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Implementation, Process, and Preliminary Outcome Evaluation of Two Community Programs for Persons with Stroke and Their Care Partners

Maria P.J. Huijbregts, Anita M. Myers, David Streiner, and Robert Teasell

Purpose: This evaluation compared a new self-management program with land and water exercise (Moving On after STroke or MOST) to a standard education program (Living with Stroke or LWS). **Participants:** Of 30 persons with stroke (average age 68 and 2 years post stroke), 18 selected MOST and 12 chose LWS. Sixteen care partners participated. **Method:** Assessments at baseline, program completion, and 3-month follow-up included the Reintegration to Normal Living (RNL) Index, Activity-specific Balance Confidence (ABC) scale, exercise participation, and goal attainment (for the MOST group). Program delivery costs were calculated and focus groups conducted to examine participant expectations and experiences. **Results:** Social support was an important benefit of both programs, but only MOST participants improved significantly on the RNL ($p < .05$) and ABC ($p < .001$). Seventy-eight percent of all short-term personal goals in MOST were achieved, and overall goal attainment was above the expected level. At follow-up, a higher percentage of MOST participants were enrolled in exercise programs ($p < .05$). **Conclusion:** Although self-management programs with exercise are more costly to deliver than standard educational programs, these preliminary results indicate that such programs may be more effective in helping persons with stroke and care partners deal with the challenges of living with stroke. **Key words:** *community participation, education, exercise, self-management, stroke*

Many people with stroke, even those with apparently minor limitations, report significant physical and psycho-social challenges in readjusting to community living following the initial stage of recovery. Such challenges include relearning skills or developing new ways of doing things, pacing, mobilizing social support, accessing resources, and redefining one's identity, including work, family, and social roles.[1] Long-term restrictions in activity and social participation are not uncommon, even for people with stroke who have good physical recovery[2]; this in turn may lead to further withdrawal from community participation, depression, and reduced quality of life.[2–4] Although it is recognized that people with stroke and their care partners may require services beyond acute care and rehabilitation,[5] currently there are very few specific prototypes for effective community programming post stroke,[6] constituting a significant gap in the stroke care continuum.

The majority of interventions post stroke have focused exclusively on education[7–10] or education in combination with social support or problem solving.[11–16] Even though such programs can increase knowledge, this may not translate into behavior change or improved well-being.[9,17] Based

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on a critical appraisal of the stroke education literature, Forster and colleagues[18] identified a need for new approaches, particularly nondidactic strategies, that can be implemented within clinical practice or community settings.

Stand-alone exercise interventions, meanwhile, have shown gains in physical functioning post stroke but failed to address barriers to community exercise participation or adherence.[19,20] A combination of exercise and education programming tailored to people with stroke may prove to be more effective than either one in isolation. Water-based exercise has been successful with elderly populations,[21,22] as well as in the stroke population,[23] and may be particularly appealing to people with stroke.

Based on success with other chronic disease populations,[24] the self-management approach that emphasizes self-efficacy, problem solving, goal setting, and support, as well as exercise, may prove to be a useful framework for poststroke programming.[25] Defined as "learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition,"[26(p11)] self-management addresses the primary tasks in living with chronic illness: (a) the work to care for the disease, such as taking medications, visiting physicians, exercising, or maintaining a special diet; (b) the work to maintain a normal life, such as doing chores, maintaining social contacts, and hobbies; and (c) the emotional work to deal with feelings such as frustration, anger, or depression.[26,27] Clients are ultimately responsible for managing their condition, but guidance and support from peers and health professionals can greatly facilitate this process and empower the client.[26] Clients are encouraged to take charge of their lives by making informed choices, adopting new perspectives or strategies, acquiring problem-solving and coping skills, initiating behavioral change (such as exercise), and maintaining or regaining emotional stability. Enhancing self-efficacy is considered a critical component of this process.[28] Based on social-cognitive theory,[29] self-efficacy is facilitated through performance accomplishment, positive feedback, modeling, and reinterpretation of symptoms.

To address the gap in community programming for persons with stroke and their care partners following rehabilitation, the Moving On after STroke (MOST) program was developed based on the self-management approach. Following a pilot evaluation, the program was formally implemented at a geriatric care facility in Toronto, Canada, in 2002. The facility has a wheelchair-accessible, warm pool and an exercise room with elevated mats. Shown in **Table 1**, the program

Table 1. Discussion topics of each program

MOST	LWS
1. Why self management? Why exercise?	1. How a stroke happens
2. Goal setting	2. Physical effects of stroke
3. How stroke affects you/prevention	3. Communication
4. Relaxation	4. Therapies and lifestyle changes
5. Daily activities and responsibilities	5. Psychosocial effects
6. Recreation and having fun	6. Stroke and the younger person
7. How stroke affects how you think and feel	7. Issues in care giving
8. With a little help from friends and family	8. Community
9. Community resources	
10. Communication	
11. Interaction with health professionals	
12. Alternative treatments	
13. Loving and caring	
14. Your doctor and your medications	
15. Nutrition	
16. Sleep and pain	
17. Wrap up/community-environment	
18. Booster session (6 weeks later)	

Note: In MOST Session 8, people with stroke and care partners meet separately for the first hour and in LWS Participants choose six out of the eight topics.

consists of 17 two-hour, group-based sessions, twice per week for 8 weeks, as well as a booster session 6 weeks later. Based on the challenge to balance the opportunity for group interaction with individual attention and given available resources, the earlier pilot study findings indicated that the MOST program should be capped at a maximum of 10 stroke participants per session.

The first hour of each session involves discussion of weekly topics, short-term goal setting, and problem solving, while the second hour is devoted to exercise. Land exercises (three sessions) concentrate on stretching, strengthening, and balance; the pool component (14 sessions) adds endurance. Guided by available research[30–32] and supported by subsequent studies,[23,33] the exercise components were designed to develop new skills and enhance self-efficacy to foster continued exercise involvement beyond the program. Although care partners are invited to attend all sessions, a specific session (Week 8) is devoted to issues involving family and friends. People with stroke and care partners meet separately with the program facilitators to discuss their concerns, and then the two groups are brought together.

