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Mainstream technology to support basic communication and leisure in people with neurological disorders, motor impairment and lack of speech

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ABSTRACT

Objective: To assess a simple technology solution to support basic communication and leisure in people with neurological disorders, extensive motor impairment, and absence of speech.

Design: The design was a non-concurrent multiple baseline across participants.

Methods: The study included eight participants and assessed a technology setup including a Samsung Galaxy Tab S2 LTE tablet and a Samsung Galaxy A3 smartphone. The smartphone, automated via MacroDroid, presented the participant with leisure, messages, and caregiver options. Choosing leisure or messages (by activating the smartphone's proximity sensor) led the smartphone to present the alternatives available for that option and eventually verbalize the alternative selected. This verbalization triggered the tablet's Google Assistant and led the tablet to present a leisure event or start a message exchange. Choosing the caregiver led the smartphone to invite the caregiver to interact with the participant.

Results: During baseline (i.e., when a standard smartphone was available), the participants did not activate any of the options. During intervention and post-intervention (i.e., with the technology described above), participants activated all options and spent most of the session time positively engaged with them.

Conclusions: The aforementioned technology seems to be a useful tool for individuals like those involved in this study.

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Introduction

People with neurological disorders, extensive motor impairment and absence of speech pose a serious challenge to rehabilitation and care contexts. Irrespective of whether their neurological damage is congenital, perinatal or acquired, these individuals are typically unable to independently engage in leisure and occupational activities or communication exchanges (1–6). Indeed, they may lack the motor skills needed to operate conventional leisure devices (e.g., television and computer devices) or manipulate objects for simple occupational activities (7,8). Similarly, they may not have (a) the communication skills (verbal or non-verbal) necessary to call the caregiver and ask for something they need or desire, and (b) the ability to use telephone devices or similar tools to exchange messages with friends and family members not present in their immediate context (8–11).

One way to help these people achieve independent communication and leisure may entail the use of technology-aided solutions capable of bridging the gap between the people's behavioral repertoire and the skill level required for their independence (12–15). The most recognized solution available in the area involves the use of eye-tracking computer systems (3,16,17). Those systems rely on specific sensors that monitor the participant's eye-gaze responses and allow such responses to serve for communication and entertainment purposes. A second solution

available involves the use of a computer system combined with a communication modem and a microswitch (18,19). The computer system is programmed to present the participant with communication and leisure options. The microswitch allows the participant to choose among those options, and eventually activate them, with simple/minimal responses.

A third solution involves the use of a smartphone and cards fitted with radio frequency identification tags (4). The smartphone is automated through a specific application, so it recognizes and responds to the cards that the participant holds against it. If the participant holds a card showing a communication partner, the smartphone verbalizes the name of that partner and asks the participant to select the message for that partner. If the participant holds a card showing a leisure event, the smartphone presents such an event.

While the use of each of the aforementioned technology-aided solutions has produced encouraging results, large differences exist about their usability, practicality, and affordability. Regarding usability, the first two solutions are suitable for individuals with minimal motor behavior and provide them with extensive and fairly elaborate communication and leisure options (16–18). The third solution is suitable for individuals with some manual skills and offers them relatively basic communication and leisure opportunities (4). Regarding practicality and affordability, the first two solutions are rather complex,

not easily portable and expensive, whereas the third is fairly simple, portable and inexpensive. In light of the above, one could envisage the relevance of developing a new technology-aided solution that would be simple and inexpensive as the last one, but could be used also by individuals with minimal motor behavior. The purpose of this study was to develop such a new solution and assess it with eight participants with neurological disorders, minimal motor behavior (unable to manipulate objects), and lack of speech.

Method

Participants

Table 1 lists the participants by their pseudonyms, and reports their ages, neurological disorders and level of functioning, as well as the time gap between the diagnosis of their neurological disorders and the start of this study. Their ages varied between 28 and 76 years. Their neurological disorders were linked to intraparenchymal hemorrhage, total anterior circulation infarct, perinatal brain injury, muscular dystrophy, Parkinson's disease, and cervical spinal cord injury. The time interval between the diagnosis of the disorders and the start of the study varied from about 5 months to 40 years. The rehabilitation and care centers in charge of their treatment had classified their general functioning as compatible with mild/moderate intellectual disability, mild cognitive impairment (20) or the VI and VII levels of the Levels of Cognitive Functioning Scale-Revised (21).

