Training To Improve Awareness of Disabilities in Clients With Unilateral Neglect

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Key Words: cerebrovascular disorders • intervention • self-awareness

Objective. Awareness of disabilities is known to be a central problem of rehabilitation among clients with large right cerebrovascular lesions and unilateral neglect. The aim of this study was to evaluate the effect of an intervention program focused on improving the awareness of disabilities in four participants with unilateral neglect. The intervention program developed for this study was based on the assumption that awareness of disabilities is a prerequisite for being able to learn and use compensatory techniques in the performance of activities of daily living (ADL).

Method. The study followed a single-case experimental ABA design. The Assessment of Awareness of Disability was used to measure awareness of disabilities; the Assessment of Motor and Process Skills was used to measure ADL ability; and neuropsychological tests were used to assess unilateral neglect and sustained attention. The intervention program used meaningful and purposeful occupations as therapeutic change agents to improve awareness of disabilities.

Results. Awareness of disabilities and ADL ability improved in all four participants; unilateral neglect decreased in three participants; and sustained attention improved in two participants.

Conclusion. The preliminary findings indicate that training to improve awareness of disabilities might improve the ability to learn the use of compensatory techniques in the performance of ADL in clients with unilateral neglect. The effects of the intervention strategy need to be evaluated further in future research.


Unilateral neglect, in combination with a lack of full awareness of impairments and disabilities, is common among clients who have experienced large right cerebrovascular accidents (CVAs) (McGlynn & Schacter, 1989). Heilman, Watson, and Wälenstein (1993) defined unilateral neglect as the inability to perceive, respond to, or orient to stimuli in the space contralateral to a brain lesion. Unilateral neglect is most common after right parietal injury and may affect a person’s perception of extrapersonal or personal space (Bisiach & Vallar, 1988). The impairment of unilateral neglect also negatively affects the performance of activities of daily living (ADL) and has been found to be an important predictor of poor functional ability in general (Chen Sea, Henderson, & Cermak, 1993; Denes, Semenza, Stoppa, & Lis, 1982; Kinsella & Ford, 1985). Clients with unilateral neglect commonly do not orient to or find objects in the left half of their extrapersonal space or are unable to wash or dress the left half of their body.

Many clients with severe unilateral neglect also have
impaired sustained attention, and this may be one of the reasons for their inability to learn and use compensatory techniques in the performance of ADL (Robertson, 1990). Another probable reason is lack of awareness of their impairments and disabilities (Diller & Riley, 1993). In the current study, we define impairments as the underlying disorders of a person's capacities (e.g., unilateral neglect, hemianopia) and disabilities as the difficulties persons have with performing daily life tasks (e.g., dressing, bathing). Clients with unilateral neglect who lack awareness of their impairments and disabilities may not be motivated to learn and use compensatory techniques in ADL (Bisiach & Geminiani, 1991; Diller & Riley, 1993; Fleming & Strong, 1995; McGlynn & Schacter, 1989; Tham & Borell, 1996). They may also insist on participating in activities that they can no longer perform (e.g., driving a car, activities related to work).

Despite the serious consequences of unilateral neglect for both the individual and society (McGlynn & Schacter, 1989), it has been difficult to find successful intervention strategies focused on teaching clients with unilateral neglect to use compensatory techniques in everyday life (Robertson, Halligan, & Marshall, 1993). Most of the intervention studies about unilateral neglect have focused on improving the scanning behavior in highly structured and artificial training tasks (see Robertson et al., 1993). The results of these studies suggest poor generalization of the training effects from the training tasks to everyday tasks performed outside the rehabilitation setting (Lin, 1996). Some authors suggested that the lack of carryover may be because clients with unilateral neglect need to be more aware of their disabilities before they can learn to use compensatory techniques in the performance of everyday activities (Diller & Riley, 1993; McGlynn & Schacter, 1989; Tham & Borell, 1996; Tham & Tegnér, 1997). Crosson et al. (1989) suggested that a client's level of awareness determines the types of compensations the client with brain damage is able to use in the postacute rehabilitation phases. There is a lack of research, however, about intervention strategies or programs that focus on improving awareness of disabilities as a precursor to improving ADL ability.

