

Outcomes of a multimodal cognitive and physical rehabilitation program for persons with mild dementia and their caregivers: a goal-oriented approach

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Background: Nonpharmacological interventions such as exercise and cognitive rehabilitation programs have shown promise in reducing the impact of dementia on the individual and the caregiver. In this study, we examine the effect of a multimodal cognitive and physical rehabilitation program for persons with mild dementia and their caregivers using conventional measures of cognition, behavior, quality of life (QoL), and caregiver burden together with goal attainment scaling (GAS), an individualized outcome measure.

Methods: Goals were set at baseline, and GAS score was calculated at the end of the program. Participants were also assessed with the Chinese Mini-Mental State Examination, functional and behavioral scales (Barthel Index), Instrumental Activities of Daily Living, Neuropsychiatric Inventory Questionnaire, QoL, and caregiver burden using EuroQoL-five dimension questionnaire and Zarit Burden Interview (ZBI). Differences in median scores postintervention were obtained. Further analysis of caregiver burden was undertaken utilizing the multidimensional classification of burden on the ZBI.

Results: Thirty-four (61.8%) patients were assessed to have met their goals (GAS score ≥ 50). Mean (standard deviation) GAS score was 48.6 (6.5). Cognition goals were set in only 20.6%, followed by goals to improve engagement and socialization; reduce caregiver stress; and improve physical function, behavior, and mood. Median scores in the cognitive, functional, and QoL measures did not differ significantly pre- and postintervention. The intervention had a positive impact on role strain, a unique dimension of caregiver burden.

Conclusion: This study provides evidence that a multimodal approach combining physical exercise and cognitive rehabilitation improves goal attainment and caregiver burden in individuals and caregivers of persons with mild dementia.

Keywords: dementia, rehabilitation, goal attainment scaling

Introduction

As the number of persons living with dementia increases, there is a need to develop effective interventions for Alzheimer's disease (AD). The fact that no new AD drug has been approved since 2004¹ underscores the importance of interventions aimed at improving the quality of life (QoL) of people living with dementia and the support given to their caregivers.² To this end, various nonpharmacological approaches have been employed, such as physical exercise and cognition-focused interventions. A growing body of literature suggests that exercise has a positive effect on cognition.³ Cognitive rehabilitation is another modality of treatment that focuses on finding strategies to maintain or cope with memory impairment, with the aim of decreasing

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functional disability and maximizing social participation and engagement in activities of daily living (ADL).⁴

The impetus for this study is twofold. While there are studies evaluating the effects of individual interventions, less evidence exists on multimodal nonpharmacological approaches.⁵ In particular, the impact of exercise programs and cognitive interventions on caregiver burden is less well defined. Second, in dementia trials, there is a need to utilize instruments that are able to capture clinically important treatment effects. Drug trials have traditionally pursued cognitive and functional ability-based end points, in part owing to regulatory fiat as the US Food and Drug Administration still requires the demonstration of efficacy in cognitive and functional domains.⁶ A four-point change in the Alzheimer's Disease Assessment Scale-Cognitive Subscale⁷ is held to be a criterion for clinical significance, but the justification for this threshold is debatable.⁸

Isolated cognitive instruments or global measures that approximate an overall level of impairment may not adequately reflect treatment effects that are important to an individual and caregiver. A different approach may thus be required to shift the focus to clinically relevant outcomes. Goal attainment scaling (GAS) is an individualized approach to measure clinical outcomes that was first introduced by Kiresuk et al⁹ for evaluating community mental health programs. It is a process of defining individual treatment goals at the outset and monitoring for goal attainment. Goals are comparable as results can be summarized using a formula. GAS provides the means for comparing individuals at various stages and presentations of disease, and is adaptable across different populations and interventions, as shown in trials of antedementia drugs^{10,11} and cognitive rehabilitation.¹²

Our primary aim is to evaluate the efficacy of a multidisciplinary cognitive and physical rehabilitation program for elderly persons with mild dementia using conventional measures of cognition, functional performance, behavior, QoL, and caregiver burden, together with an individualized, goal-oriented approach to measuring outcomes using GAS.⁹ The secondary objective is to study the effect of such an intervention on caregiver burden, highlighting the specific dimensions of burden relevant to caregivers of persons with dementia.

