

Integrated Transitions of Care for People with Geriatric Syndrome

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DECLARATION

I hereby state that this thesis titled, *Integrated Transitions of Care for Patients with Geriatric Syndrome*, is the product of my own work. It has never been submitted in part, or in full, to meet the requirements of a degree at any institution or university. The presented systematic review, separately titled *Does including informal caregivers into transitions of care provide better value care for patients with geriatric syndromes? A systematic review*, has been submitted and accepted in abstract format for oral presentation at the Asia Pacific Conference for Integrated Care in November, 2019.

This thesis contains my own research and is originally presented. I acknowledge the recommendations I received from supervisors in research conception, design and linguistic expression. All supporting evidence and literature used is appropriately referenced in the text.

The research was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007-updated 2015). The research received ethics approval from Adventist Healthcare Limited and Macquarie University Ethics Committees, approval number 2019-018.

Signed:

Date: 17th October 2019

SUMMARY

People with geriatric syndrome experience increased morbidity, fragility, cognitive decline and years lived with disability. Acute hospital length of stay has decreased, causing this vulnerable cohort to navigate fragmented community care. The risks of fragmented care may be mitigated by integrating informal caregivers into transitions of care. A systematic review examines whether integrating informal caregivers into transitions of care enables better outcomes, using the ‘quadruple aims’ framework for healthcare. Limited evidence of trends was found in this review. It may be that benefits of caregiver integration extend beyond the evaluation period of interventions. The systematic review highlighted gaps in current caregiver integration practice, research and policy, and informed a mixed methods study. The study investigates discharging planning from the perspective of eleven acute care physiotherapists. Their experiences suggest that caregiver integration is variable. The participants perspectives and experiences were used to construct experience-led solutions to ambiguous caregiver integration policy. Solutions vary from large-scale, such as restructuring funding models, to smaller-scale local solutions, for example interface changes in electronic medical record systems. Further high-quality research is required to investigate methods to successfully integrate informal caregivers, patients and health professionals into transitions of care between settings.

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LIST OF ABBREVIATIONS

ACAT	Aged Care Assessment Tool
AUD	Australian Dollar
BI	Barthel Index
CSI	Caregiver Strain Index
CTM	Care Transitions Measure
ED	Emergency department
eMR	Electronic medical record
FIM	Functional Independence Measure
GP	General practitioner
ICS	Integrated Care Strategy
IHI	Institute for Healthcare Improvement
LOS	Length of stay
MDT	Multidisciplinary team
mRS	Modified Rankin Scale
MUCHE	Macquarie University Centre for the Health Economy
NSW	New South Wales
QALY	Quality Adjusted Life Year
QoL	Quality of life
SD	Standard deviation
USA	United States of America
USD	United States Dollar
VAR	Visual analogue ruler

1. INTRODUCTION

1.1. Overview

Financial pressures and changes in practice have caused patients' length of stay (LOS) in hospital to decrease over time.¹ Currently, patients are stabilised in acute settings and discharged to the community for ongoing management. This increases the pressure for patients with geriatric syndromes (see Section 1.2) and their informal carers to self-manage chronic conditions, changes to their care demands and to navigate between fragmented community services.² Informal carers are unpaid, frequently family or friends and who can provide a variety of services ranging from assistance for transport and appointments to 24 hour care. To successfully self-manage after discharge, patients and their carers require confidence, education and technical skill. However, patients and carers frequently feel unprepared for the home environment, care demands, and are unfamiliar with discharge instructions.³ This can put patients at risk of adverse events such as medication errors,⁴ inappropriate care by caregivers⁵ and readmissions.^{6, 7}

Caregiver integration in discharge planning remains challenging due to discontinuity in providers, the siloed structure of healthcare delivery and the lack of a formal process for carer engagement.³ Patients and carers are frequently the only common factor between providers in a siloed healthcare system. Theoretically, an informed carer may navigate the system and coordinate care more effectively.³ Evidence suggests integrating caregivers into the discharge planning of people with geriatric syndromes can improve caregiver satisfaction,⁸ decrease LOS⁹ and readmission rates by twenty percent.^{6, 10-12} Conversely, critics argue that informal caregiver integration may place additional stress on the caregiver and transitional care improvement simply requires more time with healthcare professionals.¹³

Including carers in discharge planning of geriatric syndromes may increase the value of care. That is, to increase quality and satisfaction of care whilst simultaneously decreasing the burden on healthcare professionals and cost to the health system. Routine involvement of the carer in care transitions and discharge planning may be a method of achieving the objectives outlined in the New South Wales (NSW) Integrated Care Strategy (ICS) and the quadruple aims of healthcare.¹⁴

