Kable Ashley (Orcid ID: 0000-0002-1205-7712)

Title

Health professional perspectives on the discharge process and continuity of care for stroke survivors discharged home in regional Australia: a qualitative descriptive study.

Short running title

Stroke Discontinuity of Care

Authors

Ashley KABLE, PhD, RN, Grad Dip Health Serv Man¹,

Amanda BAKER, PhD, M Psychology, BA²,

Dimity POND, PhD, B Med & Surg, BA³,

Erica SOUTHGATE, PhD, B Education⁴,

Alyna TURNER, PhD, BSc(Psyc)(Hons)²,

Christopher LEVI, B Med & Surg, B Med Sc².

Authors

1 School of Nursing and Midwifery, Faculty of Health and Priority Research Centre for Brain and Mental Health, University of Newcastle, Callaghan, New South Wales, Australia.

2 School of Medicine and Public Health, Faculty of Health and Priority Research Centre for Brain and Mental Health, University of Newcastle, Callaghan, New South Wales, Australia.

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: [10.1111/nhs.12590](https://doi.org/10.1111/nhs.12590)

3 Discipline of General Practice, Faculty of Health and Priority Research Centre for Gender, Health and Ageing, University of Newcastle, Callaghan, New South Wales, Australia

4 School of Education, Faculty of Education and Arts, University of Newcastle, Callaghan, New South Wales, Australia.

Corresponding Author

A Kable – Professor, School of Nursing and Midwifery, University of Newcastle, Richardson Wing, University Drive, Callaghan, New South Wales, 2308, Australia.
Telephone + 61 2 49216334 Fax +61 2 49216301 Email:
Ashley.Kable@newcastle.edu.au

Declarations

Author Contributions

AK: Study Design and Lead, Data Collection, Analysis and Results, Draft Manuscript (60%)

AB: Study Design, Analysis, Discussion and Manuscript Review (10%)

DP: Study Design, Data collection, Discussion and Manuscript review (10%)

ES: Data analysis, Review and Discussion (10%)

AT: Study Design, Background, Discussion and Manuscript Review (5%)

CL: Study Design, Background, Discussion and Manuscript Review (5%)

Conflict of Interest: The authors declare no potential conflict of interest with respect to the research, authorship and/or publication of this article.

Acknowledgement of Funding: This work was supported by a grant from the Hunter Medical Research Institute (Dalara Foundation), New South Wales, Australia [HMRI 13-57]..

Word Count: 6354

Title

Health professional perspectives on the discharge process and continuity of care for stroke survivors discharged home in regional Australia: a qualitative descriptive study.

Abstract

Many stroke patients are discharged home, due to advances in treatment approaches and reduced residual disability. This study aimed to understand health professional perspectives on the discharge process and continuity of care, during the transition between hospital and home for stroke survivors. This qualitative descriptive study used focus groups with 25 health professionals involved in discharge processes for transition from hospital to home in 2014, in a regional area of Australia. Discontinuity in the discharge process was affected by: pressure to discharge patients, discharge medications and associated risks, inadequate or late discharge summaries, and challenges involving carers. Discontinuity in post discharge services and follow up was affected by: availability of post discharge services, number of services arranged at the time of discharge, General Practitioner follow up after discharge, delays and waiting

lists, carer problems and long term follow up. There were complex organisational barriers to continuity of care for stroke survivors discharged home. It is important to address these deficits so stroke survivors and their carers can make the transition home with minimal risk and adequate support following a stroke.

Keywords

stroke, continuity of care, qualitative, transitional care, carers, discharge process

Introduction

Recent advances in treatment mean that many stroke survivors are able to be discharged home with minimal residual cognitive and functional disability however, decline in cognitive function after incident stroke has been reported to be accelerated and persistent (Levine et al., 2015). Stroke survivors are frequently dependent on carers and require continued rehabilitation and support. They may be more vulnerable to poor outcomes such as delayed recovery; adverse events such as falls due to residual functional disability, aspiration pneumonia due to swallowing difficulties, and bleeding associated with anticoagulants; and readmission to hospital; if follow up services and support are inadequate after discharge (Ghazzawi, Kuziemy, & O'Sullivan, 2016; Naylor & Keating, 2008).

Literature review

The purpose of the discharge process is to prepare and plan for post discharge services and support, however there may be complex organisational communication,

transfer of information and coordination factors that represent threats to safe discharge and continuity of care (Kripalani et al., 2007; Naylor & Keating, 2008; Waring, Marshall, & Bishop, 2015). Health professionals involved in preparing patients for discharge have been described as well intentioned and committed to planning for this transition. However they can encounter organisational barriers such as pressure to discharge patients, difficulty accessing services (Pindus et al., 2018) and incomplete discharge documentation; and carer stress that prevent the success of these plans (Kable, Chenoweth, Pond, & Hullick, 2015).