For the purpose of this study, we developed an awareness training program for clients with unilateral neglect that was based on the assumption that awareness of disabilities is a prerequisite for being able to learn and use compensatory techniques in ADL (Crosson et al., 1989; Diller & Riley, 1993; McGlynn & Schacter, 1989; Tham & Borell, 1996; Toglia, 1991). We operationally defined awareness of disabilities as no discrepancy between observed and objectively assessed ADL abilities and the person's self-report of his or her perceived and described abilities in a specific ADL task. The aim of this study was to evaluate this new training strategy for awareness of disabilities in four clients with unilateral neglect. We wanted to examine, in detail, each client's changes in awareness of disabilities, ADL ability, and underlying impairments (i.e., unilateral neglect, impaired sustained attention) that were thought to be causing the disability.

Method

Participants

The participants were a consecutive series of four persons with right brain damage who were inpatients at a neurological rehabilitation clinic outside Stockholm, Sweden. Inclusion criteria were right CVA of no more than 10 weeks duration (verified by computed tomography scan); severe unilateral neglect verified by a letter cancellation task (detection of < 30% of the symbols on a sheet of paper; Mesulam, 1985); and physical, psychological, and intellectual capacities that allowed active participation in assessment and training. The participants' clinical data are summarized in Table 1. By chance, all participants were right-handed women.

Design

A single-case experimental ABA design was used (Barlow & Hersen, 1984; Kazdin, 1982) with an A1 phase (baseline condition), a B phase (intervention condition), and an A2 phase (follow-up). Baseline observations (A1) serve two purposes: to describe the current level of behavior and to predict what behavior would be like in the future if no intervention were implemented. A stable rate of behavior is needed to predict the behavior in the future.

The A1 phase was kept short in order to start the intervention as soon as possible after the participants' CVA. Data for the A1 phase were collected during four sessions over a 2-week period (twice a week, at least 3 days apart). The intervention phase (B) consisted of four data collection sessions over 4 weeks (once at the end of each week). Data were collected twice during the follow-up phase (A2), at 8 and 9 weeks after the B phase was completed.

Assessment

The first author conducted all the assessments. Each test session was 60-min long and composed of the assessments discussed in the following paragraphs.

Assessment of instrumental activities of daily living (IADL) ability. The Assessment of Motor and Process Skills (AMPS; Fisher, 1997) was used to measure the participants' occupational performance of two IADL tasks. The AMPS has been fully standardized internationally and cross-culturally on more than 12,000 subjects. It is used to assess simultaneously the ability to perform ADL tasks and the discrete goal-directed ADL motor and ADL process skills necessary for effortless, efficient, safe, and independent task performance. The quality of performance on each of the 16 ADL motor and 20 ADL process skill items are scored with a 4-point ordinal scale (1 = deficit, 2 = ineffective, 3 = questionable, 4 = competent). A Rasch-based computer-scoring
Assessments for 12 clients with CVA, suggested acceptable scale validity, construct validity, person response validity, and rater reliability. The preliminary findings also indicated that the AAD measures one construct (awareness of disabilities) and that scores on the AAD could be used to separate the clients into levels of ability (i.e., levels of awareness of disability) (Tham et al., 1999).

Assessments of unilateral neglect. When testing for the presence of unilateral neglect, it is usually recommended that a battery of neglect tests be used because considerable variability from test to test exists (Pizzamiglio et al., 1992). We therefore chose to use two different assessments of unilateral neglect:

- **The Letter Cancellation Task** consists of one sheet of paper that has 120 capital letters covering the page—30 letter As and 90 distractors (Mesulam, 1985). Participants were asked to mark (i.e., circle) every letter A that they could find on the paper. The number of marked As was recorded and presented as a percentage of the possible total. Unilateral neglect was defined as three levels of impairment: **mild** when the participant detected 60% to 90% of the As, **moderate** when the participant detected 30% to 60% of the As, and **severe** when the participant detected less than 30% of the As.

