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The Relationship between Staff Compliance with Implementing Discharge Planning Guidelines, and Stroke Patients' Experiences Post-Discharge

Julie Luker, MHSc¹

Karen Grimmer-Somers, PhD²

1. Research Assistant, Centre for Allied Health Evidence, University of South Australia, Adelaide
2. Professor, Director, Centre for Allied Health Evidence, University of South Australia, Adelaide

Australia

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ABSTRACT

Purpose: To investigate staff compliance with discharge planning clinical guideline recommendations in an acute stroke unit, and its relationship with post-discharge experiences of stroke patients and their carers. **Subjects:** Fifty acute stroke patients were systematically recruited for a retrospective patient record audit of staff compliance with clinical guideline recommendations related to discharge planning. **Methods:** Semi-structured interviews were conducted over six months post-discharge on patients' actual community support needs and experiences. Audit and patient experience data were integrated to seek evidence of 1) characteristics of patients receiving guideline-compliant care, 2) relationships between staff compliance with discharge planning recommendations and patient's post-discharge experiences, and 3) whether patient's post-discharge experiences of shortfalls in support related to hospital discharge planning. **Results:** Not all patients received guideline-based care. There was a trend that patients with more complex strokes received guideline-compliant care than other patients. Compliance with providing an occupational therapy (OT) home assessment was significantly related to discharge directly home from hospital. There was a shortfall with 40% of patients between community supports predicted by hospital staff and actual post-discharge support requirements. Community support requirements increased over time for 32% of patients, whose six-month post-discharge needs were actually greater than their needs at six weeks. **Conclusions:** Staff compliance with discharge planning recommendations was variable and did not always relate to improved post-discharge patient experiences. The post-discharge experiences of many stroke patients could not have been predicted whilst they were in hospital. Discharge planning and support systems thus need to be flexible and responsive to short and long-term needs.

INTRODUCTION

Stroke is a major health issue world-wide, producing often irrevocable changes to physical, social, emotional, and cognitive functioning.¹ With an aging population and increasing prevalence of chronic and complex diseases, the ramifications of stroke will become an increasing concern regarding appropriate care in acute and subacute rehabilitation settings and in maintaining patients with long-term consequences of stroke in independent community living.^{2,3}

Health services in Australia are currently challenged to provide care in hospital and in the community that appropriately addresses the changing needs of stroke patients.⁴ However, the National Stroke Foundation recently confirmed that little primary research exists to guide the provision of such services which will meet the real needs of consumers.⁵ There are a number of high quality guidelines which provide recommendations for best practice stroke care in acute and rehabilitation settings.^{6, 7} The Australian National Clinical Guidelines for Acute Stroke Management (GL) were developed according to best-practice processes

prescribed by the National Health & Medical Research Council under the direction of a multi-disciplinary expert working group and with broad professional and consumer consultation.⁶ These guidelines and other recent literature on discharge planning for stroke emphasise the need to optimise patient centred discharge planning processes in acute and subacute hospitals so that patients' post-discharge needs can be adequately projected and addressed.^{5,8} However, gaps in current evidence mean that Australian guideline recommendations for elements of discharge planning such as pre-discharge needs assessments, patient/carer education, the use of care plans, and linkages to long term support in the community are based mainly on expert opinion or research that is not specific to stroke survivors.⁶

We know from research with non-stroke specific populations that interventions to address discharge planning have limited success in improving patients' experiences and outcomes after discharge. The systematic review by Shepperd et al found no significant impact of discharge planning on readmission rates, hospital length of stay, health outcomes, or costs.⁹ Worth et al, examining a group of medical and surgical patients, suggests that it is not possible to adequately anticipate the post-discharge needs of patients when they are in the acute setting.¹⁰ This may be particularly true following acute stroke, where the average length of stay in the hospital setting is surprisingly short (7-12 days average) for individuals who have suffered a major brain insult, and where the majority of post-stroke recovery occurs out of the hospital, often in the patients' home environment.^{1,11} The post-stroke recovery processes is variably supported by an often complex, fragmented network of community health providers, which creates additional challenges to effective discharge planning.

There is currently a gap in the evidence to inform discharge planning and long term support practices for stroke survivors and their carers, who commonly describe sub-optimal post-discharge experiences.⁵ In the recently published "Walk in Our Shoes" report of stroke survivors experiences, the National Stroke Foundation reported that 50% of survivors and 64% of carers were not satisfied that all their post-discharge needs had been identified or addressed appropriately during hospital discharge planning.⁵ They also reported that they lacked post-discharge support linkages to help them cope with changing circumstances.⁵ Little is known about the usual course of post-stroke recovery as few studies have been conducted over sufficiently long time periods, thus adequate planning for discharge, and the most appropriate time and place for support to occur, has not been established.^{5,12}

We conducted this study to better understand the post-discharge experiences and support needs of acute stroke patients relative to the plans made for their discharge from the acute stroke care setting. Recommendations for making discharge plans were part of the National Clinical Guidelines for Acute Stroke Management, and these were in place in the hospital participating in this research.⁶

METHOD

Ethics

This study had ethics approvals from the relevant Human Research Ethics Committees of the authors' institutions, for accessing clinical data collected routinely by the hospital research site, the auditing of medical records (charts), and telephone follow-up interviews of study participants. Patients (or families) provided written and informed consent to participate.