One of the major forms of communication at the time of discharge is the discharge summary. This is routinely used to communicate to general practitioners (GP's), and patients and their carers, about the reason for hospitalization, treatment provided, medications at the time of discharge, and arrangements for follow up services after discharge (Kripalani et al., 2007). Some studies have reported that the availability of discharge summaries at the first post discharge visit can be as low as 12 - 34% (Kripalani et al., 2007), and only 28% of older people representing to the Emergency department had a discharge summary from the last admission (Grealish, Forbes, Beylacq, Adeleye, & Crilly, 2017). Furthermore the information in discharge summaries is reported to be inadequate and details about diagnostic test results, patient or family counselling, discharge medications and follow up plans have been reported to be missing in several studies (Cummings et al., 2010; Groene, Orrego, Suñol, Barach, & Groene, 2012; Kripalani et al., 2007). Other important information needed to achieve continuity of care for stroke survivors may include: education of patients or carers about medication monitoring and associated risks (particularly for medications such as

Warfarin). They also need allied health professional advice about diet, speech therapy, and rehabilitation (if the patient has residual functional deficits) and information about support programs (particularly if carer strain is a concern) (Camak, 2015; King, Ainsworth, Ronen, & Hartke, 2010). Carers have a critical role during the preparation phase for discharge and in the transition to home. They adopt responsibility for managing and coordinating care after the stroke patient is discharged and frequently feel inadequately prepared to undertake this role (Aziz, Pindus, Mullis, Walter, & Mant, 2016). They need to be included in planning and training for discharge (Pindus et al., 2018); and need resources to initiate services, manage finances, adapt to changes in their relationship with the stroke survivor and develop coping strategies to adapt to this sudden change in their lives (Luker et al., 2017). In addition, carers need information about stroke associations, support groups, home services and available community facilities (Pindus et al., 2018).

Disruptions in the continuity of care such as delays in service provision, missed medications, missed appointments and inadequate support after discharge, have been reported in some previous studies (Ghazzawi et al., 2016; Koh, Barr, & George, 2014; Naylor & Keating, 2008; Pindus et al., 2018); but factors that contribute to these disruptions are not well understood. The impact of discontinuity on service delivery can result in delayed recovery and readmission to hospital (Naylor & Keating, 2008); and carers feeling unsupported and that it is necessary for them to take responsibility to compensate for inadequacies in the health system (Hvalvik & Reiersen, 2015). Previous studies about discontinuity in transitional care have been focussed on older people (Cheen et al., 2017; Grealish et al., 2017; Hvalvik & Reiersen, 2015), and

people with dementia (Kable et al., 2015), patients with diminished cognition (Groene et al., 2012), carers of stroke survivors (King et al., 2010; Luker et al., 2017; Pindus et al., 2018) and general hospital admissions (Ziaeeian, Araujo, Van Ness, & Horwitz, 2012). These studies have been conducted in Australia, Singapore, Norway, USA and Spain (participating in the HANDOVER project) (Groene et al., 2012), and results may be relevant to other similar healthcare systems. The Australian health care system has been reported to be among the top ranked countries overall, in an evaluation of high income countries performance in 72 indicators of quality care (Schneider, Sarnak, Squires, Shah, & Doty, 2017). It delivers acute care services via a combination of private and public facilities, and major tertiary facilities are all public hospitals associated with major academic training programs. These services are delivered in an environment of increasing pressures and challenges due to complex organisational systems (Waring et al., 2014), increasingly complex medical problems in an ageing society (Naylor & Keating, 2008), and daily discharge targets (Kable et al., 2015). Although previous studies have identified disruptions in continuity of care during the transition from hospital to home, factors that contribute to discontinuity of care are less well understood.

Aim

The aim of this study was to understand health professional perspectives on the discharge process and continuity of care, and identify factors that contribute to discontinuity of care during the transition between hospital and home for stroke survivors.

Methods

Design

A qualitative research design was used for this study (Neergaard, Olesen, Andersen, & Sondergaard, 2009). A series of five focus groups was conducted in a regional area of New South Wales, Australia. Focus groups were selected as a data collection method because they provided an opportunity for participants to discuss issues together and this provided richer, more complex data about the phenomena of interest. The researchers were a team of academics with experience in health services research. Team members who conducted focus groups did not work in the hospitals, and participant names and hospital names were de-identified in the transcripts to ensure confidentiality of participants.

Focus group participants included nurses, allied health professionals, physicians and medical interns from an acute tertiary (stroke unit) and rehabilitation hospital to provide their perspectives about discharge planning. In addition, participants from general practice settings and community stroke programs in the area, were included to provide their perspectives about the patient's transition after discharge.

Participants/Setting

A purposive sampling approach was used for recruiting acute care health professionals who were involved in the discharge and transition process. The researchers approached key clinicians in these areas to undertake recruitment of participants. These key clinicians included clinical nurse consultants in the acute stroke unit and the rehabilitation hospital, the coordinator of the junior medical officer program, the head of the discipline of general practice and lead clinician of the practice based research network for the region, and coordinator of the community stroke team. Potential

participants were invited by key clinicians from their professional groups to participate in the study via email and phone, and provided with an information statement, prior to voluntarily consenting to take part in a focus group. There were 25 health professionals involved in discharge planning and transition from acute and rehabilitation hospitals to primary and community health care services who provided written consent to participate in focus group discussions. No further recruitment was undertaken due to time constraints for this study. Five focus group discussions were conducted with groups of health professionals involved in various aspects of the discharge process to gain an understanding of their roles and perspectives.

- Group one participants included eight Nurses and Allied Health staff from an acute care stroke unit (NAH group).
- Group two comprised two junior medical officers (Interns group) from an acute care stroke unit.
- Group three included seven Rehabilitation Health Professionals (nurses, physicians and allied health) from a Rehabilitation hospital (RHP group).
- Group four included four health professionals (general practitioners and practice nurses) from General Practice settings (GP group).
- Group five included four participants (nurses and allied health) from the Community Stroke Team (CST group).

