

**From Hospital to Home to Participation: A Position Paper on Transition Planning after
Stroke**

Kristine K. Miller, PT, PhD
Indiana University
Department of Physical Therapy

Susan H. Lin, ScD, OTR/L, FAOTA
Massachusetts General Hospital Institute of Health Professions
Department of Occupational Therapy

Marsha Neville, OT, PhD
Texas Woman's University
School of Occupational Therapy

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Corresponding Author:

Kristine Miller, 317-274-3534, kkmiller@iu.edu

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1 From Hospital to Home to Participation: A Position Paper on Transition Planning after a Stroke

2 Abstract

3 Based on a review of the evidence, members of the American Congress of Rehabilitation
4 Medicine Stroke Group's Movement Interventions Task Force offer these five recommendations
5 to help improve transitions of care for patients and their caregivers: (1) improving
6 communication processes, (2) utilizing transition specialists, (3) implementing a patient-centered
7 discharge checklist, (4) utilizing standardized outcome measures, and (5) establishing
8 partnerships with community wellness programs.

9 Due to changes in healthcare policy, there are incentives to improve transitions during
10 stroke rehabilitation. Although transition management programs often include multidisciplinary
11 teams, medication management, caregiver education, and follow-up care management, there is a
12 lack of a comprehensive and standardized approach to implement transition management
13 protocols during post-stroke rehabilitation. This article uses the Transitions of Care (TOC) model
14 to conceptualize how to facilitate a comprehensive patient-centered hand-off at discharge to
15 maximize patient functioning and health. Specifically, this article reviews current guidelines and
16 provides an evidence summary of several commonly cited approaches (early supported
17 discharge, planned pre-discharge home visits, discharge checklists) to manage TOC, followed by
18 a description of documented barriers to effective transitions. Patient-centered and standardized
19 transition management may improve community integration, activities of daily living
20 performance, and quality of life for stroke survivors while also decreasing hospital readmission
21 rates during the transition from hospital to home to community.

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28 **Statement of the purpose**

29 The purpose of this article is to review the current state of transition planning in stroke
30 rehabilitation focusing on the transition home and into the community within the framework of
31 the Transitions of Care (TOC) model.¹ Specifically, the aims of this paper are to; 1) review
32 current practice and evidence relative to transitions of care in stroke rehabilitation, 2) describe
33 gaps in transition care and offer direction for program development, 3) provide relevant
34 assessments and tools, and 4) make recommendations based on a theoretical framework and
35 evidence to improve care coordination for persons with stroke from hospital to home and
36 community.

37 **Background**

38 Stroke rehabilitation in America is often fragmented and highly variable between
39 healthcare systems,² making comprehensive and coordinated patient-centered care challenging,
40 especially during transitions of care. One of the greatest challenges is coordination and timely
41 transfer of information between providers to optimize outcomes. The National Transitions of
42 Care Coalition (NTOCC) has developed a conceptual model of Transitions of Care (TOC) which
43 defines TOC as an efficient transfer, verification, and clarification of information between
44 communicating providers.¹ The TOC model assumes that all providers are accountable in
45 communicating and receiving pertinent information, and most importantly, patients and families
46 are engaged throughout the process, ultimately leading to successful transitions (see Figure 1 for
47 TOC model diagram).² Successful transitions from acute care, to rehabilitation, to home and
48 community post-stroke should be client focused, with reliable and timely communication
49 between providers in multiple disciplines and multiple locations.

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50 In rehabilitation, transitions of care are centered on patient discharge, usually from one
51 level of care to another. Comprehensive discharge planning must begin early after stroke due to
52 the short median length of time patients spend in the acute care hospital after a stroke (four
53 days).³ This short acute hospital length of stay gives little time for patients and their families to
54 adjust to life changes as a result of the stroke,⁴ and prepare for the long road of recovery and
55 reintegration that lies ahead.

56 As transition programs have developed to facilitate the discharge process, greater
57 attention is being focused on research to identify effective strategies and processes. Evidence
58 suggests that specific transition planning tailored to patients and their families can reduce length
59 of stay and readmissions and may also improve satisfaction of patients and healthcare providers.⁵
60 Specifically, transition planning focusing on factors such as overall health, comorbidities, age,
61 caregiver support, mobility, cognition, and self-care have been shown to be essential for
62 successful transitions.^{6,7} Unfortunately, critical gaps in transition/discharge planning for people
63 with stroke remain.⁸

64 65 **Transitions of Care**

66 Successful transitioning from acute care, to rehabilitation, to home, and to integration
67 into the community post-stroke demands communication between multiple providers at several
68 clinical locations. People who have had a stroke incident and their families may experience
69 transition in the following contexts: (1) transition from place of stroke onset to acute hospital, (2)
70 transition from acute care hospital to other inpatient medical facilities, and (3) transition home.⁹
71 Each transition comes with unique circumstances and concerns, but all transitions require good

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72 communication and hand-off between providers. Even though all transitions are critical for the
73 person's care, this paper will focus on factors related to transitioning home and community
74 reintegration.

75 There are two distinct scenarios for transitioning to home. The first is a transition home
76 with continued services through either home health or outpatient agencies. In this scenario of
77 transition home there can be multiple senders and receivers of key information to support the
78 transition. This is due in part to the multiple functional impairments frequently experienced by
79 people who have had a stroke. Often when a patient transitions from an inpatient setting to home
80 with continued outpatient or home health services there will be key information from several
81 providers (nurse, rehabilitation therapists, physician, social worker) that needs to accompany the
82 patient and be received by a similar group of providers at the outpatient or home health agency.
83 Further complicating this transition is the wide variability in program types for patients leaving
84 the inpatient setting.⁹ The inherent challenges within the TOC framework at this transition is at
85 both sender and receiver levels. Challenges at the sender level involve coordinated gathering and
86 packaging of information to send and at the receiver level includes timely availability or
87 distribution of key information to the waiting receivers. These challenges can lead to
88 inefficiencies in the care being delivered at the receiving agency and an apparent lack of
89 continuity of care from the patient and family perspective.

