

Is telemonitoring useful for supporting persons with consciousness disorders and caregivers? A preliminary observational study in a real-life population

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Abstract

Introduction: Preliminary evidences showed that telemedicine may allow a reduction of costs and an enhancement of patients' satisfaction and quality of life (QoL), with the same effectiveness of conventional methods of healthcare delivery. Literature is quite absent in relation to the use of telemedicine for patients with disorders of consciousness (DoC) whose management is delegated almost entirely to the family. In order to promote an alternative setting to manage persons affected by DoC, also supporting their families, a pilot project was designed to test the feasibility of home-care assistance based on a system of telemonitoring.

Methods: In total, 11 patients were supported by a telemonitoring system via a workstation installed at the patients' homes. All patients underwent a clinical and functional evaluation at enrolment, after two months, after six months and at the end of the project, after 12 months by means of clinical scales (Glasgow Coma Scale, Rancho Los Amigos Levels of Cognitive Functioning Scale, Glasgow Outcome Scale, Disability Rating Scale), while the World Health Organization (WHO) QoL, the Hamilton Depression Rating Scale, the Hamilton Anxiety Rating Scale and a satisfaction score were completed by caregivers.

Results: Patients' scores at the clinical scales did not show statistically significant differences from T0 to T3. A trend toward the improvement of caregivers' QoL, anxiety and depression, as well as a high degree of satisfaction with regard to the intervention, were reported. The economic evaluation showed an average cost/day for a patient of about €70.

Discussion: Preliminary data suggest that the use of telemonitoring services in the management of persons affected by DoC is feasible and well accepted by caregivers, with a potential positive effect on their mood and QoL. Therefore, telemonitoring should be considered in the management of DoC patients to favour discharge from acute care and to support families in home care.

Keywords

Telerehabilitation, telemedicine, home care, caregivers, burden

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Introduction

Neurologists have reported on telemedicine being applied to dementia, epilepsy, stroke, movement disorders and multiple sclerosis;^{1–7} conversely, literature is quite absent in relation to the use of telemedicine for patients with disorders of consciousness (DoC), except for a pilot project showing that the use of videoconferencing may assist families in successfully caring for DoC individuals in the home, reducing the number of perceived family needs.⁸ A DoC can be defined as a prolonged period of reduced consciousness such as a coma, vegetative state (VS) or minimally conscious state (MCS) resulting from severe acquired brain injury (ABI)⁹ due to traumatic or non-traumatic causes.

Despite the presumably increasing number of affected individuals due to the improvement in emergency techniques and in intensive prolonged care,^{10,11}

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epidemiological data are limited, extremely variable and probably under-represent the frequency of occurrence of VS and MCS because of the lack of surveillance in sub-acute/home settings in which most of these individuals reside.¹²

In fact, after these patients are medically stable, they are usually discharged from acute care, and when they return home the management of the chronic phase relies almost entirely on the family who must provide ordinary care to prevent complications (e.g. pressure sores, infections, spasticity, muscle-tendon retractions, etc.) and maintain patients' functional status.¹³ Therefore, the family suddenly finds itself having to take on the role of primary caregiver – an overwhelming full-time job that is both physically and emotionally exhausting.^{14,15}

In order to promote an alternative setting to manage persons affected by DoC, also supporting their families, a pilot project was designed to test the feasibility of home-care assistance based on a system of remote monitoring. This paper presents and discusses the preliminary results of the project aimed at providing guidance and suggestions for the future application of telemedicine.

Methods

Study design and participants

This pilot was designed as a single-arm prospective intervention study investigating the feasibility of a telemonitoring system for DoC patients who lived at home with their caregiver. The study was conducted from April 2014 to March 2015, and the inclusion criteria were: (a) patients diagnosed as having DoC (VS or MCS) according to internationally recognized criteria,^{16,17} and (b) patients who lived at home with their family members. To be eligible for the project, a family needed to (1) have telephone access in their home, and (2) agree to participate in the study.

Patients were excluded if hospitalized for more than 30 consecutive days during the project time.

Before the enrolment a written informed consent to participate was obtained by legal representatives, and privacy procedures were applied to protect patients' and families' personal identities. Patients were free to exit the project at any time.

The study procedures were approved by the local Ethics Committee.