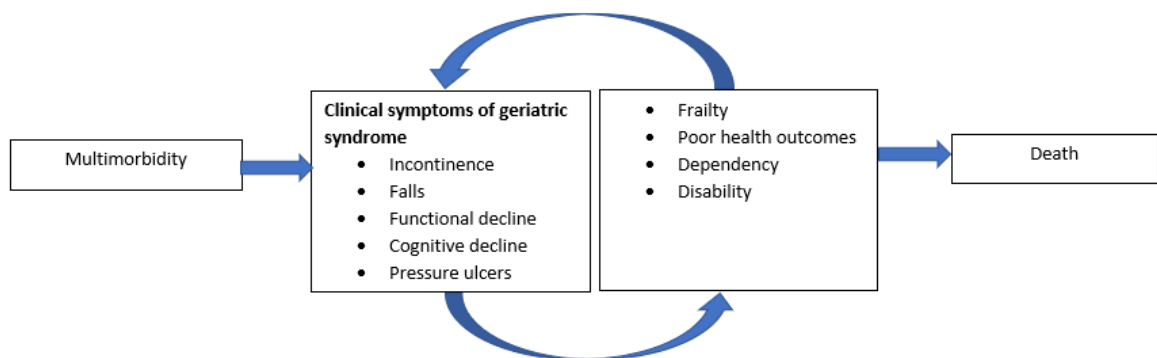
1.2. Concepts

Geriatric Syndrome

Globally, populations are achieving greater longevity. These additional years are often spent with increased disability and morbidity and are associated with a growth in healthcare expenditure.¹⁵ The traditional single-disease focused care model is not suited to the epidemiological shift to non-communicable diseases such as multimorbidity and frailty as it encourages siloed care.¹⁶ Redesigning healthcare with definitions such as geriatric syndrome, which is a combination of multimorbidity, frailty and disability, may assist in integrating care to create a model that is more suited to the population.¹⁷

In geriatric syndrome, multiple morbidities precipitate a non-specific impairment that is associated with old age.¹⁸ These impairments or symptoms include incontinence, falls, functional and cognitive decline. The concept, illustrated below, broadly refers to vulnerability caused by co-morbidity and its accumulated multi-system impairments.^{19, 20} These impairments have a cyclical and downward trending relationship with disability and poor health which eventuates in mortality.¹⁹

Figure 1: Concept map of geriatric syndrome. Adapted from Inouye¹⁹



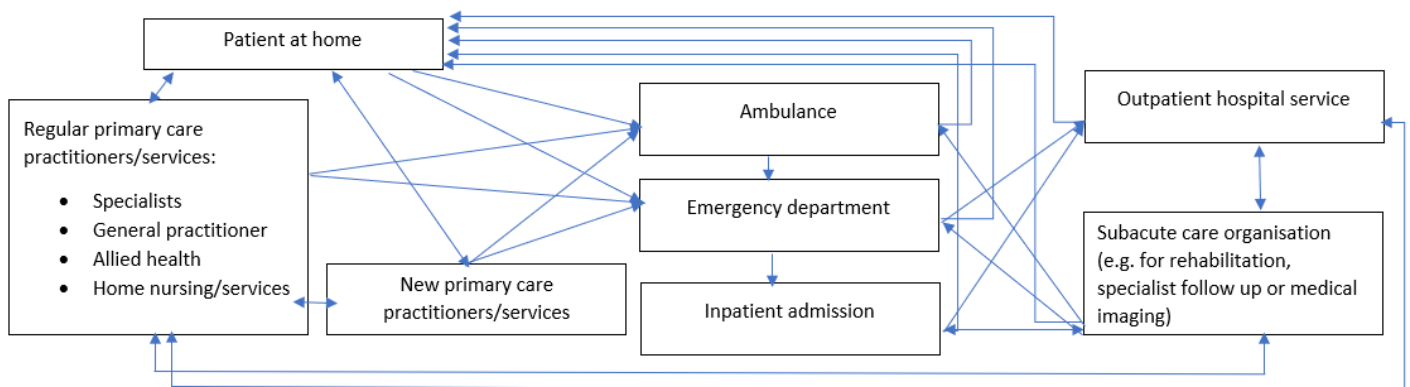
Geriatric syndrome is strongly associated with poor health outcomes, survival and high healthcare resource use.^{19, 21, 22} Geriatric syndrome remains poorly and inconsistently defined in the literature¹⁹ and as a result, prevalence in the community is dependent on definition.

