Stroke Rehabilitation at Home
Lessons Learned and Ways Forward

Nancy E. Mayo, BSc(PT), MSc, PhD

The modern hospital evolved from a place to care for the sick staffed by members of religious orders to a symbol of rationality and progress fostering medical innovation, professional development, science, research, and training. As hospitalization grew to be the norm for seriously ill patients, there was also the recognition that not all care had to be institutionalized, and in the 1960s, a practice of offering hospital care at home for the terminally or chronically ill emerged. By the 1990s, the hospital-at-home became an attractive option in response to demand for acute-care hospital beds. In 1997, hospital-at-home was tested for acute stroke patients in Italy. Published in 2004, 120 patients were randomized from the emergency department to be managed at home or to be managed in the hospital as usual. The results showed that functional and neurological outcomes improved similarly in both groups, but patients managed at home had lower depression scores, fewer complications, and were more likely still to be at home at 6 months. With the development of effective therapies for acute stroke, hospital admission was considered best practice and stroke unit care was shown to be superior to other models of care. The hospital-at-home approach changed from a focus on avoiding hospitalization to a focus on early discharge from acute care but with support for ongoing recovery by providing rehabilitation and other services in a community setting.

Home rehabilitation for stroke can now be considered under 3 broad rubrics: (1) rehabilitation at home to replace acute care—the early supported discharge (ESD) model; (2) rehabilitation at home to replace institutional rehabilitation; and (3) home exercise to prevent deterioration and promote health through physical activity. The aim of this review is to summarize what lessons have been learned from the many well-designed clinical trials evaluating the effect of providing ≥1 aspects of stroke rehabilitation in the home and identify promising avenues for implementation so that the greatest good can be achieved for the greatest number of people at the least cost. The studies that have been done are heterogeneous as to purpose, population, timing from stroke, nature of the interventions, and the type of control group. This heterogeneity provides rich learning material.

Early Supported Discharge

The evidence for ESD has been systematically reviewed. The meta-analysis of individual patients’ data from 11 trials involving 1597 patients summarized in the Figure found a reduced risk of death or dependency for the ESD group in comparison to the usual care group (summary odds ratio, 0.79; 95% confidence interval [CI], 0.64–0.97), shortened length of hospital stay by an average of 8 days (95% CI, −4 to −11 days), and showing strongly favorable effects on extended activities of daily living (odds ratio, 0.12; 95% CI, 0.0–0.25).

Table 1 summarizes the results across the different models of ESD presented by Langhorne et al. The effect was the greatest when the ESD was provided by a coordinated multidisciplinary team and for stroke patients with mild to moderate disability.

One of the striking features of these trials is that less than half (median, 41%) of patients with stroke were eligible for ESD (range, 13%–68%) because they were ill, discharge home was not realistic because of the lack of a caregiver, or the stroke was not disabling enough. The implication is that if ESD is implemented as a policy, similar eligibility criteria as the trials would need to be applied if the same benefit is to be observed. However, implementing an ESD program to a proportion of people with low disability would not necessarily be a bad thing as this group has many physical, emotional, cognitive, and participation consequences that have a negative effect on quality of life. These difficulties are often unrecognized during hospitalization and may only become evident after returning home. Whether and what kind of intervention people with mild stroke need is not fully understood as the trials of ESD did not provide subgroup analyses. A recent trial providing telephone support post discharge for people with mild stroke revealed that few availed themselves of this support service on their own and even when offered directly, there was no effect on outcomes. A more active ESD for people with low disability may be a way forward.

One way of identifying the full effect of adopting a policy of ESD is to use an outcome measure that can be linked to costs. These measures fall under the rubric of utility measures, which are designed to create a single value across different professional development, science, research, and training.
outcome domains that are weighted by their value in terms of preference. The most widely used utility measures are generic meaning that they were developed for use in the general population to identify common health states. Several overviews of these measures have been published in different contexts, but generally, gains in 1 domain are traded off against losses in others. The best known of these generic utility measures are the Euroqol-5D, Short Form-6D derived from the Short Form-36, Health Utilities Index, and the Australian developed Assessment of Quality of Life. All have been used in stroke, some extensively. A key feature of these measures is that patients rate themselves on the domains yielding a health profile. Specific health profiles are valued by members of the general population and modeled to produce a single value representing the quality of life; when linked to life expectancy, these values yield quality-adjusted life years. With this common metric, it is possible to link outcomes to cost. A further advantage of these measures is that they would meet criteria for patient-centered outcomes defined as outcomes, beyond survival, that matter to patients, symptoms, function, and health-related quality of life.

