, one CM commented on the example of a patient whose anxiety levels (as a result of reading the system data) led to an unnecessary hospital admission:

> *"Think it [the system] was more of a hindrance than a help in some ways though because it just gave him hyper vigilance, he went off to hospital because he was telling me he was nauseating and vomiting and he had a fast pulse and when he got to the hospital he told them he'd seen it on the monitor…. It [the system] was not good for him… it raises the stress levels."* [CM1 End of Trial Interview]

A consistent theme through the case conferences and reiterated at the exit interviews with the CMs was that such a system would only work if it is has the compliance of patients. The CMs also felt that this compliance would be more complex to develop amongst those that are 'more ill' as they would have greater difficulty when self monitoring etc. due to their condition. This would also be true of those that were less educated about their own condition.

"a lot more education needs to go on so that if you do get raised blood pressure that this could be this and not to worry" [CM2 during CC5]

However, patients viewing their own data was potentially beneficial when a telephone call flagged up an issue that needed to be addressed and this occurred with patients who were more knowledgeable about their own condition. This demonstrated that assistive technology can play a role in self management provided that CMs have established the conditions (awareness and education) for the data to be interpreted and acted upon sensibly.

CMs did however report during the last three case conferences that a number of their participants were using the system to self-manage. Here, patients who were actively using the system were using the readings from the system to self-manage their condition. On one such occasion, a patient identified that they were putting on weight. After calling the CM to let them know about this, the CM was able to diagnose that the patient had been retaining water, and so was able to prescribe water tablets. On this occasion the CM felt that the system being used in this way by the patient almost certainly prevented a hospital admission. This improved communication levels between patient and CM, where the information and awareness of the patient was used to empower patients in the care delivery process' no longer just the CM going in and taking measurements and recommending a course of treatment (one way communication) but rather the patient being in control of their own data:

"... it did empower them a little bit more because they were looking at there own data and able to gauge things." [CM1 during CC4]

CMs felt that this improved communication strengthened the relationships between the carer and the care door:

"the system has reinforced the partnership between CM and patient". [CM1 End of Trial Interview]

This partnership was strengthened as a direct result of the patient undertaking care decisions which the Community Matron felt responsible for. In the following example, this led directly to the prevention of an hospital admission:

"...it [the system] has worked when it stopped an inappropriate admission with one of the patients, I think it was one where they would've rang 999 normally and because they were able to see the data themselves." [CM 1 End of Trial Interview]

At the last forum theatre and in the exit interviews, CMs also talked about the improved quality of patient visits as a direct result of information generated by the system. Patients, prompted by the data, would engage in discussion with the CMs about their progression since the last visit. This conversation provided the opportunity for CMs to further educate their patient, on the reasons for fluctuations in the data and to recommend potential interventions.

Other CMs felt that there was little appetite for self-management amongst patients. Whilst choice and control were perceived as beneficial, not all patients wanted to be in a position to self manage. CMs felt that a number of patients were content to transfer decision-making to the formal carer:

> *"It's difficult to know how people are going to react, some people do not want to take responsibility for anything and they're the ones that say oh I'll do it for you love, they want you to make all the decisions for them. They want you, you're the professional, they trust your judgment, they just want you to do what needs to be done."* [CM3 End of Trial Interview]

These findings suggest that for some patients the system brings about a sense of control and independence as a result of viewing, interpreting and acting upon the data, yet for others (who do not wish to have this level of choice and independence) CMs need to be in the position to make that decision. Here, assistive technology is potentially problematic if it takes an element of the decision-making away from the CM.

6. Conclusions

Formal care providers have a key role in ensuring that older people are able to live independently in their own homes whilst receiving high standards of care. Within the context of care in the community and a case management approach, the formal carer is fundamental to ensuring that older people have the support which enables them to stay at home as they become increasingly frail and vulnerable. In this study we have explored the impact of assistive technology in helping to support formal carers to make care-related decisions with the home.

The results of the project indicate that technology can play a supportive role in helping CMs to monitor patients, enabling earlier detection of problems (proactive use) and assisting in delivering care (reactive user). Here, assistive technology can provide information which results in changes to patient lifestyle, diet and behavior. However, in delivering these benefits, assistive technology has the potential to impact upon the mechanisms for delivering care and thus the roles and responsibilities of the formal carer. Initially, the integration of technology can represent a tension, as CMs perceive its role as a threat to their own traditional forms of face-to-face delivery. As the trial progressed this perceived threat minimized, as CMs become familiar with the system, and shaped the system as a 'supportive tool' rather than using technology as the sole mechanism for delivering care. Moreover, as the assistive technology began to yield benefits for case management, they began to see it as the opportunity to increase efficiency and prioritise care. Here, issues relating to privacy and intrusions became less well cited by CMs and patients as the technology became a more familiar and accepted.

The application of technology can also have implications on the relationship between the carer and cared for. Being the main carer for the older person places them in a position of trust and responsibility; care-related decisions thus need to be predicated on timely, reliable and accurate information. It is therefore perhaps understandable that CMs are initially apprehensive in trusting assistive technology to help them make decisions that impact on the health and well-being of the older person. Moreover, CMs did not wish to compromise the close, person-centred relationship

which they developed with their patients, and so were reticent to use the assistive technology to either question the older person or to make a change to the way in which they delivered care. Over time, as CMs began to trust the system, the information delivered through the technology was relied upon to make care-related decisions.

A key aspect of the role of the Community Matron is to better educate patients (as expert patients) to self manage their condition. This study demonstrated that assistive technology can support older people, by providing them with health and well-being data in a readable format in order for them to make their own decisions regarding medication, diet and lifestyle. However, this needs to work alongside concerted efforts by the Community Matron to appropriately educate their own patients about their condition. In those older people who were not approproiately aware of their condition, accessing their own data could produce increased anxiety and tension, as they did not have the knowledge to make decisions which would benefit them. However, those that were more informed about their own condition were able to respon to changes in their own data in order to bring about changes in their life. Thus technology can assist in working alongside CMs to fill a key responsibility of their work.

Overall, the experiences of the healthcarers during the research indicate that assistive technology implemented in this way has the potential to have a positive impact on the way that they work. Continuous monitoring of patient information allows the carer to ascertain an understanding of the patient's condition outside of normal visits. When combined with the knowledge of the care giver, this enables care to be managed more efficiently. However,feedback from CMs suggests that technology cannot work in isolation; it needs to be combined with the tacit and situated knowledge of the Community Matron to arrive at a decision regarding the care of the patient. Importantly, the Community Matron is fundamental to the acceptability of assistive technology within the home, in encouraging patients to adopt the technology and accept it as part of their everyday environment. For many patients, the inclination to have it in the home is that it is of purpose and assistance to the person making the decisions about their care, thus maintaining their health and well-being status. Thus, assistive technology needs to be seen a part of an integrated care solution, at the interface between the formal carer and the cared for.

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