90 The second scenario of the transition home involves the patient being discharged from all
91 healthcare services, fully relying on the family and community resources outside of the
92 healthcare system for support. Discharges from the hospital without ongoing healthcare services
93 have a unique set of challenges which includes reliance on the primary care physician (PCP) for

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94 long-term clinical management and follow-up.⁹ Unfortunately, most primary care physicians lack
95 the time to manage the long-term issues related to functioning, community integration, and
96 quality of life of the patients and families.^{10,11} The healthcare system is being pressed to address
97 these challenges and to provide effective standardized care for patients in post-stroke
98 rehabilitation that promotes maximal functional recovery with efficient transitions home and
99 successful community integration.

100 **Healthcare System Context**

101 Optimizing transitions home and to the community for stroke survivors has been reported
102 as a key factor in achieving three important objectives of post-stroke rehabilitation: improving
103 the care experience, improving the health of stroke survivors and caregivers, and reducing
104 costs.¹² As the healthcare system seeks to align payment and performance, transition planning
105 deserves special emphasis providing a ripe opportunity to respond to patients and caregivers'
106 needs and address the barriers to successful transitions to home.

107 Evidence suggests that successful transitions can reduce costs by reducing hospital
108 readmissions which is an important quality marker for hospitals. Due to financial incentive to
109 reduce readmissions, interventions focusing on safety and medical management rather than the
110 person's ability to engage in meaningful life activities are being emphasized.¹³ This focus on
111 medical management over the person's engagement further complicates the bigger picture of
112 transition planning due to the wide range of psychosocial issues associated with readmissions,
113 such as depression, activities of daily living (ADL) limitations, malnutrition, social isolation,
114 poor self-management skills, limited health related education/literacy, and escape-avoidance
115 coping strategies.¹⁴⁻¹⁷ Instead of issuing standard discharge plans, patient specific discharge plans

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116 may be more effective to reduce lengths of stay (LOS), decrease readmissions, and improve
117 patient-reported health status in older adults.¹⁸ In a systematic review of interventions'
118 effectiveness on hospital readmissions, 15 categories were identified as important for reducing
119 readmission rates: structured discharge planning, designated service coordinator, transition
120 coach, timely follow-up appointment, patient-centered programs, education, self-management,
121 patient empowerment, medication intervention, rehabilitation, home visit, timely
122 communication, telephone follow-up, patient hotline, and electronic exchange of health data
123 between healthcare providers.¹⁹

124 **Evidence Based Practice for Transition Planning**

125 The breadth of evidence around best practice for transition planning as part of a
126 structured model of discharge planning ranges from targeted specific interventions to
127 comprehensive practice models. Beneficial targeted interventions include programs for: 1)
128 medication management,²⁰ 2) fall prevention²¹ 3) patient and caregiver education, 4) facilitation
129 of communication with providers in community,²² 5) pre-discharge home evaluations, and 6)
130 self-management programs.^{3,21,23-25} While models of discharge planning vary in structure and
131 focus, they include common characteristics, such as: 1) use of a multidisciplinary team
132 approach,²⁶⁻²⁹ 2) initiation at time of admission,³⁰ 3) engagement of the patient and care partners
133 throughout the process,^{27,31,32} and 4) high-quality communications.^{32,33}

134 Structured discharge planning is the aim of the TOC model and important for successful
135 transition home after rehabilitation. Structured discharge has been reported to require pre-
136 discharge and post-discharge processes by transition providers (accountable senders and
137 receivers of information in the TOC framework) who are involved in the day to day care of the

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138 stroke survivor in the hospital.²² These providers can be from any discipline (therapy, social
139 work, nursing, etc.).²²

140 The use of community health workers as transition specialists have reportedly been
141 helpful to patients and caregivers living in rural areas, after discharge from acute inpatient
142 rehabilitation.³⁴ These community health workers act as accountable receivers in the TOC
143 framework facilitating appropriate action by identifying barriers to patient engagement and
144 assisting the patient and caregiver with access to community resources.³⁴ Additionally, the
145 emotional health²⁵ and engagement of stroke survivors³⁵ and their caregivers³⁴ can also influence
146 transitions of care, thus making them significant accountable receivers of information in the TOC
147 model, especially at the discharge to home transition.

148 From a systematic review, integrated multi-component programs appear to be more
149 effective in reducing hospital readmissions, especially in high-risk populations.³⁶ Components of
150 these programs include patient education, checklists, resource lists, and medical follow up
151 information.^{26,37-44} In contrast, more focused intervention models such as early supported
152 discharge and home visits, have a proximal relationship to the desired outcome of rehabilitation:
153 successful transitioning of patients with stroke to home and to the community.