Throughout this research, the term geriatric syndrome is used to encompass the entire spectrum, illustrated above, in people older than 65. This includes multimorbidity (>3 comorbidities), the presence of at least one symptom of geriatric syndrome of moderate to severe on validated scales, or the presence of frailty or moderate dependence.

Transitional care

Care transitions are patient movements between healthcare settings which can provide a patient with the appropriate level of support. This research focuses on any action or care that aims to provide a smooth transition from acute and subacute care settings to the community, i.e. from hospital to home. Transitional care practices can include integrated patient care pathways, supportive communication system, staff/patient/caregiver training and education, goal setting, equipment provision, rehabilitation and coordination of follow-up services and appointments. The figure below illustrates the complexity that can occur in patient movement between hospital and community settings. To provide coordinated care, these movements require timely communication between multiple providers and care settings.

Figure 2: Transition pathways between acute and community settings in Australia.
Adapted from the Australian Productivity Commission on Aged care.²³



Communication and collaboration between settings varies by facility and local health system structure. Generally, acute and community healthcare facilities are poorly integrated and described as ‘siloed’. In Australia, the patient is often considered the most knowledgeable source of information on their health condition as they are the only constant between settings.⁷ Only 66% of people reported that their general practitioner (GP) or usual place of care appeared informed about their follow-up plan.²⁴ Poor transitional care is associated with patient harm and societal cost and occurs frequently.²⁵ A cohort study found 19% of people discharged home from hospital had an adverse event, the majority preventable.²⁶

Poor patient-centred care models and patient engagement have been identified as an underlying causes for poor transitions.⁷ Theoretically, patient-centred care may result in

patients being engaged and informed, active participants in development of appropriate care plans to act as a safety net in their own care.

Patient education is a frequently used mechanism to engage patients in transitions of care. This may not be best practice as poor health literacy and mild undiagnosed cognitive decline is common in people with geriatric syndrome.²⁷⁻³⁰ Additionally, healthcare professionals often overestimate patient knowledge, causing them to provide less information.³¹ Including informal caregivers into patient education could empower caregivers to reinforce the patient's discharge care plan and self-management skills in the community.

The World Health Organisation asserts that true patient engagement and patient-centred care goes beyond education. It requires a cultural shift in healthcare to prioritise collaborative practice with patients.³² There is broad consensus in the literature that this collaborative practice needs to be holistic and extend to patients' families and communities. The horizontal integration of patients existing support networks may assist in developing realistic treatment plans and services for patients and all involved in care.

This research considers transitional care to be any activity which aims to create a smooth transition from hospital to home and involves at least one component listed in the box below.

Figure 3: Characteristics of transitional care

- Comprehensive planning for transfer
- Clear documentation of a transitional care plan
- Proactive assessment and management of patient risks
- Medication reconciliation
- Promotion of self-management
- Organisation of follow up services or appointment
- Follow-up on outstanding investigations
- High quality verbal and written information to the consumers
- Timely and high-quality documentation to next service and discharge
- Home visits, follow-up phone calls or continuing support

In this research discharge planning is considered any action that occurs in the hospital that prepares a patient for discharge.

Informal caregivers

Informal caregivers are frequently family and friends and are not employed or paid to provide care to the patient. This assistance covers medical and social support and can range from infrequent to 24-hour care. Capturing true informal caregiver demographics and statistics is complicated as many informal caregivers do not identify as such. However, globally, informal caregiving is more likely to be carried out by women.³³ In Australia, 67% of carers are of working age and within this category 74% are women.³⁴ The likelihood of caregiving increases with age, the over 65 year old age group is the fastest growing caregiver category.^{23, 34} Older caregivers are more likely than younger caregivers to have a disability themselves, creating co-dependency.³⁴

Informal caregivers provide irreplaceable levels of care. They are exclusive sources of assistance for eighty percent of community dwelling Australians who require assistance.²³ However, policies supporting systems and models of care often treat caregivers as ‘invisible’ members of a person’s care team.²³ In 2015, the average carer provided 13 hours of care a week, which would have cost the Australian government 60.3 billion AUD a year to replace.³⁵ In future, governments could benefit from maximising caregiver efficiency given demand for informal care is increasing.^{23, 35} Additionally, the number of informal caregivers is predicted to decrease by 20% from 2015 to 2025.³⁵ This trend is caused by an ageing population and changing family structures.³⁵