Data Collection

A schedule of questions guided the focus group discussions and was comprised of two sections. The first section contained a set of general questions about discharge planning. The second section contained a set of questions that were specific for

discharging stroke patients. This schedule included questions about discharge planning, discharge information, discharge medications, follow up after discharge, factors associated with the discharge process and continuity of care, and problems stroke patients encounter after discharge (and is available as a supplementary file). This schedule was developed from current literature that identified aspects of the discharge process and transitional care (Kable et al., 2015; Kable & Pond, 2014), and checked by expert stroke clinicians for relevance to stroke survivors. The focus group schedule was not pilot tested, however a similar schedule was used in a previous study about the discharge process for people with dementia (Kable et al., 2015).

The focus groups were conducted at locations (workplace meeting rooms) and times that were convenient for the participants during the period May - December 2014. The duration of sessions was 44 - 82 minutes. The discussions were facilitated by experienced members of the research team. The sessions were digitally recorded and transcribed verbatim. All data were de-identified in the written transcripts.

Ethical Considerations

The study was approved by the Hunter New England Health Human Research Ethics Committee and the University of Newcastle (Australia) Human Research Ethics Committee (Approval numbers: 13/12/11/5.03, H-2014 - 0098). This study was related to a study of stroke patients in which discharge documentation was audited, and their carers were surveyed after discharge in the same setting (Kable, Pond, Baker, Turner, & Levi, 2018).

Data analysis

A manual process was used to analyse the data. Initially, data were categorised using the semi structured schedule content items. Transcripts were read several times by the first author and text items were organised into categories inductively. These data were read by two researchers and labels were documented independently, and subsequently combined into similar groups in the categories (organising themes) (Vaismoradi, Turunen, & Bondas, 2013). The data were reviewed again, and themes were determined based on similarities and contrasts in the data and relationships that were evident between them (Attride-Stirling, 2001; Neergaard et al., 2009). These themes were reviewed by another expert researcher (ES) to ensure rigour during the analysis process. To enhance trustworthiness the research team used peer review and debriefing to ensure credibility and confirmability of data analysis (Shenton, 2004).

Results

The health professionals in these focus groups, described various perspectives about the transition from hospital to home and how the process had led to discontinuity of care at various points. Implicit in these discussions was an understanding of how this highly complex process was intended to work to provide continuity of care between services. **Figure 1 summarizes the participants' description of an ideal discharge process and continuity of care for stroke survivors discharged home.** However, the analysis of the focus group data revealed that there were numerous factors that caused discontinuity in this transitional process. Two themes were identified: Discontinuity in the discharge process and discontinuity in post discharge services and follow up. Sub-themes are also presented and are summarised in Figure 2.

1 Discontinuity in the discharge process

Hospital staff were clearly dedicated to the task of undertaking extensive multidisciplinary team discharge planning that was coordinated by case managers. However, there were several factors that interfered with them being able to complete this process adequately for every patient at the time of discharge. Four prominent issues were found to have an impact on the discharge process including: pressure to discharge patients, discharge medications and associated risks, inadequate or late discharge summaries, and challenges involving carers.

1.1 Pressure to discharge patients quickly and at short notice

The first issue was pressure to discharge due to the need for beds for incoming patients. Acute care staff described significant pressure to discharge patients quickly, often at short notice and before post discharge services were approved. This made it difficult for staff to see the patient and to complete discharge documentation prior to their discharge. This resulted in “more than half” of these patients being discharged knowing they needed follow up but without having services approved.

It can be quite rushed once the decision is made that yes they're going . . . OK book transport in an hour . . . I might be getting pushed and harassed . . . this person we want them out today [NAH group]

(If services were not approved prior to discharge) that means they're at home . . . with nothing . . . Some of the services won't accept them because they have been discharged from hospital [NAH group]

1.2 Discharge medications and associated risks

The second issue was discharge medications and associated risks. Some medications require careful monitoring and have clinically significant risks associated with their use, and many are secondary prevention strategies. If patients miss taking medications or misunderstand changes in medications and dosage, they risk having poor outcomes such as recurrent stroke, bleeding problems and readmission to hospital. Patients are provided with a week's supply of medications at the time of discharge and are required to see their General Practitioner (GP) during that week for prescriptions for continuing medications. Patients with residual cognitive and functional impairment may have difficulty managing their medications. The patient and their carer need education about their medications, especially if they are taking Warfarin or other high risk medications because they have a high risk for medication errors and clinically significant poor outcomes. The GP also needs to know about medication changes (drug, dose, discontinued and newly commenced medications) and why they have been changed, and the pharmacist medication plan is often better than the medications documented on the discharge summary.

(Warfarin) you do need to monitor INR regularly and the implications of it being not quite right . . . they're not competent to take their medications . . . You need to know what drugs the patient is leaving on, and why they stopped the ones you had them on. . . . Because often they come with a list of drugs that weren't the list of drugs they went in on, but you have no idea why they were changed [GP group].

1.3 Inadequate or late provision of discharge summaries

The third issue was inadequate or late discharge summaries. Interns are responsible for completing medical discharge summaries, often without adequate information available to them. They are often not completed at the time of discharge and may be delayed by up to three months. The type of information provided in these documents varies depending on which health professional is completing the form. For example, the psychosocial aspects of discharge planning are not routinely documented by interns.

(It's) very important on a stroke discharge summary (to include) mechanism of the stroke . . . (and) treatment commenced . . . If you can't get the discharge done and the patient needs to go . . . I would usually try to get it done at the end of that day or the next day . . . but (in) some cases they get left (and may be for patients they've never seen) . . . If I had absolutely no idea what the person had, I'd ask the case manager (or) try to work it out from the notes first [Intern group].

They (interns) don't tend to think so much about the social aspect of . . . what life is going to be like . . . they appreciate that we have a good Allied Health (team) who cover all that stuff, . . . the medical perspective . . . is really about topography and mechanism and prevention, they really do rely on the team to fix the rest [NAH group].

