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CASE REPORT

Technology-aided leisure and communication support in extensive neuro-motor and communication impairments

Fiora D'AMICO [1], Giulio E. LANCIONI [2] *, Francesca BUONOCUNTO [3], Carlo RICCI [4], Pietro FIORE [2, 5]

[1]Silver House Health and Care Services, Bari, Italy; [2]Department of Neuroscience and Sense Organs, University of Bari, Bari, Italy; [3]S. Raffaele Rehabilitation Center, Ceglie, Brindisi, Italy; [4]Salesian Pontificial University of Rome, Rome, Italy; [5]Physical and Rehabilitation Medicine, Bari Polyclinic, Bari, Italy

*Corresponding author: Giulio E. Lancioni, Department of Neuroscience and Sense Organs, University of Bari, Corso Italia 23, 70121 Bari, Italy.
E-mail: giulio.lancioni@uniba.it

ABSTRACT

BACKGROUND: Individuals with extensive neuro-motor impairment and lack of speech are known to remain fairly isolated and rely on others. Yet, there is only limited evidence as to how one can help them to reach a level of independence in relevant areas such as leisure and communication. This study assessed a program based on everyday technology to support leisure and communication engagement in six of those individuals.
CASE REPORT: The six cases (adults) were non-ambulatory and had no speech or functional active communication. Their neurological damage was due to extensive left hemispheric hemorrhagic or ischemic lesion and to critical illness polyneuropathy aggravating a condition of neonatal encephalopathy. A smartphone-based program was developed and successfully used to enable them to access leisure activities (*e.g.*, listening to music) and communication (*e.g.*, sending text messages or calling the caregiver).
CLINICAL REHABILITATION IMPACT: Cases like those presented in this study may reach independent and functional engagement if supported *via* specific, technology-aided intervention programs.

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KEY WORDS: Movement disorders; Communication disorders; Biomedical enhancement.

Individuals with extensive neuro-motor impairment and lack of speech can remain rather passive and isolated with related problems for rehabilitation staff and families.[1, 2] Consistent staff and family assistance might be applied to help the individuals in the short run, but it cannot be considered a solution. In fact, it would be practically demanding, underline the individuals' dependence, and fail to foster their self-determination and ultimately self-sufficiency in occupation/leisure and communication.

In spite of that and the fact that these individuals are often unsatisfactorily served,[3, 4] relatively little research exists regarding intervention strategies aimed at helping them to reach a level of independence in basic leisure and communication. A few attempts to address the problem have resorted to the use of computer-aided programs,[5-7] but those programs were only partially tested and are known to present some functional limitations (*e.g.*, reliance on communication modems and lengthy operational sequences). This set of circumstances stresses the need for new research efforts that could lead to the development and testing of intervention tools to improve the individuals' situation. This study was one such effort. It developed and assessed a new intervention program (based on the use of two smartphones and cards with pictures) to enable six of those individuals to: 1) access leisure activities such as listening to music or watching videos; and 2) manage basic communication through text messages and calls to the caregiver.

TABLE I.—*Participants' pseudonyms, ages, levels of cognitive functioning (LCF), neurological damage's etiology, and intervals between neurological damage and start of the study.*

	Participants					
	Myrtle	Josh	Debbie	Coleen	Becky	Bert
Age	45	55	71	74	52	38
LCF	VI	V/VI	VI	VII	VI	VII
Etiology	Left fronto-temporo-parietal intra-parenchymal hemorrage	Left fronto-temporo-parietal intra-parenchymal hemorrage	Left temporo-parietal ischemic lesion	Left fronto-temporo-parietal ischemic lesion	Critical illness poly-neuropathy and neonatal encephalopathy	Left fronto-temporo-parietal intra-parenchymal hemorrhage
Intervals [a] (months)	4	6	28	21	4	17

[a]The interval reported for Becky is related to the critical illness polyneuropathy.

