RESEARCH

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▶ # Safety assessment of a home-based telecare system for adults with developmental disabilities in Indiana: a multi-stakeholder perspective

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Summary

We investigated the perceptions of people about the safety, security and privacy of a telecare monitoring system for adults with developmental disabilities living in residential settings. The telecare system was used by remote caregivers overnight, when staff were not present in the homes. We surveyed 127 people from different stakeholder groups in the state of Indiana. The people surveyed included those with knowledge or experience of telecare, and those without. The stakeholders were clients, their advocates, service provider administrators and independent case coordinators. The responses in each category for every group were positive except one: only 4 of the 11 telecare case coordinators agreed that the telecare system provided a secure environment. Overall, the telecare system was perceived to be as safe, secure and private as the conventional alternative of having staff in the home.

Introduction

The use of telecare to provide residential support to adults with disabilities living in community settings is a recent development.[1] Studies are now needed to investigate the social importance and acceptability of such services with a particular focus on the perceptions of clients and other stakeholders about telecare service quality.

We have surveyed clients and other stakeholders about their satisfaction with standard care and a home-based telecare system for adults with developmental disabilities. The aim was to ascertain the perception from multiple stakeholders of the level of safety, security, and privacy provided by a telecare model of service delivery for individuals with developmental disabilities during the overnight hours in place of on-site staff support.

Methods

The research was approved by the appropriate ethics committee. Each participant signed a consent form or, in the case of clients without self advocacy, their designated advocate signed the consent form.

A purposeful sample of participants was chosen based on the inclusion criteria of the residential support model used and included a total of 127 clients, client advocates, service provider administrators and independent case managers. Clients ($n = 45$) were adults between 19 and 72 years of age with a mild or moderate developmental disability. An individual with an developmental disability was defined as someone with significant limitations both in intellectual functioning and in adaptive behaviour.[2] All clients who used the telecare support model had prior experience with the on-site staffing model (standard care model). Those selected to participate were also selected based on their willingness to participate and their ability to answer yes/no questions.

Once clients were selected, their volunteer advocates ($n = 23$) were also asked to participate. Client advocates included client-related and unrelated persons who assisted the client in making decisions about support and services for both standard care and telecare options. Administrator participants ($n = 47$) were part of the management team of residential support service agencies, located throughout the state of Indiana, for individuals with disabilities. An equal number of administrators between those familiar with telecare supports and those who only used standard care supports were sent surveys. Finally, there were the independent case managers ($n = 12$), who coordinate all resources for delivering services to clients with disabilities in the state of Indiana. Since all independent case managers in the state of Indiana worked for the same company,

surveys were sent to this company's central location and then distributed.

Telecare system

The telecare system implemented in each client's home (Rest Assured, LLC) was not the same at all sites but comprised some or all of the following components: a broadband connection to the Internet using either cable or a digital subscriber line (DSL), a camera with pan, tilt, zoom capabilities, voice over IP (VOIP) communications between the client and the remote care provider, a carbon monoxide sensor, smoke detection sensors, temperature sensor, door and window break sensors, and motion detection sensors. The motion sensors were used to alert remote caregivers when there was activity in the residence that might need their direct attention. If the sensors detected movement, the remote caregiver's computer display would change the screen image from small to full screen. This was helpful because at night the remote caregivers were viewing up to 32 different camera feeds from multiple sites.

Procedures

Following receipt of informed consent, participants other than the clients were asked to complete and return a written survey by mail. The clients were interviewed after obtaining consent.

Written survey

Survey packets containing a cover letter describing the research, a consent form and a survey were given to the three different service providers that serviced both telecare and standard care clients. The service providers were responsible for selecting the rest of the stakeholder groups and for distributing the survey packets. The client advocates, administrators and independent case managers then completed the anonymous survey and returned it by mail. Each participant answered items designed to measure the safety, security, and privacy of the standard care system or of the telecare system. Individuals familiar with or using telecare answered items assessing the telecare system. The standard care groups only answered items assessing the standard care system.