154 *Early Supported Discharge*

155 As a promising model for ensuring the smooth care coordination from the hospital-based
156 multidisciplinary specialist stroke teams to the community-based teams,⁴⁵ Early Supported
157 Discharge (ESD) enable patients an earlier discharge from the hospital with more rehabilitation
158 at home when community-based therapy and support services are readily available (4-5 weeks
159 duration post-discharge).^{45,46} Early Supported Discharge is a distinct, high intensity intervention

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160 that can be offered as part of a community stroke service or by a separate dedicated team.⁴⁷
161 Distinguishing characteristics of ESD include: (1) interdisciplinary team with specialized stroke
162 care expertise, (2) cohesive team functioning with weekly meetings, (3) assignment of a
163 coordinator for each stroke survivor, and (4) screening criteria for eligibility (ESD should only
164 be provided for stroke survivors with mild-to-moderate functional impairment and minimal
165 cognitive impairment).^{46,48} A consensus document has identified eligibility criteria, potential
166 outcome measures, and processes to help health professionals plan and implement ESD
167 services.⁴⁹

168 The effectiveness of early supported discharge for individuals with mild to moderate
169 stroke is accumulating. A meta-analysis concluded that nurse-led early discharge programs for
170 inpatients with chronic disease reduced hospital readmission rates, duration of inpatient
171 readmissions, and all-cause mortality.⁵⁰ Moreover, early supported discharge has also been
172 reported to significantly improve quality of life, patient satisfaction, and caregivers' stress.^{51,52}
173 Continuing their recovery at home enables stroke survivors and their caregivers to construct and
174 adapt to their 'Flow of everyday life'.⁵³

175 Worldwide, ESD has been reported to reduce overall costs of care and healthcare
176 utilization,⁵⁴⁻⁵⁹ with outcomes similar to conventional care.⁵⁵ For patients with mild or moderate
177 stroke related disability, ESD results in improved performance of activities of daily living.^{58,59}
178 Finally, the cost savings have come with a significant cost shift, meaning that ESD required
179 significantly more occupational therapy, physical therapy, and speech therapy, and shifted costs
180 from the hospital to the community.⁵⁷

181 *Home Visits*

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182 A pre-discharge home visit (PHV) is an assessment in which a rehabilitation therapist
183 conducts an on-site evaluation of a patient's home prior to discharge, enabling the therapist to
184 make recommendations about the home environment including equipment, home modification,
185 and re-arrangement of items for safety and ease in use (e.g., accessibility within and around the
186 home, floor surfaces, communication access). Prior to the patient's discharge the therapist can
187 tailor interventions to address the specific needs of the patient.⁶⁰

188 The positive impacts of PHV include: 1) patients being able to stay in their home,⁶¹ 2)
189 caregivers perceiving a safer transfer to home after a PHV,⁶² 3) fewer falls and increased
190 participation during rehabilitation,⁶³ and 4) decreased unanticipated needs for support.⁶⁴ Two
191 negative findings associated with PHV include: (1) patients feeling anxious and judged during
192 the visit,⁶³ and (2) the time demand and cost.⁶⁵ Feasibility and effectiveness data, comparing
193 PHV and hospital-based interviews, demonstrated no statistically significant difference in
194 functional performance as measured by Nottingham Extended ADL Scale at 1-month post-
195 discharge.^{61,66} However, a recent meta-analysis of transitional care interventions for stroke
196 survivors concluded that home-visiting programs were most effective for reducing mortality and
197 improving activities of daily living (ADL) after hospital discharge.²⁹

198 Although not common in the United States, PHVs are part of routine discharge planning
199 practices in the United Kingdom, Australia, New Zealand, and Sweden.^{61,67} Pragmatics influence
200 decisions about conducting a PHV, including institutional pressure to reduce the number of
201 PHVs, overall decrease in length of stay (LOS), and time constraints.^{61,66} Average time spent at a
202 patient's home for a PHV ranges from 63 minutes⁶⁰ to 80 minutes.⁶¹

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203 Results of an economic analysis has suggested that PHVs cost more than twice as much
204 as hospital interviews but were slightly more cost-effective in terms of health-related quality of
205 life.⁶⁸ A subsequent large scale randomized control trial of 400 participants has found clinically
206 meaningful improvement; a higher proportion of patients receiving enhanced occupational
207 therapy (OT) (pre- and post-discharge visits and two follow-up phone calls) improved in ADL
208 with an incremental cost-effectiveness ratio of \$61,906 per person, compared to in-hospital
209 consultation OT.⁶⁹ A recent feasibility study found that enhanced rehabilitation, Community
210 Participation Transition after Stroke (COMPASS), which received 1 pre-discharge and 5 post-
211 discharge visits by occupational therapists, outperformed the attention-control group by 17.4
212 points on the Reintegration to Normal Living Index, a measure of community participation.⁷⁰

213 An emerging alternative to PHV uses technology to visualize the home environment and
214 simulate modifications before implementation.⁷¹ Virtual reality and 3D interior design
215 applications can increase collaboration between therapists and clients, and may serve as potential
216 mechanisms to empower the patient to be more engaged in decision-making during discharge
217 planning.⁷² The use of digital photos has also been investigated as a reliable method for making
218 accurate prescriptions for equipment in the bathroom and toilet areas as compared to
219 conventional PHVs.⁷³ As these technologies evolve, they have potential to improve access to
220 PHV as a virtual therapeutic activity and may decrease associated costs.

221 **Barriers to Transition Planning**

222 While an increasing number of programs have been developed to facilitate the discharge
223 process, critical factors remain due to several patient and system issues. Unfortunately balancing
224 the patient and system needs can lead to policies that are more system-centered instead of

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225 patient-centered, which can impede the achievement of optimal transition plans that best support
226 patients' level of potential.⁸ Barriers to transition planning can be considered within four
227 categories: systems, healthcare professional, patient, and caregiver.⁷⁴

228 *Systems*

229 System level barriers include premature discharge due to bed availability, inconsistent
230 procedures for implementation of discharge planning (piecemeal planning), insufficient
231 procedure for medication education, manpower shortages, administrative demands, transparency
232 and portability of the medical record.⁷⁵ The dynamic process of stroke recovery combined with
233 the multiple stakeholders (e.g., therapists, pharmacies, equipment vendors, specialists) required
234 to implement stroke rehabilitation increase the complexity of stroke rehabilitation from a systems
235 perspective.⁸ Further complicating these challenges from a systems perspective is the influence
236 of insurance type, eligibility criteria on the patients' progress through rehabilitation, and LOS.⁷⁶

237 The Centers for Medicare and Medicaid Services' (CMS) is collecting information about
238 discharges to the community as part of the Improving Medicare Post-Acute Care Transformation
239 (IMPACT) Act of 2014,⁷⁷ which aims to facilitate care coordination and provide quality, patient-
240 centered care across post-acute care (PAC) settings. The CMS Discharge To Community
241 Measure provides the rate of successful discharges to the community (i.e., discharge to a
242 community setting without post-discharge unplanned readmissions or death).⁷⁸ Although this
243 measure is a step in the right direction, we lack information about discharges to the community
244 specifically for stroke survivors and the non-Medicare population.