The participants were rated as suitable for (potentially capable of benefiting from) the study, irrespective of their different neurological disorders, because they (a) had receptive language skills (i.e., comprehended narratives and questions concerning daily events, family and friends), (b) possessed small hand/finger, head, or foot responses for activating the proximity sensor of a smartphone, (c) were interested in sending messages to their preferred partners (e.g., family members and friends) and enjoyed listening to messages received from those partners, (d) enjoyed leisure events such as listening to songs and watching videos, (e) were dependent on others to satisfy any needs and desires, and (f) seemed willing to use the smartphone and tablet (i.e., after demonstrations of the devices' functioning).

The participants' families were informed about the technology package and were highly favorable to its use. They also signed a written consent form authorizing the participants' inclusion in the study. The study complied with the 1964

Helsinki declaration and its later amendments and had been approved by an institutional Ethics Committee.

Setting, Sessions, and Data Recording

Quiet areas of the centers that the participants attended served as setting for the study. Sessions were conducted on an individual basis, typically two to four times a day, 3 to 5 days a week. Sessions were scheduled to last 10 min. However, the participant was allowed to complete any leisure or communication engagement, which was started within the 10-min limit, with consequent extension of the session duration.

Data recording was conducted by research assistants and concerned (a) the communication instances occurred and the leisure events accessed during the session, (b) the times the participants spent with each of the two forms of engagement, and (c) research assistant's prompts (i.e., verbal cues and response demonstrations). Communication instances included messages sent out, messages received, and caregiver calls/requests with subsequent responses by the caregiver (i.e., approaching the participant, identifying his or her need/desire, and satisfying it directly, or setting up the tablet to satisfy it) (see below). Recording agreement was checked in at least 20% of the sessions of each participant, with a reliability observer joining the research assistant in data recording. Agreement (i.e., the research assistant and reliability observer reported the same communication instances and leisure events, total engagement times for the two types of occupation differing less than 50 s, and identical presence/absence score for prompts) was obtained in more than 90% of the sessions of each participant.

Technology

The technology consisted of (a) a tablet (i.e., Samsung Galaxy Tab S2 LTE) with 8-inch screen, Android 7.0 operating system, and (b) a Samsung Galaxy A3 smartphone with Android 8.0 operating system, proximity sensor, and text-to-speech function. The tablet was provided with a SIM card, WhatsApp Messenger, YouTube, and Google Assistant. The smartphone was fitted with the MacroDroid application. This application served to automate the smartphone's working and enable its text-to-speech function to verbally present the choice options available and verbalize the participants' choices (see below). The smartphone's verbalizations

Table 1. Participants' Pseudonyms, Ages, Neurological Disorders, Cognitive Functioning, and Intervals between Disorder Diagnosis and Start of the Study.

Participants	Ages	Neurological disorders	Cognitive functioning	Time between diagnosis and start of the study
Carol	66	Cervical spinal cord injury	Mild cognitive impairment	7 years
Jill	57	Muscular dystrophy	Mild cognitive impairment	35 years
Ray	76	Intraparenchymal hemorrhage	LCF = VI	5 months
Iris	58	Total anterior circulation infarct	LCF = VI	6 months
Robyn	40	Perinatal brain injury	Mild/moderate intellectual disability	40 years
Faye	28	Perinatal brain injury	Mild/moderate intellectual disability	28 years
Paul	65	Intraparenchymal hemorrhage	LCF = VII	1.5 years
Ester	68	Parkinson's disease	Mild cognitive impairment	10 years

regarding music/videos, message contents and partners' names were arranged/formulated in such a way that they triggered the tablet's Google Assistant. This in turn (through its connection with YouTube and WhatsApp Messenger) started the process leading the tablet to present the music/video event requested or send the message indicated to the selected partner. Verbalizations concerning the caregiver served to call/request the caregiver to respond to the participant's needs or desires.

