

Telehealth Home Monitoring of Solitary Persons With Mild Dementia

Glenn E. Smith, PhD, Angela M. Lunde, BA,
Julie C. Hathaway, MA, and Kristin S. Vickers, PhD

Medication safety is a special concern for the 30% to 40% of dementia patients who live alone at the time of diagnosis, and it plays an important part in relocation decisions. Televideo monitoring could improve medication self-administration accuracy and improve mood for persons with mild dementia who live alone or spend a significant amount of their day alone. The authors used 2-way interactive video technology to monitor medication compliance of 8 persons with mild dementia. They conducted more than 4000 contacts with these persons and found adequate technical outcome in 82% of calls. End medication

compliance was 81% in the video-monitored group compared to 66% in the controls ($P < .05$). Comparison of compliance from initial to end ratings revealed that video-monitored participants' compliance remained stable while unmonitored patients' compliance fell 12 percentage points, consistent with expectations for dementia. This difference was also significant. Quantitative and qualitative outcome data from this project are presented.

Keywords: dementia; telemedicine; home health; medication; safety

Nursing home placement is an almost certain outcome for persons with dementia. Population-based studies completed in our Alzheimer's Disease Research Center revealed that 91% of persons with dementia received continuous nursing home placement by the time of death in contrast to 50.6% of matched normals.¹ Presence of live-in caregivers, especially spouses, is a factor in how

rapidly people with dementia are institutionalized.¹⁻³ Notably, live-in assistance providers are absent for a significant proportion (31%-44%) of patients with dementia.^{1,3} Safety concerns, especially inability to manage medications, play an important part in decisions to institutionalize these people,⁴ perhaps prematurely. Telecommunication technology can assist in supervision of safety issues. Two-way interactive video communications technology affords the opportunity to bring virtual medication monitors into the homes of people with mild dementia.⁵⁻⁷ The virtual caregivers can also increase social interaction, adding to quality of life. This could delay the need for more expensive and restrictive forms of care, but this remains to be established. Televideo supervision stands to extend the continuum of care options for dementia patients. We have obtained more than 2 years of experience using televideo technology to monitor medication compliance in a sample of people with mild dementia. This project involved 14 people with mild dementia, 8 of whom received the video-monitoring phase and/or a plain ordinary telephone service (POTS) monitoring phase and/or a standard unmonitored care phase. The remaining 6 participants received only POTS and/or unmonitored care as match controls to video participants that could not serve as their own control in all

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From the Alzheimer's Disease Research Center (GES, AML), the Department of Psychiatry and Psychology (GES, KSV), and Patient Education Research (JCH, KSV, Mayo Clinic College of Medicine, Rochester, Minnesota.

Address correspondence to: Glenn E. Smith, PhD, Department of Psychiatry and Psychology, Mayo Clinic, 200 First Street SW, Rochester, MN 55905; e-mail: smitg@mayo.edu.

3 phases. We conducted more than 4000 telemedicine contacts. We assessed technical success, medication self-administration accuracy, neuropsychiatric symptoms, and mood burden as key indicators of efficacy. We also conducted qualitative interviews with the caregivers regarding their experience of this project.

Materials and Methods

Participants

We enrolled 14 participants who met the following criteria:

- *Diagnostic and Statistical Manual of Mental Disorders* (fourth edition) diagnosis of dementia⁸ or mild cognitive impairment⁹;
- Clinical Dementia Rating Scale¹⁰ score of 0.5 or 1.0;
- lived alone in their own home or apartment;
- had a reliable informant who lives in the region and has regular contact with the patient;
- absence of delusions or hallucinations as assessed by the Neuropsychiatric Inventory (NPI)¹¹;
- took at least 1 medication daily; and
- if on psychotropic medications, then doses were stable;

The exclusion criterion was significant health-related risks for hospitalization.