Devices

The telemonitoring system was based on a workstation installed in the patients' home and connected to a central platform through a web connection that allowed the recording and transmission of clinical data.

The system comprised three components: (1) the architecture for bidirectional video and audio communication consisting of a videophone (a telephone with a video monitor, video camera, speakers and a CODEC); (2) an

application for a "web-based" clinical record consisting of a database that allows the storage of clinical information; and (3) an application for the acquisition and storage of physiological parameters by means of sensors that could track or check blood pressure, body temperature, electrocardiogram (EKG) (heart rate), electroencephalogram (EEG) and evoked potentials (EPs).

The system was initially developed in-house by the engineers who took part in the project; at present, it is commercially available as the "Telemedicine and Assistance System" (TiOne Technology srl, Qualiano, Napoli, Italy).

The central platform was located at the head office of the association that promoted and managed the project. Privacy and accessibility were ensured by giving each user a username and a password to access the system, while data were 256-bit encrypted with RSA keys.

In addition, a toll-free number reachable 24 hours per day, seven days per week, for additional requests and also providing psychological and social support, was available and managed by a network of health professionals (psychologists, sociologists, social workers and healthcare operators).

All costs associated with the use of the equipment, including long-distance calls, repair and maintenance, were assumed within the costs of the project. The estimated costs also included health professional involvement as consultant, professionals for assistance to the telemedicine system, costs for personnel transport, drugs and reimbursed health materials.

Procedures

The project lasted 12 months and included four clinical evaluations: at enrolment (T0), after two months (T1), after six months (T2) and at the end of the project, after 12 months (T3). All of the evaluations were performed by the same neurologist during a home visit.

In addition to home visits, one telesession/week was scheduled for the first two months (total sessions = 8), while one telesession/month was scheduled from the third month to the end of the project (total sessions = 10). The health professionals who performed the telesessions were either a psychologist or a nurse with specific experience in neurological rehabilitation and the management of disability; they interviewed the caregivers, exploring patients' clinical conditions and caregivers' emotional status or psychosocial needs. In case of specific medical issues, caregivers were contacted by the neurologist who performed the home visits.

All of the scheduled telesessions were instigated by the health professionals, and at the end of each session the date for the next contact was confirmed.

All of the contacts that were not previously scheduled, that is all the requests for additional home visits and/or telemedicine sessions due to intercurrent medical or managing problems, were recorded as "additional requests".

All of the health professionals received a 60-minute training session on the procedures and management of the system before the beginning of the project.

Prior to the start of the study, all of the primary caregivers participated in a 30-minute hands-on training session to familiarize themselves with the personal computer components and the basic technical aspects involved in managing the system. A brief step-by-step reference guide was available within the system to provide procedural assistance, and a help desk was available by phone to provide real-time support to the users, or by email.

Measures

Patients. During the home visits (T0, T1, T2, T3) performed by the neurologist, patients underwent a complete clinical and neurological examination, which included the following scales and scores:

- Glasgow Coma Scale:¹⁸ scale consists of 15 items used to assess the level of consciousness, by means of three categories – motor response, verbal response and eye opening. Points are awarded for the best response in each category and the sum provides a global score ranging from 3 (total unresponsiveness) to 15 (alert, fully responsive);
- Rancho Los Amigos Levels of Cognitive Functioning Scale:¹⁹ scale used to assess cognitive functioning, classifying brain-injured patients in one of eight levels – level “one” represents non-responsive cognitive functioning, whereas level “eight” represents purposeful and appropriate functioning;
- Glasgow Outcome Scale:^{20,21} scale used to assess functional outcome, rating patient status into one of five categories – dead, VS, severe disability, moderate disability or good recovery; and
- Disability Rating Scale:²² an 8-item measure of disability (each rated on a 3–5-point scale) that provides a total score ranging from 29 (VS) to 0 (person without disability).

The following clinical parameters for each patient were monitored by caregivers and stored by the neurologist at each home visit: pressure sores, pulmonary infections (days with fever, dyspnoea, antibiotic therapies), fever (temperature >37.5°C), seizures, vegetative crisis, deep venous thrombosis, bladder and bowel functionality and pain. Also, drug modifications and hospitalizations (reason, length of stay) were recorded. When necessary, the monitoring caregivers were supported by local health-care professionals (physicians, nurses) or by healthcare professionals involved in the project by means of the additional connections.