To evaluate the delivery process (including cost estimates) and relative benefits, MOST was compared to the Living with Stroke (LWS) education program. At the time of this study, LWS was the only widely available community program for this population. Developed by the Heart and Stroke Foundation of Ontario (HSFO) in 1997, LWS is delivered across Canada and can be considered standard practice. The HSFO provides a 1-day facilitator training workshop and facilitator and participant manuals, video clips, and information booklets. Program content and method of delivery are clearly prescribed, and the program is typically delivered by a trained health professional. The 6-week LWS program aims to increase knowledge about stroke and provide support and resources for persons with stroke and their care partners. Of the eight potential topics shown in **Table 1**, facilitators and participants choose six to discuss during their weekly 90-minute sessions. The HSFO recommends a maximum of six persons with stroke and their care partners in each group.

Method

Design

A prospective, longitudinal cohort design was used for the preliminary outcome evaluation component of this study, as illustrated in **Figure 1**. Ethics approval was obtained from the Research Ethics Board at Baycrest, Toronto, University of Waterloo in Waterloo, and West Park Healthcare Centre in Toronto. Several strategies including brochures, flyers, and presentations were used to recruit people with stroke and their care partners throughout the Greater Toronto Area (GTA). Rehabilitation professionals were asked to distribute study brochures to stroke clients being discharged from inpatient and/or outpatient services. The brochure described the two programs, associated fees ($20.00 for LWS and $30.00 for MOST; subsidized upon request), and study requirements. Organizations such as HSFO and advocacy groups for stroke were also asked to promote the study.

Interested individuals then contacted the principal investigator (PI) by phone, who determined eligibility and program preference. One of our objectives was to examine the relative demand for the two programs based on informed decision making (i.e., known differences in structure, content, fees, and time commitment). Poor attendance is well-documented in stroke education.[9,11] Allowing people to enter their program of choice (if more than one option is available) is consistent with client-centered clinical practice and community programming and has been shown to enhance client attendance and outcomes.[34,35]

The research assistant (RA) then arranged for the baseline assessment (T1) and obtained individual informed consent for both program and study participation. The T2 and T3 assessments were conducted at the end of the program and at 12 weeks post program, respectively. For the study, MOST was delivered twice consecutively at the host institution, while the LWS program was also delivered twice at a nearby rehabilitation centre. Each program was delivered by a separate team of two trained health professions; a physiotherapy assistant and three

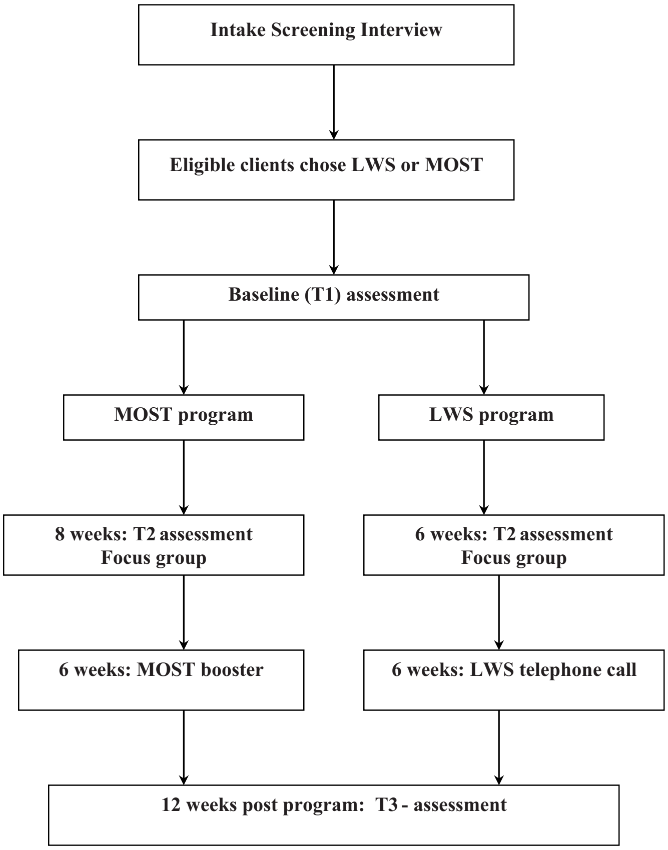

Figure 1. Flow chart

volunteers provided additional support with the exercise components of MOST.

Study participants

People were eligible for the study if they had a medical diagnosis of stroke, were at least 3 months post stroke, had completed all active stroke rehabilitation, were physically and cognitively able to participate, and had medical approval for the exercise component. Program fees were waived if individuals requested a subsidy (five did: three from LWS and two from MOST). Participants had to arrange their own transportation and be able to dress/undress independently (or attend with a care partner who could provide the required assistance). The intake criteria were both inclusive and realistic considering the limited funding available to community programs for additional personnel and transportation assistance.

Program attendance and delivery information

To determine level of participation, staff kept individual attendance records for each person with stroke and the care partner. To estimate personnel costs for program delivery, facilitators completed time sheets on preparation and delivery for each session. Total number of hours were calculated by hourly rates ($35/hour for facilitators and $18.72/hour for the physiotherapy assistant) and verified with program staff. To gain an understanding of challenges in program delivery, written and verbal feedback was solicited from each of the program facilitators. To examine consistency of delivery, the principal investigator observed two sessions (of each program) without prior notice.

