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Development of Cognitive Retraining Module for Cancer and Alzheimer's Patient

Ms. Kanika Khandelwal[1*], Dr. Akhilesh Kumar Misra[2]

[1*]PhD Scholar, Department of Clinical Psychology, Faculty of Behavioural and Social Sciences, Shree Guru Gobind Singh Tricentenary University Gurugram, Delhi-NCR kanikakhandelwal52@gmail.com/ 8376893353, ORCID ID: 0000-0003-4340-5158

[2]Professor, Department of Clinical Psychology, Faculty of Behavioural and Social Sciences, Shree Guru Gobind Singh Tricentenary University Gurugram, Delhi-NCR

***Corresponding Author:** Ms. Kanika Khandelwal

*PhD Scholar, Department of Clinical Psychology, Faculty of Behavioural and Social Sciences, Shree Guru Gobind Singh Tricentenary University Gurugram, Delhi-NCR kanikakhandelwal52@gmail.com/8376893353 ORCID ID: 0000-0003-4340-5158

ABSTRACT

Introduction: The risk for non-communicable disorders (NCD) are increasing among adults. The prevalence rate of non-communicable diseases is high in India. These patients often suffer from cognitive decline along with physical and psychological issues during the illness. To manage cognitive dysfunction among chronic illness, Cognitive Retraining Therapy (CRT) have been emphasized by the professionals.

Aim and Methodology: The present study aims to develop cognitive retraining module for patients with cancer and Alzheimer's disease (AD). Several search engines were used for the identification of the literature. Original studies, research articles, randomized controlled trials done in last 20 years were selected for the review. PRISMA guidelines were used and related literature was analyzed by the reviewer and included in the data synthesis. Based on the review, module was developed and further validated by the experts in the field of neuropsychology, psycho-oncology, clinical psychology and geriatric psychology.

Summary of Results: Current cognitive retraining module focused on attention, executive and memory function of cancer and Alzheimer patients. About seventy activities based on the above domains were included in the module. Each activity took 15-20 minutes, graded level of difficulty, paper-pencil mode with emphasis on verbal and visual modality.

Implications: Cognitive retraining module is non-pharmacological, manualized and culturally appropriated intervention for patients with cancer and Alzheimer's disease.

Keywords: *cognition retraining, dementia, cancer*

INTRODUCTION

Cancer and Alzheimer's Disease (AD) are major non-communicable diseases (NCDs). The age range between 65 to 70years showed high Disability Adjusted Life Years (DALYS) in India and globally (Kulothungan et al., 2022; Lee, 2023). The escalating cases of cancer survivors and AD tend to create problems such as poor physical health, cognitive impairments, high caregiver burden and low quality of life (World Health Organization, 2018). Globally most cancer and AD cases take place in developing countries where high-risk individuals have limited post-treatment rehabilitation services (Thomas, 2024). Post covid, the emergence of telemedicine and telerehabilitation has been a new step towards patient care in India. This step has encouraged tertiary care setups to include family-based interventions in their primary treatment. Still, it is a challenge for individuals who reside in rural areas of our nation and get access to rehabilitation services that are familiar and more readily accessible in the cities of the country (Sreelakshmi, 2022). The patients with cancer or AD tend to have limited access to rehabilitation services especially cognitive retraining during their management phase.