Patel et al used the Euroqol-5D to compare stroke unit, stroke team, or domiciliary stroke care. Table 2, recast from this study, shows that stroke unit care was superior in terms of death/institutionalization avoided as 87% were alive and at home at follow-up, 12 months after randomization, and quality-adjusted life year gain was 0.297, larger but not significantly so than the other groups. When linked to cost, the home-care group was more advantageous, ≈£30,950 per quality-adjusted life years gained not surprising as a large proportion of stroke

<table>
<thead>
<tr>
<th>Table 1. Summary of Outcomes From 3 Models of ESD</th>
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<tbody>
<tr>
<td><strong>Outcome</strong></td>
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<tr>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Services offered</td>
</tr>
<tr>
<td>Coordinated discharge planning and postdischarge care</td>
</tr>
<tr>
<td>Rehabilitation and patient care at home by the team</td>
</tr>
<tr>
<td>Regular team meetings to coordinate care</td>
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<tr>
<td><strong>n studies</strong></td>
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<tr>
<td>Death*</td>
</tr>
<tr>
<td>Death or institutionalization*</td>
</tr>
<tr>
<td>Death or dependency*</td>
</tr>
<tr>
<td>Length of stay</td>
</tr>
<tr>
<td>Cost in comparison to control</td>
</tr>
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</table>

ESD indicates early supported discharge.
*Values are odds ratios for team care vs usual care and 95% confidence interval. Values <1.0 indicate that the team approach had a lower odds of death and other poor outcomes than the usual care group; 95% confidence interval that excluded 1.0 indicates statistical significance.*
unit and team care is for hospital resources. A new generation of ESD trials are being designed in the context of early discharge with the inclusion of a utility measure to permit summarizing the expectations of patients with respect to ESD. A key expectation was that the team would provide support, so patients could manage and feel comfortable and safe being at home. Patients had concerns about safety, particularly having another stroke out of reach of professional help. They expected the rehabilitation team to facilitate the recovery of independence and of prestroke abilities, and of course, they all hoped for full recovery. They expected the rehabilitation team to help. They expected the rehabilitation team to facilitate the recovery of independence and of prestroke abilities, and of particular having another stroke out of reach of professional help. They expected the rehabilitation team to facilitate the recovery of independence and of prestroke abilities, and of course, they all hoped for full recovery. They expected the rehabilitation team to help. They expected the rehabilitation team to facilitate the recovery of independence and of prestroke abilities, and of course, they all hoped for full recovery. They expected the rehabilitation team to help. They expected the rehabilitation team to facilitate the recovery of independence and of prestroke abilities, and of course, they all hoped for full recovery.

Table 2. Selected Results at 12 Months From a Trial of 3 Models of Care for Acute Stroke From the Study by Patel et al18

<table>
<thead>
<tr>
<th>Stroke Unit</th>
<th>Stroke Team</th>
<th>Home Care</th>
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<tbody>
<tr>
<td>n randomized</td>
<td>148</td>
<td>147</td>
</tr>
<tr>
<td>Alive and home*</td>
<td>87%</td>
<td>69%</td>
</tr>
<tr>
<td>Gain in QALY (SD)*</td>
<td>0.297 (0.257)</td>
<td>0.216 (0.370)</td>
</tr>
<tr>
<td>Direct costs (SD)*</td>
<td>£11 450 (9 745)</td>
<td>£9 527 (8 664)</td>
</tr>
<tr>
<td>Cost per QALY gained</td>
<td>£38 552.19</td>
<td>£44 106.48</td>
</tr>
</tbody>
</table>

QALY indicates quality-adjusted life year.
*P<0.05; QALY as measured by the Euroqol-5D.

Rehabilitation at Home
The second set of home rehabilitation interventions was carried out to ascertain whether rehabilitation at home could replace institutional rehabilitation, inpatient or outpatient. The main impetus for these trials is that institutional care is expensive, and if rehabilitation is needed for a period of months, prolonged institutional care will not be feasible. If some care can be equivalently carried out in patients’ homes, this would free up room in rehabilitation facilities for those who need this care venue. Other patients could recover in the comfort of their own homes, removing the need for travel to and from. However, on the negative side, the therapy team would need to spend much time on the road, taking resources away from therapy.

A 2010 synthesis by Hillier and Inglis-Jassiem tested the hypothesis that home rehabilitation would cost less than clinic-based care but would not compromise recovery, essentially a noninferiority outcome hypothesis. Eleven trials of single discipline physical or occupational therapy, or multidisciplinary care, involving 1711 adults within 12 months of stroke were identified. Four of the trials found no difference between home and outpatient care; the remaining trials showed greater benefit for home rehabilitation in terms of cost, satisfaction, and caregiver strain. A meta-analysis of the results on the Barthel Index (scored out of 20) found that, depending on the time of assessment, the effect in favor of the home group ranged from 1 to 4 U. The effect of 1 of 20 on the Barthel Index may seem numerically small, but it is clinically relevant indicating a greater difference in independence level on 1 of the 10 activities of daily living. As this group scored initially >16 of 20 on the Barthel Index, a difference of 1 is likely to be on a high-level activities of daily living, such as walking and stairs, indicating an important benefit. The most recent trial included in the meta-analysis was published in 2004. Later results are concur.

While not designed to test a hypothesis about the effectiveness of home rehabilitation, the surprising results from the LEAPS study, published in 2011, contributes additional evidence that rehabilitation at home can be as, or even more effective, than institutional based care. First, the features of LEAPS study will be presented, and then some reasons why home rehabilitation is so powerful will be explored.

