

The BREATHE Project, a mobile application, video-monitoring system in family homes as an aid to the caring role: Needs, acceptability and concerns of informal carers

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Abstract

Introduction: Family carers provide 80% of care to older people in Europe. Our aim was to explore the needs and acceptability among informal carers, of a live video home monitoring system.

Methods: A descriptive qualitative design was implemented with nine interviewees and a focus group of five informal carers in Ireland in 2014. A thematic analysis of the data was conducted.

Results: Ten hours of data were recorded. Three themes emerged: routine, risk, and acceptance. Although all assisted persons had a routine, carers not living in the home stated that cameras would assist with less tangible concerns such as nutrition and loneliness. Carers were interested in monitoring risks in specific situations rather than general monitoring. The majority of carers, while expressing concerns about privacy, accepted camera technology for monitoring emergencies and, in spite of concerns, favoured a real video view. Acceptance in non-emergencies was mixed and concerns about the privacy of the assisted person were expressed.

Discussion: While video monitoring is contentious, informal carers did express a willingness for real video-footage monitoring under strict conditions that addressed specific needs.

Conclusion: The challenge for technology is to address these needs while maintaining personal dignity.

Keywords

Ageing, video, monitoring, carers, needs, acceptability

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Introduction

Family carers provide 80% of long-term care to dependent older people in Europe.¹ Within England alone, it has been estimated that 12% of people aged 16 or over in 2009/10 were looking after or giving special help to a sick, disabled or elderly person. This represented approximately 5 million adults. Half of these adults were caring for someone who was living with them, and half were caring for someone living elsewhere. The survey found that large proportions of carers reported activities such as general practical help, keeping an eye on the person, keeping them company and taking the person out. Almost a half reported

providing help in dealing with care services and benefits, and more than one-third reported providing personal care, physical help and giving medicines.²

Additionally, it is widely recognised that informal caregivers, face a number of challenges from isolation to stress and financial strain.³ Carers have reported impacts on health. Overall, just over one-quarter

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(26%) of those aged younger than 70 felt their caring responsibilities had affected their ability to take up or stay in employment. Of these more than one-third (39%) left work altogether (due to caring responsibilities); about one-third (32%) reduced employment hours; just under one in five (18%) reported that a flexible employment arrangement had been agreed; one in twelve (8%) changed job because of caring responsibilities; and smaller numbers reduced their level of responsibility at work (7%) or changed to work at home (6%).² The invisibility of informal caring has also been examined and it has been found that of those informal carers known to state agencies the majority was providing 100 or more hours of caring per week.⁴

We can see from these statistics that care provided within an informal or family setting is big business, and in England and Wales the government has placed substantial funding on the development, diffusion and adoption of telehealth and telecare technologies.⁵ One primary aim of these technologies is to monitor an assisted person's vital signs, specifically pulse rates, temperature, respiration rates and blood pressure with a view to providing information on essential bodily functions. A second aim is to assess the assisted person's personal safety and home security. Despite this, systematic reviews have found that there is little evidence for the effectiveness of such technologies, particularly in terms of personal safety and home security, and many studies reviewed failed to focus on supports for the informal carers of assisted persons in terms of isolation and stress outcomes.^{6–8}

The BREATHE Project was an Ambient Assisted Living (AAL) project cofounded by the AAL Joint Programme (Call 5, 2012), involving national authorities and local research and development programmes in Spain, the United Kingdom, Ireland and Italy. The role of the BREATHE Consortium was to develop a tool (i.e. web-based application and app running on a smartphone) to give guidance and continuous support to the informal carer in the provision of long-term care to slightly or fully dependent assisted persons.

The main aim of BREATHE was to address carers' needs via an innovative information communication technology-based solution that would support and relieve the burden experienced by informal carers and improve the quality of life of both the carer and the person who was being cared for. The platform was composed of two groups of different modules, namely an AAL home system and an informal caregiver tool. The home system was to provide real-time video information on the assisted person while they were alone at home, and the caregiver tool was to provide personalised support and guidance for informal carers via their smart phone. Details of full project results are available.^{9–11} The project was executed in three distinct sequential phases: phase

one on carer and assisted person needs and video acceptability; phase two on responding to needs and acceptability by developing a video technology solution and testing acceptability of the solution; and phase three, a live trial and evaluation of the technology within the assisted person's home across the European setting.