GP's depend on receiving discharge summaries prior to the patients' first appointment after discharge but did not always receive them. They also described receiving medical discharge summaries that did not contain adequate information about follow up and support (including diet and communication support) required for

the patient after discharge; and did not take into account cognitive and functional capacity and social issues such as living situation, mobility, transport and driving.

(The medical discharge summary) is often written by a person who doesn't understand the consequences of what's happening . . . the intern . . . the discharge summary should be ready at discharge . . . is it reasonable for a patient to go home without any information for a medical professional who might have to follow up with them . . . (without any) knowledge of a complex . . . admission to hospital? . . . The important thing to know is . . . what kind of follow up's been organised and how much of it is my responsibility? . . . am I going to have to organise things or have things already been set in place? [GP group].

1.4 Challenges involving carers

The fourth issue was challenges involving carers. Patients with residual impairment need carers to assist and support them at home. An assessment of carer needs can be used to inform post discharge planning. Carers should be educated about medications and potential complications and they may participate in a trial of medication administration prior to discharge. They should also be provided with information about appointments, referrals, medications, dietary needs and contact information for services and health professionals. Carer stress was recognised as an important issue for carers of stroke patients.

If a patient's on a modified diet we need to organise how are they getting thickened fluids? Is somebody going to buy thickened fluids pre-packaged? Are they going to learn how to make it? So you've got to have time to meet with the family member to

show them how to do something, talk about the diet consistency, things they can have and can't have, and organise all those follow-up appointments . . . so they might not be here for that (meeting) [NAH group].

It would be nice if the carer knew what was wrong with the person and what was going to happen and what all the follow up was. And it would be nice to know that the carer was capable of caring for them and wasn't going to crash and burn [GP group].

2 Discontinuity in post discharge services and follow up.

Health professionals in acute and rehabilitation hospitals described having substantial difficulty arranging post discharge services for stroke survivors being discharged home. They encountered these problems because many services had recently changed due to the introduction of the National Disability Insurance Scheme (NDIS) in Australia, and the eligibility criteria had changed (for example permanent disability eligibility criteria).

The NDIS was trialled in this regional area commencing in 2013 (prior to data collection for this study), but was not adopted state-wide until 2016. Prior to the introduction of NDIS, post discharge services were arranged through schemes such as Home and Community Care Programs (HACC) and packages, and subsequently via the Commonwealth Home Support Program (CHSP commenced in 2015) and the Continuity of Support (COS) program: however NDIS is only available to people < 65 years of age. In addition, participants stated that advocacy services and the community support team was no longer a service option due to being relocated to a Medicare local group that was about to be shut down. Furthermore, if a service was not approved for a patient prior to their (unexpected) discharge from hospital, they may not be able to

access it. After discharge, patients and their carers may also encounter difficulties with arranging appointments, delayed service provision and long waiting lists for services. This has implications for their continuity of rehabilitation especially if they have significant disability. Six prominent issues were found to have an impact on post discharge services and follow up including: Availability of post discharge services, number of services arranged at the time of discharge, GP follow up after discharge, delays and waiting lists, carer problems, and long term follow up.

2.1 Availability of post discharge services and eligibility restrictions for services

The first issue concerned the availability of post discharge services and eligibility restrictions for services. Many services had eligibility restrictions or conditions that had to be met for a patient to receive a service. Some services were being discontinued at the same time that new services were being established.

It's changing heaps at the moment. I've had all sorts of conversations about, well we don't have that funding anymore because NDIS is coming in and even though they're not eligible for NDIS they still don't have the funding . . . Some services like integrated care, I don't know who's eligible for what these days [CST group].

2.2 Number of services arranged at the time of discharge

The second issue concerned the number of services arranged at time of discharge. Some patients are discharged without appointments to attend outpatients or day hospital and these can be arranged after discharge. Some patients require immediate response services, and these services must be approved prior to discharge, and if they are not, it may actually delay the discharge of the patient. In addition, there

is a central referral information centre that arranges other follow up services based on referrals and staff advised that more than 50% of patients are discharged without these follow up services arranged.

Sometimes when we make the referral we may not have heard back before they're gone whether they've (the patient) been accepted or not . . . it's up to the service provider to contact them to arrange that [NAH group].

2.3 General Practitioner follow up after discharge

The third issue is GP follow up after discharge. GPs need information about planned services after discharge and are often requested to arrange for follow up with other specialists or for additional tests. They need to know the reason for the referral and how urgently it needs to be done. Information about medications can be confusing – a patient may have two anticoagulants listed and the GP cannot determine whether it is intentional or a mistake. In addition, the CST group were concerned that GPs were not generally aware of the community stroke programs and were not always willing to consent to their patients participating in them.

They come and see us (GPs) before the discharge summary comes out and . . . then the patient's gone and . . . we have to keep track of when that summary arrives then look to see what appointment's been made, then get the patient back again. And then they've missed it [GP group].

2.4 Delays and waiting lists

The fourth issue is delays and waiting lists. Many post discharge services have a waiting list with appointments scheduled for 4 - 8 weeks. Patients may not arrange appointments with their GP within a week which can delay arrangements for other services and interrupt their medication supply.

Our waiting time for an outpatient (appointment) is anywhere between 4 to 8 weeks depending on the urgency of the patient. So if it's a swallowing patient who needs to have their diet looked at again, then they're potentially waiting 8 weeks before they can actually get a follow-up appointment depending on the urgency [NAH group].

2.5 Carer problems

The fifth issue is carer problems. The carer becomes the care coordinator after discharge and they may encounter difficulties with transport and access to services. Carer stress may not become evident until sometime after discharge and there is limited (funded) support for carers in the community.

