SELF-MANAGEMENT OF INSTRUCTION CUES FOR PROMOTING INDEPENDENT DAILY ACTIVITIES:

REVIEW OF STUDIES WITH PEOPLE WITH MILD OR MODERATE ALZHEIMER'S DISEASE

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Samenvatting

In het herstellen en behouden van zinvolle bezigheden voor mensen met een lichte of matige vorm van van de ziekte van Alzheimer is doelstelling van groot praktisch belang. De studies gericht op dit doel hebben vertrouwd op de verschillende strategieën van zelfmanagement van instruction cues (goede vertaling?). Zeven studies werden gevonden die plaats hadden in de periode 2008-2012 (dat wil zeggen, de periode waarin onderzoek op dit gebied daadwerkelijk vorm heeft gekregen). Die strategieën bestaan uit het gebruik van (1) verbale signalen aangeboden via audiorecorders, (2) visuele signalen aangeboden via computersystemen, en (3) een combinatie van verbale en visuele signalen gepresenteerd via computersystemen. Dit artikel geeft een overzicht van de hiervoor genoemde strategieën en bespreekt de resultaten daarvan, hun algemene doeltreffendheid, op prestaties en stemmingen, en hun geschiktheid en bruikbaarheid. Thema's voor toekomstig onderzoek werden eveneens onderzocht.

SELF-MANAGEMENT OF INSTRUCTION CUES FOR PROMOTING INDEPENDENT DAILY ACTIVITIES: REVIEW OF STUDIES WITH PEOPLE WITH MILD OR MODERATE ALZHEIMER'S DISEASE

Alzheimer's disease is an irreversible neurodegenerative condition that brings about a progressive decline in memory and higher cognitive functions [4,16,19,20,22,53]. The symptoms usually vary with the progression of the disease. In the early stages of the disease, the person may show signs of increasing spatial disorientation and eventually failure to travel even in indoor contexts [37]. Their condition shows increasing disabilities also in terms of memory [71], performance on simple activities [4,19,20,52] and social/emotional behaviour [3,48,63,67,70].

During the early phases of the disease, behavioural interventions may be useful to counter the main activity problems a person is facing and reduce the intensity and impact of these problems. Behavioural research efforts have concentrated on the recovery of *daily activities* (i.e. on assisting patients to perform these activities) through technology-based instructions [14,18,36,43,69]. This research is based on the assumption that a person's ability to carry out daily activities is a way to (a) counter their decline, frustration (depression) and withdrawal, (b) promote their self-determination, alertness, and social image and (c) ultimately enhance their overall quality of life and reduce their demand on caregivers [6,19,23,27,43,59,65,69,70].

The period 2008-2012 represents a relevant time interval that has witnessed the use and evaluation of technology-based instruction strategies for promoting independent daily activity in people with mild and moderate Alzheimer's disease. This support technology is designed to help participants manage the aforementioned instructions efficiently and with limited effort. These strategies consist of (1) verbal cues presented via audio recording devices [31-36], (2) pictorial cues presented via computer-aided systems [37] and (3) combinations of verbal and pictorial cues presented via computer-aided systems [37]. This paper aims to review the application of these strategies for people with mild or moderate Alzheimer's disease.

The first aim of this paper is to provide the reader with a general picture of the studies conducted and the various strategies used. A second aim is to discuss (a) the effectiveness of these strategies in supporting performance, (b) their impact on participants' mood and (c) their suitability. Finally, the paper highlights some relevant issues for future research.

The studies included in the review were identified through a computerized search of PsycIN-FO and PubMed databases for journal articles. Only studies that considered the development of the aforementioned assistive technology for supporting the performance of activities with people with Alzheimer's disease and other forms of dementia were included in the paper.