Assessment protocol

Study participants were required to travel to their respective institution (program site) for each of three assessments (requiring about 90 minutes at T1 and 30–60 minutes at T2 and T3). Travel costs for assessments were reimbursed. At T1, the RA administered the Mini-Mental State Exam (MMSE)[36] and a background questionnaire via interview. At each assessment, the following tools were administered: the Reintegration to Normal Living (RNL) Index,[37,38] the Activity-specific Balance Scale (ABC),[39,40] the FIM™,[*41] the abbreviated version of the Geriatric Depression Scale (GDS),[42] and the Activity Inventory (AI) of the Chedoke McMaster Stroke Assessment (CMSA).[43,44] The CMSA-AI was based on physical performance; all the other tools were administered by interview.

Designed to assess adjustment following incapacitating illness or injury, the RNL Index assesses the extent to which individuals feel that they can do what they want and need to do with respect to getting around, self-care, activity participation, family roles, and dealing with social and life events.[37] Scores on the 11-item RNL Index can range from 0 to 22, with higher scores indicating poorer adjustment. This tool has been used with various clinical populations, including persons with stroke.[45] The ABC assesses balance confidence in 16 progressively challenging mobility situations. Designed for community-dwelling older adults, ABC scores can range from 0 to 100, with higher scores representing greater confidence.[39] Associated with activity restriction and functional decline, balance confidence is amenable to change.[40,46] Recently, the reliability of the ABC and associations with walk speed and balance have been documented in a community stroke sample.[47] The FIM™ captures physical and cognitive disability with respect to assistance required for activities of daily living [41] and has been validated in the stroke population.[46] Scores on the FIM™ can range from 18 to 128 (with higher scores indicating less need for assistance). The GDS assesses depression, without relying on somatic symptoms that may be a normal effect of aging or physical illness, and has been widely used with the stroke population. Scores on the short version of the GDS can range from 0 to 15, with higher scores indicating more serious depression.[42,48] Finally, the CMSA-AI assesses gross motor function and walking. Scores can range from 14 to 100, with higher scores indicating higher functioning. Although there are no published normative values,[46] the measure is responsive to change in rehabilitation interventions.[44]

Consistent with the self-management approach, goal setting is an important activity of the MOST program designed to foster self-efficacy through skill mastery. Participants were asked to set a personal, short-term goal on a biweekly basis within the group setting and a longer term goal they wanted to achieve by the end of the program. Using the Goal Attainment Scaling (GAS) method,[49] the facilitator provided individual assistance in determining the criteria for accomplishing their long-term goal on a 5-point scale, ranging from *much worse* to *much better than expected*.

Participating care partners, meanwhile, were asked to provide demographic information and to complete the Caregiver Strain Index (CSI)[50,51] and the GDS. Possible scores on the CSI range from 0 to 13, with higher scores indicating more strain (scores ≥7 indicate "severe strain"). Depression of care partners was considered important to assess, although there are no normative GDS values for this population[42,52]

To obtain in-depth feedback from both persons with stroke and care partners, focus groups were held at each program location immediately following the last session (**Figure 1**). All groups (four for the MOST; three for the LWS) were facilitated by an independent social worker with 14 years clinical experience and training in focus group methodology. Following established guidelines,[53,54] a structured script was used to examine participant expectations of, and experiences with, the program and obtain suggestions for improvement. The PI was also present and took field notes but did not take part in the discussions. All sessions lasted about an hour and were audiotaped. The tapes were transcribed verbatim by a professional transcriber.

Data analysis

Quantitative data analysis was conducted using SPSS Version 11.00 (SPSS, Inc., Chicago, IL), and significance was set at the .05 level. Descriptive

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*FIM™ is a trademark of Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc.

statistics were used to characterize the study groups. Between- and within-group comparisons on the various outcome measures involved repeated measures analysis of variance (ANOVA). To control for baseline differences, analysis of covariance (ANCOVA) was used, with T2 and T3 scores as the repeated observations and the T1 score as the covariate.[55] Formal exercise participation was examined using Fisher's exact test[55] (T1-T3). Logistic regression was conducted to determine whether preprogram (T1) exercise participation had a significant influence on exercise participation at T2 or T3. Effect sizes were calculated according to Kazis, Anderson, and Meenan.[56] Initially we also intended to examine caregiver outcomes; however, as few care partners returned for reassessment, their baseline GDS and CSI scores were analyzed for descriptive purposes only.

For short-term (biweekly) goals, the number of goals set by each participant over the course of the program and the percentage of goals achieved was calculated. For long-term goals, a goal attainment score for each individual, and a mean score for the MOST group as a whole, was calculated using established procedures.[49]

For analysis of the focus group data, transcriptions were imported into Nvivo software (QSR International Pty Ltd).[57] Initial descriptive coding progressed to interpretive and analytical coding.[58] The purpose was to gain a full understanding of client expectations and experiences with the MOST and LWS programs, respectively. Each discussion was examined separately, prior to looking at similarities and differences across groups (within and between the two programs). For verification, the facilitator independently reviewed the transcripts and resulting interpretation to ensure that findings adequately reflected the discussions.

Results

As shown in **Figure 2**, 45 persons with stroke contacted the PI and went through the intake process. Eight were not eligible for the study due to plans for further rehabilitation (four), injury from a recent fall (one), language problems (two), or physical needs (one). Upon hearing about the study requirements and timeline, seven decided not to participate due to lack of transportation (two) or ability/willingness to make the commitment at the time (five). Those who decided not to participate were not significantly different from those who did in terms of age, gender, or time post stroke. Those willing to make the commitment, however, were more significantly likely to have received program and study information directly from a health professional, $\chi^2(1) = 4.6$, $p < .05$.

Of the 30 eligible and interested study participants, 18 selected the MOST while 12 chose the LWS program (**Figure 2**). Five individuals requested a subsidy, and fees were waived. As shown in **Table 2**, the two groups were comparable with respect to gender distribution, education, marital status, cognitive functioning (MMSE scores), time post stroke, and stroke severity. The CMSA-Impairment Inventory[43] indicated moderate levels of ongoing arm and leg impairment for both groups. Most participants required assistance to get to and from the program: 67% used special public transportation for people with disabilities, and 23% were driven by their partners. Perceived health (good to poor) and number of comorbidities were also comparable. Those who chose the MOST program, however, were significantly older and more likely to report English as their second language ($p < .05$). Participants in this group were also more likely to have fallen more than once since their stroke and been injured as a result ($p < .05$).