Providing informal care can be rewarding, however, it comes with a cost. Informal caregivers are more likely to experience financial difficulty and poor mental health.^{33, 36} This association strengthens with the intensity of caregiving and may perpetuate pre-existing social inequalities such as low socioeconomic and health status.³³

Including informal caregivers into patient transitions of care may have a lasting positive impact on caregiver burden by empowering efficient and effective patient and carer self-management plans and support networks.³⁷ Caregiver integration may further benefit the carer by providing them with a place to assert their goals should they differ from the patient’s.³⁸

Alternatively, reliance on caregiver integration has the potential to increase caregiver burden by increasing pressure on their time. It may also introduce ethical issues by impacting patient privacy and autonomy in some circumstances.³⁹ Conclusive evidence to support positive or negative outcomes associated with caregiver integration is scarce.³⁷

The quadruple aim of healthcare

The quadruple aim is a recent progression of the more widely recognised triple aim developed by the Institute for Healthcare Improvement (IHI) in 2008.⁴⁰ The triple aim was designed to capture meaningful outcomes to assess high quality healthcare, from a population perspective. In doing this, this model deviated from other quality frameworks that focus on health service quality rather than population end goals.^{41, 42} The triple aim has three components: improved population outcomes and experience of receiving care whilst containing or decreasing cost. Since its inception, the triple aim has been increasingly used by healthcare providers as a framework to set goals and assess outcomes. Standard outcome measures assessed by the triple aim, as defined by IHI, are presented in the table below.⁴³

Table 1: Standardised measures used for the triple aim as set by the Institute for Healthcare Improvement⁴³

Domain of the Triple aim	Outcome measure
Population health	<ul style="list-style-type: none"> • Functional status • Disease burden • Mortality • Risk status
Patient experience	<ul style="list-style-type: none"> • Likelihood to recommend service • Measures based on safety, effectiveness, efficiency, timeliness, patient-centredness and equity.
Cost	<ul style="list-style-type: none"> • Cost per capita • Hospital and emergency department use

The quadruple aim introduces, as the name suggests, a fourth aim to the initial three. It expands the population perspective to include the people delivering care, healthcare professionals. The fourth aim is ‘joy in work’, or an improved experience of providing care for healthcare professionals.⁴⁰ It was developed in response to increasing healthcare professional burnout rates and in acknowledgement of the association between dissatisfied staff, healthcare cost and patient safety.^{40, 44} Within the literature, there is general consensus that staff satisfaction is related to patient outcomes and experience.⁴⁵

Many acknowledge the importance and impact of staff satisfaction. However, some believe it is prerequisite rather than an additional aim.⁴²

Globally, the quadruple aim is used as a framework for designing and assessing care models which aim to improve informal caregiver integration. A local example is the NSW Integrated Care Strategy.¹⁴ Currently, there is little evidence regarding the effects of caregiver integration and no evidence on how caregiver engagement affects the quadruple aims. This evidence gap gives rise to the research question: does including informal caregivers into transitions of care provide *better value* care for the quadruple aims of healthcare?

2. SYSTEMATIC REVIEW

2.1. Methods

Overview

This section describes the methodology of a systematic review to explore the research question: does including informal caregivers into transitions of care for people with geriatric syndrome provide *better value* care? Here better value is shaped by the quadruple aims of healthcare. An unpublished protocol was written and adhered to in this review.

Inclusion criteria

Inclusion criteria considered population, intervention, comparison and outcome measurements (PICO framework). This review considered any study design which enrolled a control or comparator population. Details of the inclusion criteria are provided under the headings below. The criteria were designed to be inclusive for several reasons. Firstly, complex transitional care interventions are difficult to implement in a true randomised control trial particularly in small sample sizes or performed in single facilities. Secondly, determining the presence of geriatric syndrome through secondary data is difficult. Authors often use different tools to measure disability and comorbidity. This complicates a comparison of severity between studies. Additionally, studies only measure outcomes that are appropriate to the relevant healthcare discipline. For example, a dietician only study is unlikely to report polypharmacy. Thirdly, transitional care is often hard to discern apart from other aspects of patient care. Lastly, it is unknown which outcomes are ‘best’ to use when assessing the quadruple aim.

Population

The study was excluded from the review if the population was:

- Younger than 65 years of age
- Treated under palliative care

The age restriction was applied as the prevalence of geriatric syndrome increases with age. Choosing a higher age bracket may reduce error in population selection. Palliative care is an additional limit as whilst the population with geriatric syndrome may have proximity to death, they are not dying or planning for death at the time of treatment.