Objectives

The objective of this study was to establish whether discharge planning undertaken by allied health (AH) staff, in accordance with current evidence-based National Clinical Guidelines for Acute Stroke Management, addressed the post-discharge needs of all patients in an acute stroke unit.⁶

Study setting

Subjects for this study were systematically drawn from an acute stroke unit (ASU) which was established in 2003 within a 580 bed metropolitan teaching hospital. All patients who had sustained an acute stroke or trans-ischemic attack (TIA) patients were admitted to this unit under the co-ordinated care of a team with expertise and/or special interest in stroke, including doctors, nurses, support staff, and allied health professionals from physiotherapy, occupational therapy, speech pathology, dietetics, and social work disciplines. The ASU admitted up to 30 patients at any time, and offered multidisciplinary management that aimed to reflect the recommendations of the Australian National Clinical Guidelines for Acute Stroke Management.⁶

Three recommendations in the clinical guidelines related specifically to discharge planning involving the allied health (AH) team, and they provide current best evidence benchmarks against which to compare actual care⁶.

The recommendations used in this study were:

- The multidisciplinary team should meet with the patient and family to ensure ongoing involvement in the management and planning for discharge (family meetings).
- The team should involve patients and carers in the development of a plan that outlines care in the community after discharge.
- If required, an occupational therapist (OT) should conduct a home assessment to ensure safe handling and transfer of patients and provide education in relation to the use of required equipment, prior to discharge.

Since the inception of the unit in 2002, AH staff had participated in structured guideline implementation processes, including education about the intent and implementation of the discharge planning guideline recommendations, and were encouraged to apply them to every patient.

Study Design

This paper reports the findings of two congruent studies and pulls the findings together in order to investigate whether patients who received care in line with clinical guidelines were performing better in the community during a six month follow-up.

A retrospective patient medical record audit was conducted to ascertain patients' demographic and admission data and to compare recorded discharge planning practices against the three stroke guideline recommendations. Secondly, semi-structured patient interviews were conducted six weeks and six months after the patients had been discharged from the acute stroke unit to establish their post-discharge experiences relevant to the plans made in hospital to support their discharge.

Patient sample

Fifty patients with acute stroke (or their families) sampled from the 2005 stroke patient cohort which had been admitted to the ASU (n=309) were invited to participate in this study. Recruitment was undertaken by systematic sampling during three weeks each month between April 1st and October 31st 2005, until 50 consenting participants were enrolled. This approach was taken on pragmatic grounds based on the researcher's caseload. The methodology for this study has been reported in detail elsewhere.¹³

Patients were eligible for inclusion in the study if they had been admitted to the ASU, had a confirmed diagnosis of first or subsequent acute stroke, survived their hospitalization, and had previously lived in the community with or without support services. No other diagnostic or age criteria were specified. Because follow-up contact was to be by telephone, patients or family were excluded if they did not have telephone contact, adequate cognition, or English language skills.

During their ASU admission, eligible patients were provided with written and verbal information on the study and invited to participate. In cases where patients' stroke related disabilities may have prevented informed consent or their direct participation in telephone interviews, their live-in caretakers were provided with written information on the study and invited to participate to provide a carer's perspective of post-discharge experiences. Patients or carers were given time to consider the information and discuss it with other family members if necessary, and then provide written consent if they wished to participate. Of the 50 consenting participants, only two stroke patients were unable to provide consent due to communication barriers, and in these two cases consent was provided by carers.

Audit data collection and recording

Information was collected from consenting patients' medical records (chart) on age, gender, type of stroke, functional ability on admission and discharge, length of stay (LOS) in the ASU, previous living circumstances, and community supports as well as discharge destination and referrals to post-discharge supports. This information was routinely collected throughout admission by the ASU's clinical treating team and administrative staff and was available in patients' medical records.

Patients' functional ability was routinely assessed by members of the AH team at admission to and discharge from the ASU. An objective measure of function was determined using the Functional Independence Measure (FIM™) and elements of the Functional Assessment Measure (FAM) which were applicable to the acute setting.^{14,15} FIM and FAM have been shown to be valid and reliable tools in stroke populations, and in Australia FIM scores are used routinely to benchmark the performance of stroke rehabilitation facilities.¹⁶ Members of the AH team were trained and certified FIM assessors who calculated each patient's total FIM+FAM score for 25 functional items, giving a possible perfect score of 175. Agreed admission and discharge FIM+FAM scores were obtained by consensus of the treating AH team at weekly team meetings and recorded in medical records.

We anticipated that we would find evidence in the patient's medical records regarding compliance with the three discharge planning recommendations of interest. We sought text entries in the records regarding how the recommendations had been operationalized for individual patients, using the following interpretations:

- *The multidisciplinary team should meet with the patient and family to ensure ongoing involvement in the management and planning for discharge (family meetings).*

This recommendation was considered to be met if there was documented evidence of a structured meeting between the patient/carers and relevant members of the clinical team, to discuss discharge planning – frequently known as a family meeting.