For all participants, medication regimens were established via medical records review. Baselines for medication counts, NPI scores,¹¹ and Geriatric Depression Scales—short form (GDS)¹² scores were obtained during in-home interviews of the patient and the noncohabiting caregiver. Subsequently, all participants were visited once per month by the study coordinator, who compared medication counts to the expected medication schedule. The study coordinator also conducted interviews with the noncohabiting caregiver every 4 months.

As this project commenced in 1998, before broad availability of other platforms, an Integrated Services Digital Network (ISDN) system was used. This system for digital phone connections has been widely available for more than a decade and allows voice and data to be securely transmitted simultaneously using end-to-end digital connectivity. Despite wide availability, ISDN was not available in all rural regions in our area. ISDN-based televideo monitoring equipment was installed in the homes of the 8 consenting participants for whom ISDN was available. The equipment remained in their homes for an average of 6 months.

Over the course of the project, Picturetel Swiftsite model 760, Polycom model 512, and Tandberg model 1000 units were used with roughly equal frequency and success. The 6 participants whose residences could not be served by ISDN technology (or who refused video monitoring) were retained as controls and received only the phone monitoring and/or no monitoring arms. Participants on the televideo- and phone-monitoring arms were contacted by nursing assistants (NAs) daily according to their medication schedule. So, for example, if the participant's prescription required medications in the morning, at noon, and at bedtime, he or she was contacted at those 3 times. Alternatively, if the participant required only once-daily dosing, he or she was contacted once. For the no-intervention arm, participants received standard care (ie, whatever the family might independently arrange). The study coordinator visited only for data collection purposes.

As much as possible, participants served as their own controls. Five of the 8 video participants completed at least 1 other arm of the project. For those arms not completed by the video participants, an age (± 3 years) and gender match was made to persons who completed only the phone and no monitoring arms. All analyses were thus paired (dependent) analyses comparing a video participant to themselves or a matched control in phone and unmonitored phases.

Measures

Control Measures

*Mini-Mental State Examination.*¹³ This is the most widely used measure of global mental status. Scores range from 0 to 30, with scores greater than 27 typically associated with intact function, scores from 27 to 24 associated with mild cognitive impairment, and scores less than 24 typically associated with dementia. Severity of cognitive impairment was an important covariate in this project.

Contact form. During televideo monitoring and telephone prompting, a contact form was completed by an NA each time a communication with a participant was initiated. The NA recorded whether the patient responded and any technical difficulties for both televideo and phone contacts.

Medication self-administration. At the end of televideo monitoring and telephone prompting, NAs recorded the participants' success at (1) responding to directions

to retrieve medications, (2) presenting the correct medications to the camera or describing them over the phone for the NA to document, and (3) administering to themselves the correct medications as assessed by direct observation or self-report.

Primary Outcome Measures

Medication accuracy. Participants' medication schedule was determined by review of the Mayo medical record. It was corroborated by informants and home visit review of the participants' prescription containers. An initial pill count was established. Based on this information, expected pill counts for each medication for each monthly visit were projected. Before each monthly visit, the study coordinator reviewed the patient's medical record to determine if intervening changes were made in the prescriptions or dosing. At each monthly visit, the study coordinator reconciled pill counts with the medication schedule to determine the amount of deviation from expected counts. These scores were represented as 100 minus the percentage deviation from expected. For example, if the medication schedule dictated that 10 pills should be left at the time of the visit and 8 (or 12) pills were left, then a score of 80% was entered.

Secondary Outcome Measures

Geriatric Depression Scale.¹² Participants completed this 15-item self-report regarding depressive symptoms. A score of 5 or greater is considered clinically significant.

Neuropsychiatric Inventory.¹¹ This is a widely used scale of behavioral disturbance in dementia. Twelve behaviors (eg, hallucinations, delusions, anxiety, apathy, depression, nighttime wandering, etc) are rated for frequency and severity such that each dimension can range in score from 0 to 12. The total score is the sum of the 12 dimensions and can theoretically have a range from 0 to 144, but in practice, scores greater than 40 are rare. This scale was employed to determine if the presence of the monitoring would increase neuropsychiatric symptoms in monitored patients.