Until the carer is home actually caring for them they don't know what their issues are going to be . . . 'I didn't realise the intensity of it and now I'm falling in a heap and why am I crying?' . . . A follow-up phone call I did where the carer said to me, 'They did offer us services and we said we didn't need them.' They had been home for 3 days. And she said, 'We really do.' [RHP group]

Probably months down the track but (carer stress) it's a very common thing . . . so stressed and they're admitted to hospital for that reason. "Acopia" is usually what they call it [Intern group].

We actually don't have someone to refer to, for their (carers) social and emotional wellbeing. Quite frankly the funding's gone . . . there's a very big gap in terms of social support for these people [NAH group].

2.6 Long term follow up

The sixth issue is long term follow up. The community stroke team programs are conducted in blocks of 10 weeks. This means that patients must wait until a program commences. The referrals to these programs usually come from the rehabilitation hospital, and rarely from the acute hospital.

When they get home, the problems that arise once they're home are different to what they've had in hospital . . . depression, sexuality . . . (The carers) grief process . . . To accept that maybe this is how this person is going to be. [RHP group].

People are just . . . out there in the community for many years and after a stroke can become socially isolated and . . . they're just left to their own devices without any sort of follow-up and interaction with health services. So I think it's really important that they get linked in with some sort of service that can follow them up and often they aren't [CST group].

Discussion

Participants in these focus groups identified several significant factors associated with the discharge process and continuity of care for stroke survivors and their carers. These barriers are of concern because stroke patients discharged home will encounter disruptions in continuity of care if post discharge services are not arranged and

approved at the time of discharge. Health professionals described difficulty in arranging these services and estimated that more than half of these patients were discharged without services arranged. This is similar to the recent National Stroke Audit data that reported that although 75% of stroke survivors needed ongoing rehabilitation, only 46% were referred to rehabilitation services (Stroke Foundation, 2017). The pressure to discharge patients quickly can mean that they do not receive information from all team members before they are sent home, and this is confirmed by other studies (Kable et al., 2015; Waring et al., 2015).

The participants reported that the discharge summary is not always provided at discharge and often the information in it is inadequate. Interns are required to complete discharge summaries for patients, but they often have insufficient information for this purpose and their workload pressures can result in poorer quality discharge summaries (Mueller, Donze, & Schnipper, 2013; Waring et al., 2015). Patients and carers have information overload at discharge (Ghazzawi et al., 2016; Pindus et al., 2018) and often may not know enough about the prescribed secondary preventive medications that require careful monitoring and the risks associated with them. Medications can be confusing due to similar packaging, small print, medication changes (drug, dose, new and ceased medications) and other medications at home; and it may be necessary for the community pharmacist to provide them in a medication dose decision aid because the hospital does not provide this service. Patients being discharged from the acute hospital and their carers, do not have the opportunity to trial taking their medications prior to discharge.

GP's may not receive discharge summaries or sufficient information about the patient, particularly their medication changes and associated reasons, their need for services and support, their management plan and assessments of cognitive and functional capacity. Sometimes they receive discharge summaries for patients who do not attend a subsequent appointment or who attend weeks after they have been discharged. In addition, the psychological, social and personal needs of stroke survivors may not be adequately documented in information provided to GPs because it is "less valued" than biomedical knowledge (Waring et al., 2015). It was noted during analysis that there were discrepancies between hospital staff perspectives and community staff perspectives (including GP's) about the communication that occurs at discharge.

The most significant discrepant issue was the communication of medication information to GP's. Although a list of medications is provided at discharge, this list rarely includes reasons for ceasing, commencing or changing medications and the GP needs to know about these changes. In addition, GP's need to know about cognitive and functional capacity and psychosocial aspects and post discharge plans for managing them, so they can provide adequate follow up after discharge.

Post discharge care packages and policies have less funding and less hours of care available, and staff described being very stressed due to trying to locate alternate services. They stated that more services were needed and more information was needed about the coverage available from various services. To be eligible for NDIS services, permanent disability had to be established. Eligibility restrictions, changes in available services and approval processes for services can result in patients not receiving services or having difficulty accessing them, or encountering extended

waiting times for services (Koh et al., 2014). Carers and patients may also encounter barriers such as transport, parking, distance (Ghazzawi et al., 2016), public transport schedules, being unable to drive, using wheelchairs and being obese.

During hospitalization there is a stroke team and case manager that provides support, however after discharge there is no home team service and patients and carers often have difficulty coping/ managing at home. They may not realise they need services until they have been discharged. Some patients are readmitted due to complications such as aspiration pneumonia (due to swallowing problems and insufficient advice at discharge about food preparation and positioning), falls and trips due to mobility problems, and medication related problems such as bleeding (due to Warfarin or other anticoagulants). Home medication reviews are not routinely done and there is a significant need for social support for patients and carers. Carers have been described in previous studies as being vulnerable and significant agents in the role of maintaining continuity and safety during the transition to home (Hvalvik & Reiersen, 2015). Carers may feel insignificant to health professionals; and despite feeling invisible, uncertain, powerless, fearful and isolated, they accept the responsibility for managing their loved one at home and being available to respond and act in the event that they are needed (Ghazzawi et al., 2016; Luker et al., 2017). In addition, they undertake the role of navigating the health system and coordinating appointments and services and providing emotional support and these responsibilities frequently result in high carer stress and exhaustion (Camak, 2015; King et al., 2010).