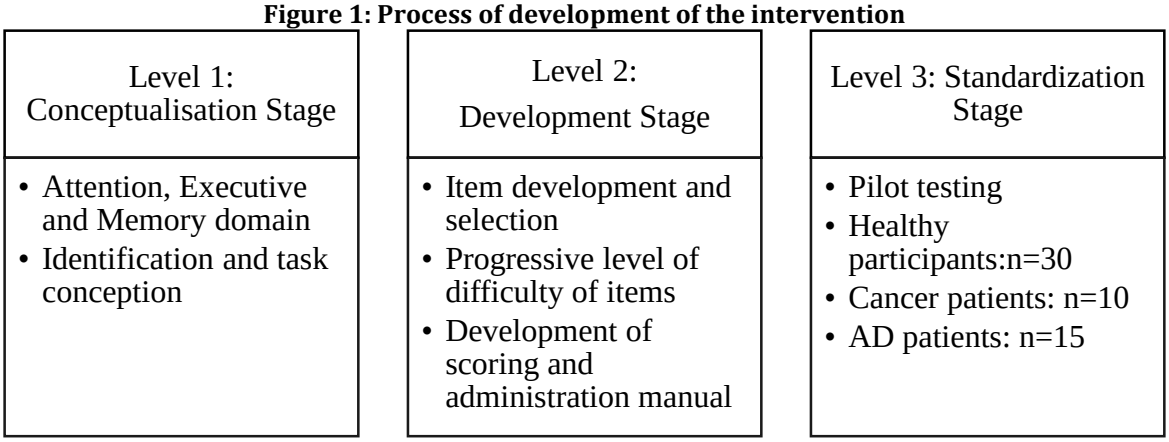
In both the illnesses the patient not only suffer from physical deficits but also from cognitive impairment which ranges from mild to severe conditions such as dementia. Dementia is diagnosed based on acquired cognitive impairment. The development of this disorder is progressive, meaning it starts slowly and gradually impacts the psychosocial functioning of an individual (Kao, 2023). Post treatment care focus on physical and psychological health. The primary focus is on pharmacotherapy and psychotherapy and thereby minimises the scope of other healthcare professionals such as neuropsychologists, occupational therapists and speech-language therapists (Bamfod, 2021). Usually, patients and their caregivers have limited or no information about post-treatment rehabilitation services. Moreover affordability and accessibility of such

services are challenging in most parts of the developing countries. Hence, they act as an obstacle to rehabilitation services (Kamalakannan et al., 2016). The involvement of family members in providing rehabilitation services, especially cognitive retraining has been lacking in our system (Gulati, 2018). There is a need to create caregiver-delivered services for the patients and their family members in developing countries. The current paper focuses on the development, validation and feasibility of a home-based caregiver-delivered cognitive retraining emphasizing on attention, executive functions and memory deficits in cancer and AD patients.

SUBJECTS AND METHODS

The intervention module was developed as a part of a doctoral thesis with approval from Institute Ethics Committee. The cognitive retraining module was developed in the following process as evident in Figure 1.

Figure 1: Process of development of the intervention



Level 1: Conceptualisation of the intervention

In the first phase, extensive theoretical and empirical review and focused group discussions (FGDs) were used as a reference to develop exercises and tasks for cognitive retraining. The FGDs comprised of four moderators (two professors in clinical psychology and one professor in neurology, one professor in oncology) and four clinical psychologists (who were not directly related to the study). Inputs were taken from the experts in the area of neuropsychology and psycho-oncology (professors in cognitive rehabilitation, dementia, cancer, rehabilitation). An open-ended interview was conducted which was facilitated by the researcher. The exercises were selected on three points: a) Relevance of the tasks (b) Validity of the tasks and (c) Applicability of the tasks with the target population (Bajpai et al., 2020).

Level 2: Development of the intervention

The module was developed as follows: a) development of the outline, b) construction of the items, c) evaluating the items, d) conducting a task analysis, e) administration of the training on healthy controls (HCs), f) analysing data from HCs, g) revising and reviewing items, h) rearrangement of exercises based on difficulty level, and i) administering the training on patient group (Chopra et al., 2020).

Item development and selection

The frequently occurring deficits are memory, executive function and attention that were emphasised in the development of the module. The memory component included structured exercises such as face-name recall, object recall, word association, letter fluency. The executive component included structured exercises such as verbal fluency, mazes, spot the difference. The attention component included connecting the dots, cancellation.

It was based on a current review of literature that emphasises the role of structured psychological care and provides strategies that can maximise the quality of life of an individual. Psychotherapy, awareness program, behavioural activation, active participation and empathetic communication were used in every session with the cancer and dementia and their caregiver. The intervention was based on specific, measurable, attainable, realistic and timely (SMART) goals (Wilson, 2009).

The items for the stimulus in the intervention consist of verbal and nonverbal tasks that were selected on familiarity, culturally appropriate and usage of that item in day-to-day life. After extensive review, the tasks and items which were relevant and suit the demand of the domains to be targeted were selected as evident in Table 1.

