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A pilot study on the use of tracking technology: Feasibility, acceptability, and benefits for people in early stages of dementia and their informal caregivers

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Objectives: Caregivers and clinicians may be confronted with the dilemma whether to allow people in early stages of dementia to go outside independently with the risk of getting lost, or to limit their autonomy and mobility. Newly available technology may offer a solution. This pilot study is focused on the feasibility, acceptability, and effectiveness of a three-month use of Global Positioning System (GPS) by care receivers and caregivers.

Method: Numbers and percentages of participants with positive responses to self-report questions were calculated. Differences between the pre- and post-test scores of role-overload and worry were tested with paired *t*-tests and effect-sizes were calculated.

Results: Of the 33 dyads of care receivers and caregivers, 28 remained in the study (dropout rate 15%). The majority of the caregivers was able to use the technology and integrate the use into their daily routines and would recommend the use of GPS. Almost half of the participants with dementia experienced more freedom and were less worried when they were outside unaccompanied, a quarter mentioned that they were more outside independently and a fifth that they had less conflicts with their caregiver after three months. Caregivers showed a trend to feel less worried, especially caregivers who could reach their relative using the telephone connection. No changes in caregivers' feelings of role-overload were found.

Conclusion: The GPS device used in this study seems to be promising for people in early stages of dementia and their informal caregivers. A next step is to carry out a randomized controlled trial.

Keywords: Alzheimer's disease; GPS; spatial disorientation; worry; burden

Introduction

A significant problem faced by people in early stages of dementia is getting lost while they are outside alone. A survey showed that 43% of people with dementia had been lost at some point (McShane et al., 1998). Most lost persons were quickly found. However, 28% of them had been lost on more than five occasions and 14% had been lost for six or more hours on at least one occasion. This substantially increases the risk for involvement in dangerous situations or even death (Hope & Fairburn, 1990; Meredith & Vikki, 2003). Finally, research shows that in people with dementia, those who often get lost are much more likely to be placed in nursing homes (McShane et al., 1998; Rasquin, Willems, de Vlieger, Geers, & Soede, 2007).

Caregivers of people with dementia are keenly aware of the risks and consequences of disorientation and getting lost. Specifically, knowing that a care receiver with dementia may get lost is an independent stressor, an extra burden for the caregiver, leading to the onset of symptoms such as depression and/or anxiety (Hope et al., 2001; Miyamoto, Ito, Otsuka, & Kurita, 2002; White, Montgomery, & McShane, 2010).

At the moment, regular ways to cope with these problems are providing permanent supervision, psychotropic drugs or restraints reducing the mobility of

the person with dementia (Chiu et al., 2004; Rowe & Glover, 2001). Reduced mobility particularly affects the person's autonomy, self esteem and well-being (Passini, Rainville, Marchand, & Joanne, 1995; Woods, 1999), and all important aspects of quality of life (Lawton, 1991).

Caregivers and clinicians are confronted with the dilemma of balancing the tendency to get lost with the need for autonomy (Cohen-Mansfield, Werner, & Marx, 1991; Coltharp, Richie, & Kaas, 1996; Rasquin et al., 2007). To this end, newly available technology may be helpful in allowing the person with dementia to go outside independently while the caregiver is able to monitor his or her location. Several tracking and communication devices designed to support people with dementia and their caregivers are available.

One of the most promising devices is the 'Global Positioning System' (GPS). The GPS was initially developed for the US Army. Through contact with satellites at high altitude, the system can quickly determine the position of a transmitter box which is carried by the individual. Given the frequent recurrence of the positioning, the system can track the person carrying the transmitter box with minimal margin of error.

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Many researchers have investigated tracking devices, but only a few empirical studies have been carried out (Hermans, Htay, & McShane, 2007). Research on the use of GPS in dementia has focused thus far on identifying the feasibility of using these systems, as well as their technical operation, usability, and related ethical issues (McShane, Hope, & Wilkinson, 1994; Miskelly, 2005). This article reports the findings of a pilot study with regard to the impact of the use of track and trace technology for people with dementia, in addition to the feasibility and usability, carried out in accordance with the guidelines for testing new interventions (Campbell et al., 2000).