Methods

Study participants

This is a prospective observational cohort study involving community-dwelling elderly persons with mild dementia attending the MINDVital rehabilitation program in the outpatient Geriatric Clinic, Tan Tock Seng Hospital, Singapore, between June 2012 and March 2014. Participants were excluded if

they did not have a caregiver. Enrollment in the program was based on referral by the participant's attending geriatrician, with participation being voluntary. Mild dementia was defined according to the *Diagnostic and Statistical Manual of Mental Disorders*, Third Edition, Revised criteria. Dementia etiology was assigned using the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association criteria for AD,¹³ and the International Workshop of the National Institute of Neurological Disorders and Stroke-Association Internationale pour la Recherche et l'Enseignement en Neurosciences¹⁴ criteria for vascular dementia (VaD). Participants with non-AD or non-VaD diagnoses or with mixed etiology were classified under the category "others". Ethics approval was obtained from the National Healthcare Group Domain Specific Review Board for a retrospective data review.

MINDVital

MINDVital is a multidisciplinary rehabilitation program comprising once-weekly group therapy sessions, each session lasting 3 hours over 8 consecutive weeks. To ensure that each participant receives individualized attention, group sizes were limited to ten participants. A trained nurse coordinator on-site provides overall supervision, and sessions are facilitated by a multidisciplinary team of physiotherapists, occupational therapists, and psychologists.

All participants and their caregivers attend a brief interview at the beginning of the program to define their individual treatment goals. Each weekly session includes the following activities, with scheduled breaks between: 1) 45-minute multicomponent physical exercise program of light aerobic exercises, range of motion and resistance exercises, as well as balance training; 2) 1-hour cognitive stimulation and rehabilitation with social and mental activities such as reminiscence therapy; and 3) 30-minute tailored individualized activities delivering person-centered care.

Regular feedback on progress is provided to the participant and caregiver in the form of a progress card during the program, with advice to continue the learned activities at home between therapy sessions. At the end of the program, goal attainment is reviewed and scored.

Measures

Assessment measures

Participants were assessed pre- and postintervention with the cognitive scale Chinese Mini-Mental Status Examination,¹⁵ functional and behavioral scales using the Barthel Index,¹⁶ Instrumental Activities of Daily Living,¹⁷ Neuropsychiatric

Inventory-Questionnaire (NPI-Q),¹⁸ QoL and caregiver burden using EuroQoL-five dimension questionnaire¹⁹ and Zarit Burden Interview (ZBI).²⁰

To further explore the different domains of caregiver burden that may impact on QoL, we used four subscales of the ZBI as identified in our previous study:²¹ factor 1 – demands of care and societal impact on caregiver (role strain); factor 2 – confidence or control over the situation (role strain); factor 3 – psychological impact on caregiver (personal strain); and factor 4 – worry about caregiving performance.

GAS

GAS is a clinimetric measure that evaluates treatment effects relevant to an individual.⁹ It is a process of defining individual treatment goals at the outset and monitoring for goal attainment. Goals are comparable across individuals and populations as the results can be summarized using a formula.

The process of goal setting begins at the initial interview with the participant and their caregiver, which first involves the identification of issues that will be the focus of treatment. The identified problems are then translated into goals, without restriction on the types of goals that can be set. The next step is to specify the expected level of outcome of the intervention for each goal, where possible outcomes are much less than expected (–2), somewhat less than expected (–1), expected (0), somewhat better than expected (+1), or much better than expected (+2). The criteria for scoring at each level are determined in an observable way and described specifically. Participants are reviewed at the end of the intervention and scored on the basis of this continuum of possible outcomes. Follow-up assessment of goal attainment involves a summary GAS score, which is converted to a standardized T-score via the formula presented in Table 1. A GAS score of 50 is, by definition, an indication of overall goal attainment at