The following definition of geriatric syndrome was adapted from previous reviews.^{22, 46} Studies were included if the population was 65 years and older and demonstrated greater than moderate severity in at least one of the following traits:

- Functional decline
- Frailty
- Cognitive decline
- Falls history
- Incontinence
- Comorbidity
- Polypharmacy
- Undernutrition
- Recurrent readmissions and emergency department presentations

Additional information on specific inclusion and exclusion criteria and rationale for selection is provided in Appendix 1, Section 1.

Intervention

Studies were included if they had at least one component of transitional care as outlined above. Additionally, all included studies should routinely engage the informal caregiver in a collaborative relationship at some point in the transitional care process. The transitional care intervention must have commenced during the patient's admission or within one-week post discharge from an acute facility, as follow-up within seven days of discharge may be beneficial to patient outcomes in this high-risk population.⁴⁷ A seven-day follow-up period has also been identified as transitional care goal.^{48, 49} Multifaceted or integrated care programs which included transitional care were included if there was enough description of the transitional care process, and explicit informal caregiver engagement. Early supported discharge programs were included in this review.

Comparator

Routine patient care includes contact with informal caregivers. The comparator group could receive any treatment which reflected routine engagement with informal caregivers.

Outcome measures

The quadruple aim of healthcare was used to frame the outcomes of interest. Some outcome measures such as patient readmission and emergency department (ED) use were considered both a population health and cost outcome. Studies were included into the review if they addressed one or more of the outcomes displayed in the table below.

Table 2: Included outcome measures in systematic review, stratified by the quadruple aim

Quadruple aim	Outcome
Patient/caregiver experience	Patient/caregiver experience Patient/caregiver satisfaction
Population health	Patient health <ul style="list-style-type: none">• Patient mortality• Patient quality of life• Patient outcomes (e.g. independence)• Patient readmission/ presentation to ED• Patient length of stay Caregiver health <ul style="list-style-type: none">• Caregiver burden• Caregiver/patient preparedness for discharge• Caregiver stress
Cost	Patient/caregiver use of healthcare resources <ul style="list-style-type: none">• Patient readmission/ presentation to ED• Patient length of stay
Healthcare professional experience	Health care professional satisfaction Healthcare professional experience

Search method

Search strategy

The following databases were searched: Medline Ovid, EMBASE Ovid, CINAHL EbscoHOST, Scopus and Proquest from March to June of 2019. Each database was searched more than four times and received review from the Faculty of Medicine librarian. Final database search strategies are detailed in Appendix 1, Section 2. Handsearching was conducted in the Australian New Zealand clinical trials registry, The United States National Institutes of Health trial register and Open Grey to identify unpublished literature. All search strategies were limited to English and populations over 65 years of age. No contact was made with authors of unpublished studies.

Screening study selection

The screening process is illustrated in Figure 4. Initial and full text screening was conducted by the primary author (student) using the forms in Appendix 1, Section 3 in a Microsoft Access database. The search and screening process identified 23 studies; 14 randomised control trials and 9 quasi-experimental trials. This process was reviewed by academics (supervisors).

To minimise over representation of the same intervention in different populations, one publication was selected for inclusion into the review. This was either the first publication or the first publication with a randomised control trial design. Multiple studies by one author, Naylor, were included in the review because the intervention changed slightly (follow up time and number of home visits increased over time) in each study. Data collected from follow-up publications was collated and considered in the discussion.

Data extraction

Data were extracted using a standardised form informed by recommendations in the Cochrane Handbook for Systematic Reviews. The data extraction form was reviewed by academics and a librarian. The data extraction form is presented in Appendix 1, Section 4. This form was used in Microsoft Access to collect results.