Case series

Table I lists the six participants involved in the study by their pseudonyms and reports their ages, neurological damage's etiology, levels of cognitive functioning (based on the Levels of Cognitive Functioning Scale-Revised[8]) and intervals between the occurrence of their neurological damage and the start of this study. The participants, aged 38-74 years, were characterized by extensive neuromotor impairment requiring them to sit in a wheelchair or in bed, but they could use their hands to manipulate cards. They did not have speech or other forms of functional active communication. Yet, they possessed or were recovering receptive language skills (*e.g.*, with clear or growing comprehension of autobiographical or family-related questions). The neurological damage at the basis of their condition had occurred between 4 and 28 months prior to the beginning of this study and had been documented by different medical centers. For five participants, the damage was due to extensive left hemispheric hemorrhagic or ischemic lesion, which followed total left anterior circulation stroke (Debbie and Coleen), brain hemorrhage (Josh), aneurysm rupture (Myrtle), and road accident (Bert). For the sixth participant (Becky), the damage was related to critical illness polyneuropathy, which followed acute distress respiratory syndrome and added to a condition of neonatal encephalopathy (Table I). The participants used antiepileptic (Becky), antidepressant (Coleen), antiepileptic and antidepressant (Myrtle, Josh, and Bert), or antidepressant and antispastic (Debbie) medication.

The six participants were reported together in this case series, as they shared the same clinical condition of dependence in leisure and communication, and were assumed to benefit from the same intervention program (*i.e.*, regardless of their variability in the interval between brain damage and start of the study as well as in the nature of the neurological damage). The participants were in rehabilitation centers or medical care centers in which they received conventional treatments, such as physiotherapy and occupational and language therapy, but they did not have any specific support devices for managing basic leisure and communication on their own. They were rated to be between the V/VI and the VII levels of cognitive functioning.[8] They showed willingness to be involved in the study and their legal representatives signed an informed consent on their behalf. The study complied with the 1964 Helsinki declaration and its later amendments and was approved by an institutional Ethics Committee.

Intervention program

The intervention program developed for the participants relied on two Samsung Galaxy A3 smartphones with Android 6.0 operating system and on picture cards representing preferred leisure and communication options and containing radio-frequency code labels (which allowed the cards to be recognized by the smartphones). The smartphones were fitted with: 1) near-field communication function; 2) WPC-Walden Personal Communicator and KLets applications; 3) SIM card; and 4) audio and video files representing the leisure and communication options available to the participant. Short (*i.e.*, 10-min) sessions were used to implement the program. In fact, short sessions were deemed fairly undemanding for the participants and the centers they attended, and still adequate to afford reasonable evidence on the program's potential. At each session, the participant was provided with 20 or 21 cards arranged on a panel. Eight of those cards concerned leisure events (*e.g.*, songs or comedy videos). One showed a communication symbol. Four represented communication partners (*e.g.*, daughter and friend). Six or seven concerned specific messages (*e.g.*, "I am doing fine" and "I love you"). The last represented the caregiver.

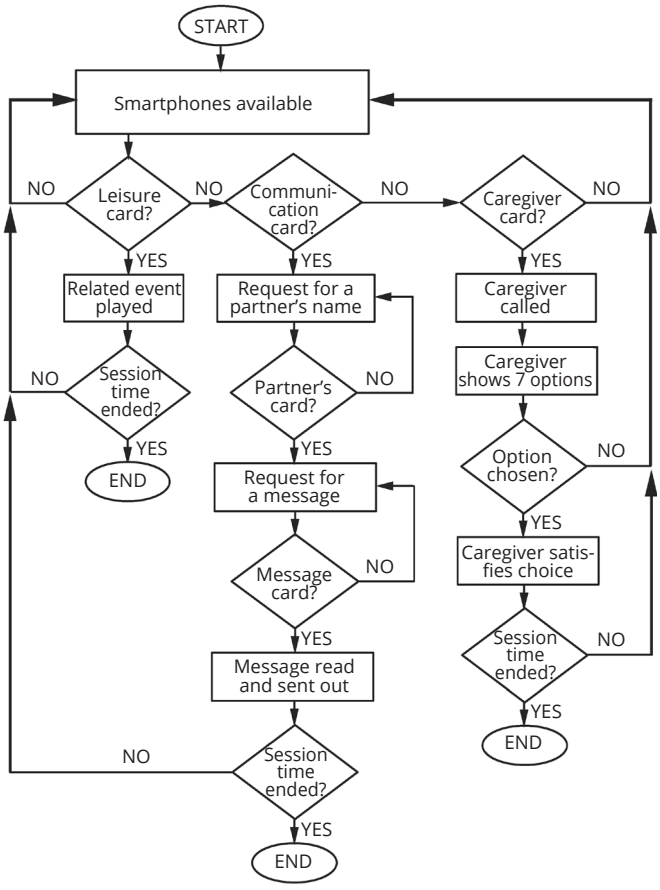

Figure 1.—The flowchart illustrates the smartphones and cards' functioning and the caregiver's responding.