In total, 16 care partners (all spouses) participated: seven in the two MOST programs and nine in the two LWS programs. As shown in **Table 3**, the MOST care partner group was older and had more health problems and resulting caregiving limitations. Although average GDS scores indicated "normal" psychological function, five people (three in MOST and two in LWS) scored in the "mild" and one (in the LWS) in the "severe" depression range. Care partners experienced substantial caregiving strain or burden as indicated by scores on the CSI. As noted, scores ≥7 indicate severe strain. The overall mean was just below this value and half the sample (three in MOST and five in LWS) scored in this range.

Program and study adherence

The two MOST programs consisted of 8 and 10 people with stroke, respectively, while the two LWS programs comprised 5 and 7 participants.

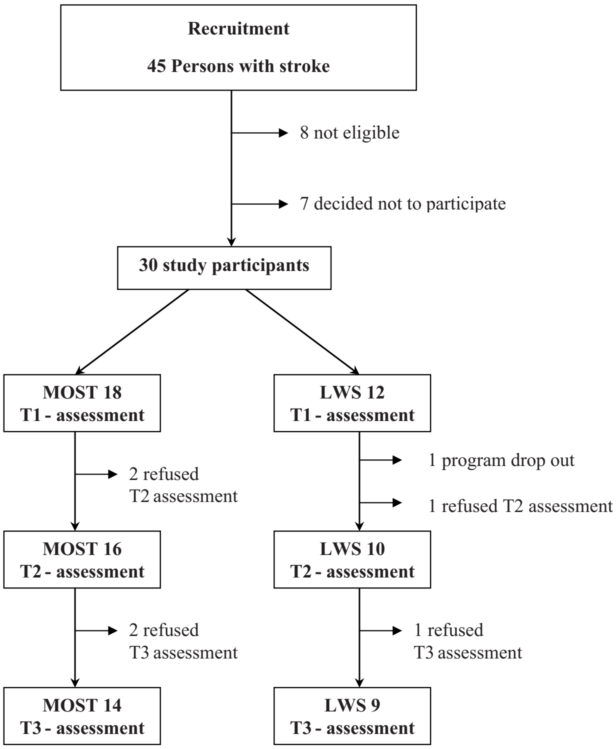

Figure 2. Study and program participation

Defined as the percentage of sessions attended, overall program adherence was high for both programs: 89% for the MOST and 90% for the LWS programs, respectively. Eight stroke participants (67%) attended all eight LWS sessions, while four stroke participants (22%) attended all 18 MOST program sessions (**Table 2**).

For the MOST program, attendance was higher for the discussion component (first hour) than for the exercise component (second hour) (89% vs. 77%; $t = 4.79$, $df = 1$, $p < .001$). Various reasons were given for not attending the exercise sessions such as injury, backache, presence of a rash or open wound, or another appointment. Fourteen of the 18 MOST participants (78%) returned for the booster session, which took place 6 weeks after completion of Session 17.

As shown in **Figure 2**, there was only one program dropout from the LWS program. This person dropped out because his wife returned to work and therefore was no longer able to provide transportation or to accompany him. Moreover, not everyone was able to return to the host institution for the T2 (program completion) and T3 (3-month follow-up) assessments. Such individuals should be considered study versus program dropouts.[54] The four participants (two from each program) who did not come for the T2 assessments (due to lack of or difficulty with transportation and/or fatigue) had high levels of attendance during the regular program. The number of participants assessed at each stage is shown in **Figure 2**.

Care partner overall attendance rate (**Table 3**) was lower than for people with stroke: 70% for the MOST program and 85% for the LWS program. Two LWS care partners returned to work and did not attend the T2 or T3 assessments. All MOST care partners completed the program and all study assessments.

Functional outcome indicators for persons with stroke

Table 4 shows the scores of the LWS and MOST participants, respectively, on the standardized measures at each time point. Average baseline (T1)

Table 2. Characteristics of people with stroke participants

Characteristic	Total sample (*N* = 30)	MOST group (*n*= 18)	LWS group (*n* = 12)
Age*	68 (10.5) 42–82	71 (7.6) 56–82	63 (12.4) 42–80
Male gender	20 (67%)	13 (77%)	7 (58%)
English as first language*	23 (77%)	11 (61%)	12 (100%)
Married	23 (77%)	14 (78%)	9 (75%)
Less than high school	10 (33%)	5 (28%)	5 (42%)
Months post stroke	24 (26) 3–89	30 (26) 6–83	15 (23.6) 3–89
Months post rehab	17(26.5) 0.5–86	22 (27.4) 1–83	9 (24.3) 0.5–86
MMSE (*n* = 27) 0–30	27 (3.2) 18–30	27 (3.0) 21–30	27 (3.6) 18–30
Stroke severity-CMSA: Arm impairment 1–7	3.6 (1.5) 2–7	3.4 (1.5) 2–6	3.75 (1.5) 2–7
Stroke severity-CMSA: Leg impairment 1–7	4 (1) 3–6	3.8 (0.9) 3–6	4.2 (1.2) 3–6
Walk aid/assistance	28 (93%)	17 (94%)	11 (92%)
Fallen since stroke	19 (63%)	13 (72%)	6 (50%)
Fallen more than once*	15 (50%)	12 (67%)	1 (8%)
Injured as a result*	6 (20%)	6 (33%)	—
Program attendance rate	89 (12.4) 50–100	89 (9) 72–100	90 (17) 50–100
Attended all sessions	12 (40%)	4 (22%)	8 (67%)