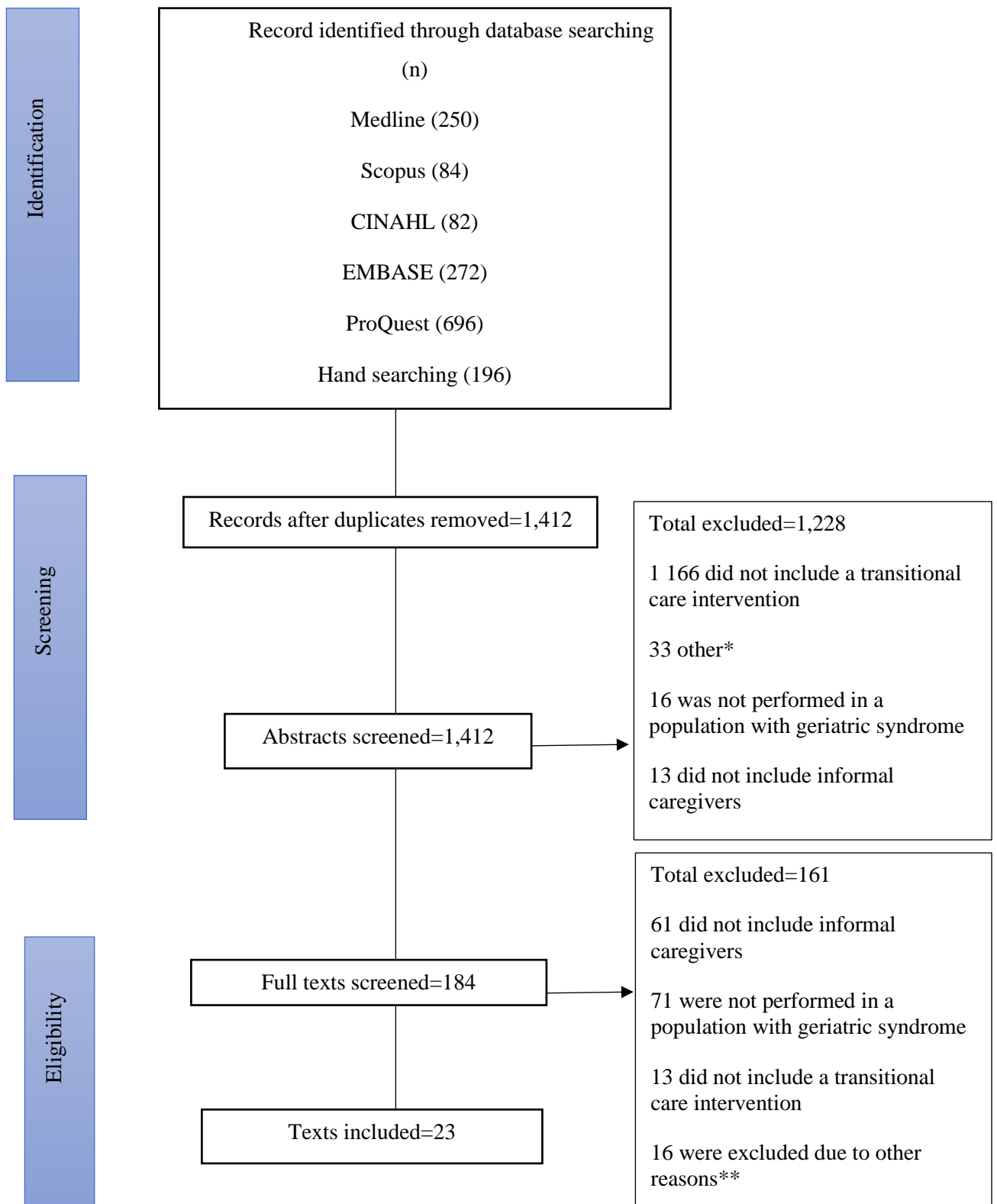
Data presentation

Results are discussed in the next chapter and results tables are presented in Appendix 2. Results are displayed in their original format unless specifically stated. Some results were combined, when appropriate, using simple mathematics.

Risk of bias assessment

Risk of bias was assessed using ROBINS-I, for non-randomised control trials⁵⁰ and ROB 2 for randomised control trials.⁵¹ This was performed at the outcome level to determine the validity of the results. These tools, created by the Cochrane collaboration, use signalling questions in features and an algorithm to produce a judgement on bias. Bias assessment was conducted by two reviewers (student and supervisor). All papers were discussed with a third party (second supervisor) to settle disagreement between two reviewers and to communicate findings within the research team.

Figure 4: PRISMA flow chart



*reasons for “other” exclusion at abstract screen: was not performed within one week of discharge (9), was not performed in the correct setting (6), was a conference abstract/letter to the editor/thesis not publicly available (12) and not in English (2) and did not have a comparator group (3) pilot study of an included paper (1)