Figure 1 illustrates the smartphones and cards' functioning and the caregiver's responding during the program. If the participant used (placed on the first smartphone) a card concerning a leisure option, the smartphone played that option (*e.g.*, a song or a video) for about 2 min (see left column of the flowchart). If the participant used the communication symbol card, the two smartphones linked together to verbalize: "To whom do you want to send a message?" Placing a card with one of the partners on the first smartphone led this smartphone to verbalize the name of the partner and the second to ask: "What message do you want to send?" Placing a message card on the first smartphone led this to verbalize the message and the second smartphone to send it out (see central column of the flowchart). Placing the caregiver card on the first smartphone led this to call the caregiver who approached the participant and showed seven cards illustrating possible needs and desires (*e.g.*, a change of position, being refreshed, having water). The caregiver then satisfied the participant's indicated need or desire (see right column of the flowchart). Messages received during a session were typically played to the participant at the end of the session (cards/gestures illustrating the verbal message could also be used to ensure participant's understanding). Messages received outside of a session were played before the next session.

Program assessment

The program was used over two intervention phases that followed baseline sessions, in which the participants had a standard smartphone with different files appearing on its screen. Touching any of those files opened new files that were to be activated to reach a leisure event or a connection with a partner. During the first intervention phase, research assistants guided the participants through the step sequences involved in the use of the program (Figure 1) until they reached independence. During the second intervention phase, guidance was no longer available and the participants were to use the program independently. Data recording concerned the time that participants spent with independently accessed leisure and communication events. Communication events included messages, caregiver calls, and caregiver's responses to (satisfaction of) calls/requests. The time of each event also comprised the selection process through the cards.

Program assessment also involved a social validation,[9] with sixty rehabilitation and care staff divided in groups of 10. Each group watched a 2.0 to 2.5-min video clip of one participant using the program. After watching the clip, the group rated the program's possible benefits regarding the participant's adaptive behavior, self-fulfillment, and social image. Scores of 1 to 5 (least and most positive) were used.

Results

The six panels of Figure 2 summarize the data for the six participants during baseline and the second intervention phase (when no guidance was available). The black and gray bars represent mean percentages of engagement time for leisure and communication, respectively. During the baseline, which involved four or six sessions, the participants were unable to use the standard smartphone, and thus had no independent leisure or communication engagement. During the first intervention phase, which involved 6 to 10 sessions, all participants learned to use the program. During the second intervention phase, which involved 43 to 82 sessions, participants managed to independently engage in