Table 1

Characteristics of the studies reviewed

Authors	Study	Strategy	No. Ps.	Age (years)	MMSE score	No. steps/ activities	Effects on performance	Hamilton score	Impact on mood
Lancioni et al. (2008)	I°	Verbal cues	4	59-85	11-20	17	Positive	/	/
	II°	Verbal cues	2	81-88	11-14	14	Positive	/	/
	III°	Verbal cues	3	73-81	14-15	12	Positive	/	/
	IV°	Verbal cues	1	82	19	17	Positive	/	/
Lancioni, Pinto et al. (2009)	I°	Verbal cues	3	79-86	10-22	17	Positive	/	/
	II°	Verbal cues	4	74-81	14-19	10-12	Positive	/	/
	III°	Verbal cues	3	73-81	14-15	12-14	Positive	/	/
Lancioni, Singh et al. (2009)	I°	Verbal cues	2	58-79	12-15	12	Positive	16-18	Positive
	II°	Verbal cues	2	59-73	17-18	18-20	Positive	13-18	Positive
	III°	Verbal cues	3	58-72	13-17	16	Positive	13-16	Positive
Lancioni, Singh, O' Reilly et al. (2009)	I°	Verbal cues	6	68-79	14-18	22	Positive	8-22	Mixed
	II°	Verbal cues	3	66-76	10-22	16	Positive	10-22	Positive
Lancioni, Singh, O'Reilly, Zonno et al. (2009)	I°	Verbal cues (maintenance)	9	58-81	13-22	12-22	Positive	/	Positive
Lancioni et al. (2010)	I°	Verbal cues	7	61-83	11-17	12-16	Positive	12-24	Mixed
	II°	Verbal cues	4	73-86	11-22	20-26	Positive [a]	6-20	Mixed
Lancioni, Perilli et al. (2012)	I°	Verbal plus Pictoria [b]	3	73-79	12-18	22-24	Positive	10-15	/
	II°	Pictorial Cues [b]	3	73-79	12-18	22-24	Positive	10-15	/

Note   a Interruption of the intervention for one participant
        b Comparison between strategies
        / Not available.

Table 1 provides a list of the articles (and related studies) included in the review and of the strategies employed. For each study, the table specifies the number of participants, their age and Mini Mental scores [18], the number of steps included in the activities, outcomes of the intervention phase (i.e. effects on performance), their Hamilton Depression scores (17-item version) [5] and the possible impact of the intervention on mood. The outcomes of intervention on performance and mood were classified as positive, negative and mixed. Positive findings mean that there was a satisfactory level of independent (correct) performance or positive effects on mood for all study participants. Negative findings mean that study participants showed only minimal improvement in their response/engagement rate compared to the baseline levels or showed no mood improvement. Finally, mixed findings mean that performance data or mood indices reached satisfactory levels, but not for all participants.

Self-management strategies

Use of verbal cues presented via audio recording devices
The most widely used strategy involves verbal instructions aimed at guiding participants through the activity steps and support technology designed to help participants manage these instructions successfully and independently [31-36]. The combination of these two elements (i.e. instructions and technology) is deemed to have a positive impact on patients' immediate and longer-term performance and to reduce the level of input required from staff [32]. This strategy has been investigated in 14 studies (as reported in five articles; see Table 1) with patients with mild or moderate Alzheimer's disease to recapture (manage) a variety of daily living activities [31-37]. Data have generally indicated a clear improvement in performance.

The technology consisted of (a) a microprocessor-based electronic control unit with specific software, (b) an amplified MP3 player with USB pen drive connection, (c) a pen containing recorded verbal instructions related to the activity to be performed and (d) optic sensors. Two contiguous desks were provided for the activity. One desk contained all the items required for the scheduled activity, the other served for using the items and completing the activity [32]. The photocell and light-reflecting paper were arranged in front (at opposite sides) of the table with the items necessary for the task so that the participant would break the photocell light beam each time he or she reached for the items. Activity trials started with the control unit triggering the MP3 player that presented the first instruction related to the item that the participant had to pick up. In taking the item from the desk, the participant activated the optic sensors and made the MP3 player present the next instruction for how to use/arrange the items on the implementation desk. After a programmed interval, a new verbal instruction started. The length of the intervals was programmed based on observations of the participants during the activity. The procedure continued as described above for each step of the sequence. In essence, the technology ensured that the person received one verbal instruction at a time for each individual step of the activities he or she was to perform [32,33,35,37].

A number of studies also assessed mood and found encouraging evidence regarding the positive effects of activity engagement on indices of happiness [32,33,35,37]. The indices of happiness (e.g.) were registered based on the videotaped recordings of the intervention/activity

trials and parallel non-activity trials. The registrations were made according to a partial interval system, in which ten-second observation intervals were followed by five-second scoring periods. The ten-second intervals were scored as positive if any of the expressions identified as indices of happiness appeared, regardless of their duration. Participants' performance improvement seemed to counter their increasing activity failure, frustration and withdrawal and simultaneously to promote their self-determination, alertness and social image. Their mood improvement represents an important achievement both in light of patients' tendency to be depressed and in terms of their quality of life.

Pictorial cues presented via computer-aided systems

The positive results obtained using the verbal instruction strategy are very encouraging but also suggest the desirability of devising other strategies that provide additional options for responding to different personal situations. One of these alternative strategies involves the use of pictorial cues [37]. Pictorial cues stored in computer-aided systems have been used to restore the performance of sequences of familiar activities scheduled in patients' environments. Each activity is then represented through picture cues projected on a screen [28].