Table 1: Domain-wise tasks used in the intervention

Domain	Module	Task	Principle
Attention	Module 1	1. Cancellation 2. Spot the difference	Visual scanning
Executive function	Module 2	1. Verbal fluency 2. Maze 3. Mental maths 4. Rearrange the story	Categorisation Planning Working memory Organisation
Semantic & episodic memory	Module 3	1. Picture-recall task 2. Draw geometric shapes 3. Match the pairs (Similar) 4. Object recognition	Mental imagery Top-down processing Association Spaced Retrieval

Principles of the intervention

The difficulty of the tasks was increased at two levels. First, at the content level and second at the number of items in the task. At the content level, the exercises in the module were depended on cognitive load theory. This theory states that brain can store information within limit and simultaneously it tend to process the same and these factors help in the storage of information (Sweller, 2011). The cognitive exercises were sorted in hierarchical manner. It was arranged on the basis of ambivalence, information, high concentration of stimulus. The practice will be spaced out over time. This spaced practice will improve attention, concentration, problem-solving, learning new information. Therefore, repetition trail in memory tasks was used. Stimulus information is presented repeatedly so that individual can retain the information and produce when given cue (Kang, 2016; Finn et al., 2015). The rehearsal learning was used in verbal tasks which help in better learning of stimulus. Consequently, stimuli are encoded and retrieved more effectively. Errorless learning method, vanishing cues, accumulating cues and face-name matching were some of the techniques that were used for retraining. (Sholberg et al., 2001; Middleton, 2012).

Development of administration manual and scoring

The module was developed in the form of worksheets with an administration guide having standard operating procedures so that it can be delivered by the caregiver after training [Table 1]. It has 3 modules, equivalent to 70 worksheets for 10 weeks of home-based exercises for the different domains. A summary of each domain for the retraining has been given in Table 1.

All the exercises in the workbook were scored on the basis of time taken to complete each exercise and the number of errors done while finishing the exercise. Total time for each trail is defined as the total time taken to identify the right item or time taken to reach the correct response. The total number of errors and correct responses were calculated for each task for each day. Then the final score was plotted on graph. It gave the overview of the improvement in the patient. It helped in analysing the progress or decline of the patient during cognitive retraining. After finalising the exercises that were based on principles of cognitive psychology, the procedure to administer each task was conceptualised for the both caregiver and participant in Hindi and English language. The psychological factors were not scored as it included basic counselling and supportive sessions.

Level 3: Standardization of the intervention

After the development of the interventional domains, tasks and its internal components, it was proceeded for preliminary testing on HCs, CS and ADs.

- Healthy Controls (HC): The healthy participants were between the age of 45-70 years, with education upto 10th and above, any gender, monolingual, bilingual and with no previous history of any major neurological and psychiatric disorder.
- Cancer Survivors (CS): Clinically diagnosed with Non-Central Nervous System Cancer, either stage 1/stage2/cancer survivors, both gender, age between 45-70 years, can read and write and no major psychiatric or neurological disorder.
- Alzheimer's Disease (ADs): Early-stage AD as per NINCDS criteria, age between 45-70 years, both gender, education upto 10th and above, can read and write.

CS and ADs were included in this step to examine the feasibility of the conceptualised tasks. The time taken and errors committed by HCs were recorded for arranging the exercises for each domain to maintain increasing difficulty order.

The developed retraining was later validated on 10 CS and 15 ADs using a pre-post assessment to ascertain the feasibility of the developed intervention to be used as a home-based caregiver-delivered program. The abovementioned inclusion and exclusion criteria for CS and ADs were followed. The pre-post assessment was done using the ICMR-Neurocognitive ToolBox (ICMR-NCTB) which included 3 domains, such as, attention, executive functioning and memory (Verman et al.,2021). Here the scores are expressed in terms of percentile. But in the current study we have taken raw scores and

compared it with post-assessment results. Geriatric Depression Rating Scale (GDRS) was used (Burke et al.,1991). The scores are expressed as raw score.

Delivery of the intervention

The retraining was developed as a 10-week home-based cognitive retraining which was provided along with the standard of care treatment based on standard operating procedures (SOPs). The duration of each session with the researcher for the experimental group lasted for 30 minutes. The only prerequisite for the intervention was that the caregiver should be a primary care provider who stays with the patient and was willing to accompany the patient in all the retraining sessions. The caregivers were given the training session once a week for about 60 minutes where they had to observe the tasks being done by the researcher and perform them in front of the researcher.

Follow-up

The CS, ADs and caregivers have to maintain a weekly follow-up for a minimum of 10 weeks, i.e., once a week for 10 weeks. At each follow-up, the tasks were introduced based upon the performance and adherence to CS and ADs. The performance and adherence to the intervention were assessed by evaluating the time taken and errors committed by the CS and ADs on each task for each domain. Based on the successful completion of the tasks after attaining the ceiling effect, new tasks were introduced in the following week.