- **The Baking Tray Task** (BTT) requires clients to place 16 blocks of wood on a 50-cm x 75-cm hard-board in as symmetrical a layout as possible—as if the blocks were buns being placed on a baking tray (Tham, 1998; Tham & Tegnér, 1996). Clients without unilateral neglect do not place the blocks more skewed than 7.5 of the field and 9 in the other. In this study, the number of blocks placed on the left half of the tray was recorded and presented as a percentage of the total. The unilateral neglect was again defined as three levels of impairment: **mild** when participants distributed between 5 (32.5%) blocks and 7 (45.5%) blocks on the left side, **moderate** when the participants distributed between 1 (6.5%) block and 4 (26%) blocks on the left side, and **severe** when the participants distributed none of the blocks on the left side.
Assessment of sustained attention. Sustained attention was measured by a task in which the participants listened to an audiotape of a person reading letters aloud at a rate of 1.35 per sec (Lezak, 1983). The participants were asked to indicate, by tapping a finger or a pen, when they heard the target letter E. The duration of the test was 7 min, and it included 53 targets and 259 distractors. The number of correct answers was recorded and presented as a percentage of the total. The impairment of sustained attention was defined as mild when the participant had 84% to 90% of the answers correct, moderate when the participant had 77% to 83% of the answers correct, and severe when the participant had less than 77% answers correct.

Intervention Program
During the baseline (A1) phase (2 weeks) the participants received occupational therapy 1 hr to 2 hr a day, 5 days a week, that focused on training in self-care activities by using the participant’s available abilities and by adapting task demands and contexts (Trombly, 1995). Participants also received other rehabilitation services throughout all three phases of the study, such as physical therapy. During the intervention (B) phase (4 weeks), the focus for the occupational therapy intervention was on training awareness of disability, 1 hr to 2 hr a day, 5 days a week. After the B phase, the awareness training was discontinued, and the participants continued receiving the individualized rehabilitation services outlined in the A1 phase. Between the end of the B phase and the follow-up (A2) phase, Participant 1 (P1) stayed at the clinic, Participant 2 (P2) and Participant 3 (P3) moved to nursing homes, and Participant 4 (P4) moved to her own apartment.

During the 4-week intervention period, four different experienced occupational therapists were responsible for the intervention and were supervised by the first two authors. Purposeful and meaningful (for the participant) daily occupations were used as therapeutic change agents to improve awareness of disabilities. The activities included in the AMPS were not used in training. The intervention strategies the occupational therapists used are discussed in the following paragraphs.

Supporting the participants to choose motivating training tasks. Participants were supported in choosing training tasks that they had a strong interest in performing. For example, P1 chose to read the morning paper, P2 to prepare a “delicious” meal in the training kitchen, P3 to garden, and P4 to write postcards. The expressed motivation to perform a specific task was seen as a change agent in the therapeutic process. Through participation in meaningful occupation in a variety of occupational situations, the participants were expected to become more aware of their disabilities.

Engaging the participants in discussions. These discussions took place before and after the training tasks with the aim of enabling participants to better evaluate, describe, and plan their task performances. For example, before performance of chosen tasks, the occupational therapists asked the participants to describe their anticipated difficulties in the planned activities or encouraged the participants to link their earlier experiences of disability to new tasks and to plan how they would handle new situations. After the task performances, the occupational therapists asked the participants to evaluate and describe their performances and to think about whether they could have done the task in another way to improve their performance. Then the therapists gave different kinds of feedback about the observed difficulties. For example, P1’s occupational therapist gave verbal feedback (described to the participant her difficulties with reading and understanding the text in the left half of the page) as well as gave visual feedback (gave visual guidance to show the “neglected” text in the left half of the page). P2’s occupational therapist gave physical guidance to support P2’s understanding that she did not find some ingredients in the training kitchen. P3’s occupational therapist gave visual feedback to demonstrate that P3 did not sow seeds in the small pots placed on the left side of the table. P4’s occupational therapist gave both verbal and visual feedback to demonstrate that P4 had “forgotten” to write text in the left half of the postcard. As soon as the participants could describe their difficulties, the occupational therapists and participants discussed compensatory techniques that could improve task performance. Finally, the participant performed the task again, using the newly learned compensatory techniques.