The technology used in studies involving pictorial cues included (a) a computer with specific software, (b) two screens with speakers located on the item desk and implementation desk, respectively, (c) optic sensors and (d) pictorial images/cues projected on the screens. At the start of an activity trial, the screen on the implementation desk showed a pictorial cue. This represented the first instruction related to the item the participant was intended to pick up from the item desk. In picking up the item, the participant activated the optic sensors, triggering the appearance of a pictorial cue (signalled by a sound) on the screen on the item desk. This cue represented the second step of the task that the participant was intended to perform at the implementation desk. After a programmed interval, a new pictorial cue signalled by a sound appeared on the screen on the implementation desk. This cue represented the third instruction. The procedure continued this way through each successive step of the activity [38]. In their second study (see Table 1), Lancioni, Perilli et al. (2012) compared a strategy using pictorial cues with the strategy (described above) using verbal instructions. Each strategy was used in one activity. The pictorial cues strategy was effective with all participants involved. The percentages of correct activity performance observed with this strategy were comparable with those obtained with the existing verbal instruction strategy.

Combinations of verbal and pictorial cues presented via computer-aided systems

TThe development of more powerful instruction strategies may involve various adaptations to the strategies currently available or the development of new solutions. One new solution that was recently assessed consisted of a technology combining pictorial cues with verbal instructions, differing from the technology using solely pictorial cues in that each pictorial image was accompanied by the matching verbal instruction. Verbal instructions that had been recorded on a computer were played from loudspeakers in coordination with the appearance of matching images [37].

In their first study (see Table 1), Lancioni, Perilli et al. (2012) compared the strategy using pictorial cues and verbal instructions combined with the strategy using verbal instructions alone. Each strategy was used in one activity. The results indicate that the new technology-aided strategy with pictorial cues and verbal instructions combined was effective with all participants involved. The overall levels of correct activity performance observed with the new strategy (i.e. combinations of verbal and pictorial cues) were comparable with the levels obtained using the existing verbal instruction strategy, which served as a standard [26].

Discussion

Effectiveness of the strategies on performance

The results of intervention were positive in (a) the 14 studies (as reported in five articles; see Table 1) that used verbal cues stored in audio recording devices, (b) the study using pictorial cues stored in computer-aided systems and (c) the study using combinations of verbal and pictorial cues. The participants generally showed improved performance within a brief period of time and with only relatively modest external guidance. This could be considered a highly relevant achievement, countering some of the major problems these patients experience and simultaneously promoting their self-determination, alertness and social image [14,28,44,60]. These results may also be very valuable for family and caregivers in general, providing them with (a) some (momentary) respite in the level of direct assistance they need to supply, (b) a more positive perception of the person they are caring for, possibly also improving their emotional ties with that person, and (c) new, positive expectations and new motivation to extend the intervention to other daily activities [50,21,39,58]. Nevertheless, to gain a better understanding of the general situation, it is useful to consider participants' actual level of functioning and the length of the training they received.

The generally rapid improvement among participants suggests that they (a) were fairly capable of understanding the instructions provided for the activity steps (largely tailored to their individual characteristics and cultural background) and of planning/performing the related responses and (b) possessed the motor schemes (and related skills) required for the individual activity steps. Essentially, the intervention strategies used in these studies were effective with participants whose poor performance prior to the intervention was probably due to their lack of initiative, deteriorated operative memory and poor general planning [54,61]. This clarification may be important towards determining an intervention strategy's applicability and basic prerequisites.

In terms of length of training, the studies can be divided into two categories: (a) those that continued the training until a successful performance criterion was achieved [31-36] and (b) those that continued the training until a fixed (practical) time limit was reached for comparing the two different strategies [37]. In the first category, data from the studies reviewed support the notion that using verbal instructions and basic technology to control its presentation can be quite effective at helping people with mild or moderate levels of Alzheimer's disease recapture relevant daily activities [12,16,28]. In the second category, the objective was not necessarily to reach a highly stable/satisfactory performance but to measure differences in the effectiveness of these strategies over a fixed period of time. Lancioni, Perilli et al. (2012) found that the use of verbal instructions stored in a recording device, pictorial cues stored in a computer-aided system or a combination of the two led to an improvement in performance.