RESULTS

As evident in Table 2, there was no significant difference in sex and education between HCs, CS & ADs. However, on age variable, there was a significant difference between the groups. For HCs, maximum number of participants (33%) were in 50-59 years, followed by 23% participants in 60-69 years; followed by 20% participants fall within 70-79 years. Similarly in CS group, maximum number of participants (40%) were between 40-49 years of age, followed by 30% in 60-69 years. Similarly, ADs group, the maximum number of participants (40%) fall between 60-69 years of age, followed by 27% in 70-79 years of age. This showed that CS and ADs groups had cognitive deficits than healthy group from early age. Therefore, intervention tasks were all pictures based where education and age have no role in study outcome. Therefore, literacy and age are unlikely to be confounding factors.

Table 2. Comparison of the baseline socio-demographic characteristics between healthy control group (HCs), cancer survivors group (CS) and Alzheimer's disease group (ADs).

Variables		HCs (n=30) f (%)	CS (n=10) f (%)	ADs (n=15) f (%)	p value
Age (years)	40-49 50-59 60-69 70-79 80-89	2 (7) 10 (33) 7 (23) 6 (20) 5 (17)	4 (40) 2 (20) 3 (30) 1 (10) 0 (0)	0 (0) 2 (13) 6 (40) 4 (27) 3 (20)	0.01*
Sex	Male Female	12 (40) 18 (60)	3 (30) 7 (70)	7 (47) 8 (53)	0.71
Education (years)	10-12 >13	13 (43) 17 (57)	5 (50) 5 (50)	3 (20) 12 (80)	0.22

*The level of significance was tested at 0.05 level.

Attention domain

As evident in Table 3, for HCs group, the time ranged from 148.3 to 54.1 seconds, while for the CS the time ranged from 107.5 to 63.4 and for ADs the time ranged from 272 to 106 seconds which was higher than the time taken by HC. For all three groups, the progressive difficulty was maintained throughout the ten weeks. In addition to this, there was a large difference between the medians of HCs, CS and ADs throughout the ten weeks. For HCs at the first week, the middle quartile was at 129 seconds whereas the middle quartile for ADs was at 251 seconds and middle quartile for CS was at 78 seconds. The time difference of 51 & 122 seconds between HCs, CS and ADs at the first week suggested that the items of the intervention were sensitive enough to detect the change between the HCs, CS and ADs responses. While on the 8th week, for HCs, the middle quartile was at 93 seconds whereas CS middle quartile was at 38 seconds and ADs middle quartile was at 35 seconds. The time difference between HCs, CS and ADs reduced to 55 & 58 seconds which indicated that intervention has significant improvement in attention ability of CS and ADs.

Table 3. Comparison of the progressive difficulty of the attention domain of the intervention between healthy control group (HCs), cancer survivors group (CS) and Alzheimer's disease group (ADs) by using mean time taken in seconds.

Group	Week 1	Week 2
HCs n=30	148.3±58.3	54.1±24
CS n=10	107.5±76.0	63.4±31
ADs n=15	272±77.4	106±61

Values are expressed as mean ± standard deviation.

Executive function

As evident in Table 4, the trend of time taken by HCs remained same, for CS it reduced drastically and for ADs the time taken increased with each week which was attributed to the progressive difficulty of the tasks. For HCs group, the middle quartile decreased in the first three weeks, but at sixth week it heightened. For ADs group, the distribution of time taken was fluctuating. It can be attributed to the progressive difficulty of the tasks. For CS group, middle quartile decreased by the second week and increased in third week and eventually remained stable thereafter. The median heightened by the end of sixth week and came parallel to HCs median value. Such trend was attributed to the interventional effect on the executive function domain.

Table 4. Comparison of the progressive difficulty of the executive functions domain of the intervention between healthy control group (HCs), cancer survivors group (CS) and Alzheimer's disease group (ADs) by using mean time taken in seconds.

Group	Week 3	Week 4	Week 5	Week 6
HCs n=30	83.5±10.2	63.5±26	91.2±46	81±25.5
CS n=10	60±0	68.2±81.3	30.2±15.2	22±22.0
Ads n=15	133.5±43.1	93.3±42.0	148±56.2	152.5±60.2

Values are expressed as mean ± standard deviation.