Note: Values are means (*SD*) and ranges or *n* (%). Score ranges are given from worst to best. MMSE = Mini-Mental State Exam; CMSA = Chedoke McMaster Stroke Assessment

*Significant group difference ($p \leq .05$).

scores on all measures were comparable for the MOST and LWS groups. Compared to previous stroke samples, the mean balance confidence (ABC) score for our total sample (53 ± 18.7) was lower than that reported by Botner and colleagues[47] for a community stroke sample (68.3 ± 17.5). Although comparable in age, their sample (*N* = 77) was on average 4 years post stroke. Scores on the RNL Index, meanwhile, were similar to values found in a prior sample 3 to 4 months after stroke.[45] The average GDS score (5.3 ± 3.5) bordered "normal" (0–4) and "mild" depression (5–9).[59] When categorized as "normal" (43%), "mild" (43%), and "severe" (14%), depression rates were similar to those reported by other researchers for poststroke samples[60,61] Physical, social, and cognitive functioning, as indicated by the overall FIM™ score (101 ± 10.5), was comparable to

Table 3. Characteristics of care partner participants

Characteristic	**Total sample (N = 16)**	**MOST group (n = 7)**	**LWS group (n = 9)**
Age*	63 (13.1) 40–82	70 (5.7) 66–82	57 (14.5) 40–79
Male gender	5 (31%)	2 (29%)	3 (33%)
English as first language	12 (75%)	7 (100%)	7 (78%)
Married	14 (88%)	14 (78%)	9 (75%)
Less than high school	8 (50%)	3 (43%)	5 (56%)
Employed	3 (19%)	0 (100%)	3 (33%)
No. of medical conditions*	1.8 (1.5) 0–5	2.9 (1.5) 1–5	1 (1) 0–3
Limiting illness*	5 (31%)	4 (57%)	1 (11%)
Other support available	12 (75%)	5 (71%)	7 (78%)
Expected self benefits	12 (75%)	6 (86%)	6 (67%)
CSI 13–0	6.4 (3.7)	5.1 (4.6)	7.4 (2.5)
GDS-15 15–0	4.4 (3.52)	4.3 (4.6)	4.6 (3.9)
Program attendance rate	78.5 (27) 5.6–100	70 (35.5)	85 (17.6)
Attended all sessions	6 (37.5)	2 (29%)	4 (44%)

Note: Values are mean (*SD*) and ranges or *n* (%). Score ranges are given from worst to best. CSI = Caregiver Strain Index; GDS = Geriatric Depression Scale (abbreviated version: 15 items)

*Significant group difference ($p \leq .05$).

that found in a prior community stroke sample.[62] Scores on the Activity Inventory of the CMSA indicated that some individuals still required assistance from others in order to live alone in the community.[44] Taken together, these results indicate that, similar to prior samples, our sample of people with stroke still had persistent limitations in well-being, activity, and social participation as a result of the stroke.

With respect to within-group change, participants in the MOST program improved significantly on the ABC Scale ($F = 8.94$, $df = 2$, $p < .005$), the RNL Index ($F = 3.43$, $df = 2$, $p < .05$), and the FIM™ ($F = 3.97$, $df = 2$, $p < .05$). Post hoc *t* tests revealed that ABC scores significantly differed ($p < .05$) from T1-T2 as well as from T1-T3; RNL scores between T1-T3; and FIM™ scores between T1-T2. In contrast, LWS participants showed significant improvement ($p < .05$) only with respect to FIM™ scores ($F = 4.73$, $df = 2$, $p < .05$) between T1-T2 and between T1-T3. Although between-group differences (ANCOVA results) were not significant ($F = 3.26$, $df = 2$, $p < .09$), scores on the ABC Scale approached significance in favor of the MOST program.

To examine magnitude of change, effect sizes were calculated. For the MOST group, effect sizes between T1-T2 and between T2-T3, respectively,

Table 4. Mean (*SD*) scores on functional outcome indicators at baseline, Time 2, and Time 3 by program

	LWS program			**MOST program**		
Outcome indicators	**Time 1 (*n* = 12)**	**Time 2 (*n* = 10)**	**Time 3 (*n* = 9)**	**Time 1 (*n* = 18)**	**Time 2 (*n* = 16)**	**Time 3 (*n* = 14)**
ABC 0–100	(*n* = 9) 54.9 (21.7)	(*n* = 8) 62.9 (23.4)	(*n* = 7) 65.1 (22.4)	51.6 (17.5)	66.3 (19.9)	67.9 (21.4)
RNL 22–0	(*n* = 9) 6.1 (4.0)	(*n* = 8) 4.8 (2.5)	(*n* = 7) 4.7 (2.5)	6.4 (4.7)	4.9 (4.0)	(*n* = 13) 5.4 (4.0)
GDS 15–0	(*n* = 10) 4.7 (2.8)	(*n* = 9) 3.8 (2.7)	(*n* = 8) 6.00 (1.4)	5.6 (3.9)	4.3 (3.2)	6.2 (3.0)
FIM™ 18–126	100 (9.8)	103.6 (9.0)	107.6 (7.9)	102.3 (11)	107.4 (8.8)	106.2 (9.5)
CMSA-AI 4–100	73.4 (8.8)	74.1 (8.9)	78.9 (4.2)	73.2 (14.9)	77.8 (8.5)	77.4 (10.6)
Exercise participation	Yes: 1 (8%) No: 11 (92%)	Yes: 2 (20%) No: 8 (80%)	Yes: 3 (33%) No: 6 (67%)	Yes: 5 (28%) No: 13 (72%)	Yes: 11 (69%) No: 5 (31%)	Yes: 11 (79%) No: 3 (21%)

Note: Score ranges are given from worst to best. ABC Scale = Activity-specific Balance Scale; RNL Index = Reintegration to Normal Living Index; GDS = Geriatric Depression Scale; CMSA-AI = Chedoke McMaster Stroke Assessment-Activity Inventory.

were .76 and .90 for the ABC Scale, .30 and .34 for the RNL Index, and .38 and .30 for the FIM™. For the LWS group, meanwhile, the effect size for the FIM™ was .29 between T1-T2 and .59 between T1-T3.