Effectiveness of the strategies on mood

As suggested above, the possibility that patients may obtain some benefit in this area is particularly important in light of their reported tendency towards depression and sadness [1,46,53,3,48,63,67,68,70]. Such a benefit can be considered a clear indictor of improvement in quality of life. Happiness can be viewed as the most defining feature of the whole concept of quality of life [30,45]. Higher indices of happiness (quality of life) can also be highly motivating for patients' caregivers and others in their surroundings and, in particular, can (a) provide them with reassurance regarding the intervention approach being applied and (b) alleviate the burden of care and associated anxieties [20,36,40]. Mood was not directly investigated in all the studies, including in those involving pictorial cues and a combination of pictorial and verbal cues. Nevertheless, the aforementioned positive effects on mood are likely given that both general conditions and general performance levels were comparable across all studies [6,19,27,32,43,45,49,65,69,70].

Suitability of the strategies

The three strategies reported in the studies reviewed appear fairly suitable for persons with mild or moderate Alzheimer's disease [54,61]. This suitability should be understood in relation to the overall cost, compatibility with the situation and need to respect patients' dignity.

A social validation assessment was therefore carried out to gather information about the suitability of the three strategies. Advantages of the verbal cues strategy are not only the simplicity of its technology, which enables caregivers to set it up with minimal time investment and procedural difficulty [10,14], but also its relatively low cost (around US$750) [28,25,2,56]. This low cost would put it within the reach of most rehabilitation centres and families [10,13]. The use of two screens in the pictorial instruction strategy, though effective in terms of outcome [37], seems to be less convenient compared to the verbal instruction technology. Moreover, the financial cost of the pictorial instruction strategy is obviously higher, though this is difficult to quantify as it only exists in a preliminary version. The time entailed in setting up the pictorial cues may also be slightly more given this strategy's reliance on two screens and two sets of optic sensors. These differences between the strategies appear to be reflected in the social validation assessment [24].

The concept of compatibility refers to the extent to which the strategy can coexist with other activities and individuals connected with the patient without creating excessive interference. In this regard, the pictorial cues strategy seems more compatible with the patient context than the verbal instruction strategy. In fact, unlike verbal cues, pictorial cues can be geared towards specific individuals in a given environment without interfering with others sharing that environment or hampering their activities [37].

Respect for participants' dignity can be viewed in two different ways. A strategy could be considered respectful if it allows the participant to independently obtain a high level of performance (percentage of correct responses) [25,37,57]. Respect for the participant's dignity could also be determined by the nature of the instructions/cues a strategy uses. If these are highly suited to the participant's circumstances, the strategy can be more easily managed. A simpler (less demanding) strategy may be considered more respectful of the person responsible for managing it. It is also possible that the judges (psychology students) involved in the social validation assessment evaluated the pictorial instruction strategy more positively than the verbal instruction strategy because they felt the pictorial cues to be more effective, permanent, comfortable and friendly for participants [47,51].

Conclusions

In the past four years, the literature on developing constructive occupation for people with mild or moderate Alzheimer's disease has relied on three strategies for self-management of instruction cues. The studies reviewed have shown that a strategy using verbal cues, pictorial cues or a combination of the two can provide effective support for people with mild or moderate Alzheimer's disease and can enable them to carry out daily activities. The overall picture to emerge from the studies reviewed is fairly encouraging as regards the possibility for people with mild or moderate Alzheimer's disease to achieve independent occupation.

Several technical issues are still open to investigation, however, and may need to be addressed first in order to define the most practical and acceptable solutions to help patients. For example, there are no data on the best way to formulate verbal instructions in terms of sentence structure. Yet the length and structure of sentences may be critical to discrimination and understanding, thus determining a person's success or failure [7,29,41,62]. The strategy based on pictorial cues also requires additional evaluation, for example to assess (a) simplified versions of the strategy (e.g. with a single screen) and (b) possible alternatives such as video prompting (i.e. the use of video clips demonstrating the actions required to perform each step of an activity) [42]. Such a video option could be more transparent and less ambiguous than static pictorial cues [9,11,59,64].

In addition to the aforementioned technical issues, new research initiatives could explore (a) participants' preferences for different strategies [16] and (b) staff opinions about advantages and drawbacks of the strategies in particular, as well as their practicality, respectfulness and compatibility with other environmental aspects [8,9,32,33,66]. ∎

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Abstract

Helping people with mild or moderate Alzheimer's disease restore and maintain constructive occupations is an objective of great practical importance. Studies targeting this goal have relied on different strategies for self-management of instruction cues. Seven studies were identified in the period 2008-2012 (i.e. the period in which research in this area has actually taken shape). These strategies consist of the use of (1) verbal cues presented via audio recording devices, (2) pictorial cues presented via computer-aided systems and (3) combinations of verbal and pictorial cues presented via computer-aided systems. This paper reviews these strategies and discusses their outcomes, their overall effectiveness on performance and mood, and their suitability and practicality. Issues for future research are also examined.