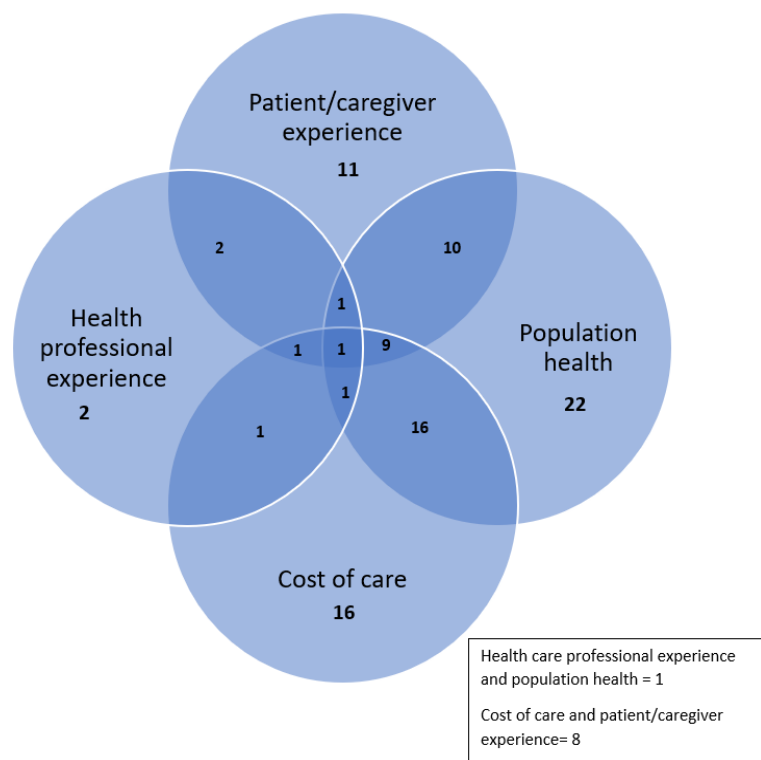
**reasons for “other” exclusion in full text screen: secondary studies to an intervention already included (9), did not have a comparator group (4), not performed with 1-week post discharge (4) and was not performed in the correct setting (1)

2.2. Results

Overview

The following section presents the data extracted during the systematic review stratified by the quadruple aims. Figure 5 illustrates how the quadruple aims are addressed by included studies. In this graph studies can be included between one and four times dependent on how many of the quadruple aims they addressed.

Figure 5: Included studies stratified by the quadruple aims



Participants

The pooled population size was 16,657 patients. Patients were on average aged 77.8 years and 46.4% were male. On average, 9.9% of patients died during the study's follow up period. Data was available for 1,532 caregivers despite all studies aiming for routine caregiver engagement. Caregiver demographics and outcomes were considered in seven studies. On average, caregivers were 59.8 years old and 71.7% were female. All studies were performed in high income nations, most commonly in the USA (34.7%). Fifty two percent of studies were included due to meeting co-morbidity eligibility criteria. Poor patient function was the next most frequently addressed (43.5%) eligibility criteria. The prevalence and severity of symptoms of geriatric syndrome was difficult to compare

between studies due to different definitions and methods of collecting and presenting information. In this review 83.7% of the pooled population arose from studies of general medical conditions, the remainder arose from stroke specific studies. Appendix 2, Table 28 displays study characteristics regarding study population, intervention, setting and comparison details.

Interventions

Case management was the most common intervention, it was applied by 13 studies. This model included a nominated person, frequently a nurse, to organise the transition to the community, caregiver engagement and follow-up care. Caregiver education was applied by four studies. This frequently involved organised seminars or bedside one-on-one education by a healthcare professional. The remainder of the studies implemented integrated care pathways (3), early supported discharge (2) and discipline specific interventions (1).

Caregiver engagement

Caregivers were most frequently involved in verbal education and manual handling skills training by healthcare professionals. Ten studies included caregivers in discharge planning⁵²⁻⁶¹ and eight included caregivers in initial patient assessments.^{52, 55-58, 62-64} Two studies included caregivers and patients during the design process.^{52, 65} Generally, plans for caregiver engagement were poorly described and only two studies documented how often caregivers were engaged in practice.^{63, 66} Forster found that caregivers were included in the intervention aim 43.6% of the time and total time spent with caregivers did not differ between groups.⁶⁶ Legrain found that the education program was delivered to 92.7% of participants. Of these, the caregiver received the intervention 58.8% of the time.⁶³ Patients received for the intervention the remainder of the time.⁶³ Further details of caregiver engagement methods is provided in Appendix 2, Table 29.

Population Health

Throughout this review, readmission and ED presentation are considered both a population health outcome and a cost.

Patient readmission

Seven^{55-57, 61, 63, 65, 67} of the eleven studies^{54-58, 61, 63, 65, 67-69} which investigated patient readmission reported that there was a decrease in readmissions during the follow up period in interventions which included caregivers. The effect varied significantly between

studies, ranging from 11% to 5.8% reduction at 90 days. When reported, the confidence intervals of all results, regardless of significance, were large. Three studies reported that the decrease in readmissions was temporary.^{55, 63, 65} Four studies investigated the LOS on readmission.^{54, 56, 57, 69} One of these found a decrease in LOS on readmission with the intervention.⁵⁶ Patient readmission results are displayed in Appendix 2, Table 30.