Experimental Conditions and Data Analysis

The study was carried out according to a non-concurrent multiple baseline design across participants (22). The baseline was followed by an intervention phase (introducing the participants to the use of the automated smartphone and tablet) and a post-intervention phase. The research assistants, who conducted the data recording, were also responsible for the implementation of the sessions. The participants' baseline and post-intervention data on communication and leisure engagement were reported in graphic form. The Kolmogorov-Smirnov test was to be used to assess the differences between baseline and post-intervention if overlaps existed in the session engagement times of those phases (23). No such overlaps however existed.

Baseline

The baseline phase included four to eight sessions, according to the design requirements. During these sessions, the participants had the smartphone near their hand/fingers, but the smartphone was not yet automated with MacroDroid. The smartphone's screen showed the YouTube and WhatsApp icons and a file containing the recording of a vocal call/request for a caregiver. At the start of the sessions, the research assistant told the participant that he or she could send messages by using WhatsApp, access music and videos by using YouTube, and call for the caregiver by opening the related file. If the participant did not succeed in using the smartphone for 2–4 min (given their poor/insufficient motor skills), the research assistant intervened on his or her behalf by sending a message to one of his or her partners or activating a video/song.

Intervention

The intervention phase included 6 to 10 sessions. The participants had the tablet in front of them while the smartphone automated via the MacroDroid was positioned beside their fingers (Jill, Ray, Iris, Paul, and Ester), head (Faye) or foot (Carol and Robyn). Such positioning allowed the participants to activate the smartphone's proximity sensor with small finger, head, and foot responses, respectively. During the initial intervention sessions, the research assistant provided prompts (i.e., verbal cues and response demonstrations) to help the participants send messages, access music/video events, and call for the caregiver (24). During the following sessions, prompts were reduced and eventually eliminated. A rapid fading out of the prompts was possible since choice processes and responses were highly viable for the participants.

Every session started with the smartphone verbally presenting the three options available (i.e., music/videos, messages, caregiver) (see Figure 1). The participant could choose the

first, second or third option by triggering (touching/approaching) the smartphone's proximity sensor once, twice, or three times. If the participant chose the music/videos option, the smartphone presented three possible music/videos alternatives (which could change within and across sessions). As soon as the participant chose via the aforementioned response one alternative (e.g., a singer), the smartphone verbalized such alternative and one of four events (e.g., songs) related to it, so as to trigger the tablet's Google Assistant and in turn lead YouTube to open the relevant song/video event (see left column of Figure 1).

If the participant chose messages, the smartphone presented the names of three partners (which could change within and across sessions). As soon as the participant chose a partner, the smartphone presented three possible messages that could be sent to that partner (e.g., "How are you?", "A big kiss/hug", and "When do you visit me?"). As soon as the participant chose the message, the smartphone verbalized the request to send such message to the partner so as to trigger the tablet's Google Assistant and thus open the partner's WhatsApp connection and send the message (see central column of Figure 1). Incoming messages and the name of the senders were read by the smartphone or the research assistant at the beginning and at the end of each session.

If the participant chose the caregiver, the smartphone called (presented a vocal request) for the caregiver who in response showed the participant seven cards indicating basic needs (e.g., change of position, water, and leg massage) or extra music/videos. The caregiver pointed to the single cards until the participant chose one of them (i.e., through sound, or movements of the head or fingers). If the choice concerned a basic need, the caregiver went on to satisfy it. If the choice concerned extra music/videos, the caregiver asked the participant to select one out of two or three alternatives, then set up the tablet to play an event related to it (see the right column of Figure 1).

Post-intervention

The post-intervention phase included 49 to 106 sessions. Conditions were as at the end of the intervention phase with no research assistant's prompts. An exception (i.e., a prompt) could occur only if the participant was not involved in any communication or leisure for 1–2 min.

Results

The eight panels of Figure 2 summarize the participants' data during the baseline and the post-intervention phase. The intervention sessions are not reported in the figure, as they simply introduced the participants to the use of the automated smartphone and tablet. The circles and black diamonds indicate mean percentages of session time spent in communication and leisure over blocks of sessions, respectively.