The following research questions were investigated. (1) Feasibility and acceptability: How is the technology evaluated by the participants? (2) Effectiveness: To what extent are people with dementia less worried and do they experience more freedom because of the use of GPS? Are effects found on caregivers' feelings of worry and feelings of role-overload?

Design

In this pilot-study, dyads consisting of a person in an early stage of dementia and his or her informal caregiver started the use of tracking technology. The feasibility, acceptability, and benefits for both, the people with dementia and their caregivers, were investigated in a one-group pre-post test design. The post-measurement took place directly after the dyads used the system for three months.

Caregivers as well as the people with dementia were asked for their informed consent. The study was approved by the medical-ethics committee METiGG.

Intervention: The use of a tracking device

For this study, respondents used a tracking device combining GPS and General Packet Radio Service (GPRS). The device has the size of a pager and can be worn on the belt. It includes three functions. For the track and trace function, the device sends position coordinates to a secured website, via the mobile phone network, after contact with the GPS satellites. The caregiver can go to the secured website and log in at any time, and look at the actual position of the person with dementia and the route he or she took on a map. The second function concerns telephone contact. The person with dementia can get into contact with his or her caregiver with one push on a button after programming the phone number of the caregiver. The device also has a loudspeaker function. The caregiver can get into direct contact with the person with dementia who does not need to push any button to hear and talk to his or her caregiver. Instructions for the use of the device were provided by one of the researchers to both the person with dementia and the caregiver.

Participants

In this pilot study, 343 dyads were included. The participants were recruited by asking stakeholders (Alzheimer Nederland, Alzheimer Café's, meeting centers, psychologists, day treatment centers, home care, and other instances) to inform people with dementia and their informal caregivers about the possibility to participate in this research.

People with dementia were eligible to participate in this study when they had a diagnosis of dementia confirmed by a physician, lived at home and were competent to make a decision on the use of tracking technology and participation in this study. To check their competence, we briefly explained the use of the tracking device and what participation in the study would mean for them. In addition, we asked a few open-structured questions. If their answers were not in line with what had been told, we did not consider them as competent to make their own decision and they were not included in the study. Finally, people with dementia had to be able to move independently (with or without ambulatory aids) and to participate safely in traffic. This was based upon the opinion of the caregiver.

Caregivers were eligible when they had a computer with internet and were able to use both, when they were living either with the person with dementia (e.g., partner, sibling) or no longer than at a 30 minutes' distance. When they were not able to interrupt their activities and, if necessary, pick up the person with dementia, somebody else needed to be willing to do so.

Measures and measurement

Feasibility and acceptability

Caregivers were asked to grade their overall global impression of the device on a scale ranging from 1 to 10. Furthermore, people with dementia as well as their caregivers answered several questions on the use of the device with structured response categories ranging from 'Totally agree' to 'Totally disagree' and 'agree to disagree', respectively. For example, 'I find the use of the device difficult'. In addition, the caregivers were asked a few open questions, such as: 'How do you evaluate the use of the device?'

To measure care receivers' acceptability of the use of the tracking device they were asked to respond to several statements ('Agree', 'Neutral', 'Disagree'). For example, 'By using the tracking device I go more often outside independently.' Caregivers were asked the same sort of questions.

Effect-evaluation

Care-receivers were asked if they felt less worried after three months and were satisfied with the use of GPS. The impact on the caregivers was measured by their feelings of role-overload measured with the Self-Perceived Pressure from Informal Care – Scale

(SPPIC: Pot, van Dyck, & Deeg, 1995; Pot, Deeg, van Dyck, & Jonker, 1998). The scale is comprised of nine questions measuring the demands of the caregiving situation in proportion to the personal interests of the caregiver, such as other thoughts, activities, or roles. These nine items form a one-dimensional hierarchical Rasch scale, with an index of subject separation of 0.66 (which indicates how well items discriminate between subjects) and a reliability (Rho) of 0.79.

For measuring caregivers' feelings of worry concerning their care receiver going outside alone, a short questionnaire was developed, because no validated instruments were existing. The statements of this newly developed questionnaire are based on those of the Night Time Activity Worry – Scale (Rowe, 1999). Response categories vary from 'not worried,' 'a little worried,' 'fairly worried' to 'very worried' (Cronbach's alpha in this study = 0.88). For example: 'To what extent are you worried that something bad will happen to your care receiver, when he/she goes outside alone?' (for the items of this scale in Dutch and English, see www.nkop.nl).