The aim of the present paper is to explore in more detail phase one of the BREATHE Project and describe the needs, requirements, acceptance and concerns of the informal caregivers towards a video-based home monitoring system prior to the BREATHE Project's detailed design and evaluation in the European setting. The setting for this phase of the BREATHE Project was the Republic of Ireland in 2014.

The objective was to determine if, and in what format, informal carers would be willing to accept home-based video technology as an aid to caring and specifically to ask them if they would be willing to have live video-feed monitoring in the home. To the best of our knowledge this research combination of informal carer need and video monitoring had not been researched previously.

To ultimately obtain ethical approval for private, home-based video monitoring and related research, a sequential approach was also taken with the ethical approval process; ethical approval for each separate phase of the study was obtained from the legally constituted ethics committee of the Faculty of Health Sciences of the university-based research team. Each phase of the study built upon the needs and requirements expressed by the research participants and, as a result of this phased process, ethical approval was granted. The COREQ 32-item checklist was used to aid the reporting of this study.¹² This is a formal reporting checklist for in-depth interviews and focus groups, the most common methods for data collection in qualitative health research.

Methods

Research design

A descriptive qualitative research design was adopted for this study. Qualitative descriptive studies tend to be more flexible in terms of philosophical and theoretical underpinnings. Given the research aims and objectives, an interpretivist paradigm was deemed appropriate. The goal of interpretivist research is to understand the world of human experience from the perspective of the person experiencing it. The aim is to uncover the meanings people attach to those experiences.¹³

Data collection

Data collection methods were one-to-one interviews and focus groups. The one-to-one interviews were

Table 1. Section C outline interview guide.

Section C — The BREATHE system and monitoring	
Now we are going to talk about the new technology that we are planning to design. You might have mentioned some of these already, which is fine, but please consider each of these different possibilities:	
1. Would it be useful to you to find out about X in any of the following ways, in order to be reassured about X's wellbeing?	
a. Would you like to know about X's daily routine?(for example, sleeping, eating, drinking, going out)	
b. What about risky situations?(for example, having a fall, leaving appliances switched on, going out at night)	
c. What about location within the home and how active they are?(for example, whether they are moving between rooms or staying in one place)	
d. Would you like to know about any social activity?(for example going out, talking on the telephone, having visitors)	
e. Are there any other specific activities you would like to know about?	
2. If there was an emergency relating to X, do you think it would be useful to be able to look at X at home in a way that is described on the sheet?	
3. Would you also like to be able to see what X is doing in some way, in some non-emergency situations?	

conducted using an extensive interview schedule, and included structured and semi-structured questions. The focus group schedule was semi-structured and aimed to facilitate a more in-depth discussion of the topics. The overall interview schedule for informal carers consisted of four sections: section A, on demographics and experience of technology; section B, experience of caring; section C, monitoring and needs given a potential BREATHE monitoring system; section D, guidance and support and the requirements from a potential BREATHE system; and section E, obtaining and using a potential BREATHE system. This paper reports on the findings arising from section C of the overall interview schedule. Table 1 provides the outline for section C of the interview guide.

Finally, the guide for the focus group contained similar topic headings after an initial introduction section. During the section on monitoring, participants were invited to provide feedback on the types of video views they would prefer from the system. The choices presented are provided in figures 1a and 1b.