In the long term, patients and their carers may fear a further loss of independence and isolation if they are not coping. They may suffer from social isolation, depression,

fatigue, frustration, loss of previous roles and identity, cognitive and functional challenges, loss of confidence, loss of friends, grief and the challenge of rebuilding their lives over many years. Participants recognised that carers suffer considerable stress and carer burden due to the increased complexity of patients being discharged home, and some may not be capable of providing care. They need information about where to get help and useful contacts. In addition, referrals to the community stroke program were reported to be low and there is a three month waiting time for these programs. Previous studies have emphasised the risk of suffering high carer stress (Aziz et al., 2016; Ekstam, Johansson, Guidetti, Eriksson, & Ytterberg, 2015; Kable et al., 2018; King et al., 2010). They also highlight the significance and complexity of the carer role during transitions between services and in maintaining continuity of care (Ghazzawi et al., 2016; Hvalvik & Reiersen, 2015); and associated difficulty for carers when stroke survivors are discharged home and their need for support (King et al., 2010) particularly with medications (Pindus et al., 2018); as they coordinate services and provide the stroke survivor with instrumental and emotional support (Aziz et al., 2016; Luker et al., 2017).

The implications of this study are broader than the issue of inadequate discharge planning. Future studies should develop and implement targeted interventions to improve processes during and after discharge to ensure patient safety and continuity of care during transition to the community. These interventions should target organisational barriers and support staff to address communication via discharge summaries, medication safety and reconciliation, and carer stress. The Acute Stroke Clinical Care Standard (published after data were collected in this study) also contains

a quality statement (indicator) about transition from hospital care for patients with stroke that specifies that clinicians should develop an individualised care plan for patients before they leave hospital, and health services should provide appropriate resources so that clinicians can develop these plans prior to discharge (Australian Commission on Safety and Quality in Health Care, 2015). This requirement has potential to improve discharge processes at transition from hospital, however, in the 2017 National Stroke Audit, this indicator was reported to be 62% in Regional areas and 66 % Metropolitan areas, suggesting this is similar across participating hospitals in Australia (Stroke Foundation, 2017); and has increased from 56% in 2015.

Strengths and limitations

The strength of this study is that it contributes health professional perspectives about factors that influence continuity of care during and after discharge for stroke survivors and their carers. The qualitative descriptive methodology **adopted** in this study used a low inference approach to analysis and therefore data were described rather than interpreted. Although this approach may be affected by the researcher's perceptions, we used independent analyses by the research team to minimise this risk. These data were provided by health professionals who volunteered to participate in a regional area in Australia and consequently the results are not generalizable. However, the results may be relevant and transferable to other stroke units in tertiary referral and rehabilitation hospitals in **comparable** healthcare systems where similar organisational issues and barriers exist.

Conclusion

This study has identified numerous factors that caused discontinuity in this transitional process and resulted in delayed service delivery, inadequate information being provided to patients and their carers and GPs, potential for adverse events including readmission, and carer stress. Overcoming the barriers to prevent discontinuity of care for stroke survivors discharged home is a significant challenge. The factors that contribute to discontinuity represent complex organisational processes and communication and information challenges for health professionals in contemporary practice. However, it is important to address the deficits in this process, so that stroke survivors and their carers can make the transition to home with minimal risk and adequate support. In addition, the communication of critical information to GPs will contribute to a smooth transition for these vulnerable patients. Communication via discharge summaries and additional attention directed towards medication safety are critical aspects of this process that require improvement. Although previous studies have reported about deficits in the discharge process, the findings from this study provide novel qualitative insights about the organisational pressures and process factors that contribute to poor and/or delayed communication at the time of discharge and discontinuity of care after discharge. Unless these organisational factors are addressed, it is unlikely that continuity of care outcomes for stroke survivors can be improved.

Implications for clinical practice

Alleviating the pressure to discharge quickly, would allow the team more time to complete the discharge process more comprehensively. They could provide patients and carers with education about the patient's diagnosis, medications and associated

risks; and routinely provide a list of medications and appointments and planned follow up services to patients and GPs. It would be helpful to allow patients and carers to have a trial of medications prior to discharge from acute care; and provision of medications in medication dose decision aids would assist patients with residual functional and cognitive impairment. Education should be considered to improve consistent documentation in discharge summaries, and registrars could check discharge summaries before they are sent to GPs and patients. Discharge summaries should be completed and sent on the day of discharge. Routine provision of home medication reviews after discharge could contribute to reduced medication risk and fewer complications and readmission to hospital (Kable et al., 2015). Improved carer involvement and support may make it possible for carers to cope better and to assist stroke survivors at home to avoid adverse outcomes (Hvalvik & Reiersen, 2015; King et al., 2010; Naylor & Keating, 2008) . Increasing referrals to the long term stroke program would be beneficial for patients by reducing social isolation and depression, and improving support. These solutions could potentially overcome some of the barriers described above, but may be quite challenging to adopt due to the organisational complexity of this process in the acute and rehabilitation hospital settings.

This paper is relevant to clinicians in acute care and primary care settings who are involved in management of stroke patients as they are discharged from acute care and rehabilitation hospitals, to be managed in the primary health care context, with a focus on improving this process for stroke survivors and their carers. Interventions to improve communication and medication safety should be tested in clinical practice settings.

Acknowledgement of Funding: This work was supported by a grant from the Hunter Medical Research Institute (Dalara Foundation), New South Wales, Australia.