This important study, published in the prestigious New England Journal of Medicine, was designed to test the hypothesis that, in addition to usual care (physical therapy provided according to current standards of practice), provision of a specialized locomotor-training program delivered early (2 months after stroke) or late (6 months after stroke) would be more effective in increasing the proportion of study participants who had higher functional walking levels at 1 year than provision of a control intervention that included progressive resistance training. The work by Nordin et al in summarizing the expectations of patients with respect to ESD provides information on how to move forward with implementing ESD. A key expectation was that the team would provide support, so patients could manage and feel comfortable and safe being at home. Patients had concerns about safety, particularly having another stroke out of reach of professional help. They expected the rehabilitation team to facilitate the recovery of independence and of prestroke abilities, and of course, they all hoped for full recovery. They expected to learn different strategies to deal with these challenges and to create a new everyday life. They felt being home would make them feel more capable.

But the reality is that people face huge changes because of stroke, and it may be a struggle to accommodate their changed selves in an unchanged house, which may not even feel like home anymore. What better way of doing this than with the support of an ESD team?
walking speed, <0.4 m/s), the critical value to leap over was
0.4 m/s or faster and (2) for people with initially moderate
gait impairment (gait speed, 0.4 to <0.8 m/s), the leap was to
0.8 m/s or faster. Fifty-two percent of people achieved the tar-
gested response with no significant differences across groups.

The home rehabilitation program was offered as an active
control and was not conceived of as potent with exercises tar-
geting flexibility, range of motion, strength of arms and legs,
coordination, and static and dynamic balance; participants
were also encouraged to walk daily. This approach was better
accepted than was intensive rehabilitation as the attrition rate
was only 3% where as it was 13% and 17% for those in the
early and late locomotor-training groups, respectively.

The finding of a similar degree of improvement in the home
rehabilitation group as with intensive locomotor-training
came as a surprise to the rehabilitation community.27 However,
the finding that 52% met the targeted response should be
celebrated as therapy commenced on average, 64 days post
stroke, outside the window of the greatest recovery. This find-
ing supports the benefit of ongoing therapy for people with
stroke, therapy of any kind. Another notable finding is that,
at 6 months post intervention, the home group and the early
training groups responded more favorably on all secondary
outcomes than the late training group. These findings support
the widespread effects of therapy and also that there is no need
to wait to provide therapy for people with stroke, the earlier
the better.

The authors concluded that home exercise requires less
expensive equipment, its implementation requires a smaller
number of staff members, less training is required for physical
therapists, and patients are more likely to adhere to the regi-
men. Another interpretation is that rehabilitation is so power-
ful it can be done in any venue.

A way forward with implementing such a program at a
population level would be to weigh the travel costs of therapy
staff against the benefits and select implementation where
travel would be minimized, likely in large urban centers where
patients would live close to the hospital. People who could be
easily treated at home should be, saving expensive hospital-
based resources for those who would be more difficult for the
team to access.

Home Exercise Programs

The third form of home-based rehabilitation is providing
home programs for people with stroke, so they may at least
maintain, if not augment, gains made during formal rehabilita-
tion and to reduce cardiovascular risk profile. American Heart
Association recommend28 that people with stroke perform
aerobic exercises 3 to 7 days per week, as well as strengthening,
flexibility, and neuromuscular exercise 2 to 3 days a
week, for their life time. Clearly institutionalizing this ongo-
ing intervention is not feasible, and home-based programs, if
successful, would be a solution.

Olney et al29 tested this by comparing the outcomes
achieved by 2 groups of people with chronic stroke, 1 with
10 weeks of supervised training (n=38) and 1 group with 1
week of supervised training to learn the program followed by
9 weeks of unsupervised training carried out at home (n=36).
Both groups made equally modest gains on indicators of
motor impairment (gait speed, >6 minutes; muscle strength)
and cardiovascular risk (weekly physical activity, physiologi-
cal cost of walking) and on physical and mental health. Gains
in some outcomes were maintained for 1 year. The authors
concluded that a brief period of exercise instruction followed
by home exercise produced changes in physical function that
are retained >1 year as similar to a supervised program. The
home program is much more feasible.

In a study published in 2004, Salbach et al30 found that 6
weeks of supervised walking training resulted in greater gains
in the distance walked in 6 minutes (40 m) than did an atten-
tion controlled intervention involving exercise for the upper
extremity (5 m). However, further analyses (published as abstract31) found that, on average, differences post interven-
tion were lost by 6 months with only 1 of 3 of people who
improved during the walking intervention maintaining these
gains to 6 months. A major limitation to this type of interven-
tion is that many people eligible for this trial (251/344, 73%)
opted out of participating because they were not interested or
too tired to attend the clinical setting for therapy.