- *The team should involve patients and carers in the development of a plan that outlines care in the community after discharge*

This recommendation was met if there was documented evidence of any discussions occurring between relevant members of the team and the patient/carers to identify, discuss, and plan for post-discharge needs. This will be referred to as involvement in "informal" discharge planning discussions, to differentiate it from family meetings.

- *If required, an occupational therapist (OT) should conduct a home assessment to ensure safe handling and transfer of patients and provide education in relation to the use of required equipment prior to discharge.*

For audit purposes, evidence was sought in the medical records of whether a home assessment by an OT had occurred or not. It was not possible to determine whether an assessment was required for any particular patient.

A purpose-built checklist was developed for the audit (see Appendix 1). Data relevant to the audit was extracted manually by the primary author from medical records and recorded on a purpose-built MS Excel spreadsheet for analysis. A discharge planning guideline recommendation was only considered to be met if there was adequate documented evidence of this in the patient's records. Compliance was measured in binary terms (Yes/No), with each guideline weighted equally.

Telephone interview data collection and recording:

The 50 participants were followed up by telephone by the primary author at six weeks and six months after discharge from the acute setting. Interviews were conducted at mutually agreed times, were typically 10-20 minutes long, and took a semi-structured format.^{17,18} Steps were taken to ensure consistency of delivery of the questions and recording of the findings through the use of a data collection prompt sheet (see Appendix 2). Patient's and/or carer's responses were recorded on this sheet in point form, and exemplar comments were recorded verbatim.

The telephone interviews specifically sought examples of how discharge plans had suited patients' requirements post discharge (or not). Information was collected on;

- readmissions to hospital and other changes in accommodation
- the uptake and usage patterns of community support services for which referrals had been made during discharge planning by the ASU
- additional support services needed post-discharge which were not anticipated during discharge planning.

Particular attention was paid to differences between the support arranged during hospital discharge planning and the support actually required by stroke survivors in the community. This was used to determine short-falls in community support arrangements or post-discharge needs which were unanticipated during admission. We also sought stories and comments from participants which put this data into context in terms of patients' post-discharge lives.

DATA ANALYSIS AND REPORTING

Generalizability of the sample

Data on age, gender, LOS, and type of stroke was extracted from the medical records. This was compared with the same data from the entire 2005 hospital stroke cohort to establish the appropriateness of the audit sample in reflecting the experiences of all stroke patients in that particular hospital during 2005. This comparative demographic and diagnostic data is routinely collected by hospital staff for all patients in South Australian public hospitals and is collated at a central point to enable reporting of institution

performance for benchmarking purposes. Researcher access to this de-identified data was granted by the hospital site and the ethics committees.

Gender and type of stroke were reported in categories as percentages of the total sample. Age and LOS were reported as averages and standard deviations (SD). Comparisons between the complete 2005 sample and the study subset were undertaken to test for homogeneity in age, gender, type of stroke and LOS using Student t-tests, and Chi-square analysis, with significance set at $p < 0.05$.

Descriptions of the audit data

Functional abilities at admission were reported as total FIM+FAM scores and expressed as mean (SD). Each patient's functional change was calculated as the difference between their admission and discharge FIM+FAM scores and expressed as average (SD) change. Functional change was analysed as the difference in change in FIM+FAM scores from admission to discharge, expressed as a percentage of the admission score.

Compliance with the relevant discharge planning guideline recommendations was expressed as the percentage of records in which the recommendations were reported to have occurred.

The influence of compliance with discharge planning guidelines on continuous study variables (age, functional ability on admission, percentage functional change during admission, and LOS) was assessed using Student t-tests. To further understand compliance with guidelines and study variables, the continuous data was interpreted as categories by dividing it at the median value. Gender was treated as a binary variable, and discharge from the ASU directly to home was classified in binary form as yes/no. The associations between compliance with the three guidelines and the binary divisions were expressed as odds ratios (95% Confidence Intervals).¹⁹

Telephone interviews

Short-falls in support services experienced by patients following discharge were determined when patients or carers reported the need to use support services in the community that were unanticipated prior to discharge (see details in methodology section above). Student t-tests were applied to test associations between short-falls in support services experienced by patients following ASU discharge and patient LOS, and functional abilities on admission (FIM+FAM scores). The probability of problems occurring after discharge, related to the ASU's provision of discharge planning practices as recommended in the clinical guidelines, was calculated using odds ratios from 2x2 tables.¹⁹ Statistical significance was set at $p < 0.05$.

Pertinent quotes from respondents were recorded verbatim as exemplar experiences. Common themes and emergent patterns in responses were noted and changes in experiences over time were reported.¹⁷ Patients with good and poor experiences were clustered, and the discharge planning practices identified from the audit were compared between the clusters.

RESULTS

Patient sample

Of the 50 patients originally recruited, two were lost to follow-up after the six week interview; one had moved address and could not be contacted, and the other chose to withdraw for unspecified reasons. Thus, although 50 records were audited, a total of 98 telephone follow-ups were completed.