Patients' scores on the clinical scales, as well as clinical data (pressure sores, respiratory infections, seizures, vegetative disorders, drug therapy), were considered as measures of the effectiveness of the intervention.

Caregivers. In order to evaluate the caregivers' psychological wellness and QoL, the following scales were completed by the caregivers at T0 and T3:

- (a) WHOQoL, 26 items WHOQoL-BREF Italian version: a 26-item self-report instrument investigating four domains (physical, psychological, social relationships and environmental), plus two facets for assessing overall QoL and general health. A higher score is associated with a better QoL;
- (b) Hamilton Depression Rating Scale (HDRS):²⁴ a multiple-item questionnaire assessing the severity of depression (0–7 scores: normal; scores of 20 or higher: moderate, severe or very severe depression); and
- (c) Hamilton Anxiety Rating Scale (HARS):²⁵ a 14-item scale assessing the severity of anxiety symptoms. The total score ranges from 0 to 56, where <17 indicates mild severity, 18–24 mild to moderate severity and 25–30 moderate to severe.

Moreover, at the end of the project the caregivers were also asked to express their global satisfaction rating on a Likert scale ranging from 0 (minimum satisfaction) to 5 (maximum satisfaction). Specifically, caregivers were asked to consider the continuity of care, the experienced health benefits, the increased self-efficacy and independence, the emotional safety due to regular meetings and access to special competence, the maintenance of motivation and the comfort with audio/visual technology.

The adherence and satisfaction with the intervention were considered as primary outcomes, and were assessed by means of self-reported caregivers' questionnaires. The QoL and psychological well-being of caregivers were also considered.

Data analysis

Score distribution and descriptive analyses were used to report data from patients and caregivers. The longitudinal analysis used to compare patients' scores at the clinical scales from T0 to T3 was performed by means of the Friedman Test; the post-hoc analysis was performed by means of the Wilcoxon signed-rank test with the Bonferroni correction applied.

The comparison of caregivers' scores for WHOQoL, HDRS and HARS was performed by means of the Wilcoxon signed-rank test.

Non-parametric statistics were used, as the Shapiro-Wilk test revealed that data were not normally distributed.

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 17.0 for Windows (version 17.0. SPSS Inc., Chicago, IL, USA).

Regarding the costs evaluation, a daily standard cost for the management of a DoC patient via the use of telemedicine was obtained through a simulation and compared to the costs sustained by the Public Health System for different care settings (ABI units, long-term care, traditional home care).

Results

A total of 11 patients (four female/seven male, age range 5.5–80 years) were enrolled in the project with their caregivers; all patients completed the project for the whole 12 months. Brain damage causing DoC was due to traumatic brain injury in seven cases (63.6%), while the remaining four cases (36.4%) presented a cardio-vascular aetiology (hypoxic-ischemic); among the traumatic injuries, most cases (5, 45.4%) were the result of a road accident.

Seven patients (63.6%) were diagnosed as VS, while four patients (36.4%) as MCS.

The time after the acute event was, on average, 33.8 ± 22.7 months.

Table 1 summarizes patients' demographic and clinical features, as well as the scores on the clinical scales at enrolment (T0).

All of the connections scheduled according to the project were performed. In addition to the scheduled connections, a total number of 161 sessions were completed (Table 2).

Throughout the project (from T0 to T3) the scores on the clinical scales did not change, revealing non-statistically significant differences.

No patient developed pressure sores; two (18.2%) reported respiratory infections, fever and dyspnoea with short hospital admissions (less than three days); two (18.2%) experienced seizures that required the adaptation of antiepileptic drugs; three (27.3%) required tracheostomy tube substitution; and five (45.5%) needed percutaneous endoscopic gastrostomy substitution as routine care. A total of 211 bladder catheter substitutions were performed, and four bladder outlet obstructions were recorded after bladder catheter substitution, resolved with catheter repositioning.

EKG, EEG and EPs were recorded at each evaluation time, without significant changes.

With regard to caregivers' measures, the scores on the scales assessing anxiety, depression and QoL showed a trend toward improvement without reaching a statistical significance (Table 3). The scores for the level of satisfaction are also reported in Table 3.