Author Contributions

AK: Study Design and Lead, Data Collection, Analysis and Results, Draft Manuscript (60%)

AB: Study Design, Analysis, Discussion and Manuscript Review (10%)

DP: Study Design, Data collection, Discussion and Manuscript review (10%)

ES: Data analysis, Review and Discussion (10%)

AT: Study Design, Background, Discussion and Manuscript Review (5%)

CL: Study Design, Background, Discussion and Manuscript Review (5%)

References

- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, 1, 385-405.
- Australian Commission on Safety and Quality in Health Care. (2015). *Acute Stroke Clinical Care Standard*. Sydney: ACSQHC.
- Aziz, N., Pindus, D., Mullis, R., Walter, F., & Mant, J. (2016). Understanding stroke survivors' and informal carers' experiences of and need for primary care and community health services - a systematic review of the qualitative literature: protocol. *BMJ Open*, 6(e009244), 1-7.
- Camak, D. (2015). Addressing the burden of stroke caregivers: a literature review. *Journal of Clinical Nursing*, 24, 2376-2382.
- Cheen, M. H., Goon, C., Ong, W., Lin, P., Wan, C., Leong, M., & Khee, G. (2017). Evaluation of a care transition program with pharmacist-provided home-based medication review for elderly Singaporeans at high risk of readmissions. *International Journal for Quality in Health Care*, 29(2), 200-205.
- Cummings, E., Showell, C., Roehrer, E., Churchill, B., Turner, B., Yee, K., . . . Turner, P. (2010). *A Structured Evidence-Based Literature Review on Discharge, Referral and Admission*. Retrieved from
- Ekstam, L., Johansson, U., Guidetti, S., Eriksson, G., & Ytterberg, C. (2015). The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: a mixed methods study. *BMJ Open*, 5(e006784), 1-8.
- Ghazzawi, A., Kuziemy, C., & O'Sullivan, T. (2016). Using a complex adaptive system lens to understand family caregiving experiences navigating the stroke rehabilitation system. *BMC Health Services Research*, 16, 538.
- Grealish, L., Forbes, M., Beylacy, M., Adeleye, A., & Crilly, J. (2017). Older persons who re-present to the Emergency Department: An observational study. *Collegian*, 24(6), 557-562. doi: <http://dx.doi.org/10.1016/j.colegn.2017.01.001>
- Groene, R. O., Orrego, C., Suñol, R., Barach, P., & Groene, O. (2012). "Its like two worlds apart": an analysis of vulnerable patient handover practices at discharge from hospital. *BMJ Quality and Safety*, 21(Suppl 1), i67-i75. doi:10.1136/bmjqs-2012-001174
- Hvalvik, S., & Reiersen, I. (2015). Striving to maintain a dignified life for the patient in transition: Next of kin's experiences during the transition process of an older person in transition from hospital to home. *International Journal of Qualitative Studies on Health and Well-being*, 10. doi: 10.3402/qhw.v10.26554
- Kable, A., Chenoweth, L., Pond, D., & Hullick, C. (2015). Health professional perspectives on systems failures in transitional care for patients with dementia and their carers: a qualitative descriptive study. *BMC Health Services Research*, 15, 567.
- Kable, A., & Pond, D. (2014). Chapter 8: Discharge Planning and Continuity of Care. In T. Levett-Jones (Ed.), *Critical Conversations for Patient Safety*. Frenches Forest, NSW: Pearson Australia.
- Kable, A., Pond, D., Baker, A., Turner, A., & Levi, C. (2018). Evaluation of discharge documentation after hospitalization for stroke patients discharged home in Australia: A cross-sectional pilot study. *Nursing and Health Sciences*, 20, 24-30.

- King, R., Ainsworth, C., Ronen, M., & Hartke, R. (2010). Stroke Caregivers: Pressing Problems Reported during the First Months of Caregiving. *Journal of Neuroscience Nursing*, 42(6), 302-311.
- Koh, W., Barr, C., & George, S. (2014). Factors influencing post-stroke rehabilitation participation after discharge from hospital. *International Journal of Therapy and Rehabilitation*, 21(6), 260-267.
- Kripalani, S., LeFevre, F., Phillips, C., Williams, M., Basaviah, P., & Baker, D. (2007). Deficits in Communication and Information Transfer Between Hospital-Based and Primary Care Physicians. *Journal of American Medical Association*, 297(8), 831-841.
- Levine, D., Galecki, A., Langa, K., Unverzagt, F., Kabeto, M., Giordani, B., & Wadley, V. (2015). Trajectory of Cognitive Decline After Incident Stroke. *Journal of American Medical Association*, 314(1), 41-51.
- Luker, J., Murray, C., Lynch, E., Bernhardsson, S., Shannon, M., & Bernhardt, J. (2017). Carers' Experiences, Needs, and Preferences During Inpatient Stroke Rehabilitation: A Systematic Review of Qualitative Studies. *Archives of Physical Medicine and Rehabilitation*, 98, 1852-1862.
- Mueller, S., Donze, J., & Schnipper, J. (2013). Intern Workload and Discontinuity of Care on 30-Day Readmission. *The American Journal of Medicine*, 126(1), 81-88.
- Naylor, M., & Keating, S. (2008). Transitional care: Moving patients from one care setting to another. *American Journal of Nursing*, 108(9), 58-63.
- Neergaard, M., Olesen, F., Andersen, R., & Sondergaard, J. (2009). Qualitative description - the poor cousin of health research? *BMC Medical Research Methodology*, 9, 52-56.
- Pindus, D., Mullis, R., Lim, L., Wellwood, I., Rundell, A., Aziz, N., & Mant, J. (2018). Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. *PLoS ONE*, 13(2), 1-23.
- Schneider, E., Sarnak, D., Squires, D., Shah, A., & Doty, M. (2017). *Mirror, Mirror 2017: International Comparison Reflects Flaws and Opportunities for Better U.S. Health Care*. Retrieved from New York: http://www.commonwealthfund.org/interactives/2017/july/mirror-mirror/assets/Schneider_mirror_mirror_2017.pdf
- Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63-75.
- Stroke Foundation. (2017). *National Stroke Audit Acute Services Report*. Retrieved from Melbourne, Australia:
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, 15(3), 398-405.
- Waring, J., Marshall, F., & Bishop, S. (2015). Understanding the occupational and organizational boundaries to safe hospital discharge. *Journal of Health Services Research and Policy*, 20(Suppl. 1), 35-44.
- Waring, J., Marshall, F., Bishop, S., Sahota, O., Walker, M., Currie, G., . . . Avery, T. (2014). *An ethnographic study of knowledge sharing across the boundaries between care processes, services and organisations: the contributions to 'safe' hospital discharge*.