End-of-study qualitative data. Participants and their primary caregivers were asked open-ended questions to assess their opinions of the telemedicine service, with a semistructured individual interview script. Memory impairment limited the quality of information provided by the participants; most qualitative data

Table 1. Patient Demographics

	Video	Phone	Control
Age, y	79.8 (11.4)	81.9 (11.0)	85.5 (6.6)
Education, y	11.9 (2.8)	11.6 (3.5)	12.1 (4.1)
MMSE score ^a	23.2 (1.9)	22 (2.1)	25.7 (3.3)
Neuropsychiatric Inventory score	0.4 (1.3)	0 (0)	0 (0)

MMSE = Mini-Mental State Examination. Values are presented as mean (SD).

a. Video differs from control, $P = .06$.

came from the caregivers. Interviews were audiotaped and transcribed verbatim. Predominant themes (ie, issues, feelings, or opinions repeated or common across multiple participants) were identified and agreed on by 2 of the authors (J.C.H., K.S.D.) who were not primarily involved in the conduct of the project. These authors developed a coding strategy and independently coded all interviews using methods of content analysis (ie, systematic process of sorting and coding information based on themes).¹⁴ QSR's N6¹⁵ qualitative data software analysis program was used to aid in data analysis. Independent coding results were compared, and important themes and representative quotes were identified.

Data Analysis

All analyses were based on 8 sets of triadic data. As noted above, most participants served as their own control for at least 1 comparison arm. When they did not, an age and gender surrogate was used. Scores from the video arm were compared to the phone arm and the control (no monitoring) arms via paired t tests. For the demographic and cognitive data, a 2-tailed test was completed as we had no basis to expect a directional difference. For the compliance, depression, and NPI data 1-tailed dependent t tests were used as we hypothesized superior scores for the video arm.

Results

Table 1 provides descriptive statistics regarding demographics and level of cognitive impairment for the sample at the beginning of each phase of the study. Mini-Mental State Examination (MMSE) scores at initiation showed a trend for no-monitoring scores to be higher than video phase scores ($P = .06$). Age, education, GDS scores, and NPI scores at initiation were not significantly different across phases.

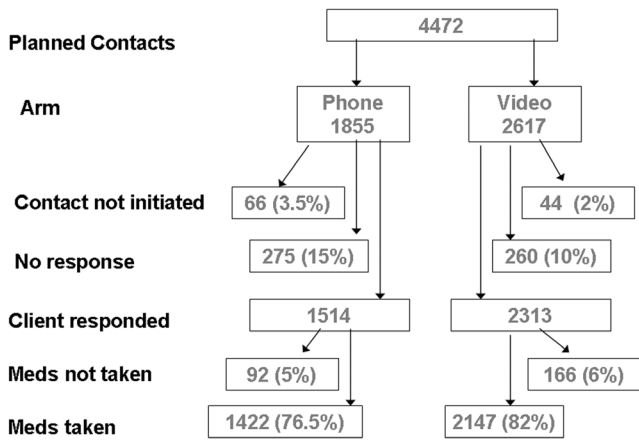


Figure 1. Technical success of monitoring patients with mild dementia who were living alone.

Figure 1 describes our experience in providing the video versus phone contacts. In both groups, we had only nominal technical difficulty in delivering the services. In only 2% of cases was a video link not established. In a portion of these cases, it was because the NAs forgot to initiate the call. The scope of this problem is reflected in the phone arm wherein no contact was established in 3.5% of the cases. This was never due to phone line failure but typically to NAs forgetting to initiate the contact. Thus, the video arm fared even better than the phone arm in terms of NA success. Given the large number of contacts, even this small difference was statistically significant ($P < .05$).