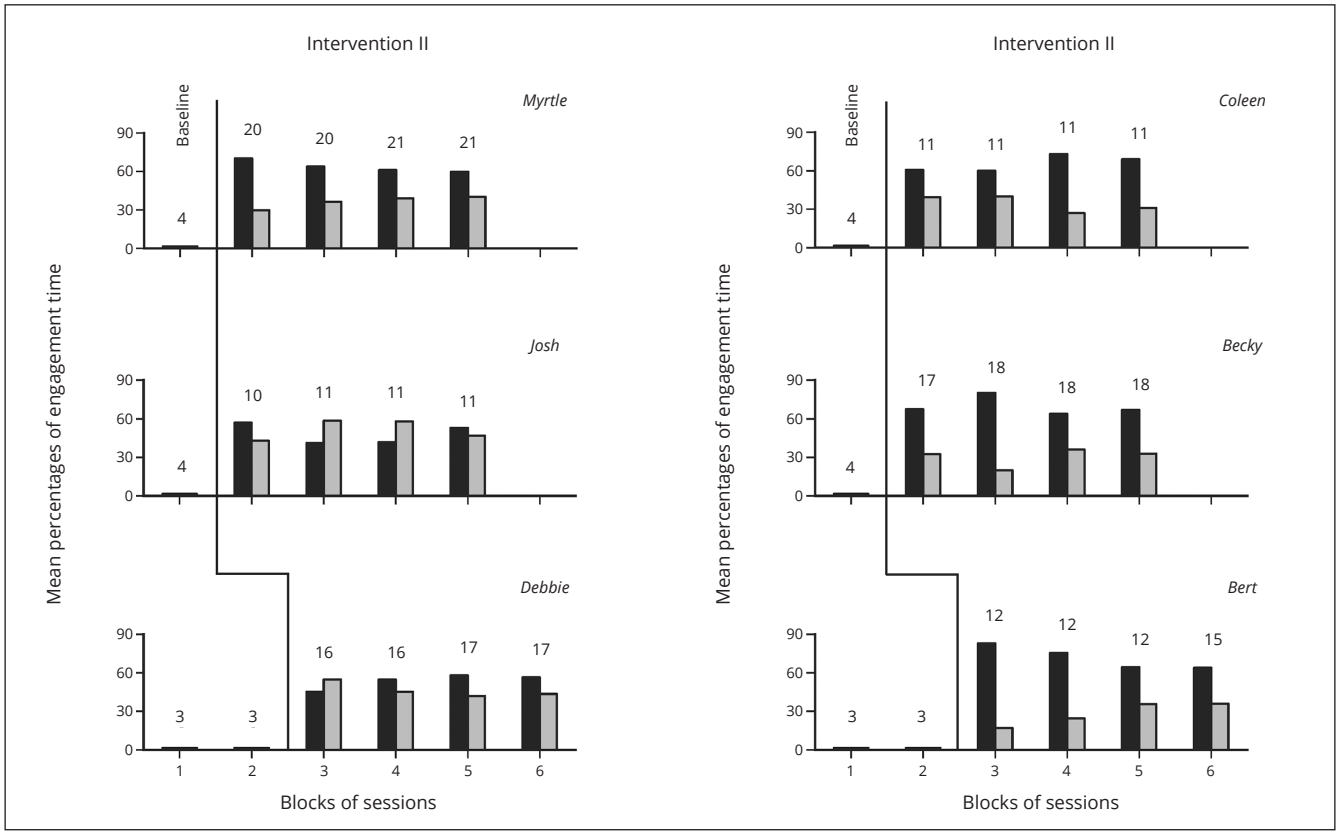

Figure 2.—The six panels report the data for the six participants. Black and gray bars represent mean percentages of the session engagement time that the participants spent with leisure and communication events, respectively, over blocks of sessions. The number of sessions included in the blocks is indicated by the numerals above them.

leisure and communication events for most of the session duration (*i.e.*, for averages of more than 8 min per session). The mean engagement time spent with leisure events was about 50 to 70% of the total engagement time. Conversely, communication engagement represented about 30 to 50% of the total engagement time. During the social validation, staff's mean scores regarding program's benefits exceeded 4 (*i.e.*, were quite positive) on each of the aspects rated.

Discussion

The results are encouraging as they show the possibility of enabling individuals with extensive neuro-motor and communication impairments (individuals who are often underserved) to reach sustained levels of leisure and communication engagement. Essentially, one might argue that the program is feasible in terms of material involved, easy for the participants to use, and acceptable to staff. In terms of material, it is obvious that smartphones are readily accessible and affordable devices even though they require preparatory work before they can serve for the intervention program. Indeed, they need to be fitted with a variety of audio and video files, and automated in their functioning through specific applications. With regard to user-friendliness, data showed that the participants learned to use the program independently with a small amount of practice (*i.e.*, the 6-10 sessions of the first intervention phase) and easily maintained their independence through the study. Informal reports, moreover, indicated that the participants enjoyed the program sessions (without any visible risk or drawback). Regarding the issue of acceptability, the social validation showed that staff provided favorable scoring of the program, thus underlining their positive opinion about the program's benefits and functionality.

Limitations of the study

This case series has some limitations: 1) only a few cases were included in the study; 2) the number of sessions

available to them was relatively contained; and 3) the leisure and communication options accessible through the program were fairly circumscribed in terms of content and variety. New studies should focus on each of these aspects to determine the dependability, extendibility, and overall functionality of the program.

Conclusions

Data suggest that individuals with extensive neuro-motor and communication impairments, who are often underserved in their daily contexts, may benefit from the use of a fairly simple smartphone-based program, like the one used in this study. Obviously, new research will have to address the points/limitations mentioned above and eventually also assess the feasibility of making the program available for significant sections of the day (rather than specific sessions), possibly arranging periodic changes of leisure and message cards, and pursue technology upgrades that would enable a single smartphone to support the program.

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Conflicts of interest.—Carlo Ricci is professionally connected to the Walden Technology srl, which produces the WPC (*i.e.*, one of the applications used in the smartphones).

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