All interviews and the focus group were audio-recorded using a digital audio recorder and transcribed verbatim. Sound files were uploaded from the digital audio recorder to a password-protected computer, and deleted from the digital audio recorder once uploaded. Access to the sound files was restricted to

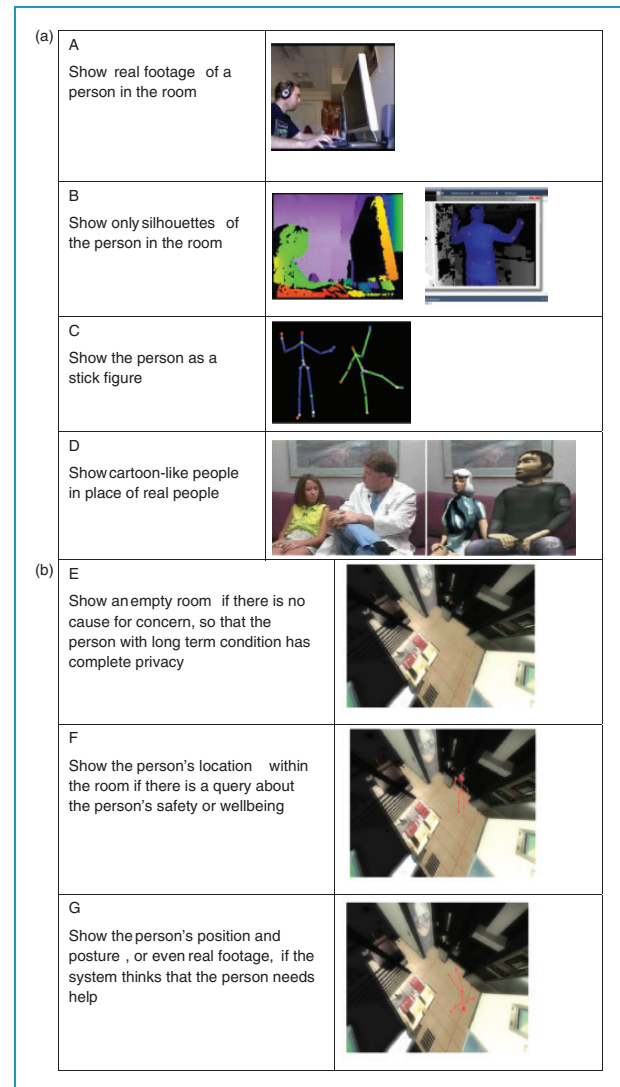


Figure 1. (a) Show card on the types of personal video views that the BREATHE system may provide. (b) Show card on the types of video view of a room that the BREATHE system may provide.

the members of the research team. All information that could identify participants was removed from the transcriptions.

Sampling and recruitment

A convenience sample of participants was recruited through a national voluntary caring organisation working with carers and people with long-term conditions. This organisation acted as a gate keeper. Nine carers took part in the one-to-one interviews, and five carers participated in the focus group. While every effort was made to reach data saturation, there were practical constraints on the number of participants recruited in terms of time and resources.¹⁴ However, it has been pointed out that transparency about limitations on

reach data saturation does not necessarily invalidate the findings, arguing that if data saturation is not reached, ‘this simply means that the phenomenon has not yet been fully explored rather than that the findings are invalid’.^{15,16}

Inclusion criteria were caring for a person with a long-term condition; carers aged between 18 and 90 years; and being able to communicate clearly in English. Carers who had a significant cognitive impairment or physical illness that was likely to impair their ability to give fully informed consent were excluded from the study.

Data analysis

Thematic analysis of the transcribed interviews and focus group was employed to analyse the data. Thematic analysis has been identified as a method for identifying, analysing and reporting patterns (themes) within data.¹⁷ It is compatible with the interpretivist paradigm. The analysis was driven by the research question and the qualitative descriptive research design, with the aim of describing the needs, requirements, acceptance and concerns of informal caregivers towards a video-based home monitoring system.

Analysis of both the interviews and the focus group were completed separately and findings triangulated. Analysis of the data was completed independently by two researchers (KD and SG) working on the project. The coded data were compared and contrasted for agreement and finally reviewed by an independent researcher (psychologist) for verification and in order to ensure homogeneity of procedure. All coded data were in English. Participant anonymity and confidentiality were maintained at all times. The analysis was completed manually and Braun and Clarke’s six phases of data analysis were followed.¹⁷

Results

There were nine one-to-one interviews and one focus group with five participants. Each interview and focus group was of approximately one hour’s duration, providing over 10 hours of data. Details of the participants’ demographics and living arrangements are provided in Table 2.