We did a *post hoc* analyses, because not every caregiver could reach the care recipient. For this reason, we divided the caregivers in two subgroups: caregivers who could and those who could not reach the person with dementia using the telephone connection for whatever reason. The tracking device used in this study was especially meant for those dyads that could make use of the telephone connection.

Other measures

For a description of the participants involved in this pilot study, demographic characteristics like gender and age of the people with dementia and their caregivers were measured. In addition, some baseline information was gathered using three standardized questions to be answered with a 'yes' or 'no': whether or not the care receiver was still going outside unaccompanied; whether or not the care receiver would want to go outside independently more often; and whether or not the care receiver had been lost. The cognitive functioning of the person with dementia was measured using the validated short version of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE-N: de Jonghe, Schmand, Ooms, & Ribbe, 1997). Items are focused on the comparison of the current functioning of the person with dementia with that of 10 years ago. Walking behavior of the person with dementia was measured with selected domains of Algase Wandering Scale (AWS; Algase, Beattie, Bogue, & Yao, 2001; Algase et al., 2004). The revised version was used, designed for people with dementia living at home. Caregivers were asked to assess 23 items concerning four dimensions, namely, 'Eloping Behavior,' 'Repetitive Walking,' 'Spatial Disorientation,' and 'Negative Outcome.'

Analysis

To assess the feasibility and acceptability of the tracking device, numbers and percentages of participants with positive responses were calculated. To assess the effectiveness of using the device, means and standard deviations (SDs) for the SPPIC and Worry scales at pre- and post-tests were calculated. With paired *t*-tests, we looked for significant changes ($p < 0.05$). To determine the clinical relevance of the changes, we also expressed the mean differences as Cohen's *d* by dividing the absolute difference between the average scores on the outcomes at both measurements by dividing them by the SDs at baseline (Lipsey & Wilson, 1993). From a clinical perspective, an effect size of 0.56–1.2 can be interpreted as a large effect, while effect sizes of 0.33–0.55 are moderate, and effect sizes of 0–0.32 are small (Cohen, 2005). The data were analyzed with SPSS 15.0 software.

Results

Characteristics of the sample

Of the 33 dyads of care receivers and caregivers, 28 completed the study during the three months between pre- and post-measurement (Table 1).

The majority of care receivers who completed the study were male (82%), had a mean age of 73 and all except one had a middle or high educational level. The majority was diagnosed with Alzheimer's disease (57%). Care recipients' cognitive deterioration was relatively high and their wandering behavior relatively low, as shown by their scores on the IQCODE and AWS (Table 1). Before the start of the use of the tracking device, 78.6% of the people with dementia went outside alone, whereas 64.3% wanted to go outside unaccompanied more often. Six of the caregivers that completed the study did not let their care receiver go outside alone before they were using GPS. The use of the system made most of them decide to let their family member go outside alone again.

It is observed that 50% had already been lost once or more than once before using the GPS device. The majority of the care receivers lived in a town or city (61%).

Caregivers who completed the study were predominantly spouses (82%); the others were children of whom one lived together with the parent with dementia. The caregivers were mostly females except two, with a mean age of 63. Only one caregiver had a low educational level, the others had a middle or high educational level. Before using the tracking device, caregivers used the internet for 6.7 h per week.

Feasibility

Five of the 33 dyads of care receivers and caregivers included in this study dropped out (15.2%). Reasons mentioned for dropout were: the person with dementia cannot go safely outside alone anymore or does not

Table 1. Demographic characteristics of care receivers with dementia and their caregivers at baseline (T₀).