Using the home environment. Between two and four home visits were made during which participants performed tasks they commonly had performed before their strokes, such as making coffee or tea. This familiar task was used as a means to confront the participants with their disabilities in well-known home environments. The participants were asked to compare their performances in these tasks with their performances in the same task before the onset of stroke.

Using video feedback. Because video feedback has helped clients with unilateral neglect to become more aware of their neglect behavior associated with left hemispace involvement (Söderback, Bengtson, Ginsburg, & Ekholm, 1992; Tham & Tegnér, 1997), it was used in the beginning of the intervention (B) phase to confront participants with their difficulties during performance of selected tasks. The occupational therapists chose activities during which the participants clearly exhibited their neglect behavior. For example, baking cookies or pizza was used because both a tray of cookies and a pizza have distinct left and right halves. When reviewing the video, the participants could see their failures in left hemispace on the right side of the television monitor. The occupational therapists asked the participants to describe their performances, and...
they discussed possible compensatory techniques that could be used to improve performance of the task. After the video feedback, the participants repeated the task in order to have an opportunity to apply the newly learned compensatory techniques.

Using therapeutic narratives. The participants were interviewed several times during the intervention (B) phase both to collect phenomenological data for a separate study and to have an opportunity to express, reflect on, and interpret their experiences of task performances and, therefore, heighten awareness of their disabilities.

Data Analysis

The data were plotted graphically to facilitate visual inspection (Barlow & Hersen, 1984; Kazdin, 1982). The criteria for the visual inspection were changes in level across the three phases in terms of clinically relevant or meaningful changes and stability of the data. Our criteria for a change in level for the AMPS and AAD are discussed in more detail in the following paragraphs.

Changes in ADL ability assessed by the AMPS has been shown to be significant if the change (improvement) in the ADL motor or ADL process ability between Test 1 and Test 2 is at least .5 logit (Kirkley & Fisher, 1999) and clinically meaningful if the change is at least .3 logit (Fisher, 1999). In this study, we compared the mean ability measures for each participant on the AMPS ADL Motor and ADL Process scales in the A1 phase with their mean ADL ability measures in the B phase to determine whether the changes were at least .3 logit across the two phases. Changes in awareness of disabilities assessed by the AAD were judged to be clinically meaningful if the changes were larger than 1.0 logit between the A1 and B phases. Changes in unilateral neglect assessed by the Letter Cancellation Task and the BTT were judged to be clinically meaningful if the level of impairment (mild, moderate, severe) had changed between the A1 and B phases. Changes in sustained attention were judged to be clinically meaningful if the level of impairment (mild, moderate, severe) had changed between the A1 and B phases.

Results

The results are summarized across participants. The individual results for each participant are presented separately in Figures 1 through 4.

Awareness of Disabilities

Three participants (P1, P2, P3) showed a stable baseline in awareness of disabilities in the A1 phase, and one (P4) closely approached a stable baseline. All the participants showed a clinically meaningful change (3.1 logits [P1], 2.7 logits [P2], 2.7 logits [P3], 4.0 logits [P4]) in level of mean ability (awareness of disabilities) between the A1 and B phases. Three participants (P1, P2, P4) maintained the changes in the A2 phase, and one (P3) came close to maintaining the change. In terms of awareness of disabilities, three participants (P1, P3, P4), could describe at the end of the B phase the major difficulties encountered in the performed AMPS task, although they could not describe in detail their difficulties associated with unilateral neglect and with organizing the task. One participant (P2) could describe, at the end of the B phase, some of her major difficulties in the performed task, yet she stated that she was satisfied with her ability to perform the task despite several failures during task performance.