Figures 2a to 2d depict the change scores from initial assessment to the end of the phase. For all measures, there were no statistically significant differences between the phone arm and the video arm, although the video arm consistently outperformed the phone arm on these measures. Note that while the measures of cognition, burden, and neuropsychiatric symptoms were completed at the beginning of the phase, medication compliance could not be established until 1 month into monitoring. Thus, initial medication compliance was established after phone and video monitoring had begun. Figure 2a shows that MMSE scores were nominally but not significantly higher for the control arm. As expected, participants' MMSE scores declined over time. There was no difference in rate of MMSE change. Figure 2b shows the medication compliance data. There were no significant differences between groups at initial assessment. Initial compliance rates (1 month into the phase) were 80% for

video, 85% for phone, and 75% for controls ($P = .23$). Over time, the video-monitored group remained stable in their compliance while the other groups declined. The rate of change between video and no monitoring was significantly different ($P < .05$), as was end compliance ($P < .05$), with end-of-phase values of 81%, 80%, and 62%, for video, phone, and no monitoring, respectively. Figure 2c depicts initial and final neuropsychiatric symptoms. There was a very mild trending up of neuropsychiatric scores across all phases consistent with worsening dementia. There were no differences across phases. Finally, Figure 2d provides GDS scores. Overall, levels of depressive symptoms were very low initially and remained low with no real differences across groups.

Tables 2 and 3 summarize key themes generated by the qualitative data analysis. Structured analyses of the interview transcripts identified 6 main themes: decreased caregiver worry, medication compliance, social support, impact on placement, technology issues, and medication delivery problems. These are organized by positive aspects of the intervention and areas for improvement.

Discussion

Mild dementia patients can be monitored. The technical data from Figure 1 reflect our ability to establish a 2-way interactive link with these mild dementia patients in their own homes with high frequency. There were rare technical glitches in the video wherein the video equipment “failed.” This was occasionally because the patient had turned off the monitor or camera. This problem was often regularly resolved by phoning the patient and talking them through the process of rebooting the equipment. Nevertheless, if home video monitoring were to be in wide use, obscuring the power switches of the home-based equipment or choosing equipment that had no obvious switches would be a valuable modification.

A bigger problem for monitoring patients at home was the frequency with which participants failed to respond to the video equipment after it had been activated. Here again, this problem was greater for the phone arm than the video arm. The 10% to 15% rate of failure to respond largely reflects the independent and active status of these mild dementia patients. Their failure to respond was often the result of their being out with family or friends, at appointments, and so forth. Within our rigorous method of accounting for contact success, this was