Generalizability of sample

The audit sample was representative of the entire 2005 stroke cohort admitted to the acute stroke unit in terms of age, gender, hospital LOS, and type of stroke experienced, with homogeneity supported by the lack of significant difference between datasets in all tests, as outlined in Table 1.

Table 1: Comparison of audited sample to entire 2005 hospital stroke population

	Age	Gender	Type of stroke	LOS days
Audit group (n= 50)	75 years (SD 9.5).	34% female	Ischaemic 96% Haemorrhagic 4% R. hemisphere 50% L hemisphere 34% Cerebellar 16% Brainstem 0%	17 (SD 16.2)
Entire 2005 group (n= 309)	76.3 years (SD 11.5).	44.9% female	Ischaemic 86% Haemorrhagic 13% Unknown 1% R. hemisphere 50% L hemisphere 40% Cerebellar 6% Brainstem 2% Unknown 2%	16.6 (SD 17.2)
P value	>0.05	>0.05	>0.05	>0.05

Footnote: LOS = length of stay

SD = standard deviation

R = right L = left

Guideline compliance

Compliance with the three discharge planning guideline recommendations was variable, as shown in Table 2.

Only 8 (16%) patients/carers had documented evidence that they were involved in a formal family meeting to discuss discharge options. There was a trend for the provision of a family meeting to be associated with a longer LOS, a lower admission FIM+FAM score (lower functional ability), and greater functional improvement during admission (greater FIM+FAM change) as shown in see Table 2.

The audit identified that 36 (72%) of patients/carers had been involved in "informal" discharge planning discussions with appropriate staff (all those who participated in a family meeting had also been involved in this informal discharge planning). Although not statistically significant, patients with smaller functional improvement during admission (FIM+FAM change <25%) were 4.9 times more likely to be involved in discharge planning than those who experienced greater improvement (see Table 2).

An OT conducted a home assessment prior to discharge for 18 (36%) people in the sample. The provision of a home assessment was significantly associated with discharge directly to home from the ASU, but not with other patient variables, as shown in Table 2.

Residential changes and readmissions following ASU discharge

There was variability in the discharge destinations from the ASU as shown in Figure 1. The most common discharge destination for patients in the follow-up sample was home to a private residence (n= 24, 48%) or to a subacute rehabilitation facility (n= 24, 48%). During the six months following discharge, 11 (22%) people sampled required more supportive accommodation by six months than had been anticipated on discharge from the ASU.

Approximately one third of stroke survivors experienced unanticipated acute hospital readmissions within six months of their initial discharge from the acute stroke unit. Reasons for readmission included pain management, cardiac conditions, acute infections, injuries related to falls, recurrent strokes, and elective procedures (pacemaker insertion, endarterectomy, plastic surgery). Five patients from the sample had two or more readmission during the six month follow-up period. No association could be found between patients need for readmission and their functional ability, functional change, nor LOS during their original stroke admission.

Figure 1: Accommodation of participants at acute hospital discharge and at six month follow-up