Client interview

Once signed consent or assent for participation was received for each client, surveys were conducted in each client's home with just the interviewer and client present. The interviews lasted 7–15 min, depending on the length of each answer and the concentration level of the client. At the onset, clients were presented with three index cards representing the three possible answers to interview questions ('yes', 'no' and "I don't know") along with pictorial representations in the form of a smiling, neutral or frowning face for each answer. Clients were provided with at least one baseline question such as 'Are you wearing a blue

shirt today?' and encouraged to either point to the index card that represented the answer or to respond verbally. If the client was able to answer correctly, the interviewer then concluded that he or she was capable of accurately answering survey questions and began the survey. Throughout the survey, the index cards remained visible to the client. If he or she hesitated in providing an answer to a survey question, the interviewer restated the question and prompted the client to point to the index card that represented their answer. If the client did not respond to a question, no response was recorded.

Instrumentation

The original surveys were generated in several steps. Based on a literature review,[1,3–11] we identified the most important aspects of client support services and then grouped them into three categories: safety, security and privacy. We also reviewed assessment instruments used in other telecare research.[9,10] Specific questions were then created by a panel of experts with knowledge of quality assurance, assessment and developmental disabilities, to assess a participant's perception of how well the respective service model satisfied each of the three categories. Some of the questions are provided in Table 1.

Written surveys

Survey instruments consisted of a series of questions designed to gauge the perception of client safety, security and privacy based on the residential support services for which respondents were familiar. For the administrators, independent case managers and advocates, items were closed-format with 5-point Likert-type responses ranging from 'strongly disagree' to 'strongly agree'. Participants were asked to circle the response with which they most agreed based on the survey question. The surveys also contained open-ended questions in each area (safety, security and privacy) to allow for comments and suggestions.

Common items for both the standard care and telecare groups included questions about response time in cases of

Table 1 Sample survey questions

Client telecare	Someone on the camera will watch and tell me if I need to be careful.
Client standard care	In my home, someone will tell me if I need to be careful.
Independent case manager telecare	The on-site staff services delivery helps enhance the safety of the clients.
Independent case manager standard care	The telecare system helps enhance the safety of the clients.
Service provider – telecare	The telecare system provides equal or greater privacy to the clients than the traditional current on-site staffing services delivery model.
Service provider – standard care	The current method of on-site staff delivery provides client privacy.
Volunteer advocate – telecare	I feel that someone will immediately help the client if there is an emergency.
Volunteer advocate – standard care	I feel that on-site staff will immediately help the client if there is an emergency.

emergencies (e.g. 'I feel that in-home direct care staff will immediately help the client if there is an emergency' or 'The remote caregiver will call 911 if the client has an emergency'), for protecting client data (e.g. 'It is my understanding that the information collected by on-site direct care staff is protected against abuse' or 'It is my understanding that the data collected by the telecare system can only be accessed by authorized individuals'), for enhancing client safety (i.e. 'The on-site staff services delivery helps enhance the safety of the clients' or 'The telecare system helps enhance the safety of the clients'), and for privacy (i.e. 'I feel that the client has appropriate privacy in his or her home'). For the telecare groups only, additional items targeted preventing abuse of clients by staff (i.e. 'I feel that there will be less chance of in-house caregiver or support person abuse with the telecare system in place than without it'), additional benefits (i.e. 'I feel that the client is safer with the video monitoring in place than without it'), and comparisons of telecare and traditional on-site support (i.e. 'The telecare system provides at least the same or better support for the direct care staff compared to the traditional current on-site staffing services delivery model').