245

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246 *Healthcare Professional*

247 Healthcare professionals face many barriers to successful discharge planning across
248 settings due to dynamic complex variables and frequently, non-linear pathways. Barriers
249 identified by healthcare professionals include poor communication across disciplines and
250 misunderstanding of roles and responsibilities, leading to patient/caregiver unpreparedness.^{75,79}
251 Specific barriers include miscommunications regarding patient education, ordering of equipment,
252 delayed or lack of critical EMR information, and discharge destination. A coordinated, timely,
253 and efficient communication of the discharge plan between healthcare professionals is vital to
254 optimize outcomes of stroke survivors. Factors that influence communication during the
255 transition from sender to receiving provider include lack of standardized discharge
256 documentation and multiple modes of communication (e.g., phone, email, text message,
257 document).^{75,80}

258 *Patient*

259 From a patient perspective, the effects of a stroke can disrupt day to day living, affecting
260 mental and physical functions. Stroke survivors may have to cope with more limitations of
261 movement, speech, and daily functioning within a relatively short time period. Meanwhile,
262 discharge planning teams identify patients' resources and levels of family and caregiver
263 support.⁷⁶ Patients' knowledge of their condition, risk factors, and stroke prevention may vary,³⁴
264 necessitating the tailoring of patient education to improve health literacy. Social determinants of
265 health, such as lack of transportation and financial hardships, can affect follow-up care,
266 particularly in rural communities.³⁴ Confusion for patients and caregivers resulting from multiple

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267 recommendations (some conflicting) and limited resources or social support can also create
268 significant barriers for patients at the time of discharge or transition home.⁸

269 Some common issues around discharge planning for patients include confusion over
270 medications, follow up appointments, getting needed referrals, having necessary equipment at
271 home, coordinating home health services, and inadequate self-management.¹⁴ Issues related to
272 self-management may influence patients' ability to locate resources such as transportation and
273 exercise. The most commonly reported barriers to exercise in post-rehabilitation stroke patients
274 were cost, lack of awareness of fitness facilities, lack of transportation, and lack of knowledge of
275 how to exercise.⁸¹ Other possible barriers for people with stroke involve access to participation
276 in social interactions and return to important roles in their homes and communities.

277 *Caregiver*

278 Common issues faced by caregivers include poor communication about discharge dates
279 and specific responsibilities of the caregiver. Additionally, caregivers' needs change across
280 stroke survivors' recovery trajectory and across the care continuum.⁸² Since the median length of
281 stay in acute care post-stroke is only four days,³ giving little time for patient and family to adjust
282 to life changes,⁷⁶ discussions about discharge planning should begin as soon as possible.

283 Despite stroke practice guidelines' recommendations to include caregivers throughout the
284 continuum of stroke care,⁸³ a critical gap between actual and ideal services for caregivers of
285 patients with stroke remain.⁸⁴ A care support program for patients with stroke and their caregivers
286 in a rural area found that assistance was required for the following areas: patient-provider
287 communication; insurance support; accessing follow-up care; education on managing chronic health
288 conditions, the stroke process, transfers and mobility; and accessing durable medical equipment and

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289 essential medications.³⁴ Furthermore, participants in this navigator program showed good health care
290 utilization outcomes: no 30-day emergency department visits and only one 30-day hospital
291 readmission, which was not stroke-related.³⁴ Thus, caregivers should be considered as receivers of
292 information in the TOC framework for patients as they discharge to home. Although addressing these
293 elements requires resources and time, patient-centered discharge planning that includes caregivers as
294 team players in the TOC framework will likely improve the health and patient-reported outcomes of
295 stroke survivors and their caregivers.

296 **Recommendations**

297 Structured transition planning is challenging due to lack of standardized processes and
298 quality markers for implementing and assessing the effectiveness of transition planning during
299 post-stroke rehabilitation. As members of the Movement Interventions Task Force we developed
300 five recommendations organized into three broad categories to help clinical providers improve
301 success and standardization of patient transitions to home (see Table 1).

302

303 Category 1: Improve Communication Processes

304

305 The complexity and multiple step processes required for preparing patients with stroke
306 for safe discharge to their homes has been highlighted by several clinical practice guidelines.^{33,85-}
307 ⁸⁷ Two common themes among these guidelines include communication between care providers
308 (within settings and across transitions) and utilization of case managers/stroke navigators to
309 follow-up after discharge.^{8,85,88} Unfortunately, no quality measures specifically for patients with
310 stroke exist in National Quality Forum's measures database to address these recommendations,
311 which can lead to less incentive within the healthcare system to develop and implement

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312 programs to comply with the guidelines.⁸⁹ The themes of communication and case managers
313 can be easily conceptualized within the TOC framework. Communication between providers is
314 inherent throughout the TOC framework, requiring identification of sending and receiving
315 providers at all levels of care within the healthcare system.

316 Under the category of *Improve Communication Processes*, **the first recommendation** is
317 for clinical care providers to establish sending and receiving providers within each level of care
318 and to confirm who the sending and receiving providers are within systems from which patients
319 are referred, and **the second recommendation** is inclusion of a case manager/transition
320 specialist as a receiving provider at the discharge to home transition.