ADL Motor Ability

On the measures of ADL motor ability, one participant (P3) showed a stable baseline in the A1 phase, and three
(P1, P2, P4) closely approached stable baselines. All participants showed significant changes (1.1 logits [P1], .5 logit [P2], .9 logit [P3], .6 logit [P4]) between the A1 and B phases. The changes were maintained in the A2 phase.

**ADL Process Ability**

On the measures of ADL process ability, three participants (P1, P3, P4) showed a stable baseline, and one participant (P2) closely approached a stable baseline. Three participants showed significant changes (1.5 logits [P1], .7 logit [P2], .7 logit [P3]) between the A1 and B phases, and one (P4) showed a clinically meaningful change of .4 logit. In one participant (P1), the change in level increased further in the A2 phase; in two participants (P3, P4) the changes were maintained; and in one participant (P2) the change was not maintained.

**Unilateral Neglect**

On the BTT, two participants (P1, P2) showed a severe unilateral neglect, and two (P3, P4) showed a moderate unilateral neglect in the A1 phase. The baselines were stable in two participants (P1, P2), almost stable in one participant (P4), and unstable in the last participant (P3). Three participants (P1, P2, P3) showed clinically meaningful changes between the A1 and B phases on the BTT, and one (P4) did not. The changes were maintained in two of the three participants (P2, P3) and closely approached maintenance in the other (P1) in the A2 phase.
In the Letter Cancellation Task, all the participants showed a severe unilateral neglect and a stable baseline in the A1 phase. Three (P1, P2, P3) showed clinically meaningful changes between the A1 and B phases, and one (P4) did not. The changes were maintained in two participants (P1, P3) and increased in one participant (P2) in the A2 phase. At the end of the B phase, two participants (P1, P3) continued to show a mild unilateral neglect, one participant (P2) showed a moderate unilateral neglect, and one participant (P4) showed a severe unilateral neglect.

Sustained Attention

Across all phases of the study, one participant (P4) showed a normal sustained attention impairment, and one (P1) showed an unstable moderate-to-mild sustained attention impairment. Two participants (P2, P3) showed an unstable and severe sustained attention impairment in the A1 phase and a clinically meaningful change between the A1 and B phases. The changes were maintained in one participant (P3), and the other (P2) closely approached maintenance in the A2 phase.

Discussion

The findings of this pilot study demonstrate that during participation in a program focused on improving awareness of disabilities, four participants with unilateral neglect became more aware of their disabilities, as measured by the AAD. In this study, the findings demonstrated that the participants' abilities to accurately describe their limitations in ADL improved. All four participants also clearly improved in their ability to perform varied ADL tasks for which they had not specifically received training during the intervention program. These findings suggest that the participants might have transferred knowledge gained from the disability awareness training tasks to the ADL tasks assessed by the AMPS. The intervention strategy of disability awareness training in clients with unilateral neglect can be seen, therefore, as a possible way to increase general ADL performance. Generalization of learning has been shown to be the most challenging task in the rehabilitation of clients with unilateral neglect (Lin, 1996; Robertson et al., 1993).

Participants P2 and P4, however, did not improve in ADL ability to the same extent as P1 and P3. It is noteworthy that P2 and P4 had a lower level of awareness of disabilities than did P1 and P3 in the A1 phase, which may have made it more difficult for P2 and P4 to learn to use compensatory techniques in tasks for which they had not specifically received training. This finding is consistent with Crosson et al.'s (1989) view that persons with brain damage need to have a high level of awareness to be able to use compensatory techniques and that persons cannot apply compensations for which they do not have the prerequisite level of awareness.

The findings indicate that training in awareness of disabilities in daily activities may be a fruitful therapeutic agent not only to improve occupational performance, but also to remediate impairments like unilateral neglect and impaired sustained attention in some persons. Three participants (P1, P2, P3) showed a clinically meaningful decrease in their unilateral neglect between the A1 and B phases, and two participants (P1, P3) showed a clinically meaningful improvement in sustained attention. Although impaired sustained attention has been shown to be a possible reason for the inability to learn and use compensatory techniques among clients with unilateral neglect (Robertson, 1990), a clear relationship among impaired sustained attention, unilateral neglect, and ADL ability across the different phases was not found. This finding suggests that improved occupational performance may occur...
Despite persistence of impairments thought to be the underlying cause.