Three main themes were identified from both the interviews and the focus group. These were summarised as routine, risk (with the sub-theme responding to risk),

Table 2. Demographics, living arrangements and use of existing technology of participants.

	Individual Interviews, <i>n</i> = 9	Focus Group, <i>n</i> = 5
Age range	40–60 years	60–78 years
Gender	6 female, 3 male	4 female, 1 male
Caring for whom	Six carers were currently caring for parents, two cared for a husband or wife, and one was caring for a neighbour	Two carers were caring for their husbands and one for his wife, while the remaining two, one cared for a brother and the other a daughter
Long-term conditions of the assisted persons	Parkinson’s disease Dementia Arthritis Diverticulitis Cancer (skin/arm) Incontinence Depression Diabetes Permanent urinary tract infection Hearing loss Pelvic floor dysfunction Atrial fibrillation	Stroke Chronic obstructive pulmonary disease Downs Syndrome Epilepsy Intellectual disability Mental health
Carer’s health	Good (<i>n</i> = 3), average (<i>n</i> = 3), fair (<i>n</i> = 1), poor (<i>n</i> = 2)	Good (<i>n</i> = 1), average (<i>n</i> = 2), fair (<i>n</i> = 1), unstated (<i>n</i> = 1)
Living with the assisted person	Yes (<i>n</i> = 7), No (<i>n</i> = 2)	Yes (<i>n</i> = 4), No (<i>n</i> = 1)
Use the Internet	Yes (<i>n</i> = 8), No (<i>n</i> = 1)	Yes (<i>n</i> = 3), No (<i>n</i> = 2)
Use assistive technology	Yes (<i>n</i> = 7), No (<i>n</i> = 2)	Yes (<i>n</i> = 4), No (<i>n</i> = 1)

and camera acceptance and privacy (with the sub-themes of emergencies and non-emergencies).

Theme 1: Routine

The informal carers were asked whether they would like to know about the assisted person's daily routine. The majority of carers who took part in one-to-one interviews said that this did not apply in their situation because the assisted person in question was never left alone, or because the carer already knew the routine of the assisted person. One carer stated that she would be more concerned about knowing whether the assisted person was lonely or upset.

It would be lovely to know when ... if she needed anybody to talk to if she was upset. Because ... there's loneliness there and she mentions it and she thinks nobody wants to come to see her. But anytime I call there's somebody there ... you know (TCD 6).

Within the focus group a difference emerged between the needs of carers who live-in with the person cared for, and those living away from the person cared for. When living-in, carers know the daily routine of the assisted person:

Well, if you are caring full time with the people in your own home, you know every minute, every hour of the day, what's going on (TCDFG).

On the other hand, two participants who were not living-in were particularly interested in knowing about the eating habits of the person for whom they provided care, as they are concerned he eats a proper diet.

Theme 2: Risk

Six carers who took part in one-to-one interviews were asked whether they would like to be able to use camera technology to monitor the assisted persons for risky situations.

Three carers talked about the monitoring of risks particular to specific situations. These findings would suggest that for many carers a focus on very specific aspects of the assisted person's daily routine, or daily life, may well be beneficial for them in their caring role.

One respondent who was concerned about issue-specific risks also wanted to know about potential longer-term risks for both the assisted person and the carer:

Yes, I think that would be nice because what was said to me yesterday was, we have to plan for the future now. The short term is kinda not going to happen, we are looking at more long term, with the diseases

that [assisted person] has. It's obvious they are not going to improve, so we have to look at something going forward (TCD 7).

Sub-theme 2a: Responding to risk. In the one-to-one interviews, carers were asked whether they felt that camera technology would be useful in terms of monitoring the assisted person's location in the home and how active they are. Only two carers discussed this in detail, both of whom provided 24/7 care to assisted persons and who, interestingly, had originally felt that camera technology would not be useful in the home.

