

Potential for digital monitoring to enhance wellbeing at home for people with mild dementia and their family carers

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Title: Potential for Digital Monitoring to Enhance Wellbeing at Home for people with Mild Dementia and their family carers.

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ABSTRACT

Digital technologies have the potential to assist people with dementia to monitor day to day activities and mitigate the risks of living independently.

A purposive pilot study; using the '3Rings™ digital plug, participants were surveyed for frailty, wellbeing and perceived carer burden.

30 paired participants used the digital device for four months. People with dementia reported a decline in wellbeing and increased frailty. Family carers reported a decline in wellbeing but 18 reported a reduction in burden

The use of digital monitoring by family carers demonstrated a reduction in their perceived burden and the device was acceptable to people with mild dementia living alone.

Key words - assistive technology, digital monitoring, dementia, family carers, wellbeing, burden, frailty.

INTRODUCTION

One third of people with dementia who live in the community (i.e not in residential care) live alone [1] in the UK, amounting to more than 215,000 people. As the population of PwD grows[2] the community of carers, families and other social support will also grow in number. Frailty is strongly associated clinically diagnosed dementia among persons aged 76 and older [3] and can result in a range of functional limitations that also affect their care [4]. Older adults wish to remain living at home for as long as possible [5-7] and this is also favoured by policymakers [5-8] who want family carers (FC) to support PwD at home.

Caregiving can feel stressful [9-12] with variation in wellbeing and levels of burden depending on the duration and the severity of the dementia and the consequent need of the PwD for support[4]. In primary care, for those caring at home the level of burden was lower than reported in other settings [9]. The focus on maintaining independence and detecting decline was important to both parties [10, 11] with an important distinction between burden and wellbeing [12]. Burden appears to be associated with any behavioural changes in the PwD and the hours when care is needed [12] and overall psychological wellbeing of the carer is significantly associated with social support and coping mechanisms [13].

Home-based digital technology may provide a range of solutions to enable safe, comfortable, and acceptable means to remain at home by helping people with dementia (PwD), particularly in relation to routine daily living tasks. Evidence suggests that family carers (FC) find tele-health devices helpful [14] and smart technologies are being developed to support family carers of PwD, including provision of information about daily routine. This may also support PwD to live independently at home [15]. Smart technology is seen as a cost- effective means of maintaining the wellbeing of the PwD [5, 11, 16, -18] demonstrating how most older adults recognise the convenience and support for daily activities. Barriers to digital technology usage and home monitoring are well documented too [5, 17-23] with issues of privacy invasion being the greatest concern. There is essentially a pay-off to the use of devices related to costs and benefits. Research is needed into the usefulness and acceptance of devices, along with robust evidence of the impact on health and wellbeing [24].

Smart technologies integrate physical objects, technology, and people, in order to share information [25] and this can be deployed to recognise routines and repeated activities [26, 27] of daily living. Monitoring the use of an electrical appliance in the home has the potential to demonstrate that a PwD is well and carrying out usual activities. This study sought to investigate whether a FC could check the daily routine of the PwD, and whether it reduced perceived burden felt by the FC. It also sought to identify the effect on wellbeing of both parties.

Method:

A purposive pilot study investigated the outcomes of implementing the 3Rings™ digital plug with PwD who lived alone and their FC's, over a period of four months. Funded by the South Yorkshire Perfect Patient Pathway (Testbed) Programme. Ethical approval ER5178396 was granted by Sheffield Hallam University Ethics Committee.

Third sector partners identified potential recruits and information was sent to the potential participants specifically excluding anyone with formal care or a live-in relative. Participant Information Sheets and consent forms were sent to family carers for them to read with the PwD. Telephone contact confirmed inclusion criteria with FC and the study was explained in detail.

Formal written consent was taken from both PwD and FC in the PwD's home and the 3Rings™ plug was installed with a routinely used electrical device, typically an electric kitchen kettle. The 3Rings™ system is set with an 'event time' period; where use of the appliance in this period is a significant indicator of the likelihood of the routine behaviour taking place. 'Event time' for a kettle would cover the time-frame for a morning or evening drink. Habitual activities could be predicated with PwD and their FC, recognising the usual routine. Other devices, i.e. a TV or bedside light were also acceptable providing they were in regular use in the PwD's home. The plug was installed according to manufacturer's guidance with agreement to use the smart device as part of usual daily routine. Then the FC was instructed in the use of the digital monitoring application on their mobile phone. Survey tools were used with both parties.