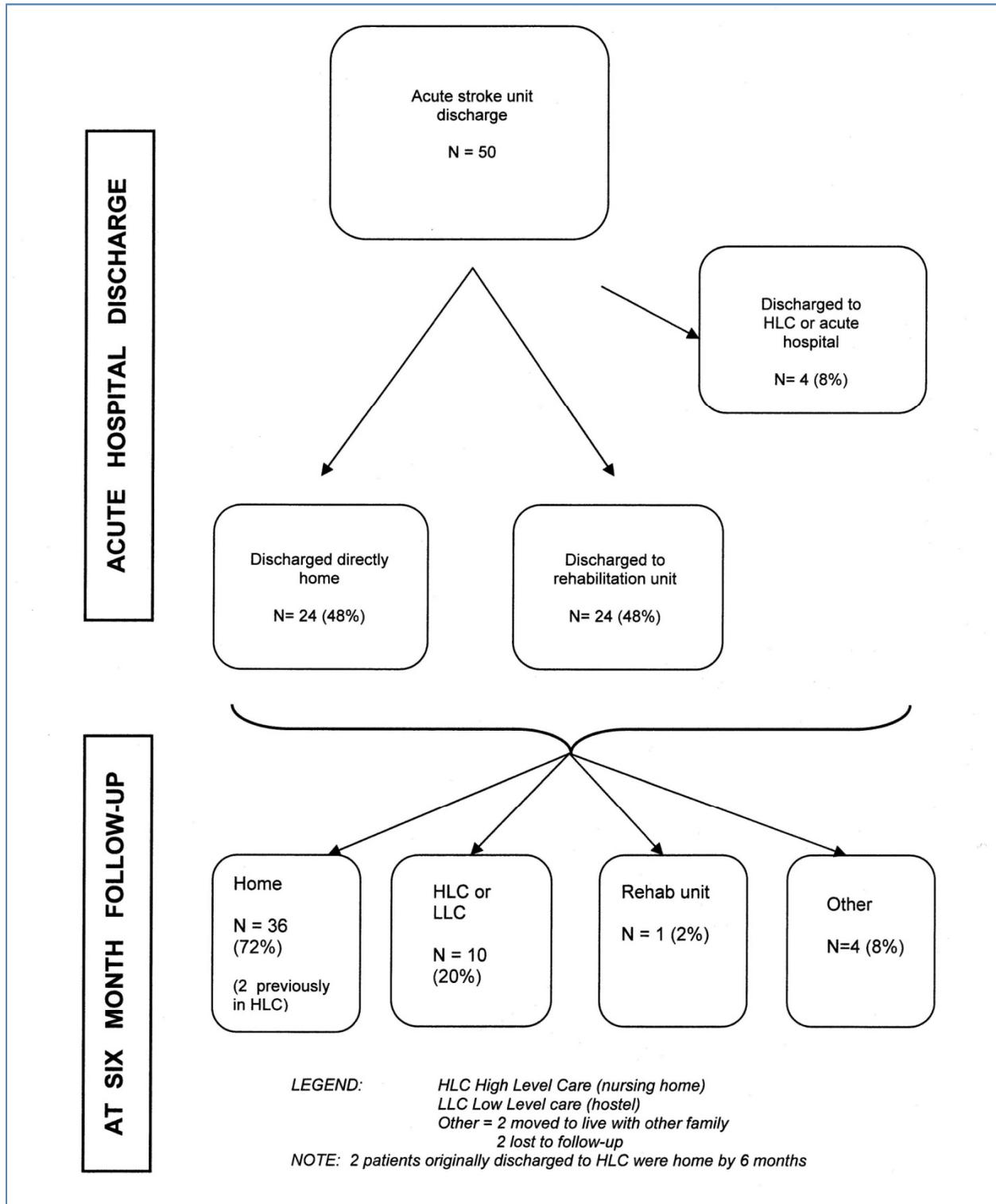


Table 2 The influence on binary-form study variables of compliance with discharge planning recommendations

Outcome	Predictor	Criteria	Odds ratio (RR) [95% CI]
Patient/ carer participate in family meeting	Gender	Female	1.2 (1.2) [0.2 – 7.1]
	Age	>77 years (median)	2.3 (2.0) [0.3 – 18.4]
	Admission FIM+FAM score	< 119.5 (median)	∞
	FIM+FAM percentage change	< 25% (median)	∞
	LOS	≥ 10 days (median)	∞
	D/c directly to home from ASU	Yes d/c home	0.1 (0.2) [0.01 – 1.2]
Patient/carer involved in d/c planning	Gender	Female	2.3 (1.2) [0.5 – 12.8]
	Age	>77 years	1.7 (1.2) [0.4 – 6.9]
	Admission FIM+FAM score	< 119.5 (median)	1.5 (1.1) [0.4 – 6.2]
	FIM+FAM percentage change	< 25% (median)	4.9 (1.5) [1.0 – 27.3]
	LOS	≥ 10 days (median)	1.3 (1.1) [0.3 – 5.5]
	D/c directly to home from ASU	Yes d/c home	0.5 (0.8) [0.1 – 2.2]
OT home assessment	Gender	Female	0.3 (0.4) [0.1 – 1.2]
	Age	>77 years	0.4 (0.6) [0.3 – 1.3]
	Admission FIM+FAM score	< 119.5 (median)	0.5 (0.6) [0.1 – 1.9]
	FIM+FAM percentage change	< 25% (median)	1.0 (1.0) [0.3 – 3.7]
	LOS	≥ 10 days (median)	0.3 (0.4) [0.1 – 1.1]
	D/c directly to home from ASU	Yes d/c home	28.5 (9.4) [4.5 – 237.6]*

∞ = insufficient data spread to calculate Odds Ratio

* = Odds Ratio reached statistical significance

Community support services usage following discharge home

Variable patterns of community support usage were reported and these frequently differed from the discharge plans described in the patient record audit. Table 3 presents the patterns of community support usage experienced by participants post-discharge.

Table 3: Patterns of community support service for entire sample (n=50) following return home

Patient/family experience	N (%)Sample
Using community support services prior to ASU admission	8 (16)
Referred to community support services for discharge home from ASU	21 (42)
Arranged own additional supports by 6 weeks post-discharge	11 (22)
Arranged own additional supports by 6 months post-discharge	20 (40)
Needing more support at 6 months than at 6 weeks	16 (32)

Of the 24 stroke survivors discharged from the ASU directly to home, or to a family member's home, discharge planning during admission resulted in 21 (87.5%) being referred to one or more community support services. Referrals in the order of frequency were to a comprehensive regional community rehabilitation and home support service, driving assessment services, day therapy centres, local councils (shopping and domestic cleaning assistance) and domiciliary care services (personal care assistance and domestic help).

Unanticipated support service requirements

Some patients who were living at home at the six week follow-up telephone call had decreased the supports put in place by the hospital as a result of discharge plans. This was either because they declined to use the referred services or more commonly because functional improvements led to a reduced need for assistance. However, many stroke patients or carers experienced the need for higher levels of community support than had been anticipated by the discharge plans, evidenced by 13 patients who had arranged more support for themselves at six week follow-up (40.6% of those home at six weeks).