To address this, Mayo et al32 subsequently designed a trial
of home-based therapy testing 2 types of interventions: a
task-oriented exercise and walking program (exercise group;
n=44) and a cycling regimen (cycle group; n=43) for a 1-year
period. Although the programs were not supervised directly,
both groups were provided with instruction, the program was
progressed, and all equipment was supplied. All were visited
at home 13× for the 12 months and had regular telephone
monitoring. Both groups had elements of repetitive training,
but the cycling regimen was simpler with more opportunity
for continuous repetitive training, the cycle was a visual
reminder to exercise, and removed the dependence on opti-
mal weather conditions. The hypothesis was that, for a 1-year
period, walking capacity would improve in both groups, but
the cycle group would experience greater increases in walking
ability, secondarily to developing better exercise habits, and,
consequently, greater gains in participation and health-related
quality of life. The premise was that no exercise is beneficial
if it is not done and adherence to the cycling regimen might be
greater because of its simplicity. Of the 607 people eligible,
only 87 agreed to enter the trial claiming lack of interest in
exercise as the primary reason. The trial was stopped early
because of difficulty recruiting and futility. Of those who did
enter, retention was poor with 28 of 43 (65%) randomized to
the cycle group available for the 1-year assessment and 37 of
44 (84%) in the exercise group, necessitating data imputation
for the analysis.

There were no remarkable differences between groups on
the primary outcome measure, distance walked in 6 minutes,
with both groups showing no change, on average. However,
there was a tendency for the exercise group to have a larger
proportion of responders, people making a change in the dis-
tance walked in 6 minutes of >20 m: ≈40% versus ≈23%, for
exercise and cycle groups, respectively. Secondary outcomes
were analyzed using a global response method. For global
physical function, estimated across 5 measures, the odds of
response disfavored the cycle group but not significantly so..
Adherence was measured as best it can using diaries and personal interviews, and there were no differences between groups in the proportion with high adherence (36% versus 33% for exercise versus cycle). Depression affected adherence. There was a tendency for greater adherence to result in greater change in the distance walked in 6 months, most marked in the exercise group. The study concluded that the 2 programs were equally effective in maintaining walking capacity or equally ineffective in improving it, depending on whether the view is of a glass half full or half empty.

This study indicates that providing unsupervised home rehabilitation is difficult, but at least a proportion of people, ≈1/3, will adhere and benefit. It remains to identify early on after stroke those most likely to adhere and to benefit and to ensure that they are offered programs. A challenge will be to engage the approximately 2/3 of people who cannot easily adhere to home rehabilitation.

These challenges also become opportunities to develop successful implementation strategies. For those who will likely do well, provide them with the tools to do well: (1) clearly written instructions for continued home exercise progression; (2) regular follow-up at clinic where progress is actively measured and communicated back to the patient and family; (3) provision of self-management tools (4) referral to community-based programs that provide opportunities for physical, social, and personal development. There is emerging evidence for these tools.33–36

For those with limited capacity to adhere to home rehabilitation, professional team input to a home-care team could be an option. At the least, support, regular follow-up, and perhaps a booster rehabilitation program could keep this group independent enough to remain at home. The costs of admission to long-term care could offset the additional expense of keeping in touch with this difficult to manage group.

Why Does Rehabilitation at Home Work or Not?

What could contribute to this powerful effect of home rehabilitation? Even in a research context with therapy as an established protocol, providing therapy in the home environment supports continuity of care, establishes a relationship that the therapist and patient are making a journey together, provides an authentic environment for the experiences of functioning, and encourages patients to develop problem-solving skills.37,38 Jensen39 observed that physical therapists use a great deal of skilled communication grounded in observation, active listening, and thoughtful questions. It is likely that these skills contribute to a successful read of the patient.

This read is likely to motivate the patients and also facilitate developing problem-solving skills in a realistic and relevant setting, the home. Problem solving is emerging as a component of developing healthy coping strategies for people post stroke.40

Why else might home rehabilitation work? Siemonsma et al21 systematically reviewed the determinants of successful implementation of home-based rehabilitation for people who experienced a recent stroke. The home environment enables a more client-centered approach, encourages patients’ involvement in the rehabilitation process, and calls on problem-solving skills. In my study of ESD in Montreal,41 the qualitative information volunteered by subjects, family members, and service providers strongly supported that the ESD intervention empowered the subject and his or her family to take charge of the care, and this involved active decision making and concrete action plans.

A qualitative study by Olofsson et al42 summed up the importance of home post stroke: “If only I manage to get home I’ll get better.” Although in hospital, the patient with acute stroke felt that they became a depersonalized object for caring measures. However, Tamm43 argues that home rehabilitation can also be perceived as negative as essentially the public sector moves into private space such that the home now has to function as a public workplace, and patients have to ensure a good working environment.

Perhaps the greatest barrier to successful home rehabilitation is the lack of motivation. In a rehabilitation facility, an unmotivated patient will still receive therapy and is likely to be swept along with the crowd for other activities. At home, they will not. A recent systematic review of apathy post stroke44 estimated a prevalence in the postacute phase of ≈34%. Mayo et al45 in a longitudinal study of apathy post stroke found that any degree of apathy had a strong effect on participation in meaningful activities and life’s roles likely explaining in part why 50% of people 6 months post stroke lack for meaningful activity.46 Apathy poststroke is under studied, poorly measured, and largely ignored in the rehabilitation process.