321 Due to the lack of one accepted guideline, we have created a “*Patient-Centered Checklist*
322 *for Discharge to Community*” (PCC-DC) to help facilitate communication between the patient,
323 transition specialist, and other providers. **The third recommendation** is consistent utilization of
324 the PCC-DC, or a similar checklist, to ensure that the appropriate information is being forwarded
325 to receiving providers and that patients are included in the process at each transition of care. The
326 PCC-DC is a compilation of common items from several checklists and practice guidelines to
327 facilitate discussion and development of standardized practices for effectively transitioning
328 patients to their homes for community reintegration after discharge from stroke rehabilitation
329 (see Table 2).^{33,85-88,90,91} This checklist offers specific medical and functional components for
330 planning, implementing, and following up after discharge. Further, the checklist addresses a gap
331 by including a category of Home Readiness, which includes home modifications and equipment
332 needs. This checklist could potentially be used to help determine if a stroke survivor is a good
333 candidate for early supported discharge. The PCC-DC includes patients and caregivers as

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334 receivers in the TOC model by ensuring that patients and families are engaged in the process
335 (i.e., sign off per item), making this checklist more patient-centered. Another important aspect of
336 this checklist is that it may be customized for each organization. Finally, the checklist also
337 identifies other key receivers, such as Primary Care Physician (PCP), as well as specific
338 information that should be forwarded to appropriate community resources for the patient.

339 Category 2: Use standardized assessments

340

341 Establishing sending and receiving providers at all levels of care can help facilitate
342 continuity of care only if the information being shared is translatable in each level of care as the
343 patient transitions. We have identified several outcome measures for use with people with stroke
344 that can inform discharge/transition decisions. An overview of common assessments across
345 functional domains (i.e., cognitive function, ADL, community integration, balance, walking,
346 motor skill, and quality of life) is provided in Table 3 to guide clinicians. These general domains
347 of assessments were selected because of evidence linking the domain to problems related to
348 discharge. Clinicians can search for other relevant assessments and their review summaries on
349 Shirley Ryan's Rehabilitation Measures Database.⁹² **The fourth recommendation** is consistent
350 utilization of appropriate standardized outcome measures between levels of care and healthcare
351 systems to support smooth transitions of care for patients and their caregivers.

352 Administration of standardized assessments to stroke survivors is important for informed
353 clinical decision-making and care planning, as well as measuring of progress and quality.⁸⁷
354 Standardized patient assessment data provides an objective measure of: (1) the impact of stroke,
355 (2) patients' progress, and (3) effectiveness of the intervention trial.^{93,94} If consensus about the
356 standardized assessments is reached across facilities regionally and along the care continuum, we

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357 can better understand: (1) the longitudinal recovery of stroke survivors and (2) outcome
358 variations across similar settings.^{95,96} Consensus across the care continuum could make care
359 more efficient by reducing the need for assessments when patients transition to another clinical
360 setting (e.g., acute care to rehabilitation). As utilization of standardized measures increases, it
361 will be necessary to establish consensus on the best measure for each domain (see Table 3).

362

363 Category 3: Fill in the gaps in the TOC

364

365 The objective of improving discharge planning is to facilitate an efficient, effective, and
366 patient-centered TOC between rehabilitation and post-rehabilitation activities. Unfortunately,
367 there is an apparent lack of sending and receiving providers between medical rehabilitation and
368 community-based wellness stakeholders leaving patients struggling to find access to safe and
369 meaningful leisure/recreational and fitness activities. Instead of making connections with
370 community-based stakeholders that can facilitate participation in the context of the broader
371 community, patients find themselves struggling to “...renegotiate their disabled bodies and
372 changed identities in real life”.^{97(p8)}

373 This struggle calls for a change in the traditional discharge approach from rehabilitation
374 to post-rehabilitation activities. Although the traditional approach is prescribing a home exercise
375 program to promote recovery after rehabilitation, adherence rates have been reported to be less
376 than ideal,⁹⁸ except in a structured supervised program where adherence was 100%.⁹⁹ Low
377 adherence outside of a structured supervised program indicates that rehabilitation therapists
378 should explore partnerships within the community to educate community stakeholders, advocate
379 for patients, and start bridging the gap for patients and caregivers as they move beyond the walls

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380 of the rehabilitation clinics to the community to renegotiate their life in a way that is productive
381 and meaningful.

382 Limitations in life participation after stroke has been frequently reported,^{100,101}
383 particularly in the areas of social, recreation, and leisure activities.^{81,102} Stroke survivors and
384 caregivers report a variety of reasons for this limitation in participation: more sedentary
385 lifestyle,⁸¹ lack of motivation, low self-efficacy, inaccessibility of community programs,
386 weakness, poor balance, lack of transportation, and cost.^{81,101} Walsh and colleagues identified
387 four themes related to community integration after stroke including: (1) *primary effects of stroke*
388 (fatigue, poor mobility, memory problems, and communication difficulties; (2) *personal factors*
389 (optimism, hope, perseverance, confidence, meaningfulness of activities, adjusting expectations,
390 and finding new life values and life goals); (3) *social factors* (stigmatization from family and the
391 broader community, family support, feeling like a burden, environmental barriers, ability for key
392 activities such as climbing stairs and driving, and ability to contribute); and (4) *relationships*
393 *with professionals* (correlation between therapy activities and own home environment, good
394 support and encouragement, losing momentum with delays or discontinuous care, feeling
395 controlled and limited in options).¹⁰³ These findings suggest that care coordination between
396 medical rehabilitation professionals and community wellness professionals is needed to help
397 patients transition home.