By the six month follow-up, 20 stroke survivors (40% of the sample) reported the need for additional services that had not been predicted or arranged at discharge. These patients had made their own arrangements to put requisite services in place after they left hospital (see Table 3). Furthermore, the need for increasing assistance did not diminish over time, as 16 (32%) patients needed more help at six months than they had at the 6-week follow-up. Although it might be unreasonable to expect discharge plans to predict needs several months post-discharge, there were no systems in place to assist these stroke survivors or their carers to find the additional assistance they required.

Types of additional assistance set up by the sample varied. In decreasing frequency these included additional private physiotherapy, house cleaning, other supported exercise options, meal preparation, personal care assistance, assistive equipment purchase and installation, comprehensive aged care packages, safety checks, shopping assistance, acupuncture, community transport, stroke support groups or self management groups, gardening help, and admission to nursing home facilities. Some of these supports were provided by formal community support agencies; however, many were arranged from privately employed providers, neighbours and family members.

The impact of ASU discharge planning

The small percentage of patients living at home at six week follow-up (n= 29) precluded statistical analysis as there was less than five in some cells. However, trends were identified that require further testing in larger samples. Patients' unpredicted support needs at six week follow-up were not related to their functional ability on ASU admission or discharge, their functional change during admission, or their LOS in the ASU. However, in Table 5, there was a moderate association between short-falls in support needs following discharge, and aspects of discharge planning in the ASU, which trended towards significance. Where an OT home assessment visit had been provided prior to, or at the time of discharge, there was a trend that patients were 5.3 times more likely to avoid unpredicted support needs than patients who had not received an OT home visit. Although similarly non-significant, patients with evidence of negotiated discharge planning in the ASU (from involvement in "informal" discharge planning) were approximately 3 times more likely to avoid experiencing unpredicted needs after discharge. It was not possible to examine factors associated with the use of a formal discharge planning meeting (family meeting), because of few patients receiving this service prior to discharge directly home (3.4%).

Table 4: Factors associated with unpredicted support needs for 29 patients at home by 6 week follow-up

Variable	Unpredicted needs	No unpredicted needs	p value	Odds ratio [95% CI]
Evidence of a formal family meeting (% compliant)	3.4	0	#	#
Evidence of patient/carer involvement in discharge planning discussions (% compliant)	20.7	48.3	p>0.05	2.9 ([.4 - 20.6])
Evidence of home assessment by OT (% compliant)	10.3	41.4	p>0.05	5.3 [0.8 - 39.8]
Functional ability on admission to ASU (FIM+FAM mean; (SD))	129 (27.2)	129.3 (32.1)	0.98	
Functional change during admission (FIM+FAM mean change; (SD))	25.1 (12.1)	28.3 (25.6)	0.70	
Length of stay in ASU (mean days; (SD))	7.3 (3.5)	9 (8.4)	0.52	

Footnote:

= insufficient numbers to calculate

Associations between ASU discharge planning and community service requirements between the six week and six month follow-up were not able to be viably calculated, as many discharge plans had been made redundant by hospital readmissions in that time. No trends could be found to explain stroke survivors' experiences after six weeks post-discharge.

Patients' and carers' experience of unanticipated support service requirements

The patients who had experienced short-falls in the support they required after discharge, reported mixed reactions to their experiences during the interviews. Eleven of the 20 patients in this group (22% of the entire sample) were outspoken regarding difficulties they had experienced, including a lack of education and preparation for returning home, inadequate support once home, and difficulty navigating the health support system to source additional assistance.

"...there is a need for some counselling and more help for the family.....my husband didn't have a clue you know....it was just so traumatic for everyone"

Mrs A (66 years)

"You just come out and you're left...it is so traumatic and you are just left."

Mrs B (72 years)

"To get in touch with all the community services is hard."

Mr C (82 years)

In contrast, a number of patients reported no concerns regarding their need to find additional supports for themselves.

"I'm not a person who expects to be waited on. I like to get on with things myself ...I insist on dressing myself when the ladies come (Aged Care Package staff).....The other day I had four neighbours here, the men they were buzzing around doing things for me. They are marvellous to me."

Mrs D (80 years)

It was not only patients who reported difficulty in managing after discharge. Carers also reported distressing situations associated with inadequate supports in the community.

"He wants everything done for him. ...I would like it if he would go somewhere to give me a break, even a few hours, but I don't know if he would go really. He's a bit stubborn like that."

"I am exhausted ...but he doesn't seem to realise it"

Ms E (carer daughter 32 years)

As with the patients themselves, there were numerous examples of carers who demonstrated great resilience to the additional burdens stroke had imposed on them.

"It's been no hardship, but I have had to help him with the diet (feeding) and all."

Mrs F (carer 82 years)

"They say you find out who your friends are...we've lost contact with many. I have a good neighbor and we talk over the fence. I would go mad without that."