During the baseline, the participants failed to operate the non-automated smartphone, and consequently did not manage to start any communication or leisure engagement process. During the intervention sessions, the participants learned to use the automated smartphone and tablet, becoming successful in accessing music/videos, sending messages to their preferred partners, and calling for the caregiver to satisfy needs and desires. They also

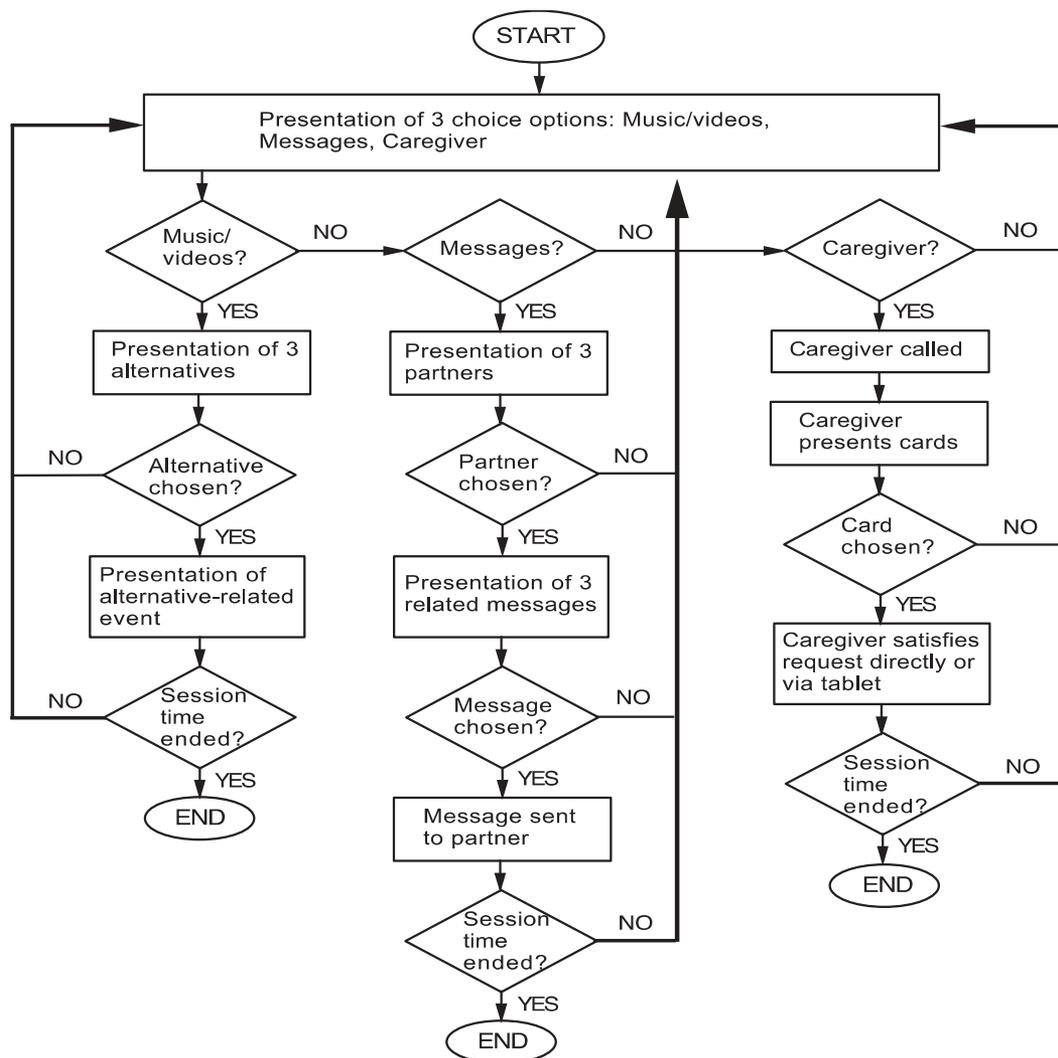


Figure 1. The flowchart illustrates the conditions available during intervention and post-intervention.

received messages from those preferred partners (i.e., messages which were read to them at the start and the end of the sessions).