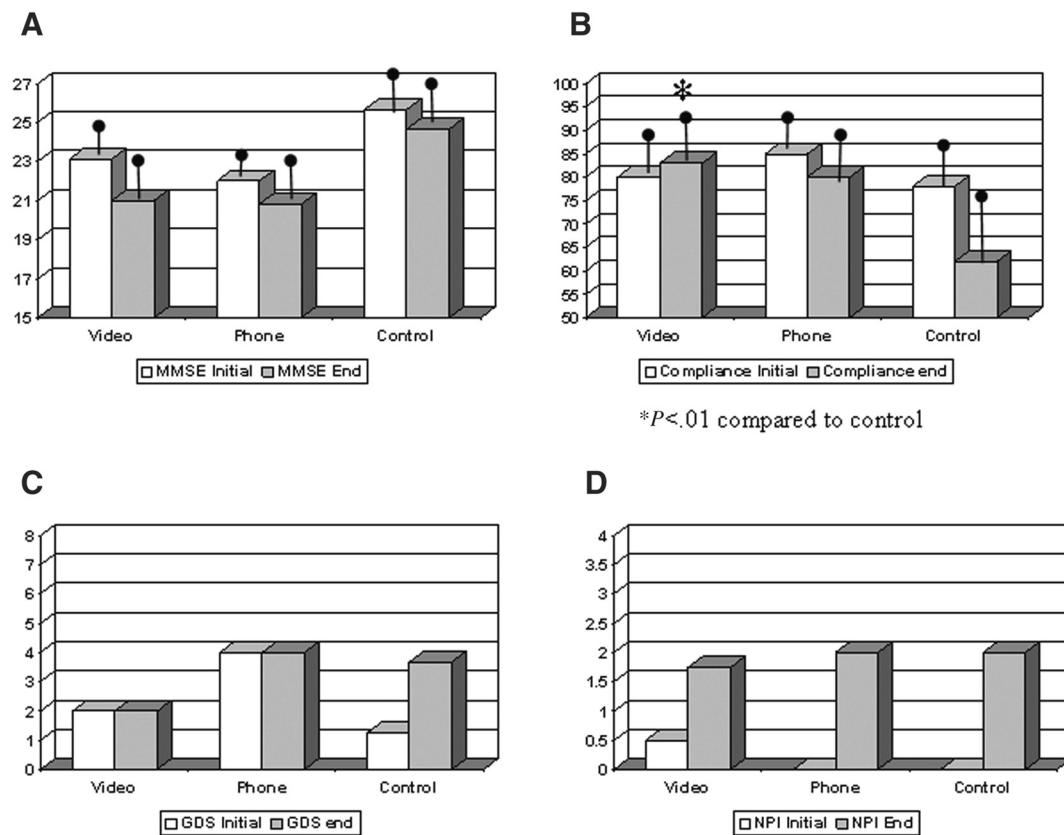


Figure 2. Outcomes. (A) Mini-Mental State Examination (MMSE) scores at initiation and end of video-, phone-, and no-monitoring phases. There was a trend for initial no-monitoring score to be higher than video phase ($P = .06$). (B) Medication compliance at 1 month and end of phase. End compliance ($P < .01$) and change in compliance ($P < .02$) were different for video- versus no-monitoring phases. (C) Geriatric Depression Scale (GDS) scores and (D) Neuropsychiatric Inventory (NPI) scores at initiation and end of phase. There were no significant differences (so standard error bars are not included).

deemed a failure. This is probably too stringent, and in retrospect, we might have done a better job of accounting for excused absences. After all, a high level of independence is a key goal for this type of technology.

As noted in Figure 2c, this monitoring occurred without inciting neuropsychiatric symptoms such as paranoia, delusions, or agitation. Monitoring did not have a clear impact on mood, but this may have been a floor effect because there were not real mood symptoms initially.

Monitoring appears to prevent deterioration in medication compliance. The medication compliance data in Figure 2 show a statistical stabilization of medication compliance in the video-monitored phase relative to the control phase. This occurred even as global mental status was declining roughly equally in all phases.

It is acknowledged this is a small- N study. This is in part because of the intensity and expense associated with this project. Because of the small N , the present findings might be unreliable or generalize poorly. Moreover, it would have been ideal if all patients could have served as their own controls for all 3 phases of the study. This is, however, an unstable population, so maintaining participants through all 3 phases (ie, 18 months) is challenging. It remains unclear if the video arm outperformed the phone arm. A larger and longer study might clarify this issue and also address cost-effectiveness. Yet with the ability to detect compliance differences, given the limited power, this study is encouraging.

Qualitative analysis captured additional aspects of the program. The interview of primary caregivers at study end was structured to elicit both positive and

Table 2. Positive Aspects of Telemedicine Service

Theme	Representative Quotes	Respondent
Decreased caregiver concern/worry	It was just very reassuring to know that twice a day somebody would actually see her and check on her.	Son of patient 5
	It gave me peace of mind knowing that she was taking her pills. I like the idea that other people are here checking on her and also assuring me that she's getting the right medications and the right amount of medications.	Daughter of patient 6 Paid caregiver of patient 1
Medications	I think it's great that they come on and they remind her to take her medications. It really helped with the medicine. . . . It helped her to get the accurate amount of medicine and the right time of the day.	Paid caregiver of patient 1 Son of patient 5
Social support/rapport with telemedicine caller	They take the time to call and to talk a little bit with the patient . . . they seem to be very interested . . . if he has something to say, even if it's not related to anything in particular, they'll comment on it and have a little visit with him to make sure he's okay. It was very personal.	Daughter of patient 4
	She enjoyed it. She's a very social person, and she felt like she made a new friend.	Son of patient 5
Impact on nursing home placement decisions	I know that some day she was going to have to move, and she was very much against moving, and we've always tried to let her stay there as long as we could. So this, with some other changes in the house, made it safe for her to stay there.	Son of patient 5
	[Relative] was very concerned . . . [relative] wanted to put dad in a nursing home, like last May. I was like no—they can actually see them take his medication . . . it's not just a telephone.	Daughter of patient 4