Mr G (carer 84 years)

Integrating audit and telephone follow-up data

This research highlighted three related issues of guideline compliance in hospital and post-discharge patient experiences. Australia's National Clinical Guidelines for Acute Stroke Management discharge planning recommendations are "one-size-fits-all," with an expectation that all patients will be provided with equitable discharge planning by staff. The results indicated variable staff compliance with implementing recommendations for discharge planning, and evidence of patient prioritising regarding who was provided with guideline-based care. For at least one-third of the sample, staff compliance with discharge planning recommendations did not relate to improved post-discharge experiences. This highlighted the variability and unpredictability of patient health pathways after leaving hospital. However, patient feedback indicated that many post-discharge experiences could not have been predicted whilst patients were in the hospital, which suggests that discharge plans, whether they complied with guidelines or not, may not meet the rapidly changing longer-terms support needs of stroke survivors and their families.

DISCUSSION

This study provides insight into the way staff compliance with clinical guideline recommendations for discharge planning influenced the experiences of stroke survivors and families following discharge. There was evidence that not all patients received guideline-based care. Irrespective of this, this study highlights that discharge plans made in the acute setting are often unable to predict patients' needs over time. For many patients, the discharge plans and accommodation arrangements made prior to discharge did not relate to their actual requirements after discharge, suggesting that discharge plans made in an ASU may not predict patient health pathways or needs, and hence may quickly become obsolete in the face of changing patient circumstances.

Guideline compliance

The medical record audit provided evidence of variable staff compliance with three discharge planning recommendations. There was a trend for patients with more severe strokes who were making measurable recovery, indicated by low admission FIM+FAM scores, longer LOS, and greater FIM+FAM change, to be more likely to have a formal family meeting to plan discharge. This suggests that staff targeted patients for participation in family meetings, if they were perceived to have more complex post-acute needs and thus may benefit from more formal and detailed multidisciplinary discussions regarding the various rehabilitation and community support choices. The organisation and conduct of family meetings is time consuming for staff and families, and the results of this audit suggest that staff prioritise the use of this discharge planning strategy for the patients with the most complex discharge decisions. Further research is needed to determine whether prioritizing patients to receive guideline compliant care is appropriate. Evidence is needed regarding the cost effectiveness of conducting family meetings in the acute stroke setting and whether particular patients should be targeted for this discharge planning intervention.

There was evidence that the majority (72%) of patients and/or their carers participated in planning for their discharge through "informal" discussions with appropriate staff. Although there was a trend for shorter LOS and milder strokes (higher FIM+FAM scores) to be associated with a lack of patient/carer participation in any discharge planning, this did not reach statistical significance and does not fully explain why 28% of the sample were uninvolved in discharge preparations.

Despite low sample numbers and a lack of statistical significance (as indicated in Table 5), this study highlighted that conducting an OT home assessment was associated with better post-discharge outcomes for patients discharged home from an ASU. This finding warrants further research. There was a significant association between this discharge planning service and patients discharged directly home from the ASU. This again suggests that OT staff may have prioritised this time-consuming intervention to patients with a greater indication for benefit.

Some aspects of discharge planning, as recommended in the clinical guidelines, are time and resource intensive for staff and families. It would not be possible to offer formalised family meetings or home assessments to all patients admitted to a busy ASU, without increased staffing resources. The results of this audit suggest that staff prioritise their case loads so that patients with specific indicators for family meetings or home assessments are provided with these services. Further research is required to determine if patients' functional ability on admission, functional change in the ASU, or LOS could be used as valid indicators to prompt the use of specific discharge planning strategies.

ASU discharge planning and actual experiences

This study presents evidence of the highly changeable and unpredictable nature of stroke survivors' accommodation and support requirements post-discharge from acute care. The direct impact of stroke on patients' functional abilities, and their fragile health status was highlighted by high readmission rates. This had a flow-on effect to their need for changes in accommodation, community supports, and social networks.

The large proportion of this sample that experienced the need for additional post-discharge supports, which had not been anticipated during discharge planning, indicates a mismatch between perceived need whilst in hospital and actual need post-discharge for many stroke survivors. No significant associations were identified between staff compliance with discharge planning recommendations and the avoidance of short-falls in community supports, except for a trend for the potential benefits of an OT home assessment.

The patient and carer experiences of living in the community post-stroke highlight the many things that can go wrong, as well as the way in which different individuals respond to the challenges of changed physical capacity and other effects of the disease. For some patients, the discharge plans made whilst in hospital were sufficiently flexible to support their recovery. For others, the plans were either inadequate to meet their needs, or failed to address changing needs which had not been predicted. It would seem unreasonable to expect acute stroke unit staff to anticipate the highly changeable needs of stroke survivors as time goes by; however, for this sample, there was also a lack of responsive post-discharge systems in place to assist stroke survivors to link with additional support services.