Memory domain

As evident in Table 5, the comparison of the time taken by the HCs, CS and ADs was found to be progressive in nature. Time taken by ADs group to complete the tasks was six times more than HCs group and CS group completed the tasks faster than the HCs group. It can be due to significant difference in age variable. As participants in their 40s-50s could perform better than people in their late 60-70s. For HCs and ADs group, the middle quartile was flatulating. It can be due to progressive difficulty of the tasks. For CS group, the middle quartile remained stable. There was a large difference between the medians of HCs and ADs in the seventh week but by tenth week, both groups showed minimal difference in time taken to complete the tasks. Moreover, CS group remained stable throughout this week. It showed that memory domain was relatively better in this group than others. Moreover, the efficacy of the intervention helped the ADs to attain the level of HCs group.

Table 5. Comparison of the progressive difficulty of the memory domain of the intervention between healthy control group (HCs), cancer survivor group (CS) and Alzheimer's disease group (ADs) by using mean time taken in seconds.

Group	Week 7	Week 8	Week 9	Week 10
HCs n=30	630±96	129±59	58±12	11±40
CS n=10	28±38	56±36	86±47	77±29
Ads n=15	571.5±47	164±23	65±36	75±46

Values are expressed as mean ± standard deviation.

DISCUSSION

There is high prevalence and incidence rate of cancer and dementia patients worldwide. It tend to increased the financial and psychological burden worldwide. The co-occurrence of cognitive deficits in cancer and dementia patients impacts their course of rehabilitation and recovery.

The current retraining was developed with an aim to focus on cognitive deficits during the process of rehabilitation. The retraining was developed for the urban and rural population of India. It is beneficial,

easy to understand, use and score. In rehabilitation setups, there are scarcity of manpower and resources, therefore home-based caregiver facilitated rehabilitation services are recommended. Therefore caregivers become the important pillar in it. The pilot study has shown fairly promising results and good feasibility of the retraining in cancer and dementia patients, specifically in the areas of attention, executive function and memory. This method of home-based caregiver-delivered intervention thus will help develop the neuropsychology continuum of the healthcare model (Nehra, 2019).

Cognitive functioning: The present intervention includes exercises with an aim that training should be conducted within natural communication environments. It included exercises for attention, executive functions and memory. The tasks included sustained attention, planning, organisation, remembering, recalling. Weekly stimulation on attention, memory, language and orientation can potentially be useful for Alzheimer's disease treatment, not only slowing the disease progression but also improving cognitive functions and performance on ADL (Bottino et al., 2005). Patients treated with cognitive retraining showed improvements in visuospatial memory, verbal memory, and sustained attention (Lakshmi, 2019).

Need for home-based intervention: Though it is highly recommended to provide specialised rehabilitation services for a favourable outcome, cancer and dementia patients provided rehabilitation includes a multidisciplinary team with inputs from oncologist, neurologists, psychiatrist, physiotherapist, palliative nursing, neuropsychologists, speech and language and occupational therapist (Pauranik, 2019). This intervention comes as a promising alternative in situations where specialised conventional rehabilitation programs and professionals are unavailable. In such cases, medical, paramedical and nursing staff can be trained to facilitate the intervention. Results from previous studies that have used family-led interventions have emphasised on the need to incorporate behavioural change theories while developing such caregiver-based intervention (Lindley, 2017; Janagama, 2017). In India, the home-based caregiver led rehabilitation comes as a promising rehabilitation intervention for cancer and dementia patients where the daily costs of caregiving add to the financial burden of non-communicable diseases in India.

From India, home-based rehabilitation has been used and have generated positive research outcomes in favour (Chopra, 2018), early Alzheimer's diseases (Bajpai, 2020) and other neurological and psychiatric conditions (Rajeswaran, 2012). The use of this developed intervention for cancer and dementia have shown promising results to be used as a home-based caregiver-led intervention which is cost-effective (Stewart et al., 2017; Sandman, 1993; Lakshmi, 2019).

To test the further efficacy of the intervention, a formal randomised clinical trial has been conducted taking into account the effectiveness, fidelity, estimates of recruitment and retention effects of using cognitive retraining as a home-based caregiver-led intervention in comparison to he standard medical care. Nonetheless, future longitudinal research with a larger sample size will evaluate the efficacy of the intervention and assess the acceptability and feasibility of the intervention for the rural and urban population.

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Conflicts of Interest: None

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