During the post-intervention phase, all participants consolidated their successful (independent) use of the automated smartphone and tablet and managed to be largely active throughout the sessions. Their mean percentages of session time spent engaging in communication varied between about 35 (Carol) and 55 (Faye). Their mean percentages of session time spent engaging in leisure varied between about 30 (Faye) and 45 (Carol, Jill and Paul). Their mean cumulative percentages of session time spent engaging in the two types of occupation were within the 80–90 range. Prompts were absent or virtually absent throughout the post-intervention phase.

Discussion

The results indicate that participants with neurological disorders, minimal motor behavior, and lack of speech successfully used the new mainstream technology solution to exchange messages with preferred partners, make functional requests to the caregiver, and access leisure events. These results, which match those previously obtained with participants capable of

using cards (4), provide reasonable hope for individuals who are in great need of help (25, 26). These individuals, in fact, (a) can only marginally benefit from traditional interventions (e.g., speech therapy) and (b) rarely qualify for the use of complex and expensive technology solutions (e.g., eye-gaze systems) (27,28). In light of the above, several considerations are possible.

First, the technology solution adopted in this study is readily available and easily affordable in terms of components (29–31). Indeed, the smartphone and tablet are common and relatively inexpensive everyday devices. Similarly common and free of cost is the WhatsApp application. Moreover, the MacroDroid application or comparable applications can be downloaded for negligible costs. In addition to being advantageous in terms of accessibility and affordability, the present technology solution also appears highly suitable for individuals with very limited motor behavior. In fact, the smartphone's proximity sensor may be activated by minimal movements of different parts of the individuals' body (e.g., fingers, head, or foot).

Second, while easily accessible/affordable and adaptable to the participants' response repertoire, the technology solution employed in this study is not ready-made for use. Such technology requires some preparation in order to satisfy the