Pre and Post Survey

Two standardised survey tools were used with the PwD and with the FC, at first meeting and after four months.

The Edmonton Frail Scale was used with the PwD as it has good construct validity and reliability [28, 29] and allows a diagnosis of frailty to be assumed from the score [28]. The Warwick-Edinburgh Mental Wellbeing Scale (short form) is a positively worded validated scale to measure wellbeing measured on a five -point Likert Scale [30, 31] and was used with both PwD and FC. These assessment tools are both validated for PwD [32]. The Zarit Burden Interview has a high reliability and validity, and is often used to measure the challenges presented to the care-giver over time [12] and was used with the FC. The relevance of this measure was associated with the wellbeing of family carers and the possible difference experienced with remote digital support.

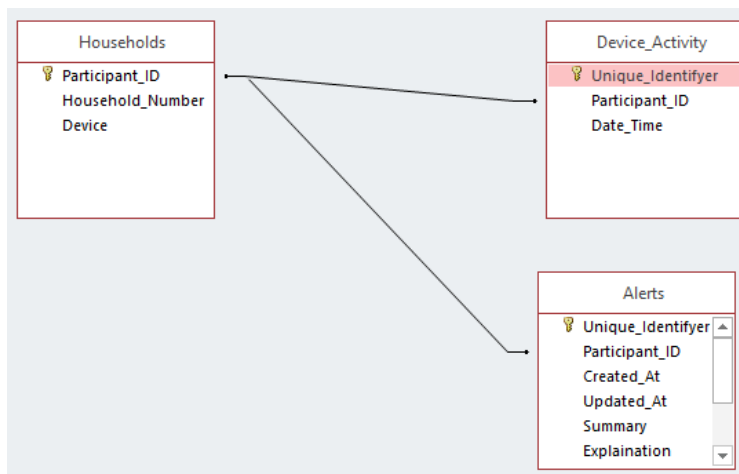
Semi-structured interview

A short interview was constructed from the literature and used with the participants. The focus was on subjective experience of using the 3Rings™ device relative to their individual context, emphasizing individual differences [33]. The data was intended to provide a narrative explanation of the findings and to generate some explanation about the value of the monitoring process to families.

Remote digital data collection

Background appliance activity is logged for each appliance, and accessed via the digital interface; usually FC's digital mobile phone. Daily patterns of use, using the 'timed -event' data is evident to the FC with alerts send when no activity occurred in a pre-set 'event- time' window, (see Figure 1). Alerts operated automatically irrespective of the reason for inactivity and are continuously sent until an action in response is taken. The explanation refers to the decision about whether this constituted an emergency based on the understanding of the PwD and FCs. Response to alerts by the FC were collected , the explanations categorised under four options: emergency, action needed, no action needed, false alert.

Figure 1- 3Rings™ utility monitoring via digital alert data



Analysis of the alerts sent and received was collated by the research team, together with summary and explanation of device usage for all PwD participant using the participant ID. This data identified the number of times that the 'timed events' were not carried out during the set parameters; indicating risk through unpredicted activity.

Analysis

The first and second wellbeing questionnaire scores, burden scale and the frailty data were manually input into an Excel spreadsheet and difference was calculated. Descriptive analysis was applied to correlate frailty and wellbeing for the PwD, and level of burden and wellbeing for the family carers.

The digital monitoring data was then compared with the questionnaire results to generate some explanation about the value of the monitoring process to families. Other qualitative data was collated using simple content analysis to identify subjective experiences aiming to illustrate the usefulness or problems with adoption of digital monitoring.

Results

Recruitment and retention- 46 potential participants were identified and 31 participant pairs (PwD and FC) were recruited. The analysis was completed on 30 pairs who were retained for the full period of the study and who used the device for four months. Population reach [34] was calculated at 0.75% of the total population of people living in the region who have dementia and live alone based on an third of those diagnosed with dementia in the region [35]. The demographic characteristics of the group (Table 1.) were representative of the population.

Table 1. The demographics of the paired participants.