Conclusions

Among the lessons learned are that ESD is effective. Another valuable lesson is that rehabilitation for stroke is so powerful that it can be offered in any setting without sophisticated equipment or technology. We also learned that without supervision only ≈1 of 3 of people with stroke will be able to follow or benefit from a home rehabilitation program.

The ways to move forward are to implement what we do know and to develop optimal implementation strategies and policies. We also need to implement home or community-based rehabilitation programs to those who can and will engage and benefit. We need to identify this group early and provide resources, so they can optimize their outcomes. We need to develop solutions for the challenging patients, which may mean institution-based, not home-based rehabilitation, or closer follow-up with home care. We need to address apathy post stroke and to use advancing knowledge on neuroscience to develop interventions. Those that show promise, an emphasis on goal setting, and the development of problem-solving skills could be achieved through self-management programs, which are now delivered through media. We have information, we can interpret this information at the individual and population level, and we have effective interventions; we are still lacking appropriate and focused implementation strategies. I suggest that the 4Is—information, interpretation, intervention, and implementation—as shown in the Figure are the lessons learned and the ways forward.


Key Words: exercise ■ hospitalization ■ rehabilitation ■ stroke
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卒中家庭康复
现状与展望

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关键词：锻炼;住院;康复;卒中

现代医院源自过去的宗教团体成员负责照顾病患者的场所,已发展成为理性并促进医疗创新、专业发展、科学研究和培训的机构。随着危重患者住院治疗成为常态,人们对护理照料都必须在医院进行。20世纪60年代,出现了为晚期慢性病患者提供家庭照料;到了20世纪90年代,为应对急性病住院治疗问题,医院-家庭照料成为一个具有吸引力的选择。1997年,医院-家庭治疗首次在意大利用于急性卒中患者。据2004年文献报告,120例来自急诊的患者被随机分到两组,一组常规住院治疗,另一组予以家庭照料。结果显示,两组患者在神经功能改善方面基本一致,但家庭照料组患者抑郁评分较低,并发症少,且6个月时在家的康复比率更高。随着急性卒中有效治疗技术的发展,住院治疗被认为是最佳治疗模式,而卒中单元的医疗照料被认为优于其他照料模式。医院-家庭护理模式从着眼于避免住院治疗,转变为重点关注出院后不再需要紧急救治但仍在恢复期并需要在社区继续提供康复及其他服务的患者。

目前卒中后家庭康复包含以下三大准则: (1) 家庭康复代替急性照料-早期出院支持治疗模式(early supported discharge, ESD); (2) 家庭康复代替专业机构康复;(3) 通过家庭运动锻炼防止病情恶化及通过物理促进健康。本综述的目的主要通过总结从众多严格设计并且至少有一方面有关家庭卒中康复疗效评价的临床试验中获取的结果,确定确实可行的方法,以便能用最小的成本使最多的人获益。这些研究在研究目的、人群、卒中时间、干预措施的性质以及对照组的类别方面各有不同。这种异质性给我们提供丰富的借鉴资料。

早期出院支持

ESD 的有关证据已有系统综述。一项涉及11项临床试验包括了1597 例患者的荟萃分析数据(详见图)显示:与普通照料组相比,ESD 组患者死亡及依赖风险更低(比值比( oddes ratio, OR ), 0.79; 95% 可信区间 ( confidence interval, CI ), 0.64~0.97),平均住院日减少 8d (95%CI , -4~ -11 d)，而且对增强日常生活能力有益 (OR 值，0.12; 95%CI, 0.0~0.25)。表 1 总结了 Langhorne 等给出的多种 ESD 模型的结果。结果显示由多学科协作的 ESD 以及用于轻到中度残疾的卒中患者治疗效果最好。

由于缺少家庭看护者,这些患者在护理和出院回家记录不详,或者由于卒中致残过于轻微,这些试验的一个突出特点是符合 ESD 条件的卒中患者不到一半(中位数 41%, 13%~68%)。提示如果将 ESD 作为一项措施来实施,就要使用与临床试验相似的筛选标准,才能观察到同样的获益结果。然而,对轻度残疾的卒中患者处理 ESD 未尝不是一件好事情,因为这些患者的存在对生存质量有影响的躯体、情感、认知和社会参与能力异常。这些问题往往在住院期间不被发现而在回家之后才明显。由于 ESD 试验未提供亚组分析,因此对于轻症卒中患者而言,是否需要干预或者需要何种干预措施,目前还不清楚。