398 According to the World Health Organization (WHO), rehabilitation for persons with
399 disabilities must aim to enable the person to participate in meaningful roles, routines, and
400 activities, and must address the physical, sensory, intellectual, psychological and social
401 functioning of an individual.¹⁰⁴ The WHO defines participation as “*involvement in a life*

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402 *situation*” and describes efforts to promote participation as interventions (accommodations,
403 public education, anti-discrimination law, and universal design) or prevention strategies
404 (environmental change, employment strategies, accessible services, universal design, lobbying
405 for change, and preventative rehabilitation).¹⁰⁴ Although many of these strategies involve action
406 at a community level, there are still opportunities for rehabilitation therapists to directly
407 influence participation at an individual patient level. Prevention strategies such as environmental
408 change, accessible services, and preventative rehabilitation may all be amenable to post-stroke
409 rehabilitation across all levels of post-acute care (PAC) with a focus on eventual transition to
410 home. Unfortunately, successful transitions through rehabilitation to the community that
411 maximize patient’s life participation have yet to be fully realized. Therefore, **the fifth and final**
412 **recommendation** is establishment of partnerships with community-based wellness programs to
413 establish receiving providers within the community in the TOC model for patient hand-off at the
414 transition to community living after completion of all structured medical rehabilitation.

415
416

Conclusion

417 Transition planning for people with stroke can be challenging and complex requiring
418 careful advanced planning, excellent communication among many stakeholders, and tailored
419 education and training. The TOC model has defined good transition management as efficient
420 transfer, verification, and clarification of pertinent information between providers to facilitate
421 appropriate action for the patient. Despite practice guidelines, programs, models, assessments,
422 and interventions that can serve as resources to support efficient information transfer, there is not
423 yet a consensus based on best practice for facilitating smooth and efficient TOC throughout the
424 continuum of post-stroke care.

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425 The following recommendations have been developed based on the current evidence to
426 focus efforts on standardizing transition planning and to facilitate more efficient transitions
427 throughout the stroke continuum of care: (1) establish sending and receiving providers as defined
428 within the TOC framework for facilities managing patients with stroke; (2) establish a case
429 manager or transition specialist as a receiving provider within the TOC framework at the
430 discharge to home transition; (3) consistently utilize comprehensive discharge checklists such as
431 the PCC-DC; 4) consistently utilize standardized outcome measures to improve consistency of
432 information passed between levels of care; and 5) include community-based wellness programs
433 as receivers in the TOC framework to improve patient hand-off at the rehabilitation to
434 community transition.

435 More efficient transitions are vital at all levels of care and an important focus for all
436 stakeholders. A focus on efficient TOC has potential to promote integrated and coordinated care,
437 maximize functional recovery, and support return to the least restrictive living environment for
438 stroke survivors. Thus, high-quality discharge planning can facilitate good community
439 integration and life participation, which is the ultimate objective of rehabilitation, and perhaps
440 the best defense against secondary stroke risk factors and costly hospital readmissions.

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Table 1. Recommendations for Transition Management during Stroke Rehabilitation

Improve Communication Processes	<ol style="list-style-type: none">1. Establish and confirm sending providers (discharging facility) and receiving providers (admitting facility) within each level of care2. Establish case manager/transition specialist as a receiving provider at discharge to home transition3. Utilize PCC-DC or similar checklist to ensure forwarding of appropriate information and inclusion of patients
Use standardized tests and measures	<ol style="list-style-type: none">4. Consistent use of standardized tests and measures in all level of care
Fill-in the gaps on the TOC	<ol style="list-style-type: none">5. Establish partnerships with community-based wellness programs as receiving providers in the TOC framework

Table 2. Patient-Centered Checklist for Discharge to Community (PCC-DC)		
Healthcare	Transition planning tasks	Patient or Caregiver
Date/Initials		Date/Initials
Patient engagement and communications		
	<ol style="list-style-type: none"> 1. Patients/caregivers are asked about goals, resources, preferences, and concerns about transfer of care. 2. Discharge summary is explained to patients/caregivers (use teach-back if needed). 3. Patients/caregivers receive training in care (eg, techniques for personal care/handling, communication strategies, prevention and health maintenance, safe swallowing/dietary modifications, management of behaviors and behavioral health issues). 4. Notify and provide to patient/caregiver, pharmacy, Primary Care Physician (PCP), & home health agency: Discharge Summary Plan, Medication Reconciliation Form, contact information of hospital staff. 5. Agreed health and social care plan is in place with all stakeholders, and patient/caregiver knows whom to contact if difficulties arise. 	
Follow-up		
	<ol style="list-style-type: none"> 6. Confirm and identify patient's PCP; alert care team if no PCP and/or begin PCP search. 7. Stroke rehabilitation team member follows up within 72 hours after discharge to check on patients/caregivers' needs. 8. Patients are regularly reviewed by stroke team to assess recovery, prevent deterioration, maximize functional and behavioral health outcomes, and improve quality of life (eg, first week, 6 months, 12 months). 	

9. Patients who experience a change/decline in functional status should be re-assessed, even if months after stroke.

Medication and health management

10. Teach patients/caregivers how to properly use discharge medications and how these relate to their previous medications.
11. Patient's medication management ability has been assessed.
12. Interventions and resources for safe and accurate medication management (eg, low vision, decreased dexterity, cognitive deficits) have been provided.
13. Monitor second stroke risk factors (eg, blood pressure, blood sugar, cholesterol, smoking cessation, stress, exercise, weight management, sedentary lifestyle)

Home readiness

14. For patients with mild/moderate stroke, assess if early supported discharge (comprehensive multidisciplinary rehabilitation available) is feasible.
15. Assess patients and need for a home visit (eg, OT/PT/Nursing, family), to ensure functioning and safety in self-care activities.
16. Assess caregivers and need for home modifications (eg, grab bars, tub bench, ramps) and plans/resources are discussed with patients/caregivers.
17. Appropriate equipment (eg, specialist seating, wheelchair) is in place at patient's residence by discharge date.
18. Provide referrals and resources for aids/equipment and support services to maximize recovery and enable participation (ie, transportation, support groups, day programs).