Participants	Number	Gender	Age range	Relative
Persons with Dementia	30	Male-7 Female-23	Male -65-92 Female 78-96	
Family Carers	30	Male- 8 Female- 22	Male - 28-62 Female 30-65	Son-7 other -1 Daughter 16 other -6

Digital Monitoring data- The mean number of alerts in the first two months was <3 per participant pair and decreased to <2 or less at 4 months. This reflects a pattern of highly routine behaviours, within the event-times configured at device set-up. The median value of alerts throughout the study was 1 per PwD. Only 5 alerts out of 266 in total required an action by the family carer (215 'no action needed', 46 'false alerts', 0 emergencies, and 5 'Action needed'). One FC failed to understand the device and its alert management process, resulting in 19 alerts in the first month. One PwD

unplugged the device as part of their evening routine causing 'false alerts'. However, all family carers learned how to resolve the alerts quickly after a short period of use.

Survey data

All 30 paired participants completed pre and post survey tools allowing scores to be analysed. Table 2 shows that around half the PwD (17) and FC's (15) reported a decline in wellbeing. 17 of 30 PwD's frailty improved or stayed the same with 13 demonstrating a decline in scores of the Edmonton Frail Scale. 18 of 30 FC's reported a decrease in burden; almost double the number that reported an increase in burden.

Table 2. A summary of the comparison of the survey scores pre and post showing the number of scores that improved or declined.

	PwD Short Warwick Edinburgh	PwD Edmonton Frail Scale	FC Short Warwick Edinburgh	FC Zarit Burden
Improvement	13	7	10	18
Decline	17	13	15	10
Stayed the same	0	10	5	2

Subjective Experience

There were a number of comments from the FC interviews that can be reported with the following experiences;

- The PwD had a patterns of behaviour that was predictable and the 'timed events' led to a re-assurance that their relation was 'okay' at home
- That the use of the device promoted less checking and a more satisfactory relationship based on better quality social contact.
- For PwD there was an appreciation that they were 'connected' to their FC through the device
- FC reported that they 'waited' for the timed event period to pass each morning and then when there were no alerts they would relax.

Discussion

PwD and FC agreed to the use of digital monitoring and understood the implications, recognising the connectivity that the device afforded their families [7]. This study adds to the understanding of the potential benefits of using a monitoring device and the impact on wellbeing insofar as participants

found the technology acceptable and usefully demonstrated the relative stability of routine for PwD. There were a low number of missed event-times causing few alerts that suggested routine behaviours over the four month period. This stability was useful as additional information to support family care.

The reported reduction in burden for the FC group (18 of 30) was noted and important to recognise in relation to both increases in PwD frailty and decline in PwD wellbeing. This supports the suggestion that remote monitoring technology has the potential to reduce the stress and burden felt by family carers [11] perhaps due to the behavioural feedback and regular patterns [12], which gives families 'peace of mind' [18, 35]. Whilst family carers mostly want to support PwD to maintain their independence and 'age in place' for as long as possible [1, 17], many FCs, have a range of other social commitments and caring responsibilities that are competing for their attention. Remote monitoring can enable family carers to have a greater understanding of their relative's daily routine [11,36] which can assist in planning and reduce conflicting demands- this is a direct product of being able to predict risk and assume routine behaviours. It may also provide useful insights on behaviours they were not aware of [37] for example where early rising or night time routines diverted from a regular pattern and an intervention can be planned [6].

A PwD who lived alone but who is at ease with their surroundings was able to repeat a daily tasks (as indicated by the 3Rings device, in a safe and familiar way, albeit for the relatively short period of this study. Dementia is considered to be a progressive condition [38,39,] with a variable trajectory of gradual decline in function [11,37]. The importance of habit and routine as an indicator of wellbeing is an under researched area and has been shown to have potential to facilitate independence. The PwD may accommodate to privacy and intrusion if the alternative would be going into a care home [6, 11, 16, 18, 19] and monitoring could provide a means of connection resulting in feeling safer [18,36], and cared for [22,]. Lower burden and higher wellbeing in FC appears to directly benefit the PwD sometimes irrespective of the PwD's functional status and personal wellbeing. The monitoring of a valued routine can be an important indicator of continued ability for the PwD to remain at home.

Strengths and Limitations

The study was a time-limited study using a simple device that had the advantage of engaging paired participants who were new users of technology with FC and PwD participating equally.

Conclusion

This paper reports on the benefits of digital monitoring to PwD and FCs, in relation to predicted patterns of PwD behaviour; demonstrating a regular daily routine that could be predicted. This is important for FC in relation to burden over time. Overall this study contributes to the understanding of how digital monitoring devices have the potential to facilitate independence for PwD living alone. It provides because this may reduce the stress that carers experience, particularly if they do not live close to their relatives.

2306 words

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

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