Table 1 Goal attainment scaling formula and sample of goal setting

$$T = 50 + \frac{10 \sum w_i x_i}{\sqrt{(1-\rho) \sum w_i^2 + \rho (\sum w_i)^2}}$$

Where x_i represents the attainment score for each goal (a value from –2 to +2), and w_i represents the weight assigned to a particular goal. As goals in this study were unweighted, $w_i = 1$. ρ -value reflects the expected correlation of attainment scores, which is assumed to be 0.30. In practice, the GAS T-score can be directly obtained from a summary score conversion table,⁹ doing away with the need for manual calculations

Domain	Current	Goal	8-week review
Cognition (reality orientation with cues, eg, clocks, calendar)			
Self-initiated reality orientation >1 time daily (+2)			
Self-initiated reality orientation 1 time daily (+1)			
Caregiver-initiated reality orientation >1 time daily (0)		✓	✓
Caregiver-initiated reality orientation 1 time daily (–1)			
Not oriented, no reality orientation (–2)	✓		
Carer stress			
No carer stress (+2)			
Very occasional, <1 time a month (+1)			✓
Minimal stress (0)		✓	
Moderate stress (–1)	✓		
Extreme stress, not coping (–2)			
Engagement in leisure activities (watercolor painting and Chinese calligraphy)			
Leisure activities for 30 minutes daily (+2)			
Leisure activities for 30 minutes >3 times a week (+1)			✓
Leisure activities for 15 minutes >3 times a week (0)		✓	
Leisure activities for 15 minutes <3 times a week (–1)	✓		
No initiation of activities (–2)			
Sleep			
Sleep 6–8 hours a night (+2)			
Sleep 4–5 hours a night (+1)			
Sleep 2–3 hours a night (0)		✓	
Sleep less than 2 hours a night (–1)	✓		✓
No sleep (–2)			

Note: ^aData from Kiresuk et al.⁹

Abbreviation: GAS, goal attainment scaling.

the expected level. Scores greater than 50 indicate a better-than-expected outcome, and scores less than 50 indicate a less-than-expected outcome.

Examples of GAS for cognition, caregiver stress, engagement in leisure activities, and sleep goals are shown in Table 1. For carer stress, if a goal was set at the level of “minimal stress”, then a score of 0 was assigned, indicating the expected outcome. At the end of 8 weeks, if the goal was exceeded as described “very occasional, <1 time a month”, then a score of +1 would be obtained, and +2 if the goal of “no carer stress” was achieved. Scores of -1 or -2 were given at described levels below the expected outcome.

Statistical analysis

Descriptive data are presented as mean \pm standard deviation (SD) or median (interquartile range, IQR) for quantitative variables, and as absolute and relative frequencies for categorical variables.

The Wilcoxon signed-rank test was used to compare cognitive and functional performance, neuropsychiatric symptoms, QoL, and caregiver burden including the four-factor structure of the ZBI pre- and postintervention. Effect sizes were calculated as an index of responsiveness of the outcome measures used in this study. Cohen's d was used to obtain effect size estimates for GAS scores, calculated by dividing change in scores by pooled SD (population standard deviation).²² For nonparametric data, effect size estimates r were calculated with the formula $r = z/\sqrt{N}$ using the z score of the Wilcoxon test and N , the total number of observations.²³

Correlation between GAS scores and other assessment measures was calculated using Spearman rank correlation coefficients. Statistical analyses were performed using IBM SPSS Statistics for Windows, Version 20.0 (IBM Corporation, Armonk, NY, USA; 2011). Statistical significance was taken to be $P < 0.05$.

Results

This study included 55 participants, with a mean age of 79 ± 6.3 years. Forty-six percent of the participants were female. All the participants were diagnosed with mild dementia, and the etiology of dementia was AD in 65%, VaD in 13%, and mixed in 22% of the participants. Approximately 69% of the participants were on cognitive enhancers (cholinesterase inhibitors or memantine) for the duration of the intervention. The mean number of years of education was 9 ± 5 . Table 2 shows the main characteristics of the study participants.