The economic evaluation in this study showed an average cost/day for a patient of about €70, while, in the other settings, the following costs were reported: approximately €382/day in ABI units; approximately €177.5/day in long-term care; and approximately €79.5/day in traditional home care.

Discussion

Data from this pilot study highlight the feasibility and potential cost-effectiveness of the use of telecommunication technologies in promoting care management and enhancing healthcare outcomes in persons with severe disabilities and their family caregivers.

Although the magnitude of effects varied across measures, the overall pattern of findings for this pilot study was

Table 1. Patients' demographic and clinical features at admission.

Patient	Sex	Age (years)	Time from event (months)	Aetiology	Craniotomy	Tracheostomic tube	Spontaneous breathing	PEG	Bladder catheter	Baclofen pump	POA	Pressure ulcers	Sleep-wake rhythm	GCS	LCF	GOS	DRS
1	F	67.1	29	Traumatic (car accident)	•	•	•	•	•	•	•	•	•	6	1	VS	26
2	F	5.5	41	Traumatic (car accident)	•	•	•	•	•	•	•	•	•	5*	1	VS	26
3	F	80	11	Hypoxic (vascular)	•	•	•	•	•	•	•	•	•	9	1	VS	24
4	F	57.2	18	Hypoxic (cardiac arrest)	•	•	•	•	•	•	•	•	•	9	1	VS	24
5	M	22.7	63	Traumatic	•	•	•	•	•	•	•	•	•	6	1	VS	26
6	M	25.10	71	Traumatic (car accident)	•	•	•	•	•	•	•	•	•	5	1	VS	26
7	M	29.10	10	Hypoxic (cardiac arrest)	•	•	•	•	•	•	•	•	•	12	3	SD	21
8	M	28.5	26	Traumatic (car accident)	•	•	•	•	•	•	•	•	•	10	2	SD	25
9	M	59.2	22	Hypoxic (cardiac arrest)	•	•	•	•	•	•	•	•	•	9	1	VS	26
10	M	33.4	11	Traumatic (fall)	•	•	•	•	•	•	•	•	•	11	3	SD	22
11	M	48	70	Traumatic (car accident)	•	•	•	•	•	•	•	•	•	11	3	SD	22

PEG: percutaneous gastrostomy; POA: paraosteothrathy; GCS: Glasgow Coma Scale; LCF: Levels of Cognitive Functioning; GOS: Glasgow Outcome Scale; DRS: Disability Rating Scale; VS: vegetative state; SD: severe disability.

*Paediatric Glasgow Coma Scale for nonverbal children.

Table 2. Descriptive data about the additional connections.

Patient	Connections (n)	Time (minimum)	Time (maximum)	Mean	SD
1	15	10	29	19,60	6,288
2	14	13	26	20,00	4,297
3	16	11	27	18,44	5,228
4	14	9	29	18,93	6,032
5	16	12	26	18,38	4,801
6	14	12	30	19,36	5,458
7	15	12	28	18,53	5,181
8	14	14	25	19,36	4,162
9	15	12	27	18,53	5,370
10	14	10	26	18,93	5,470
11	14	14	26	20,43	4,415
Total	161	9	30	19,11	5,077

Time is expressed in minutes.
SD: standard deviation.

Table 3. Comparison (T0–T3) of caregivers' scores at the clinical scales.

Measures	T0	T3	p
HARS	14.7 ± 3.8	12.7 ± 2.8	ns
HDRS	12.1 ± 2.6	10.9 ± 1.8	ns
WHOQoL			
Physical domain	59.6 ± 12	65 ± 11.4	ns
Psychological domain	58.3 ± 9.8	63.8 ± 7.4	ns
Social domain	46.6 ± 15.3	57.5 ± 13.9	ns
Environmental domain	46.6 ± 11.2	50 ± 10.8	ns
Level of satisfaction		3.6 ± 0.8 (range 2–5)	

HARS: Hamilton Anxiety Rating Scale; HDRS: Hamilton Depression Rating Scale; WHOQoL: World Health Organization Quality of Life; ns: not significant.