Change was not found to be significantly associated with participant age, time post stroke, or program attendance rate for any of these measures for either group or the sample as a whole. At T2 (program completion), however, it was discovered that two of the LWS participants were still receiving physiotherapy services. When these individuals were subsequently removed from the within-group ANOVA, change on the FIM™ was no longer significant.

Exercise participation

As shown in **Table 4**, at baseline (T1) a greater percentage of the MOST versus the LWS participants (28% vs. 8%) were already enrolled in formal structured exercise programs or were exercising regularly on their own. This difference was not statistically significant. At T2 and T3, those in the MOST group were 8.8 (95% CI 1.35–57.43) and 7.3 (95% CI 1.11–48.26) times more likely, respectively, to be participating in a formal exercise program than those in the LWS program ($p \leq .05$). When exercise participation at T1 was taken into account, the between-group difference neared significance at T2 ($p = .06$) and was significant at T3 ($p = .05$).

Short-term and long-term goal accomplishment

The total number of short-term goals set during the MOST program ranged from 1 to 12 (median = 3; interquartile range [IQR] 2–4.25; mean = 3.6; *SD* 2.8). The number of goals accomplished per person ranged from 0 to 9 (median = 2; IQR 1–3.25; mean = 2.6; *SD* 2.3), representing 78% of all short-term goals. Typical examples of short-term goals were the following: "I will make my own breakfast twice in the coming week"; "I will make a lunch date with a friend before the end of this week"; "I will write a letter to my brother"; "I will walk to the shopping center"; or "I will go for a walk outside with a friend." Only the MOST participant with the lower MMSE score did not meet any of his identified short-term goals.

Although long-term goals were also highly individualized, the majority pertained to social participation (eight), physical activity (seven), or household management activities (three).

Some examples of long-tem goals were to go to a family picnic and take part in conversation, to walk from parking lot to program area at least nine times during the course of this program, and to go shopping with a family member once per week. Goal attainment was ascertained at T3 by the research assistant who was not involved in the initial goal-setting process. Of the 18 MOST participants, 13 (72%) met or exceeded their long-term goal, while 5 did somewhat less than expected. The mean GAS score across the 18 MOST clients was .11 (slightly better than the expected level of zero). Formal goal setting was not part of LWS, precluding program comparisons.

Program delivery

Based on 10 stroke participants per group, the cost of delivering the MOST program (in Canadian dollars) was $384 per participant. In comparison, the equivalent cost for running the LWS program was only $105. If there were only six participants per group (as recommended by the HSFO for LWS), the delivery cost would increase to $175/client. If participant fees were taken into consideration (and subsidies not requested or provided), delivery costs per participant were reduced by $30 and $20, respectively. Total time commitment for program participation was also much higher for MOST (36 hours) than for the LWS progam (9 hours), not including time for travel. For MOST, the cost per mean point of improvement on the ABC Scale was $26.12 and on the RNL Index it was $256.00. For LWS the cost per mean point of improvement on the ABC Scale was $13.13 and on the RNL Index it was $80.76.

Researcher observations indicated that both programs were delivered consistently, following program guidelines. Feedback provided by the program deliverers (from the two discussion facilitators, the pool therapist, and the physiotherapy assistant for MOST and from the primary facilitator for LWS) was generally positive. Most participants were actively involved, with one exception, an individual in the MOST program with a low MMSE score. Staff questioned his ability to benefit but believed that the program was helpful for his wife. Overall, staff felt that participants worked well together, especially considering their different backgrounds. All staff members commented that people with stroke and care partners were dealing with many different issues and had many ongoing needs. Staff in both programs expressed concerns about participants' ability to make ongoing community linkages and felt that additional assistance would have been helpful. Optimizing the exercise component for each individual was challenging due to variation in participant abilities and available time and personnel. Even though care partners helped with the exercise, not all care partners could attend and some had physical limitations themselves.

Participant feedback

A total of 26 participants took part in one of the four separate focus groups held immediately following the last session of each program: 16 of the 18 MOST clients and 10 of the 12 LWS clients. Separate focus groups were also held with 16 care partners: 7 in MOST and 9 in the LWS programs.

The atmosphere in all groups was positive and lively. Everyone contributed to the discussion, including the people with communication difficulties. The structured discussion addressed participant expectations (reasons for choosing a particular program), perceived benefits, and suggestions for program improvement. **Tables 5** and **6** summarize the main findings regarding each of the programs from the perspective of the persons with stroke and of care partners, respectively.

Those in the LWS program enrolled primarily to obtain more information and/or to meet others who had had a stroke. Many also said that it was very important that their care partners were included. Those in the MOST program, on the other hand, enrolled primarily for the exercise, which they hoped would lead to physical improvement. Expectations ranged from "hope, that I could get better totally" to very specific improvements such as hand function or ambulation. Only two MOST participants specifically indicated that they wanted more information on stroke or were looking for social support.

When asked what they got out of the program, several LWS participants commented on enjoyment, whereas MOST participants put more emphasis on the value of the goal setting and exercise, including

Table 5. Summary of focus group findings for people with stroke

	Expectations	Perceived benefits	Suggested improvements
LWS participants	• Support • Socialize • Information • Didn't know • Support for spouse	• Social support: o Being part of a group o Participating in discussion o A sense of commitment to others o Encouragement o Putting own problems into perspective o Understanding others and being understood o Partner understanding o Getting out • Information • Enjoyment	• Ongoing group meetings/outings • More information on community programs • Separate sessions for care partners
MOST participants	• Improve physically • Information	• Social support o Encouragement o Exchanging ideas/sharing feelings o Understanding partners o Learning coping skills • Information • Getting out • Accomplishing goals • Gaining confidence • Being more active • Learning exercises • Physical improvements	• Ongoing social support group • Exercise o More practice of land exercise o Individual exercise prescription o More structure in pool program o Ongoing pool program

increased confidence. However, both groups were extremely enthusiastic about the opportunity to meet and interact with others with stroke. The sentiment that they felt less alone emerged from both groups, as typified by this comment from one of the participants:

> It was information, and getting out, being able to speak about how you really feel, because they go through a series … and it's sort of a relief to talk about the way you feel rather than generalizations.