One of these carers, who cared for an assisted person 24/7, spoke about how camera technology between rooms in the house would be useful to monitor the assisted person during the daytime if they were, for example, resting in bed while the carer was in the kitchen. However, she questioned whether she would want to know the kind of specific detail that such functionality would provide about the movements of the person she cared for when she was out of the house.

I mean the chances are that [the assisted person] is going to stroll from room to room whether I know it or not so I am probably as well off not knowing (TCD 3).

Theme 3: Camera acceptance and privacy

Sub-theme 3a: Emergency situations and choice of personal video view. Carers in the one-to-one interviews and in the focus group were shown show cards (figures 1a and 1b) that illustrated how the BREATHE video-monitoring system would display the assisted person at home in the case of an emergency. Carers were asked whether they felt this would be a useful functionality. Eight people (three in the focus group and five in one-to-one interviews) felt this would be useful for them.

However, one of the carers expressed concerns about privacy issues and that having a camera in the house could be intrusive in terms of the assisted person's privacy, (TCD 9).

Figure 1a also illustrated four options for the type of camera view of the assisted person that the BREATHE system could provide in an emergency situation: 1. 'real footage' of the assisted person in the room; 2. a silhouette of the person in the room; 3. showing the assisted person as a stick figure; and 4. showing a cartoon figure instead of the real person in the room. When asked about the kind of camera view that they would prefer from the options given to them, eight carers in the one-to-one interviews identified the real footage or video footage as the view that they would prefer. The reasons

for this were associated with the fact that that the real footage seemed more normal to carers; that real footage would work better where the technology was being used for monitoring at night; and that real footage would allow for more accurate assessment of the status of the assisted person.

Privacy aside, I really think maybe it's best to see the person because you can tell a lot by their face. And their features (TCD 6).

However, some carers chose other options. One respondent picked the cartoon or stick image stating that this was being picked due to privacy concerns. This respondent had concerns about public access to the footage where it is being viewed out of the house and, on another level, protection of the privacy from the perspective of the assisted persons themselves (TCD 5).

The cartoon image was chosen by another respondent who suggested creating different levels of access to a monitoring system based on the relationship between the carer and the assisted person. In this person's case, the assisted person was a neighbour. Therefore, the carer spoke about access to a monitoring system based on pre-agreed levels and settings that were agreed between the assisted person and the carer,

You could have a menu that could be set access like Facebook – access to family only, access to the whole range so that could be on a menu option, settings could be changed and different people could be let into different levels of access (TCD 9).

When the focus group participants were asked to choose a camera view, the conversation also centred on privacy issues. One participant was concerned about public access to the images on her mobile phone. She speculated about being in a restaurant or a pub with her mobile phone.

Most carers when they are out will keep their mobile phone in view. If the real-life person picture comes up on that phone, whereas the person that owns the phone will know what's going on but if somebody else took that phone they would have an awful lot of information about that [assisted] person (TCDFG3).

Having discussed the possibility of this occurring, even with the recognition of a PIN-protected view, the consensus among the focus group was that for security purposes they would opt for the stick person view.

Yeah, for security reasons, yeah definitely, yeah. Well, I would love to be able to see the [real] person. But when you think of the security side of it (TCDFG2).

Sub-theme 3b: Non-emergency situations and video view of room. Carers in the one-to-one interviews and the focus group were asked if they would like to be able to see what the assisted persons were doing in some way, in certain non-emergency situations. Three of the five focus group participants said they would like to be able to monitor non-emergency situations with the use of a camera. Six carers discussed this in one-to-one interviews. One respondent said that he would not like monitoring of non-emergency situations to occur. The interviewee thought that this would be too intrusive as the assisted person was independent. The rest of the carers said they would like to be able to see the assisted person in non-emergency situations, but they also expressed some concerns about this functionality.

Privacy was the concern raised by two respondents. In the case of one carer, she reported that she would be happy for non-emergency situations to be monitored but that the person she was providing care for might not agree.