Client surveys

The standard care instrument consisted of eight demographic questions, 18 questions allowing for 'yes', 'no' or "I don't know" responses and two open-ended questions. The telecare instrument consisted of nine demographic questions, 23 questions allowing for 'yes', 'no' or "I don't know" responses and three open-ended questions. The clients could either verbally answer a question or point to an index card with a pictorial representation of the answers consisting of smiling, neutral, or frowning faces and the printed text.

Client items also focused on emergency and privacy issues. In addition, clients were asked questions about their caregivers (i.e. 'My in-house caregiver or support person is nice to me' or 'The person on the camera is nice to me') and about the amount of safety they felt in their homes (i.e. 'I feel the in-house caregiver will protect me when I am at home' or 'I feel safe knowing that the person on the camera is watching me').

Results

According to the service providers, 64 packets were either mailed or hand-delivered to the stakeholders from June until September 2008. Thirty-two packets were mailed to the standard care stakeholders and 32 packets mailed to the telecare stakeholders. Surveys were returned from nine standard care and 14 telecare client advocates, 17 standard care and 30 telecare administrators, and one standard care and 11 telecare independent case managers. Because of the low response rate from the standard care independent case managers, this group was dropped from the overall analysis. In total, 27 telecare clients and 18 standard care clients were interviewed during the period June to August 2008.

The number of participants who either agreed or strongly agreed (or in the case of the clients, answered 'yes') to the various safety, security and privacy items was tabulated, and converted to percentage scores. These scores were then ranked.

The overall responses in each category for every group were positive except one, see Table 2. The results for privacy were fairly even except for the service providers who felt more strongly that the telecare system provided more privacy. The results for security were also fairly balanced except the responses from the telecare case coordinators: only 4 of 11 agreed that the telecare system provided a secure environment. This may have been due to a lack of training and awareness because they were the group most removed from the day-to-day living of the clients. The results for safety showed no significant differences, i.e. the independent case coordinators perceived telecare to be secure, but not as safe, as standard care.

Both the standard care and telecare groups provided numerous comments about the two models of caregiving. One perceived difference between the two systems was that the telecare system was more of a one-way system that provided safety whereas the standard care system, which had staff on-site, was a two-way system that provided more interaction with the client and companionship. One standard care client stated that he missed the staff when they were not there. Similarly, a volunteer advocate discussed the benefit of having on-site staff for the client with 'She is a very special person; she thrives on the one-to-one conversation with the staff. She has someone she can relay her feelings to.' The clients that had the telecare system in their homes acknowledged that the people on the camera 'watched everything', and this often produced negative associations. One telecare client stated, 'they follow me, I don't like people watching me.' Another client offered a possible solution to the negative, distant experience when he stated that he would like to 'see their faces when they talk.'

Another perceived difference between the two models of caregiving was the differences in achieving the goals of

Table 2 Stakeholders' perceptions. The values shown are the percentage of each group who agreed with the belief. T = telecare; S = standard care

Belief	Administrators		Volunteers		Coordinators		Clients	
	T (*n* = 30)	S (*n* = 17)	T (*n* = 14)	S (*n* = 9)	T (*n* = 11)	S (*n* = 1)	T (*n* = 27)	S (*n* = 18)
Private	88	65	82	91	82	N/A	93	91
Secure	90	82	78	100	91	N/A	93	92
Safe	80	84	78	92	36	N/A	98	93

independence versus safety. The majority of standard care advocates (93%) felt that the on-site staff made the client feel safe and liked a person being in the client's home. As one independent case manager stated, 'The concern is if the client is choking, needs immediate assistance in emergency situations, or exhibits extreme behaviour towards a housemate that requires immediate intervention.' The majority (86%) of telecare advocates felt that the telecare system allowed the client to be independent.