In this pilot study, a single-case experimental design provided us with detailed information about each participant’s impairments, disabilities, and changes during the described rehabilitation process. It was limited, however, by having only four participants. These results, therefore, cannot be generalized to a larger population of clients with unilateral neglect.

The fact that data collection started early during rehabilitation was another limitation because the possibility for concurrent spontaneous recovery was high. When spontaneous recovery is an issue, a multiple baseline design across subjects, in which individual participant’s baselines vary in length before moving into the intervention phase, might have been more appropriate (Barlow & Hersen, 1984; Kazdin, 1982). Nevertheless, in this pilot study, a stable baseline across subjects suggests that the intervention program resulted in positive effects with respect to awareness of disabilities and performance in ADL. The design was also a strength in that it provided these participants with an early opportunity to become engaged in their own rehabilitation. The clinical reality of the study setting also influenced our design with respect to the limited number of “probes” per phase. Although there was a risk for practice effects on the different tests, we believed these risks to be minimal.

The BTT probably also is insensitive to practice effects because there is no simple way to memorize the outcome from earlier trials (Tham & Tegnér, 1996).

There is a lack of performance-based assessments of awareness of disabilities, that give valid and reliable information about how persons with disabilities perceive and describe their disabilities (Gage, Noh, Polatajko, & Kaspar, 1994). Therefore, it was necessary for us to construct a new assessment for the purpose of this study—the AAD (Tham et al., 1999). The AAD needs to be evaluated further, however, in future studies to ensure that it is a valid and reliable measure of awareness of disabilities.

The awareness training program focused on using intervention strategies that were individualized to meet each participant’s needs and abilities in the context of everyday life. The role for the occupational therapists was to guide the participants to better know their disabilities and to teach and guide them to solve problems and to use compensatory techniques in meaningful daily occupations. The study did not yield understandings about the relative benefits of each of the five separate intervention strategies used in the program.

Further research is needed to verify the effects of intervention focused on awareness of disabilities in clients with unilateral neglect. Future controlled studies could also contribute to the body of knowledge about different types or levels of awareness and compensatory strategies. It seems important for occupational therapists to gain more knowledge of how therapeutic occupation (Fisher, 1998, 1999) can be used as a change agent to improve awareness of disabilities and how such intervention may influence occupational performance in clients with brain damage.

Acknowledgments

We thank the occupational therapists at the clinic that made this study possible and Hans Jonson for technical support. The research was funded by The University of Health Sciences, Stockholm, Sweden, and the NVV, Karolinska Institutet, and The Vardal Foundation, Sweden. This study is included in the first author’s doctoral dissertation.

Appendix

Assessment of Awareness of Disabilities

Test Items (Questions)

1. How do you think you managed to perform the task compared with how you used to do it at home before you had your stroke?
2. Can you describe whether you experienced any specific difficulties during the performance (in specific steps of the task)?
3. Can you describe whether you needed to do the task in a new way compared with how you used to do it at home?
4. Can you describe how you managed to use your left and right hand in this task? Did you have any difficulties?
5. Can you describe how you managed to move or transfer your body during the task performance (stand, walk, or use the wheelchair)? Did you have any difficulties?
6. Did you have any difficulties in remembering what you should do, how you should organize the task, or how to do the steps in the right order?
7. Did you have any problems in seeing, finding, or locating the objects you needed to use in the task?

Scoring

4 = The client has a completely realistic opinion about his or her disabilities (can exactly describe his or her difficulties in the Assessment of Motor and Process Skills task).
3 = The client has a realistic opinion about his or her disabilities in general but cannot describe his or her difficulties in detail.
2 = The client has a somewhat unrealistic opinion about his or her abilities (overvalues his or her abilities or underestimates his or her disabilities).
1 = The client has a very unrealistic opinion about his or her abilities (overvalues his or her abilities very much or underestimates his or her disabilities very much).
0 = The client completely denies his or her disabilities.

References