最近一项对轻度卒中的出院后的电话回访研究显示,即使直接向患者提供这项服务,也很少有患者从中获益,并且对结局也没有太大的影响。对轻症患者进行更加积极的 ESD 也许是一个未来发展方向。将成本与结局指标相结合是一种评价 ESD 整体效果的方法,该方法在实用的指标条目下,设计用单个指标来评价不同结局,而这些结果通常要用不同指标才能反映。使用最广泛而实用的量表是采用源自一般人群健康状况评价的通用参数。有关这些量表的适用场合已有研究论述,但一般这些量表都只关注其中一个方面而忽略其他方面。这些量表中最有名的是欧洲五项健康量表(Euroqol-5D)15, 来源于生存质量评价量表SF-36(Short Form-36)的 SF-6D(Short Form-6D)16, 健康效用指数12以及澳大利亚生存质量评估量表17。这些量表都用于卒中评估,有些还用于卒中之外的其它疾病。这些量表的一项重要特征是患者可以自我评价健康状况。从一般人群中获得对特定健康状况的评价,并将其模型化,从而产生一个能代表生存质量的指标,当指标涉及预期寿命时则使用生存质量校正。用这个通用指标可以将结局和成本联系起来。这些量表的另外一个优势是符合以患者为中心的标准,不仅关注生存结局,而且注重患者本身、症状、功能以及与健康相关的生存质量11。

Patel 等18用 Euroqol-5D 研究比较了卒中单元、卒中团队以及家庭卒中照料的效果。根据这项研究重制的表 2 显示,卒中单元在降
低死亡率/避免在专门机构康复方面效果较优，因为有 87% 经卒中单
元照料的患者在 12 个月后随访时仍然存活且没有再住院。这些患者生
存质量调整年平均延长了 0.297 年, 并且高于其他组别, 但未达到统计
学差异。当综合成本考虑时，家庭照料组优势更大，平均每延 1 年生
存质量调整年所支出的费用大约是 30 950 英镑, 低子院内卒中单元或卒
中团队所产生的费用。新一批结合成本 - 效益分析方法, 针对
出院早期患者
的 ESD 临床试验正在筹划中。鉴于 ESD 具有强有力证据, 下一步的研究重
点和一系列新的科学问题是对有关如何最佳去实施。最近一篇综述指出专业人员价值观和信
念的不一致也降低了执行力度。越多学科团队外, 管理团队和患者
之间的康复协作以及患者和照料者提高解决技巧都是成功的基础。这
些方面进行特别培训可能是需要的。

在加拿大安大略区, 自 2012 年至 2015 年 4 月已有 5 个中心也积
极开展 ESD。正在进行的 ESD 研究涉及了项目评价方法学, 包括流
程、结局、目的和目标的一致性。还应考虑来自项目接受者经历的各
种流程和结局。Nordin 等
总结了患者对如何推进实施 ESD 的期望。其中一个重要方面是患者可以获得团队的支持, 这样就能在家中进行
管理并感到安全和舒适。患者关注众多安全问题, 特别是再次卒中时
是否能得到专业诊治。患者期望康复团队能够促进恢复他们的独立生
活能力并卒中前能力, 当然更希望能在愈。也希望能够学习到应对疾病所
带来的各种方法并开始新生活, 能到在家使自己更有能力。

但现实是患者必须面对由于卒中造成的巨大变故。在没有相
应变化的房子里, 要适应因为残疾导致的自身改变是一个严峻挑战,这使得他们再也没有家的感觉。有比 ESD 团队支持更好的办法来解
决这个问题吗?

### 家庭康复

进行家庭康复干预措施的第二步就是确定家庭康复是否能取代专
门机构康复或者住院、门诊治疗。这些研究的原因在于医院照料费用
昂贵。如果康复期需要数月时间, 长期的专业机构照料就不太可行。如
果同样的照料可以在患者家中进行, 这可以为那些真正需要的患者
腾出康复设施。而其他患者可以在他们舒适的家中进行康复, 也避免
了往返的劳顿。然而, 不利的一面就是治疗团队得舟车劳顿, 并
花费更多的医疗资源。

<table>
<thead>
<tr>
<th>研究数量 (个)</th>
<th>9</th>
<th>3</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>死亡 *</td>
<td>0.69 (0.44-1.07)</td>
<td>0.95 (0.52-1.74)</td>
<td>1.90 (0.90-3.98)</td>
</tr>
<tr>
<td>死亡或依赖</td>
<td>0.65 (0.45-0.93)</td>
<td>0.75 (0.50-1.14)</td>
<td>1.32 (0.75-2.33)</td>
</tr>
<tr>
<td>相对于对照组的成本</td>
<td>未见相关报道</td>
<td>未见相关报道</td>
<td>未见相关报道</td>
</tr>
</tbody>
</table>

注: ESD: 早期出院支持。

* 值是团队治疗与常规治疗组之间的比值比和 95% 可信区间。值提示团队治疗相比常规治疗组死亡率更低; 不包含 1.0 的 95% 可信区间提示有统计学意义。
2010年，Hillier和Inglis-Jassiem综合分析了一系列试验，以验证家庭康复可能比临床护理成本低而且不影响康复效果的假设是否成立。11项有关单一物理疗法、职业疗法及多学科护理的试验对这个假设进行了验证，包含了1711例病程在12个月内的成年卒中患者。其中4个试验发现家庭护理和门诊护理无显著性差异，其余的试验则显示家庭康复在成本、满意度和照顾者压力方面更优。一个有关巴氏指数（20分为满分）的荟萃分析结果发现，家庭护理组的效果优越1~4个单位且与评估时间相关。巴氏量表20分中的每1分从数字上看似乎很小，但实际上它已经能从临床相关的角度阐明10个不同级别的日常生活能力差异。比如这个组最初巴氏指数大于16分者，1分之差很可能代表高水平的日常生活能力，比如能够行走和上下楼梯，这预示预后良好。最新的荟萃分析报告已于2004年发表。之后的研究结果与之基本一致。