	Care receivers included (N = 28)		Care receivers who dropped out (N = 5)	
	N	(%)	N	(%)
<i>Sex</i>				
Male	23	82	1	20
Female	5	18	4	80
<i>Educational level</i>				
Low	3	12	2	40
Middle	10	39	1	20
High	13	50	2	40
<i>Marital status</i>				
Married	23	82	4	80
Not married	1	4	–	–
Widowed	4	14	1	20
<i>Number of children</i>				
0	1	4	1	20
1–3	18	64	3	60
>3	9	32	1	20
<i>Urbanization</i>				
Village	11	39	2	40
Town/city	17	61	3	60
<i>Type of dementia</i>				
Alzheimer disease	16	57	4	80
Vascular dementia	6	21	–	20
Other	6	21	1	–
Age (M, SD)	72.9	8.1	69.2	10.5
Care receiver is going outside alone	22	78.6	4	80.0
Care receiver wants to go outside alone more often	18	66.7	1	20.0
Mean number of times per week being outside alone (M, SD)	8.1	9.1	11.3	4.8
Care receiver has been lost before	14	53.8	4	80.0
Severity of dementia ^a (M, SD)	4.6	0.4	4.6	0.3
<i>Wandering^b (M, SD)</i>				
Eloping behavior	1.9	0.8	1.7	0.5
Repetitive walking	2.3	0.7	1.8	0.9
Spatial disorientation	1.7	0.9	1.4	0.9
Negative outcomes	1.3	0.5	1.3	0.3
	Caregivers included (N = 28)		Caregivers who dropped out (N = 5)	
	N	(%)	N	(%)
<i>Sex</i>				
Male	2	7	4	80
Female	26	93	1	20
<i>Educational level</i>				
Low	1	4		
Middle	16	57	3	60
High	11	39	2	40
<i>Relationship with care receiver</i>				
Partner	23	82	4	80
Parent	5	18	1	20
<i>Living together with care receiver</i>				
Yes	24	86	4	80
No	4	14	1	20
Age (M, SD)	63.0	11.5	64.4	12.0
Number of hours per week (M, SD)	6.7	6.7	5.3	6.1
Role-overload	7.8	1.4	6.4	3.6
Worry	10.6	2.8	9.0	2.4

Notes: ^aCognitive functioning has been measured with the IQCODE.

^bWandering has been measured with subscales of the AWS.

Table 2. Evaluation of the use of track and trace technology at T₁ by the caregivers ($N=28$).

	Disagree		Do not (dis) agree		Agree	
	<i>N</i>	(%)	<i>N</i>	(%)	<i>N</i>	(%)
<i>Website</i>						
Using the website is difficult	20	80	1	4	4	16
I am in control of the website	1	4	1	4	23	92
I can find my family member quickly using the website	3	12	2	8	20	80
The localization of my family member is accurate	5	20	3	12	17	68
<i>GPS</i>						
The use of GPS is difficult	21	78	4	15	2	7
I would recommend the use of GPS	4	15	2	8	20	77
<i>Telephone connection</i>						
I know how to reach my family member	1	4	0	0	26	96
I can reach my family member when needed	5	19	3	11	19	70

Note: Due to missing data, $N < 28$ in some cases.

show initiative to go outside alone anymore due to the progression of their disease ($N=4$) and technical reasons such as difficulties with localization or the telephone connection, or not enough battery ($N=1$). Dropouts were relatively more female care receivers and male caregivers in contrast to the completers in this study. We did not test the differences in demographic characteristics between subjects who completed the study and those who dropped out, because of the small number of dropouts.

In 67% of the times the person with dementia went outside alone, they took the GPS device with them when leaving the house. In the other cases, it was left at home for different reasons: familiarity with the road, reluctance to take the device, or a low battery of the device. When care receivers took the device with them, this did not mean that it was always switched on. In one case, it was always off. Out of the caregivers, 50% used the telephone connection. In about 39% of the times the person with dementia went outside alone, caregivers used the website to check where their relative was.

As Table 2 shows, 80% of the caregivers indicated that the use of the website was not difficult and almost all caregivers (92%) felt that they were in control of the website. It is observed that 80% could quickly find the person with dementia. Every caregiver except one knew how to use the telephone connection. Nevertheless, 30% of all caregivers could not always reach their care receiver when needed. Part of these caregivers did use the telephone connection, but could not reach the care receiver for several reasons. However, most of them had reservations to use the telephone connection. They were afraid the person with dementia would get confused by the loudspeaker function, hearing the voice of his or her caregiver directly without answering the phone by pushing a button. Some of the caregivers who did use the telephone connection mentioned that the participants with dementia did not always know where the voice came from. However, the care receivers did not seem to mind that they heard a voice from their

device without notification. Most of the caregivers would recommend the use of GPS (77%).