The responses to the open-ended items also revealed benefits and drawbacks of the telecare system over the standard care model or of not having a caregiver at all. Thirty seven percent of the telecare administrators defined the telecare system as 'extra monitoring' or 'providing an extra set of eyes', which were beneficial in the homes of clients who were non-ambulatory or non-verbal. However, both sets of administrators responded that implementation of a telecare system had negative consequences for the staff. One telecare administrator said 'Some case managers don't consider [the telecare system] as 'staff'. They have fought against installation.' One standard care administrator said 'Direct care staff refused to work at sites [which used the telecare system]. Not sure how to fix this.' Another telecare administrator gave a possible reason for staff resistance to the use of a telecare system, 'As a provider it helps us monitor staff actions also, even though it was not meant for this purpose'.

Discussion

The number of people with developmental disabilities who need caregiving will soon exceed the number of available caregivers.[12] One possible solution may be the use of telecare service delivery systems. These systems offer the possibility of reducing the need for onsite caregivers while ensuring that safety, security and privacy needs are met. The present investigation sought to determine the current perceptions and satisfaction levels of clients, advocates, independent case managers and administrators.

However, caution is required in interpreting the results from this study. Because of the purposeful sampling used, the findings are not generalizable. In addition, only one type of telecare system was studied. Nonetheless, the findings indicate that each stakeholder group familiar with the telecare model of service delivery perceived it to be a viable option in delivering in-home care overnight. There was majority agreement (68–94%) about the effectiveness of a telecare system in terms of providing safety, security and privacy. The small differences between group rankings in the agreement may be due to the fact that the independent case managers had little exposure to the telecare systems, even if the clients they represented used the system. The system costs may also have contributed to greater acceptance by administrators. Whereas volunteer advocates were less likely to favour the new technology over the traditional approach of having a person in the home during

the night, the clients themselves seemed to enjoy the telecare systems based on their responses during interviews. This emphasizes possible differences between the acceptance of telecare by the client and acceptance by their volunteer advocate.

There are theories to explain acceptance of a technology to users[14] or diffusion of an innovation.[13] However, new complexities arise when an external impetus mandates the spread of technology (in this case, the promotion of the system by the State of Indiana). There is also a lack of theory to explain why non-users of a technological system would support the use of that system by others. Non-users may be directly linked to a user (e.g. family members of the clients) as well as peripherally linked (e.g. service providers for the client), but these groups should be included as a part of a wider audience when diffusing the technology. Non-users of a technological system are less informed than users because they do not actively engage with the technology, and this may create a fear of or dislike towards the new system. Educational programmes for these groups should be developed as a part of the system diffusion process. For example, family members of new users could talk to clients who have experience with the telecare system.

In the present study, clients clearly indicated a desire for social interaction by noting either the absence of their on-site provider or not being able to see their remote provider. In fact, some telecare clients revealed that the topic of the communication between them and the remote caregiver was more towards correcting or restricting a behaviour or action (e.g. 'They won't let me eat at night'). Although this communication would probably also occur when a caregiver was on-site, having an image of a person delivering the message rather than merely a voice might result in a different experience or outcome. Thus, future investigations might focus on the effectiveness of two-way video telecare services and client satisfaction for improved communication.

Additional information obtained during the present study (via interviews with service providers and state officials), suggest that there are significant cost savings associated with the use of telecare. The 2008 reimbursement rate for rehabilitation support services in the state of Indiana was $23.74 per staff hour. This rate included direct care staff wages, staff training costs, employment and clinical support/supervision costs, and general administrative expenditures. Using this rate, the cost to the state of Indiana for on-site staffing during overnight hours was $69,320 per site per year (8 hours of overnight on-site service × $23.74 per hour × 365 days). The calculated cost for the telecare services was $39,741 per site per year (8 hours × $13.61 per hour × 365 days); this included one float staff member for each 3.26 sites in case of emergencies, rental of the telecare monitoring equipment and the broadband network costs (J. Darling, personal communication). There are some 455 sites for which telecare might be suitable. The differences between the costs of on-site support and telecare would produce savings of approximately $13,444,858 per year.

With the impending shortage of qualified caregivers, telecare needs to be given serious consideration as a method of care delivery.

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