2011年发表的LEAPS研究，其本意并非要研究家庭康复的效能，却额外得出一个令人兴奋的结果。此研究结果显示家庭康复和专业机构康复相比效果相当，甚至更好。下面，先讨论LEAPS研究结果，再分析家庭康复如此强大的原因。

这项重要的研究发表在著名的新英格兰医学杂志上，其研究假设是：常规照料（按照现行标准进行的物理治疗）加上对早期（卒中后2个月）或晚期（卒中后6个月）提供专门的运动训练计划与卒中后2个月开始的家庭物理治疗（包含渐进性力量和平衡训练）相比，可以增加卒中后1年功能性行走的比例。对4909例患者进行初筛后，408例（约8%）患者被随机分组，139例进入早期训练组，143例进入晚期训练组，126例进入家庭康复组。早期训练组和家庭康复组在卒中后2个月进行干预，而晚期训练组在卒中后6个月进行，每组每次进行90min的训练，每周3次，持续12~16周。

这个研究有许多独到之处。结局采用2个有效的定性指标而非均值表示：（1）对步态严重损害的患者（最初步行速度<0.4 m/s），达到或超过临界值0.4 m/s；（2）对步态轻微损害的患者（步行速度0.4~0.8 m/s），达到或超过临界值0.8 m/s为有效。52%的患者达到了目标值，但各组间的结果无统计学差异。家庭康复措施提供积极的掌控，而不会随意改变锻炼目标，从灵活性、运动范围、肢体力量、协调性和动态平衡方面进行锻炼，也鼓励参与者每天自主行走。这个方法比强化康复更容易被接受，退出率只有3%。而早期运动训练组和晚期运动训练组的退出率分别为13%和17%。

家庭康复组和强化移动训练组有着相似的改善程度，这个发现让康复界感到兴奋。Olney等比较了两组慢性卒中患者的结局，其一组接受监督训练10周（n=38），而另一组（n=36）接受1周监督训练后再进行9周无监督训练。两组在活动障碍（步行速度<6 min；肌肉力量）和心血管风险（每周体育活动，步行生理消耗）以及身心健康方面都获得了同等的轻微改善。部分获益持续1年以上。作者的结论是短期锻炼指导加上随后的家庭锻炼可以使用身体机能产生变化，并且可以持续1年以上。其所得的效果与监督项目计划相似，而家庭康复计划则更加可取。

Salbach等在2004年发表的一项研究发现，6周监督步行训练（40 m）后，6 min步行距离比口令指示的上肢锻炼对照干预（5 m）更远。然而，进一步分析（以摘要的形式发表）发现，干预后的差异在平均6个月内消失，仅有1/3参与步行训练者能维持6个月。这项干预的一个突出缺点是许多符合入组条件的患者（251/344,73%）对此不感兴趣或者过于劳累而不参加这项试验。针对这个问题，Mayo等随后设计了一个家庭治疗试验来验证2种不同的干预方法：一种是有任务导向的锻炼和步行计划（锻炼组；n=44），另一种是自行车锻炼（自行车组；n=43），两组均进行为期1年的锻炼。尽管计划不直接接受监督，但两组患者均得到指导。项目计划循序渐进，并提供相应的设备器材。所有的研究对象12个月内进行13次家庭随访并且进行定期电话回访。两组均有重复训练，但自行车组更易进行连续重复训练，自行车作为一个可视物可以提醒人们去锻炼，且不受天气影响。这个试验的假设是，经过1年训练后，两组中步行能力都能改善，但自行车组的步行能力提高更多，还能培养更好的锻炼习惯，因而最终在社会参与能力以及健康相关的生存质量中有更大的获益。前提是如果执行，没有一项锻炼是有好处的。由于自行车锻炼更简单，更易坚持因而获益更大。在607例符合纳入标准的患者中，仅有87例同意参加试验，其余多以对锻炼不感兴趣为主。

### 表2 从Patel等对3种急性卒中护理模式在12个月的研究结果筛选

<table>
<thead>
<tr>
<th></th>
<th>卒中单元</th>
<th>卒中团队</th>
<th>家庭护理</th>
</tr>
</thead>
<tbody>
<tr>
<td>QALY（标准差）*</td>
<td>0.297（0.257）</td>
<td>0.216（0.370）</td>
<td>0.221（0.344）</td>
</tr>
<tr>
<td>直接成本（标准差）*</td>
<td>£11 450（9745）</td>
<td>£9527（8664）</td>
<td>£6840（9353）</td>
</tr>
<tr>
<td>QALY每增加1年所需要的成本</td>
<td>£3 552.19</td>
<td>£440 106.48</td>
<td>£30 950.03</td>
</tr>
</tbody>
</table>