Acceptability

About a quarter of the people with dementia indicated that they were more often outside independently (25%) and almost half of them experienced that they received more freedom from their caregivers (45%; Table 3). Results show that half of the people with dementia are less worried when going outside alone (50%) when using GPS. They said for example: 'With using GPS I feel supported and protected, that is very nice.' The participants with dementia on average rated the use of GPS at 6.9 ($SD = 1.5$) on a scale of 1–10. Nevertheless, some participants felt controlled by the tracking device. One of them said 'Before using GPS, my husband allowed me to go downtown by myself. Now I can only go there of taking my GPS.'

The majority of the caregivers indicated that they provided more freedom to the care recipient (60%). Four care receivers and seven caregivers experienced less conflicts about going outside alone. About 30% of the caregivers reported that they got more time for other things since they were using GPS. The caregivers on average rated the use of GPS at 7.2 ($SD = 1.7$) on a scale of 1–10. As one caregiver aptly summarized: 'GPS gives me rest; If my husband is outside alone, he doesn't live on my energy.'

Effectiveness

Caregivers showed a tendency to feel less worried after the three month use of the track and trace technology as shown by a trend in their scores on the worry scale between pre- and post-measurement. A small effect size of -0.32 ($p < 0.10$) was found. The pre- and post-measurement score on the SPPIC did not show a significant difference or such a trend, meaning that

Table 3. Evaluation of the results of using the track and trace technology at T₁ by care receivers and caregivers (N = 28).

Care receivers	Disagree		Do not (dis) agree		Agree	
	N	(%)	N	(%)	N	(%)
<i>As a result of using GPS</i>						
Do I go more often outside on my own	12	60	3	15	5	25
Do I worry less when I am outside on my own	8	40	2	10	10	50
My (spouse, child) leaves me free more often	5	25	6	30	9	45
Do I have less conflicts with my (spouse, child) about going outside on my own	13	65	3	15	4	20
Caregivers	Less		As much as before		More	
	N	(%)	N	(%)	N	(%)
<i>As a result of the GPS, I</i>						
Provide... freedom to my family member	2	7	9	33	16	60
Get... time for other things	1	4	18	67	8	29
Have... conflicts with my family member	7	26	18	67	2	7

Note: Due to missing data, $N < 28$ in some cases.

Table 4. Effects of the use of track and trace technology on the feelings of role-overload and worry of the total group of caregivers of people with dementia, and only those who could reach the care recipient.

Outcome	M_{T_0}	SD	M_{T_1}	SD	$M_{T_1} - M_{T_0}$	SD	p	d
Role-overload ^a (N = 23)	7.87	1.42	7.39	2.15	-0.48	1.44	0.126	-0.25
Could reach (N = 17)	7.59	1.54	6.94	2.33	-0.65	1.62	0.119	-0.34
Worry ^b (N = 27)	10.48	2.86	9.59	3.02	-0.89	2.53	0.080	-0.32
Could reach (N = 19)	11.05	2.84	9.79	2.97	-1.26	2.70	0.057	-0.46

Notes: ^aFeelings of role-overload have been measured with the SPPIC.

^bFeelings of worry with a scale based on the Night Time Activity Worry-Scale.

caregivers' feelings of role-overload were not significantly reduced during the study period (Table 4).

Caregivers who could reach the person with dementia using the telephone connection showed a significant decrease in their feelings of worry, but not in their feelings of role-overload ($d = -0.46$ and $d = -0.34$, respectively, see Table 4). The effect sizes found for this group of caregivers are moderate. The results for the caregivers who could not reach their relative are not included, because of small numbers.

Discussion

The results of this pilot study show that the use of track and trace technology is feasible for people with dementia in an early stage of dementia and their family caregivers. The vast majority of the caregivers were able to use the technology and to integrate the use of the system into their daily routines. Most of them would recommend the use of GPS to others.

However, there is also room for improvement concerning the use of the system. Part of the dyads dropped out of the study or only rarely used the system because of technical difficulties. These technical

difficulties such as problems with the telephone connection or not having enough battery must be solved. Problems with the localization of the person with dementia cannot be solved completely today, because in buildings like shopping malls, in the middle of woods, or in case of bad weather there will be no connection with the satellites. Some of the caregivers did not want to use the telephone connection to get into contact with the care receiver without notification. They were afraid that the care receiver would become upset. Although this study showed that care receivers did not seem to mind that they directly heard a voice from their device, it would be recommended to let care receivers and caregivers choose whether they prefer to connect with or without notification.