Several people in MOST offered specific suggestions for improving both the land- and water-based exercises to better meet their needs and expressed a desire for ongoing land and pool exercise opportunities following the study. The most unexpected suggestion was a unanimous request for continued contact with other members. All groups from both programs expressed the desire to maintain contact, suggesting monthly meetings or organized outings as potential strategies. One person with stroke in the LWS program made light of the situation but also reflected how painful and in need of support life after stroke can be:

> If there was somebody here…who could phone for certain people that have had a stroke, and everybody just meets at a mall and goes out for a walk in the mall. … We're all in the same situation here. If one of us gets stared at, everybody gets stared at. We can all wave at them….

People from both programs also felt that it was beneficial for their care partners to attend. They felt this helped their partners understand what it meant to have a stroke and become more accepting of the difficulties the people with stroke face. As one of the LWS participants explained:

> I feel like I'm always tired and fatigued, and when everybody else was saying, I think she realized, I'm not just putting it on.

As previously described, the MOST program includes a session in which care partners and people with stroke start off by meeting separately and then have a joint discussion. This session gave people with stroke the chance to talk more freely about their own issues while also learning more about care partner issues and concerns. Even participants without care partners in the group perceived this as helpful. The LWS program does

Table 6. Summary of care partner focus group findings

	Expectations/ reasons for attending	**Perceived benefits**	**Suggested improvements**
LWS partners	• Social support for self • Knowledge for self • Knowledge for partner • Learn to deal with (consequences of) stroke • Coping skills	• Social support o Sharing of ideas/feelings o Learning from one another o Social support for partner o Chance to talk o Going out • Information o Stroke sequelae o Materials o Understanding partner	• Follow-up support group • Exercise program • Expert speakers (1)
MOST partners	• For partner o To exercise o To improve physical functioning o Social support o To have something to do	• Social support o Sharing of ideas/feelings o Learning from one another o Social support for partner o Going out • Information o Stroke sequelae o Care giving issues/solutions o Materials o Understanding partner • Goal setting (for stroke survivor): o Goal accomplishment o Improved confidence o Increased activity level • Exercise o Doing land exercise o Benefits and enjoyment of water exercise • Practical problem solving	• Follow-up support group • Exercise o Strategies to facilitate "exercising at home" o Structure of pool program o Ongoing pool program • Timing of "care giving session" to allow for more family involvement • Wider program availability

not provide an opportunity for people with stroke to talk separately.

Just like people with stroke, care partners felt that an important benefit of each program was an improved understanding with their spouses. Those in the MOST program particularly appreciated the separate session that gave them the chance to talk more freely, share frustrations with peers, and learn more about the cognitive and behavioural changes following stroke. It is noteworthy that care partners in the LWS program expressed a desire for this opportunity:

> I do think it's important for the caregivers to talk. I put that in my notes, because sometimes I find you don't want to say things in front of.... You don't want to hurt their feelings, or they might take that the wrong way. I would find that would be a big plus if there was a little bit more with that.

In addition to providing feedback on the programs themselves, the discussions provided tremendous insight regarding the challenges of living with stroke. In addition to physical limitations, people with stroke talked about accepting their stroke, ensuing financial and transportation implications, frustrations communicating, and fatigue. An overriding issue was the impact of the stroke on their identity due to changes in their work, family, and social roles (feeling dependent, left out, or different from their previous peer groups). Specific examples ranged from being let go by their partners in a law practice to no longer being able to play hockey with their buddies. People also talked about efforts expended in rehabilitation and set-backs in their recovery process. However, they also talked about accomplishments, the opportunity to spend more time with family, and unexpected help from others. Despite their determination and the time that had elapsed since their stroke, many still appeared to be learning how to deal with the accompanying physical and social challenges of living with stroke. Participants mentioned both specific adaptations (such as learning to use a wheelchair or relearning how to drive) and general challenges, such as accessing suitable community resources and services (including finding the right rehabilitation specialists). Participants were often able to articulate their problems in the focus groups but were unsure how to resolve these problems. It was apparent that many needed more active support to "make things happen" for themselves. The groups were useful in helping people think through what was involved in a particular activity (such as arranging transportation, going at a particular time of day when they were not as tired, returning home before they were too fatigued, and so on).

Discussion

The recognized gap in service provision following rehabilitation,[6] the call for new approaches,[18] as well as the success of self-management programs with other populations[24] provided the impetus for developing MOST.

The individuals who came to our programs were, on average, 2 years post stroke. Despite having gone through rehabilitation, many still had persistent physical limitations. Although many people still hope for full recovery, this may be unrealistic as most natural physical recovery occurs within the first year, especially in the first 3 months post stroke.[63] Scores on other indicators such as the GDS[60] and the FIM™[62] were quite similar to prior samples of people with stroke living in the community. Their care partners, meanwhile, were experiencing substantial strain, as indicated by scores on the CSI.[50] Older partners were often dealing with their own health issues, while younger partners had to juggle other responsibilities such as work. Clearly these individuals face a multitude of ongoing challenges.