注：QALY：生存质量调整年；£：英镑。

*P<0.05；生存质量调整年由欧洲五项健康量表衡量。
要原因而拒绝了。这项试验由于招募患者难和无实际意义而提早结束。参与者依从性差，43 例符合入组条件的患者中仅有 28 例（占 65%）随机进入自行车组并完成 1 年评估，另外 44 例符合入组条件的患者中仅有 37 例（84%）进入锻炼组。这项试验还需要填补数据才能进行分析。

参与者依从性差，43 例符合入组条件的患者中仅有 28 例（占 65%）随机进入自行车组并完成 1 年评估，另外 44 例符合入组条件的患者中仅有 37 例（84%）进入锻炼组。该试验还需要填补数据才能进行分析。两组的主要结局（步行 6 min 距离）无显著性差异。然而，有锻炼组中有效者所占比例较大，锻炼组和自行车组在 6 min 内行走距离大于 20 m 的人数比例分别约为 40% 和 23%。次要结局用总体反应法进行分析。对于总体身体机能，采用 5 种指标进行评估，自行车组的有效率低于对照组，但无统计学差异（OR 值，0.65；95%CI, 0.40~1.08）。对总体参与的 4 个参数，自行车组均没能使患者获益，结果有统计学意义（OR 值，0.51；95%CI, 0.27~0.95）。

能用日记记录和面谈的患者被认为依从性是最佳的，两组的最佳依从性比例无统计学差异（锻炼组 vs 自行车组，36% vs 33%）。抑郁可以影响依从性。研究显示高依从性患者 6 min 内行走距离有增加趋势，特别是锻炼组。本研究的结论是两个项目维护步行能力都有效或者提高步行能力都无效，就像人们看玻璃杯是半空还是半满的观点一样。

该研究提示无人监督的家庭康复是困难的，但约 1/3 的患者将会坚持并从中获益。卒中早期哪些患者容易坚持或者获益并确保其得到提供的康复计划仍需要去界定。一个主要挑战是，如何鼓励近 2/3 对家庭康复依从性差的的患者参与进来。这些挑战也可能是展成功实施康复策略的机遇。对于那些依从性可能很好的患者，给他们提供相应的工具以便做得更好：（1）清晰的持续家庭锻炼计划指导；（2）定期门诊随访以及与患者和家属沟通；（3）提供自我管理工具；（4）转诊到社区提供躯体、社会及个人康复的机会。这些工具有效的新证据在不断涌现。

对那些因执行力欠佳而不能坚持家庭康复的患者，专业团队组成一个家庭护理团队或许是一种选择。康复支持、定期随访以及一个强化康复计划至少可以使其能够独立在家里生存。减少长期住院照料成本或许可以抵消解决这些困难的额外费用。

家庭康复为什么疗效不定？

是什么因素使得家庭康复具有如此强大效果？即使使用试验时确定的治疗流程，家庭环境下提供的治疗有利于持续照料，建立治疗者和患者相互合作关系、提供卒中后康复期的可靠环境，并鼓励患者培养解决问题的能力。Jensen 观察到物理治疗师在查看患者时使用大量交流技巧、主动聆听以及细致提问。这些技巧很可能有助于更好地理解患者的需求。这种理解很可能激发患者的积极性并使之在现实生活和家庭中更加积极培养解决问题的技巧。解决问题是卒中后健康策略中的一个重要组成部分。

为什么其它家庭康复也有效？Siemonsa 等系统性回顾了近期家庭康复失败实施的决定因素。家庭环境使得患者有自主权和依从性并为患者提供了一种选择。康复支持、定期随访以及一个强化康复计划至少可以使其能够独立在家里生存。减少长期住院照料成本或许可以抵消解决这些困难的额外费用。

阻碍家庭康复成功的最大障碍可能是缺乏动机。在康复机构，即使患者毫无主动性，仍会和群体一起接受康复治疗。然而在家中，他们不会这样。新的卒中后系统性回顾发现，急性期后淡漠的患病率约为 34%。Mayo 等对卒中患者的抑郁研究发现，任何程度的卒中后淡漠都显著影响活动的主动性。生活的角色也能够在一定程度上解释为什么 50% 的患者在卒中后 6 个月缺乏主动活动。有关卒中后淡漠的研究还在进行当中，在康复训练中大部分被低估或忽略了。

结论

现有证据显示 ESD 是有效的。另外，康复对卒中有着强大的作用，并且不需要复杂的设备或技术。我们也了解到，大约只有 1/3 的卒中患者能够坚持家庭康复并从中获益。

未来发展的方向是采用并改善最佳的实施策略和政策。我们也应该为能积极参与并从中获益的患者提供家庭或社区康复计划。我们要尽早识别这类患者并提供资源，使其预后得到最大程度改善。我们应该有意识地探究康复规划、康复形式和制定问题解决的技巧，目前正通过媒体传播这些知识。我们拥有相关知识，并能将个体和群体水平发挥时作用。我们具备有效干预机制，但缺乏恰当且有针对性的实施策略，我们提议如图中所示的 4I，即信息（information）、解读（interpretation）、干预（intervention）和实施（implementation），可作为现有知识的总结和未来的发展方向。

参考文献