Retrieved from Southampton (UK):

<http://eprints.nottingham.ac.uk/42708/1/FullReport-hsdr02290.pdf>

Ziaieian, B., Araujo, K. L. B., Van Ness, P. H., & Horwitz, L. I. (2012). Medication Reconciliation Accuracy and Patient Understanding of Intended Medication Changes on Hospital Discharge. *Journal of General Internal Medicine*, 27(11), 1513-1520.

Figure 1: Participants description of an ideal discharge process and continuity of care for stroke survivors discharged home

- At the time of discharge (and modified according to residual cognitive and functional impairment), the multidisciplinary team would see the patient and explain the post discharge management plan;
- Patients and their carer would be provided with a copy of a completed discharge summary and information about planned services, appointments, and medication changes;
- Patients/carers would be provided with a week supply of medications and a pharmacists medication plan, and educated about them; and they would be advised to see their General Practitioner within a week;
- Carers needs would be assessed, and they would be provided with information about long term follow up and health professional contacts in the community.
- At the time of discharge, the General Practitioner would be provided with the completed discharge summary and information about planned services, appointments, medication changes; and requested to arrange for medication reconciliation in the home.

Figure 2: Health professional perspectives on factors that caused discontinuity in the transitional process for stroke survivors

- 1 **Factors related to discontinuity in the discharge process**
 - Pressure to discharge patients quickly and at short notice
 - Discharge medications and associated risks
 - Inadequate or late provision of discharge summaries
 - Challenges involving carers
- 2 **Factors related to discontinuity in post discharge services and follow up.**
 - Availability of post discharge services and eligibility restrictions for services
 - Number of services arranged at the time of discharge
 - General Practitioner follow up after discharge
 - Delays and waiting lists
 - Carer problems
 - Long term follow up

Title

Health professional perspectives on the discharge process and continuity of care for stroke survivors discharged home in regional Australia: a qualitative descriptive study.

Short running title

Stroke Discontinuity of Care

Authors

Ashley KABLE, PhD, RN, Grad Dip Health Serv Man ¹,

Amanda BAKER, PhD, M Psychology, BA ²,

Dimity POND, PhD, B Med & Surg, BA ³,

Erica SOUTHGATE, PhD, B Education ⁴,

Alyna TURNER, PhD, BSc(Psyc)(Hons) ²,

Christopher LEVI, B Med & Surg, B Med Sc ².

Authors

1 School of Nursing and Midwifery, Faculty of Health and Priority Research Centre for Brain and Mental Health, University of Newcastle, Callaghan, New South Wales, Australia.

2 School of Medicine and Public Health, Faculty of Health and Priority Research Centre for Brain and Mental Health, University of Newcastle, Callaghan, New South Wales, Australia.

3 Discipline of General Practice, Faculty of Health and Priority Research Centre for Gender, Health and Ageing, University of Newcastle, Callaghan, New South Wales, Australia

4 School of Education, Faculty of Education and Arts, University of Newcastle, Callaghan, New South Wales, Australia.

Corresponding Author

A Kable – Professor, School of Nursing and Midwifery, University of Newcastle, Richardson Wing, University Drive, Callaghan, New South Wales, 2308, Australia. Telephone + 61 2 49216334 Fax +61 2 49216301 Email: Ashley.Kable@newcastle.edu.au

Declarations

Author Contributions

AK: Study Design and Lead, Data Collection, Analysis and Results, Draft Manuscript (60%)

AB: Study Design, Analysis, Discussion and Manuscript Review (10%)

DP: Study Design, Data collection, Discussion and Manuscript review (10%)

ES: Data analysis, Review and Discussion (10%)

AT: Study Design, Background, Discussion and Manuscript Review (5%)

CL: Study Design, Background, Discussion and Manuscript Review (5%)

Conflict of Interest: The authors declare no potential conflict of interest with respect to the research, authorship and/or publication of this article.

Acknowledgement of Funding: This work was supported by a grant from the Hunter Medical Research Institute (Dalara Foundation), New South Wales, Australia [HMRI 13-57]..

Word Count: 6354

Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:

Kable, A;Baker, A;Pond, D;Southgate, E;Turner, A;Levi, C

Title:

Health professionals' perspectives on the discharge process and continuity of care for stroke survivors discharged home in regional Australia: A qualitative, descriptive study.

Date:

2019-06

Citation:

Kable, A., Baker, A., Pond, D., Southgate, E., Turner, A. & Levi, C. (2019). Health professionals' perspectives on the discharge process and continuity of care for stroke survivors discharged home in regional Australia: A qualitative, descriptive study.. Nurs Health Sci, 21 (2), pp.253-261. <https://doi.org/10.1111/nhs.12590>.

Persistent Link:

<http://hdl.handle.net/11343/284947>