Table 3. Standardized Measures for Domains Related to Discharge Planning

Assessment	Description	Implications for Discharge
Cognition		
St. Louis University Mental Status Exam (SLUMS)	A 30-point screening questionnaire testing orientation, memory, attention, and executive function. ¹⁰⁵	No studies linking SLUMS to discharge. Cognitive impairments were found to contribute to increase length of stay in hospital for persons with stroke. ¹⁰⁶ A study comparing the SLUMS to the MMSE suggest the SLUMS is more sensitive to mild neurocognitive deficits. ¹⁰⁷
Mini Mental State Exam (MMSE)	Eleven questions. Total score of 30. Assesses orientation, immediate & short-term memory, calculations, language, & visuoconstruction skills. ¹⁰⁸	No specific research linking MMSE to discharge. Cognitive impairments contributed to increased length of stay in hospital for persons with stroke. ¹⁰⁶ Score of 21-26 mild, 11-20 moderate, and < 11 severe impairment. ¹⁰⁸
Montreal Cognitive Assessment (MoCA)	Total score of 30. Assesses attention, memory, language comprehension and production, & visuoconstructional skills. ¹⁰⁹	Cutoff score of < 26 reflects cognitive impairment. In population with stroke, MoCA was found to be more sensitive to detecting mild cognitive deficits when compared with MMSE. ¹¹⁰ MoCA has been found to more accurately predict discharge destination in patients with stroke when compared to MMSE. ¹¹¹
Executive Function Performance Test (EFPT)	Measures performance in 4 ADLs, cooking, telephone, bill paying, & medication management. Scores initiation, organization, safety, judgement, and completion. Possible score of 0-25 in each area for total score of 100. Higher scores indicate higher functioning. ^{112,113}	EFPT during the acute phase of stroke may aid therapists in discharge planning. ¹¹⁴ For adults post-stroke, a score of 84 or less was five times more likely to need supervision after discharge. ¹¹⁵
Depression		
Patient Health Questionnaires (PHQ2, PHQ9).	The self-administered PHQ9 contains items from the DSM-IV classification for depression	On PHQ9 < 15 minimal to minor depression. A score > 14 is major depression. Depression has been linked

including anhedonia, depressed mood, trouble sleeping, feeling tired, change in appetite, guilt or worthlessness, trouble concentrating, restless, and suicidal thoughts.¹¹⁶ The PHQ2 contains 2 questions about anhedonia and mood. Items are rated based on frequency within the past two weeks. Scores range from 0 – 27 with 27 reflecting highest level of depression. The PHQ2 has a range of 0-6 with 6 being reflective of depression.

to higher levels of readmission, mortality, and decreased participation post-stroke.^{17,117,118} Identification of depression using the PHQ9 can inform healthcare providers of needed interventions including education and treatments.¹¹⁹

Activities of Daily Living

Barthel Index (BI) and Modified Barthel Index (MBI)

Observational assessment measuring 10 BADL items (feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers, mobility, and stairs).^{120,121}

BI and MBI were predictive of fall risks, functional recovery, disability, and length of hospital stay for persons with stroke.¹²²⁻¹²⁴ Barthel Index score >35 was found to be a good predictor of discharge home.¹²⁵

Assessment of Motor and Process Skills (AMPS)

Observational assessment measuring 16 motor and 20 process skills and the effect on BADLs and IADLs. The AMPS is valid with some predictive ability, its clinical utility is limited due to required certification to administer and lengthy administration time.

AMPS has been found to be predictive of assistance level for safe community living.^{126,127}

The processing component has been found to be more accurate than the motor component in determining community independence.^{128,129}

Activity Measure for Post-Acute Care (AM-PAC) and “6-Clicks” (a version of the AM-PAC)

Observational assessment measuring basic mobility, daily activities, and applied cognition.¹³⁰ “6-Clicks” assesses basic mobility (walking, moving) and daily activities (dressing, toileting).¹³¹

Scores on mobility and daily activity were found to accurately predict post-discharge destination when administered in acute care.¹³¹

Personal Care Participation Assessment & Resource Tool (PC-PART)

43 items measuring dressing, hygiene, nutrition, mobility, safety, environment, and supports.¹³²

PC-PART has low to moderate correlation with the FIM and low to moderate discriminant ability to determine discharge destination.¹³³

Medication Management

Manage-Med

The MMS has 32 questions

Able to differentiate those dependent in

Screen (MMS)	related to medication management. Possible score of 42.	taking medication from those who are independent. Mean scores were 13.8 (6.0) and 30.7 (6.1) respectively. ¹³⁴
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Community Integration

Return to Normal Living Index (RNLI)	11 question self-report questionnaire designed to assess a person's satisfaction with performance of everyday activities. Uses a 10 cm VAS with a possible total 100 (converted score). ¹³⁵	Strong correlations between RNLI-I, balance and fall self-efficacy, community mobility, and stride time. ¹³⁶ Higher scores on RNLI-I were linked to emotional and physical well-being. Engagement in valued activities. ^{117,137}
Stroke Adapted Sickness Impact Scale 30 (SA-SIP 30)	30 question self-report questionnaire. Scores are converted to percentage ranging 0%-100%. Higher scores reflect low functioning. ¹³⁸	Found to be a good predictor of community participation for persons with mild stroke. ¹³⁹ A score of > 33 reflected poor health profiles. ¹⁴⁰