Table 2 Participant baseline characteristics (n=55)

Characteristic	Value
Age, mean \pm SD	79.2 \pm 6.3
Female, n (%)	25 (46)
Years of education, mean \pm SD	9 \pm 5
Cognitive enhancers for dementia, n (%)	38 (69)
Etiology of dementia, n (%)	
Alzheimer's disease	36 (65)
Vascular dementia	7 (13)
Others	12 (22)
Median scores (interquartile range)	
CMMSE	18 (15–21)
Barthel Index	100 (95–100)
IADL	11 (7–15)
EQ-5D	5 (5–5)
NPI-Q severity	2 (1–4)
NPI-Q caregiver distress	1 (0–3)
ZBI	16 (9–29)

Abbreviations: SD, standard deviation; CMMSE, Chinese Mini-Mental State Examination; IADL, Instrumental Activities of Daily Living; EQ-5D, EuroQoL-five dimension questionnaire; NPI-Q, Neuropsychiatric Inventory Questionnaire; ZBI, Zarit Burden Interview.

The average number of goals set by the participants and their caregivers was 2.6. Cognition goals were most frequently identified, but comprised only 21% of all the goals set. The next most common goals identified were aimed at improving engagement and socialization, followed by caregiver stress, physical function, behavior, mood, and sleep. Unmet cognition goals were most frequently observed. Figure 1 shows the different goals set and proportion of goals attained.

Overall, the mean GAS score postintervention was 48.6 ± 6.5 . Sixty-two percent of participants met or exceeded their goals at the end of the intervention, as defined by a GAS score of 50 and above. Ninety-six percent of goals to increase engagement and socialization and 94% of goals to improve mood were met, followed by 92% of goals to reduce caregiver stress, 81% for behavioral and functional goals, and 55% of cognition goals were attained at the end of the intervention, also shown in Figure 1.

As shown in Table 3, scores in the cognitive, function, and QoL did not differ significantly pre- and postintervention. Effect sizes for cognitive scores, functional performance, neuropsychiatric symptoms, QoL, and caregiver burden measures were marginal, whereas a large effect size (Cohen's $d = 2.53$) was seen for GAS.

There was a trend for improvement in caregiver burden postintervention, with median ZBI score of 16 (IQR: 9–29) at baseline, and 14 (IQR: 6–26) at 8 weeks ($P = 0.080$). When caregiver burden was analyzed according to the distinct four-factor structure of the ZBI, factors 1 (demands of care and

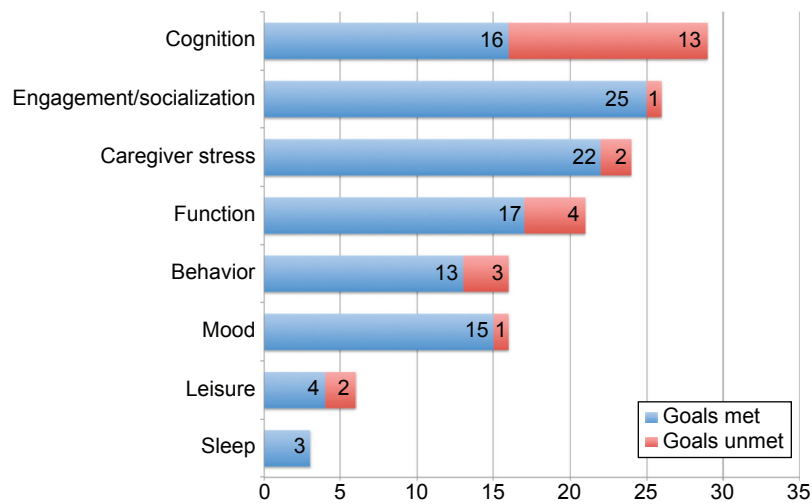


Figure 1 Types and number of goals met or unmet.

social impact) and 2 (confidence or control over the situation) revealed statistically significant improvement postintervention, as shown in Table 3.