Well it would be a bit Big Brother watching, would it? I would be ok with it but [assisted person] mightn't be (TCD 1).

The other respondent raised concerns about use of the camera in non-emergency situations in the bathroom. This respondent said that she did not think it would be appropriate to have a camera in the bathroom for privacy reasons, but that in recognition of the fact that a lot of accidents happen in the bathroom she would feel that a sensor would be a better option, particularly one that detected if the person had not come out of the bathroom.

I don't think I'd like the bathroom ... to be ... even though that's where [assisted person] had her last accident. But there could be a sensor outside the door ... if [assisted person] went in but didn't come out ... I really wouldn't like to think there was any visual ... in the bathroom, and whether [assisted person] goes to the toilet. [Assisted person] would be very well able to tell us if she did or she didn't! (TCD 6).

Discussion

The principal conclusion from this study was the willingness of informal carers to accept live video monitoring via a mobile phone application of the person they care for in a family home environment, as long as the privacy and dignity of the assisted person was protected.

The main strength of this study was the direct accessing of the needs and requirements of informal caregivers in family home settings. The weakness refers to the fact that the assisted person was not involved in the

research design and methodology. The results presented here must be interpreted within the limitations of the study design. Informal carers were recruited with the help of a carers' organisation, and participants had differing caring responsibilities and were caring for a range of assisted persons with varying life-limiting conditions. Although the caring role differed, 11 of the 14 (79%) knew how to access and use the internet and 11 of the 14 participants already had experience of other assistive technologies. The main strength in relation to other studies was the ability of the carers to identify the circumstances under which informal carers would accept the use of video-based technology to monitor the people they care for.

With regards to other relevant evidence in this field, we have seen that there is ample evidence of an ageing population in Europe and beyond, and within OECD nations. These trends are well established and will have significant effects on the economy, current healthcare models and their ability to deliver to citizens.¹⁸ Given these statistics there is a growing interest in studying ageing in place. That is, studies that allow individuals to age and live well in their own homes.¹⁹ The current study proposes and assesses the acceptability among caregivers of the introduction of video interventions for the support of carers, assisted people and the process of ageing in place. Assistive technology for ageing in place is not a new concept, however its adoption by older people has been challenging.^{20,21} Electronic health service interventions are well documented as having high attrition levels or drop-out rates. In many cases users who would benefit most from such interventions resist adoption.^{8,22,23} We have observed in the literature poor implementation and a lack of sustained use with high drop-off and abandonment, signifying perhaps a possible gap in what technology developers think is the way technology should fit the process of ageing in place and the reality of caring for an assisted person ageing in place.^{8,22,23} We have seen that there is a significant group of informal carers supporting the process of ageing in place, particularly in Europe where the number of family carers provides more than 80% of the care required.²⁴ A recent report also highlighted the increasing cost of home care and associated this with the increasing contribution of informal support. Within the informal care networks there are many challenges associated with caregiving such as depression, isolation, and formal skill shortages.^{25–27} It is remarkable that more attention has not been paid to the development and evaluation of assistive technology that aims to support informal carers. With significant growth noted and a trajectory that is unavoidable, future researchers need to look at supports for both informal carers and assisted persons, and recognise the burden and workload that are present for both.

The findings of this study illustrate for technology developers and policymakers some of the complexities that lie behind acceptance of video-monitoring technology on the part of carers, especially with regard to privacy and security concerns. Carers need to be assured that the privacy and dignity of the assisted person is preserved in such technological solutions. However, if these assurances are put in place, the findings highlight for technology developers that carers would welcome and benefit from remote video monitoring of the person they care for.

Conclusion

The challenge for assistive technology developers and the health and social care professions is to expand their collaborations to ensure appropriate video technology is developed that not only reduces burden but improves lives and protects the dignity and privacy of the person being monitored. Given this need, this research study recommends that future research recognises the importance of the carer and the dyadic approach of informal carer/assisted person in modelling the need for and acceptability of new assistive, remote video-monitoring technologies.

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