The reasons for dropout also show that the specific technology used in this study is only appropriate for care recipients in early stages of dementia. As the dementia progressed, either the wish to go outside independently disappeared or it was no longer safe to go outside independently as some of the participants told the interviewer. This was also the case for some care receivers who were still using the device after three months, but less frequently than at the start of using GPS. For some people, we assume that the

device may have come too late in the disease or caregiving process regarding the number of dyads that dropped out or used the system less frequently and the high level of caregivers' feelings of role-overload.

People did not 'simply' forget the device. This is probably due to the caregivers reminding them to take the device with them. Most caregivers lived together with the care receiver. If this had not been the case, forgetting the device might have been a problem.

This study showed some positive results for people with dementia as well as their caregivers. Almost half of the participants with dementia experienced more freedom and were less worried when they were outside on their own, a quarter mentioned that they were more outside independently after three months and a fifth mentioned that they had less conflicts with their caregiver.

On average, caregivers showed a trend to feel less worried after three months using the track and trace technology. This holds especially for caregivers who could reach their relative using the telephone connection. No changes in caregivers' feelings of role-overload were found in this study. Self-evidently, this might be due to the small sample size. In that respect, finding a trend in the decrease in caregivers' feelings of worry is promising to facilitate the caregiver role.

This pilot study has some methodological limitations. In addition to the small sample size, another limitation is the selective sample. Most dyads included in the study were predominantly women with a middle to high educational level caring for their husbands with a middle to high educational level in an early stage of dementia. For this specific group, the results of this study suggest that the use of the track and trace technology seems to be feasible, acceptable, and might also be effective. However, we do not know if this specific technology would also fit dyads with a lower educational level. At the moment, they are using the internet lesser and are probably less familiar with the use of GPS (de Haan, Klumper, & Steyaert, 2004). It might be that the use of the track and trace technology would be more difficult for them. However, the use of internet and GPS is increasing very fast, also among the very old in the Netherlands.

A third limitation of this study is related to the cognitive ability of the care receivers. The reliability of their responses was not always straightforward. In some cases, the interviewer made the decision to ask the caregiver to verify or to answer the questions for the care recipient. To what extent this also had an impact on the differences found between care receivers' and caregivers' perceptions of going out independently, getting or providing freedom and having conflicts with each other is not clear. Furthermore, we could not use general outcomes such as quality of life, because it is not clear how it changes over time as a result of the disease. Without a control group we do not know how to interpret the presence or absence of changes in general outcomes. Self-evidently, these problems are

not specific for this study, but hold for other studies on people with dementia as well.

Track and trace technology is no general solution for people with dementia who get lost. Persons with dementia and their caregivers are – like everyone else – different people with different problems and different preferences that need different solutions. For example, if a person with dementia will panic in case the technology does not work properly, it might be better not to use it. However, if this person will become depressed when he or she cannot go outside independently anymore, this negative outcome might be accepted. If the person is living in a surrounding where people will know the person and generally will bring him or her home, panic in case of technical problems with the device might also be accepted. If the person with dementia gets upset by the telephone connection, another technology might be needed than that used in this study.

Furthermore, the use of this track and trace technology does not always benefit both the care receiver and caregiver. The caregiver may want to find the person whenever they think this is appropriate, but – as found in this study for a few cases – the person with dementia may feel controlled. It is important to keep in mind that the use of track and trace technology need to benefit the care receiver in the first place. If not, there must be a very good reason to use it and it may not harm them. Therefore, before using any technological device in practice, it is important to define the specific problem of the specific person with dementia and his or her caregiver and to search for the most appropriate solution for the problems of this particular dyad. Active involvement of professional caregivers may facilitate the decision making process (Landau, Auslander, Werner, Shoval, & Heinik, 2011).

In conclusion, the track and trace technology used in this study seems to be promising for care receivers in early stages of dementia and their caregivers. This study also gives some food for thought on the potential of the use of GPS, the problems one may encounter and the limitations of track and trace technology. A next step is to carry out a randomized controlled trial with enough power to show effects of using GPS technology to the benefit of both caregiver and care receiver.

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