Table 3. Areas for Improvement With Telemedicine Service

Theme	Representative Quotes	Respondent
Technological issues Mechanical/connection concerns	There were a few times that it was kind of glitchy. The unit made a little humming noise. I think they had a little technical difficulty for one time and had to change one of the boxes . . . but very little problems.	Daughter of patient 4 Son of patient 5
	Tampering concerns	There have been times he'll turn off the monitor and things get messed up. If there is a way to change the setup so that it was tamperproof . . . to get rid of the buttons. You might have some people wanting to monkey with all that stuff.
Cumbersome equipment	It's always nice to have smaller flat screen . . . it took up a little bit of room on the counter . . . if all that electronics gets smaller it would be nice.	Son of patient 5
	It was big . . . in a small apartment like that it could be very cumbersome. If they could downsize some of the equipment somewhat.	Son of patient 7
Medication delivery problems	On the weekends when I would come back, and I would see the empty pill case of 10, there were other pills that perhaps had not been taken.	Daughter of patient 6
	It was a relief to me until these 3 times when she didn't get her medications. I don't know if she wasn't in the room or something when the monitor came on, and she missed that, because the medications were not taken.	Paid caregiver of patient 1
	It's very important to have consistency among the people that are administering the meds, and that there isn't a lot of switching because that's extremely confusing for my mother.	Daughter of patient 6

negative reactions. Despite the quantitative data suggesting rare technical issues, formal qualitative analyses of these issues suggested that these technical issues predominated the negative reactions to the program. There was concern that the equipment was a bit intrusive. Also, when medication compliance failures did occur, it was all the more disappointing to the primary caregivers. This was perhaps because their expectations had been raised.

On the positive side, qualitative data also supplemented the quantitative data. Caregivers appeared reassured by the monitoring and felt that it did improve their patient's compliance. It may be that the weight of disease progression overwhelmed the impact of intervention across all arms but that caregivers nevertheless felt positively about the intervention as it specifically pertained to the medication compliance. Also on the positive side, the qualitative data captured the beneficial social aspect of the intervention. We had not anticipated this impact in our selection of formal outcome measures.

There was a strong feeling on the part of several caregivers that the intervention prevented relocation of the patient during the course of the project. However, our study was not designed as a formal test of this notion. A large-scale longitudinal study would be necessary to directly test whether the type of intervention can delay relocation outcomes.

In summary, our small study provides encouraging results for the ability of a home telehealth application to positively affect mild dementia patients. It provides another example of use of telemedicine applications to avoid the need for home health care visits.¹⁶ Video and possibly simple phone monitoring may help stabilize medication compliance in such patients who live alone and may be at risk for premature relocation out of their homes. We estimate that it cost approximately \$25 per day to provide this service. Nearly half of this cost was the expense of the equipment and telecommunications charges. As Internet platforms become more accessible, they will likely drive this cost down. In contrast, in-home visits in our region averaged \$105 for a 3-hour (required minimum) day at the time of this project. These costs are only increasing. Nevertheless, large-scale studies are needed to assess the cost-effectiveness of such interventions and to determine the utility of such interventions in delaying relocation time. Such studies could also explore the utility of intermediate (between high-bandwidth ISDN and low-bandwidth

POTS) or computer-based platforms for monitoring medication self-administration.

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