encouraging. The rate of patients who experienced complications or needed hospitalization (18.1%), the improvement of the pre-existing chronic pressure sores, as well as the absence of new lesions, revealed that patients' monitoring and care were effective in maintaining a substantial stability of patients' clinical and functional status, as also indicated by the scores on the clinical scales that remained unchanged. Clinicians were able to see and talk with the family as they performed a treatment such as suctioning or tube feeding, and could simultaneously answer questions and make suggestions; also, pressure ulcers could be monitored and caregivers could be guided in their successful prevention, consistent with the previous published data.²⁶ The constant transfer of information proved, therefore, to be crucial to proper healthcare management, and it is safe to assume that it can help facilitate the individual's transition from hospital discharge to home.²⁷

Today's healthcare environment, also by means of telecommunication technologies, prompts caregivers to assume a consistently more proactive role in organizing, monitoring and tracking the healthcare outcomes of their relatives with severe functional disability, with a view to reducing costs.^{28–31}

Moreover, the intervention seemed to also be useful in emotionally supporting and reassuring families, as revealed by the trend toward improvement showed by the clinical scales scores measuring depression and anxiety, and by the QoL parameters. In fact, caregivers were supported in developing an effective attitude towards caregiving challenges and were encouraged to engage in pleasant daily activities to avoid stress overload. These positive results are globally summarized by the high score of satisfaction expressed by the family and by the absolute adherence to the intervention (all scheduled connections were completed), suggesting that this intervention seems to meet caregivers' needs.

Understanding and addressing difficulties families face as they bring patients home with new needs and challenges is an important part of high-quality care. Families of patients with severe disabilities may experience feelings of abandonment and increased stress during the transition from inpatient to outpatient rehabilitation.^{32,33} Often in practice, unmet needs would not be identified until the follow-up visit, resulting in a delay in assisting a family in obtaining needed care.

Therefore, our findings seem to support and further expand the growing body of research that has demonstrated the efficacy of self-management strategies and caregiver engagement for effective long-term care for individuals with chronic medical conditions through technology-based interventions.^{34–36} However, these are preliminary data that cannot be generalized until they have been confirmed by studies on larger samples.

In our opinion, an interesting point of this study is represented by the economic analysis. In fact, few telehealth studies have provided preliminary evidence of cost savings;^{37–39} methodologically robust cost-effectiveness evaluations are quite absent in literature. All this makes it impossible to draw definitive conclusions which would be useful as a guide in the strategic management of e-Health policies.

In the present study, the average daily cost for a patient assisted within the project was compared with the corresponding average daily cost of care for different settings (hospital care (severe ABI units), long-term care and traditional home care) in regions that served as "models"; the lack of a uniform system for the supply of services and facilities in Italy has, in fact, prevented a more comprehensive comparison. The Toscana and Emilia-Romagna Regions were selected because considered "excellent" for the care of VS and MCS, and the Campania Region was the place where the project was carried out. On the basis of such a comparison, it is estimated that a saving percentage for the daily cost of telemonitoring of 81.6% over hospital care, 60.5% over long-term care and

11.7% over traditional home care is made. In an era characterized by a severe reduction of healthcare resources, this figure might represent a valuable additional argument in support of a wider use of this care modality. However, we performed a rather basic cost analysis, so these results need to be replicated in larger samples that allow the execution of more in-depth and rigorous economic analysis.

Currently, telehealth is not provided by the National Health System and so, in the future, coverage via private insurance, private pay or contractual arrangements between the public health system and private providers is conceivable. In this sense, it will be mandatory to provide evidence of cost-effectiveness by increasing the studies on this topic.

Besides being cost-effective, telemonitoring approaches can facilitate in-home interventions for persons with severe disabilities due to traumatic brain injury,⁴⁰ according to the International Classification of Disability and Health⁴¹ framework that focuses on contextual factors, emphasizing the individuals' functioning within their environment. Recognizing that the social and physical environment can be facilitative (or inhibitory), rehabilitation that can occur within the patient's own home and community has greater relevance to the patient.^{42,43}

The main limit of this study is represented by the small sample size. As we explained, this project represents a pilot experience to test the feasibility, the acceptance and the effectiveness of this new kind of care delivery. Other limitations are represented by the lack of a control group, as well as the lack of a comprehensive economic analysis. For these reasons, the conclusions, although encouraging, should be interpreted with caution, and larger randomized controlled trial studies, possibly at the national level, are needed to verify these findings. Moreover, longitudinal researches should be designed to test the incremental economic benefits of home-based telehealth interventions over alternative forms of health delivery for this population, comprising high users of treatment services.

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