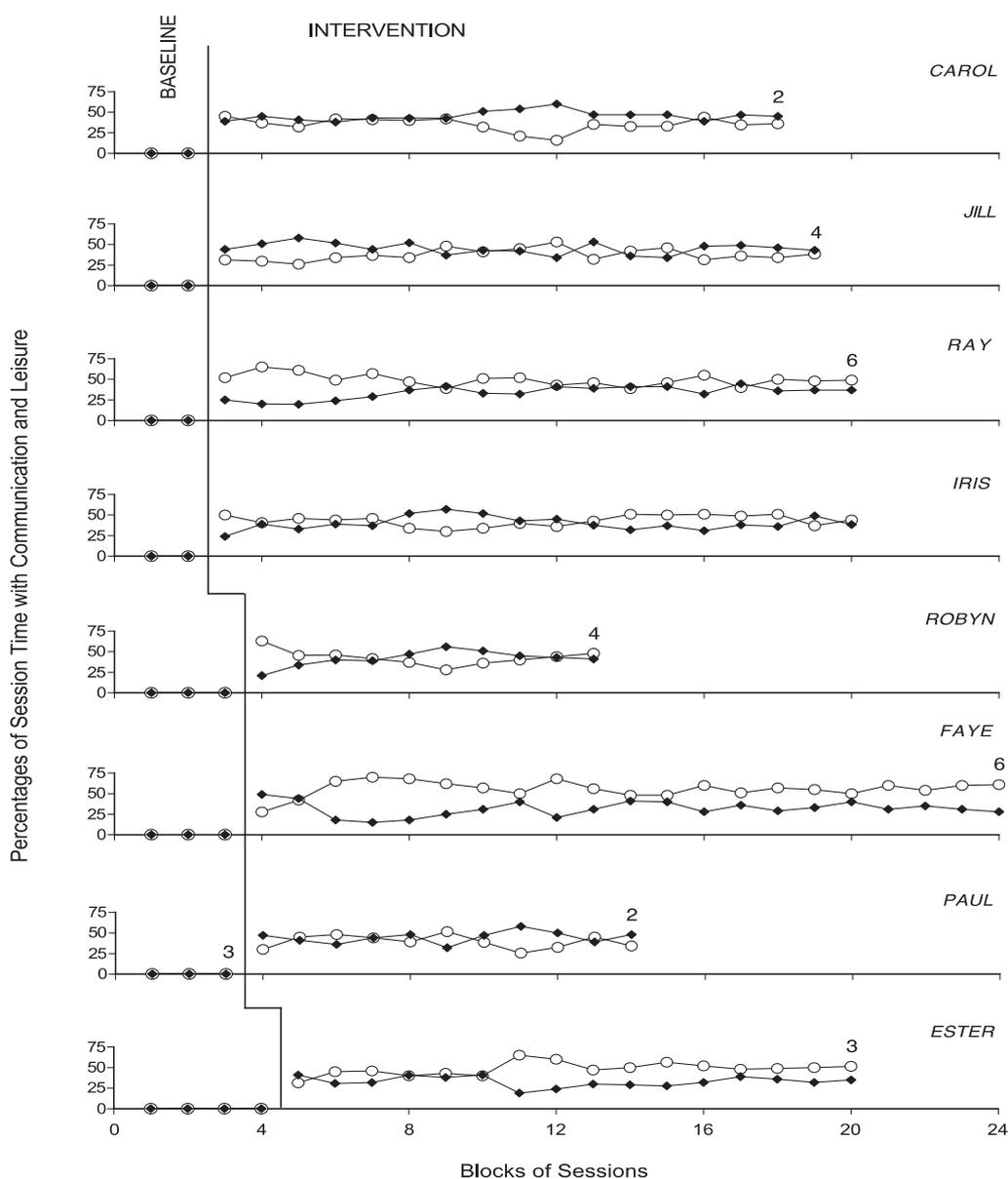


Figure 2. The eight panels summarize the participants' data during the baseline and the post-intervention phase. The circles and black diamonds indicate mean percentages of session time spent in communication and leisure over blocks of sessions, respectively. The blocks include two sessions during baseline and five sessions during the post-intervention. Exceptions may concern the last baseline or the last post-intervention block. In those cases, a numeral above the block indicates how many sessions were included.

intervention and post-intervention conditions and thus help the participants reach their goals in a simple and rapid manner. The preparation is specifically focused on automating the smartphone via the MacroDroid or a similar application (so the smartphone can link up with the tablet and function as described in this study).

Third, the technology-aided program set up in this study would be considered rather limited as to its contents (i.e., the communication and leisure opportunities it includes) compared to programs relying on eye-tracking computer systems. While the difference between programs is apparent, the question is whether a fairly limited program such as that reported here suits the requirements of the participants involved. One might argue that for these participants the use of a simple/basic program is advantageous, at least in the early treatment stages, in

that such program allows them to reach what is relevant for them with minimal efforts and virtually no risks of failure (8,32). Obviously, the program may be extended and upgraded as the participants progress. It may also be stressed that decisions in this area should take into consideration the participants' opinion (i.e., their preferences for different program arrangements and opportunities) so as to enhance the quality of their engagement and eventually their satisfaction and mood (33).

Fourth, some limitations of the study need to be mentioned here. One limitation is the relatively small number of participants involved in the assessment of the new technology solution. Further studies with additional participants may help clarify the effectiveness and robustness of the new technology solution and determine the reliability of the present data (34,35). A second limitation concerns the lack of specific data

on whether the participants enjoyed the involvement in the sessions with the use of the technology, which allowed them presumably positive (pleasant) forms of engagement (36–38). Some anecdotal reports suggesting participants' satisfaction need to be ascertained through a direct evaluation of the participants' preference for (enjoyment of) the sessions (39,40). A third limitation is the lack of a social validation of the technology solution (41,42). The social validation could involve formal interviews of staff and families aimed at determining the opinion of those people about the technology's impact, appropriateness and usability.

In conclusion, the results of this study indicate that individuals with neurological disorders, extensive motor impairment, and lack of speech successfully used the new smartphone-tablet technology for communication and leisure engagement. Before one can make general statements about this technology and its usability and implications, new research should address the limitations of this study and provide additional evidence in the area. New research may also assess ways of extending the communication and leisure opportunities offered by the technology solution adopted in this study so as to suit participants who progress in their recovery process and can benefit from extra options.

Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

Ethical Approval

Approval for the study was obtained from an institutional Ethics Committee. All procedures performed were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed Consent

The participants' families provided written informed consent for the participants' involvement in the study.

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