Balance

Berg Balance Scale (BBS)	Performance assessment of static and dynamic activities. Maximum score is 56. Each item is scored on scale of 0-4 with lower scores reflecting greater risk for falling. ¹⁴¹	BBS scores predicted length of stay, discharge destination, motor ability 180 days post-stroke and disability level at 90 days. ¹⁴² It is criterion referenced for increased fall risk (<42). ¹⁴¹
Dynamic Gait Index	Performance based 8 items scored from 0-3. Higher scores reflect higher performance. Maximum score: 24. ¹⁴³	DGI is criterion referenced for increased fall risk in people post-stroke (<19). ¹⁴⁴
Postural Assessment Scale for Stroke Patients (PASS)	Performance based 12 items scored 0-4 for a maximum score of 36. ¹⁴⁵	The PASS was found to have predictive validity for comprehensive ADL function in patients 1 year post-stroke. The PASS was found to have a ceiling effect for mild stroke. ¹⁴⁶

Walking

10 Meter Walk Test (10MWT)	Performance assessment scored by time to walk 10 meters.	Walking speed has been reported to predict category of walking status (<0.4 m/s household ambulation, 0.4 m/s – 0.8 m/s limited community ambulation, and > 0.8 m/s community ambulation) in people post-stroke. ¹⁴⁷
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6 Meter Walk Test (6MW)	Performance assessment scored by time to walk 6 meters.	Recent data suggest that walking distance, measured with the 6MWT, may be better able to discriminate between limited and full community ambulation potential than walking speed. ¹⁴⁸
Timed Up and Go	The TUG is a standardized assessment of functional mobility. The patient is timed from the point of standing from a chair, walking 3 meters, turning, returning to the chair, and sitting down. ¹⁴⁹	A greater than 14-second pace is considered a higher risk for falls. ¹⁴⁴
Motor Skill		
Activity Measure for Post-Acute Care (AM-PAC) and “6-Clicks” (a version of the AM-PAC)	Observational assessment measuring basic mobility, daily activities, and applied cognition. 122 “6-Clicks” assesses basic mobility (walking, moving) and daily activities (dressing, toileting). ¹³¹	Scores on mobility and daily activity were found to accurately predict post-discharge destination when administered in acute care. ¹³¹
Rivermead Mobility Index (RMI)	14 self-reported items and 1 observed item. Scored as a 0 or 1 for a maximum score of 15. The higher the score the greater the mobility.	Early after stroke RMI scores have been reported to be useful in predicting institutional (hospital & nursing facility) length of stay. ¹⁵⁰ RMI score >4 predictor of an early discharge home, followed by a Barthel Index score >35. ¹²⁵
Caregiver Factors		
Caregiver Strain Index (CSI)	Self-report assessing the effect of caregiving on employment, financial, physical, social, and time. ^{151,152}	The CSI can determine high levels of caregiver burden (score > 7). ¹⁵³
Hospital Anxiety and Depression Scale (HADS)	14 item scale: 7 items for depression and 7 for anxiety. Items are rated from 0-3 for a total score of 21 on each scale. The lower the score the less anxiety and depression. ¹⁵⁴	A score of 8 or more on a subscale on the HADS indicates high anxiety and/or depressive symptoms. ^{118,154}
Nutrition		
Mini Nutritional Assessment (MNA), MNA-	MNA consists of 18 items including body measurements	Poor nutrition is linked to frailty and decreased mobility in older adults. In one study the MNA-SF identified

SF and questions. The MNA can be administered in about 10 minutes with a max. score of 30. Scores indicate level of nutrition: adequate MNA ≥ 24 ; risk of malnutrition MNA 17-23.5; malnourished < 17 .¹⁵⁵ The MNA-SF was developed for screening low risk patients. The MNA-SF takes 5 minutes, max. score is 14. A score ≤ 11 suggest malnutrition and full MNA is recommended.¹⁵⁶

malnutrition or risk in 76.7% of a population 65-97 in an acute hospital.¹⁵⁷ As a health initiative, prevention of chronic disease includes healthy dietary habits. Identifying persons at risk for poor nutrition is critical for promoting healthy lifestyles.

Quality of Life

Short Form – 36 (SF-36)	SF-36 includes eight subscales: physical functioning, role limitations due to physical problems, general health perceptions, vitality, social functioning, role limitations due to emotional problems, general mental health and health transition. The 8 subscales are transformed onto scale of 0-100. A higher score indicates greater health. ¹⁵⁸	A criterion reference for predicting 5-year mortality has been reported for the SF-36 (score ≤ 40 represented a twofold higher risk for 5-year cardiovascular or all-cause mortality). ¹⁵⁹
Stroke Specific – Quality of Life Scale (SS-QOL)	SS-QOL is a patient-reported measure of 12 commonly affected domains (mobility, energy, upper extremity function, work & productivity, mood, self-care, social roles, family roles, vision, language, thinking, and personality). ¹⁶⁰	The SS-QOL and NIHSS scores independently predicted good overall health-related QOL. ¹⁶¹
National Institutes of Health Stroke Scale (NIHSS)	NIHSS is a patient-reported 15-item impairment scale. Scores range from 0-42. The higher the score the greater the severity. ¹⁶²	The NIHSS is used to classify severity of stroke as follows: mild stroke, cut-offs 0-4 and moderate stroke, cut-offs 5-15. ¹⁶²
Stroke Impact Scale (SIS)	The SIS measures 8 domains (strength, hand function, ADL/IADL, mobility,	When compared to the SF-36, the SIS may be more informative. The SIS includes a wider range of difficulty on

communication, emotion, memory and thinking, and participation/role function) and is sensitive to change over time.¹⁶⁰

the physical and participation subscales. The SIS was more accurate in measuring physical functioning and social well-being.¹⁶³

ACCEPTED MANUSCRIPT

Figure 1: Transitions of Care Process and Systems Barriers