The interviews highlighted the effect of personality, resilience, and previous lifestyles on the ways in which patients and carers dealt with adversity. This study found that some of the patients and carers who experienced short-falls in the amount of community support they required were distressed by the experience and were overwhelmed by attempts to navigate an often complex community health support system to source additional assistance. Conversely, other patients and families demonstrated a level of resilience and a capacity to find and negotiate additional assistance as needed without causing them as much distress. This indicates that the different capacities and skills of stroke survivors and families need to be factored into discharge planning whilst in hospital. Flexible post-discharge support options need to be easily accessible to survivors and carers and be responsive to the rapidly changing nature of patients' post-stroke experiences over time.

Unpredicted needs

It remains unclear where the responsibility lies for setting up community supports for stroke survivors.¹⁰ A tangible gap remains in the process for predicting appropriate support needs for acute stroke patients whilst they are in hospital and their real needs at home in the community, recovering at variable rates. The sampled patients demonstrated that their support needs were still highly changeable six months after their ASU discharge. This indicates that ongoing, flexible, responsive systems that enable patients or carers to engage different community and accommodation supports, need to be in place over the long term and not withdrawn when the patient first reaches a level of adequate community function. Implementing the Australian stroke guideline recommendation for provision of a contact person for post-discharge liaison may facilitate linkages to support services if this resource was available over the long term.^{5,6}

No indicators were found which predicted patients at risk of negative post-discharge experiences, suggesting that new models of pre- and post-discharge support need to be readily accessible to all stroke survivors and carers.

To improve staff compliance with guideline implementation in hospital requires a flexible community support system with which discharge plans can be engaged. This will ensure that that stroke patients' changing health and social needs can be considered in discharge plans made in the acute illness phase, which continue to be relevant over the longer term.

Shortfalls of this research

Caution should be used when considering the relevance of these findings to other settings because of the relatively small sample size used and because local conditions will have influenced the post-discharge experiences of this sample. The convenience

sampling used in this study, based on researcher availability, carries risks of unintended systematic bias. Furthermore, additional bias may result from the role of the researcher as sole auditor. Had resources allowed, the overall rigor of the auditing process would have been improved by the use of a second independent auditor. The retrospective auditing methodology used in the study is also associated with data accuracy issues related to the variable quality of clinical documentation in patients' case notes.

CONCLUSIONS

This research highlighted several themes that are congruent, yet require separate and further investigations. There was variable compliance by staff with the National Clinical Guidelines for Acute Stroke Management discharge planning recommendations, which suggests that some patients were not provided with opportunities to access best available care. Furthermore, there was some evidence that staff prioritized certain patients when implementing discharge planning recommendations. Little is known about why staff vary in their compliance with guideline recommendations, why they favour some patients over others, and whether these practices are appropriate for patients with stroke, thus indicating a future direction for researchers.

The research findings lend themselves to recommendations for better system integration and patient-centred care. The post discharge experiences of many stroke patients could not have been predicted whilst they were in hospital. Thus, discharge plans made in acute stroke units, whether they complied with guidelines or not, are unlikely to fully meet the rapidly changing longer-term support needs of stroke survivors and their families post-discharge. Post-discharge support systems and processes, which enable patients and families to manage unexpected events that occur later, need to be established and evaluated. These systems should provide an ongoing and responsive conduit with liaison staff who can assist them to navigate the complex health system to ensure that their post-discharge needs are met over time. In order to respond to patients' ongoing requirements, strong linkages are required between hospital and community systems, and within and between community services.

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APPENDIX 1 AUDIT CHECK LIST

NATIONAL CLINICAL GUIDELINES FOR ACUTE STROKE MANAGEMENT⁶

Guidelines audited and compliance found

Guideline Number	CLINICAL GUIDELINE	Evidence of compliance	
		YES	NO
7.1b	Multi-D team develops a discharge plan which outlines care in the community including provision of equipment, support services, OP appointments (Patient & carers involved)		
	Comments:		
7.2b	If required, an occupational therapist should conduct a home assessment to ensure safe handling and transfer of patients, and provide education in relation to the use of required equipment prior to discharge		
	Comments:		
7.5	Family meetings -The team should endeavour to meet regularly with the patient and family to ensure ongoing involvement in the management and planning for discharge		
	Comments:		

APPENDIX 2 Six week telephone follow-up prompt questions

Participant No:

Date..... Interviewed: Patient / Carer

1. Where were you discharged to, when you left FMC?

- If **straight home** → have you been able to remain at home since then? Yes / No
 - If No → details (especially hospital readmissions).....
- **Other destination** → details of where & for how long.....

2. Are you presently living at home? Yes / No

If they were discharged straight home from the ASU:

3. You were referred to theservices (see below) prior to leaving the ASU.

How long did that service assist you following your discharge from FMC?

Do you have any comments regarding that referral?

Service referred	How long used	Comments
<i>Data from medical records audit</i>		

If they were discharged to a post-acute Inpatient Rehab Unit from the ASU:

4. Where did you go once you left theRehab Unit? (eg home, hostel, HLC, other)

5. What support services were arranged for you before leaving theRehab Unit?

Service	How long used	Comments

All respondents:

6. Have you arranged other assistance for yourself, since leaving the ASU? (record details).....

7. Any other comment you would like to make regarding your stroke recovery?.....