A mixed-methods approach was used to evaluate the implementation, delivery, and potential benefits of this new program relative to an existing, education-only program (the only formal educational community program available to this target group at the time). In contrast to highly controlled efficacy studies, evaluation strives to examine program delivery and effectiveness under routine or normal conditions.[35,54] Accordingly, the programs were advertised through multiple avenues, interested individuals contacted the coordinator for further information, program fees were charged, and participants had to arrange their own transportation and assistance with toileting or dressing (for the exercise component) if needed. The intake criteria were both inclusive and realistic given the limited program funding for personnel. Consistent with routine practices, and to enhance motivation and adherence,[34,35] participants were permitted to enter their program of choice.

When provided with descriptions of both programs, 60% of the study sample chose to enter the MOST over the LWS program, despite higher fees ($30 vs. $20) and greater time commitment. In keeping with usual institutional policies, program fees were waived for the five people who requested this. Preference for MOST was likely influenced by recommendations from rehabilitation professionals and participants' desire for exercise in the hopes of further physical recovery. It appears that exercise (particularly water exercise) provided an incentive for program adoption.

Despite the fact that MOST was much longer, adherence was high for both programs (89% for MOST and 90% for LWS), and 78% of participants returned for the booster session 6 weeks later. Partner attendance rates were higher for the shorter LWS (85%) than for the MOST (70%) program. The fact that one participant dropped out of the LWS program when his care partner could no longer accompany him speaks to the critical role of care partners. Aside from transport, those who needed assistance in toileting and dressing or had communication difficulties could not have participated without their care partners.

Participation in a research or evaluation study requires additional commitment for assessment above and beyond the program itself. Reimbursement for transport was provided, and assessments were conducted at the same facility as the program for participant convenience. Unfortunately, not all participants were able or willing to return for assessments at program completion (T2) or follow-up (T3), reducing the sample size available for repeated measures analysis. The small number of care partners precluded meaningful examination of change on the GDS or CSI measures. In addition, the findings concerning participant change on the functional measures must be interpreted very cautiously due to the sample size. For instance, to detect a difference of half a standard deviation on the RNL (with 80%, alpha .05, two-tailed test), 63 subjects per group are required.[64] The small sample size was therefore the primary limitation of the current study. We had planned to implement the program concurrently in one other local organization, however this was not feasible due to resource issues. This limited the ability to recruit for the study.

Although preliminary and requiring replication with larger samples, the findings were encouraging. The MOST group (but not the LWS group) improved significantly on the ABC Scale, a measure of self-efficacy related to balance[47] and community mobility,[40] and the RNL, a measure of satisfaction with social participation.[37] Perceived abilities to carryout activities of daily living (as measured by the FIM^{TM}) also improved in the MOST group and may have been influenced by the practical problem-solving activities in the group.

Following the program, MOST participants were also significantly more likely than LWS participants to be enrolled in a formal exercise program. When exercise participation at T1 was taken into consideration, this finding was still significant at T3. This finding might be expected as people indicated at the outset that they were interested in exercise, however the program may have reinforced this lifestyle change by enhancing self-efficacy. For this population in particular, the social benefits of group exercise classes may be equally or more important than the physical benefits[54] although more difficult to quantify.

Although it is important to examine indicators of functional status with standardized measures commonly used in this population (such as the CMSA, FIM^{TM}, and GDS), other approaches are needed to capture potential program benefits in a population with such diverse and individual needs and expectations. Consistent with the self-management approach, personal goal setting is a vital component of MOST and one of the key features that distinguishes this program from strictly education programs like LWS. All but one of the MOST participants achieved at least some of their short-term goals and 72% met or exceeded their long-term goals. Even though GAS scores provide a quantitative indicator of the level of goal attainment for each individual and the group as a whole,[65] a qualitative examination of the types of goals participants set for themselves provided tremendous insight into the hopes and expectations of this population as well as the challenges they experience in their daily lives. For instance, some people simply wanted to try and make their own breakfast, write a letter, or go to the shopping centre.

The qualitative data from the focus group discussions provided further insight into the needs of this population. The expectations of people in the LWS program for information and social support were met while they were in the program. Although one individual subsequently joined a recreation program with assistance from the LWS facilitator, it did not appear that participants acquired the ability to access community programs independently or to deal effectively with ongoing and new issues. The opportunity to exercise on land and in the water met the initial expectation of many of the MOST group, although they would have liked these exercises to be more individually tailored. Although several felt that they had improved physically, such gains were not reflected in changes on the FIM^{TM} or on the CMSA-Activity Inventory. The problem-solving component of the MOST is intended to help people manage or take charge of various aspects of their lives. Even though only continued exercise was examined in this study, several people put plans in place in this regard.

The psychosocial aspect of programs such as LWS and MOST was clearly very important. The shared experience of the stroke was able to bridge the diversity in backgrounds and became the foundation for strong group cohesion in both programs. Improved mutual understanding and communication with partners emerged as one of the strongest findings. The opportunity for care partners to meet separately, followed by a joint session with stroke participants, was considered an invaluable aspect of the MOST program and should be considered by other programs such as LWS. Participants were unanimous in their desire for continued contact with group members, suggesting monthly meetings or organized outings as potential strategies.

Conclusions

Although others have suggested that the self-management approach may be valuable in helping individuals with stroke make the transition from rehabilitation to independent living,[25] to our knowledge this is the first attempt to develop such a program or to compare such a program to an existing education program. Even though MOST is more expensive to deliver, these preliminary findings suggest that the added benefits may justify the cost. In fact, the Canadian Heart and Stroke Foundation is adapting the LWS program to incorporate self-management principles. Planned further investigation of MOST includes a formal randomised Waiting List Control study into the feasibility and effectiveness of telehealth delivery of MOST as well as evaluation of ongoing clinical delivery.

This current study provides an important understanding of issues pertaining to program development and delivery as well as benefits perceived by participants in MOST and LWS. The importance of psycho-social factors is emerging in the clinical and research community. The current study is confirming these findings and will be informative for further examination of the self-management approach for people with stroke living in the community.

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