GAS significantly correlated with improvements in caregiver burden on the ZBI and behavior severity on the NPI-Q as shown in Table 4, although the correlation was modest.

Discussion

Despite the stability of scores on standard scales measuring cognition, function, and behavior, over half of the persons with mild dementia in our cohort achieved or exceeded their goals following a multimodal cognitive and physical rehabilitation program. Goals to improve socialization, mood, and caregiver burden were most frequently attained. Contrary to the conventional emphasis placed on cognitive abilities in dementia trials, cognitive goals constituted only 21% of goals set. In particular, we observed that goals to reduce caregiver burden comprised a significant proportion of goals

set. Nonpharmacological interventions have potential benefit in persons with dementia and their caregivers. Physical activity may reduce the risk of progression of ADL disability in patients with dementia,²⁴ with exercise conferring benefits on behavioral and psychological symptoms of dementia, especially depressed mood, agitation, and wandering, and may also improve nighttime sleep.²⁵ Cognitive interventions share the common underpinning of cognitive and neural plasticity in AD.²⁶ Participants in MINDVital undergo cognitive stimulation and rehabilitation, an approach that also emphasizes a collaborative process between the caregiver and the person living with dementia, with intervention developed to address personally meaningful goals relevant to daily living.²⁷

Combining nonpharmacological approaches in dementia rehabilitation has shown promise. In an AD rehabilitation program involving physical exercise and cognitive stimulation activities, a 4-year intervention group showed no decline

Table 3 Comparison of scores pre- and postintervention, with effect size estimates for each measure

Measure	Preintervention	Postintervention	P-value	Effect size
GAS ^a	36.8 (1.0)	48.6 (6.5)	<0.001	2.53
CMMSE ^b	18.0 (15.0–21.0)	19.0 (15.8–21.3)	0.14	0.14
Barthel Index	100 (95–100)	100 (95–100)	0.60	0.05
IADL	11 (7–15)	12 (8–14)	0.24	0.11
EQ-5D	5 (5–5)	5 (5–5)	–	–
ZBI total	16 (9–29)	14 (6–26)	0.080	–0.17
Factor 1 (demands of care and social impact)	8 (4–16)	7 (2–7)	0.046	–
Factor 2 (confidence or control over the situation)	1 (1–5)	0 (0–2)	0.004	–
Factor 3 (psychological impact on caregiver)	3 (1–7)	2.5 (0–6.25)	0.068	–
Factor 4 (worry about caregiving performance)	3 (2–4)	3 (2–4)	0.899	–
NPI-Q severity	2 (1–4)	1 (0–3)	0.24	–0.11

Notes: ^aMean (±SD) for GAS scores. ^bMedian (IQR) for CMMSE, Barthel, IADL, EQ-5D, Zarit, and NPI-Q severity scores.

Abbreviations: GAS, goal attainment scaling; CMMSE, Chinese Mini-Mental State Examination; IADL, Instrumental Activities of Daily Living; EQ-5D, EuroQoL-five dimension questionnaire; NPI-Q, Neuropsychiatric Inventory Questionnaire; ZBI, Zarit Burden Interview; IQR, interquartile range; SD, standard deviation.

Table 4 Spearman correlation coefficients for change scores and GAS scores

Change score	Correlation coefficient	P-value
Barthel Index	-0.155	0.281
IADL	-0.089	0.540
EQ-5D	-0.179	0.214
NPI-Q severity score	-0.461	0.001
ZBI	-0.352	0.013

Abbreviations: IADL, Instrumental Activities of Daily Living; EQ-5D, EuroQoL-five dimension questionnaire; NPI-Q, Neuropsychiatric Inventory Questionnaire; ZBI, Zarit Burden Interview; GAS, goal attainment scaling.

in several cognitive and language outcome measures.²⁸ In another pilot 3-month program consisting of cognitive stimulation, physical activity, and socialization, the intervention group demonstrated stability of cognition and marked improvement in apathy, mood, and QoL compared to a control group.²⁹ It is notable that while we had failed to demonstrate significant improvements in cognitive, behavioral, and functional scores, a majority of these individual set goals were actually met at the end of the rehabilitation program.

In our cohort, caregiver stress was identified during goal setting in a significant proportion of participants, despite the low median score on the ZBI that would correspond to the experience of no-to-mild burden. It is increasingly recognized that caregiver burden is a multidimensional concept that goes beyond the total score on the ZBI.³⁰ Our intervention impacted two distinct dimensions of caregiver burden: 1) the demands of care or social impact on the caregiver and 2) the confidence or control over the caregiving situation. These two factors reflected the concept of role strain, broadly defined as the caregiver's felt difficulty in fulfilling the caregiver role. Predictors for role strain have previously been identified – mutuality, defined as the ability to find gratification and meaning in the relationship with the person living with dementia and the caregiving situation, and preparedness for caregiving, pertaining to one's perceived self-efficacy in managing the problems that come with dementia caregiving.³¹ As education and engagement were a key component of our intervention with encouragement to continue learned activities at home, this may have contributed to a greater degree of confidence in caregiving. We further hypothesize that the involvement of the caregiver through goal setting is itself a facilitative process, and may indirectly contribute to the reduction in role strain by reinforcing the benefits of mutuality through shared decision-making and goal setting.

The use of GAS in this study enabled an individualized approach to measuring outcomes and may have better reflected clinically relevant change. Measuring goal

attainment in cognitive rehabilitation with GAS may be particularly appropriate, due to the personalized nature of cognitive rehabilitation goals.^{27,32} The psychometric properties of GAS have previously been described.⁹ GAS is a responsive outcome measure, as seen in the high effect size statistic consistent with previous studies.³³ GAS also has good interrater reliability,³⁴ and is feasible and acceptable to both individuals and caregivers.³⁵ The intrinsic properties of GAS render evaluations of validity more complex as the individual domains identified would necessarily vary across diseases and populations. It is hence suggested that content validity be assessed on a case-by-case basis.³⁶ Construct validity is usually evaluated via correlations with standard outcome measures. Similar to previous studies,^{35,37} we found that GAS correlations with standardized tests in our cohort were expectedly variable. As GAS utilizes individual goals, it may be less relevant to compare GAS with a construct using the same items across subjects. Nonetheless, in our study, GAS correlated significantly with improvements in caregiver burden on the ZBI and behavior severity on the NPI-Q, which highlights the potential utility of GAS in these domains.

Limitations

Limitations of this study include its lack of comparator group, small sample size, short duration of intervention, and limited generalizability beyond mild dementia. The degree to which different interventions contribute to goal attainment and caregiver burden is also not apparent. A potential concern of using GAS is appropriate scaling, although this problem is not unique to our study. Care has to be taken to ensure that goals set are neither too easily attainable nor too difficult to achieve. The higher proportion of unmet cognition goals in our study possibly reflected goals that may have been too difficult to attain. In our cohort, unattained cognition goals were nonspecific, nondescriptive goals targeted at improvements in cognitive scores, which highlighted the importance of appropriate, guided goal setting. On the other hand, this process allowed us to glean new insights on how the illness and treatment is perceived at an individual level, and hence better manage the expectations and concerns of the patient and caregiver.

Conclusion

In conclusion, our data provide preliminary evidence of the efficacy of a multimodal exercise and cognitive rehabilitation program for persons with mild dementia, particularly on goal attainment and caregiver burden. A goal-oriented approach may be more relevant in dementia trials, given the clinical heterogeneity of the AD syndrome, where deficits may be

subtle and may not be reflected in standard scales. Education level, cultural perceptions, and the social environment may also influence treatment outcomes. Thus, a goal-oriented approach yielded more clinically relevant information on treatment effects and outcomes important to the individual and caregiver, beyond producing statistically significant improvements in routine neuropsychological tests and global functional outcomes. Further studies over a longer duration and a larger sample could be undertaken to determine the effects of multimodal interventions on reducing cognitive decline and the impact of dementia on the individual and the caregiver.

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