Patient emergency department use

Two^{61, 68} of eight^{56-58, 61, 63, 67-69} studies found statistically significant reduction in ED use. Another reported a decrease in ED use but it is not known whether this was significant.⁶⁷ Two studies found a temporary increase in ED use. This was small and not significant (difference 1.9% and 0.4%¹).^{58, 63} A summary of ED results is provided in Appendix 2, Table 31.

Length of stay of index admission

One study found an increase in LOS during inpatient rehabilitation. This was likely due to the intervention, which required the patient and caregiver to have a ‘therapeutic weekend’ at home in order to trial the home environment prior to discharge.⁷⁰ No other studies found a difference in LOS during the index admission.^{53, 63, 70} These results are displayed in Appendix 2, Table 32.^{54, 64, 70, 71}

Discharge destination

Of the three studies which investigated discharge destination,^{52, 53, 72} one study found improvement in number of patients discharged home at all follow up points (at 3 months 83% in the vs 58.1%, $p=0.004$ were discharged home and at 9 months this was 88.6% vs 41.9% $p=0.004$).⁵² Another found transient improvements in discharge home (64.4% of the intervention group returned home vs 45.6% of the comparator group ($p=0.01$) at six weeks this was 74.4% vs 55.60% $p=0.004$). However, there was no statistical difference at the 26 weeks final follow-up (78.8% vs 73.1%, $p=0.239$).⁵³

Patient physical health

Six^{53, 64, 66, 70, 72, 73} of nine studies^{52, 53, 56, 57, 64, 66, 70, 72, 73} which investigated patient function were interventions performed in stroke populations. Three studies performed in general medical populations all used a self-reported outcome tool.^{52, 56, 57} Three of nine

¹ Calculated figure

studies found a transient improvement in patient function,^{52, 53, 73} whilst the remainder found no difference. Data extracted from patient function outcomes is presented in Appendix 2, Table 33.

There was no difference in patient mortality,^{53, 63, 66, 68, 72} adherence to medications⁵⁴ or deterioration⁷⁰ as a result of the transitional care interventions which included caregivers.

Patient and caregiver mental health

Of the seven studies which investigated patient mental health and four that investigated caregiver mental health,^{52, 56, 66, 69, 70, 72, 74} one study found an improvement in both patient and caregiver mental health due to caregiver education. The effect, although small, was significant at 12 months post intervention.⁷² Patient and caregiver mental health results are displayed in Table 34 and Table 35, in Appendix 2.

Quality of life

Three^{57, 68, 69} of eight^{52, 57, 66, 68-72} studies investigating patient quality of life (QoL) found a small, largely transient improvement in QoL. Between eight studies, nine different assessment tools were utilised. Quality Adjusted Life Years (QALYs) were calculated in two studies by using the EQ-5D and EQ-5D-5L. No statistical difference was found in either of these.^{66, 68} Caregiver QoL was assessed by three studies.^{52, 66, 72} One of these found small improvements at all follow up points.⁷² The tools and significant results for patient and caregiver QoL are presented in Table 36 and Table 37 in Appendix 2.

Patient/caregiver experience

Preparedness for discharge

Two studies found that patients and caregivers were more prepared for discharge with the intervention than the comparator.^{59, 68} A study investigating caregiver preparedness found significance on objective assessment tools (Nurse Evaluation of Caregiver Preparation Scale mean in intervention 12.75 (SD 1.83) vs. 11.73 (SD 2.25) in control, $p=0.004$) and on subjective assessment tools prior to discharge from acute care (Preparedness for Caregiving Scale mean in intervention 26 (SD 5.15) vs. 23.13 (SD 6.54) in control, $p=0.008$).⁵⁹ A study investigating patient preparedness for discharge using the B-PREPARED tool found it improved in the intervention group (mean diff 2.65, $p=0.01$).⁶⁸

Patient and caregiver satisfaction

All studies that investigated patient satisfaction used unvalidated investigator developed questionnaires. Three studies found improvement in patient satisfaction in some or all of questionnaire items.^{54, 57, 71} Results are displayed in Appendix 2, Table 38. One study investigated informal caregiver satisfaction using a validated scale. The researchers found that caregivers in the intervention group were more likely to be satisfied (mean 3.55 SD 0.47 vs 2.09 SD 0.79).⁵⁹

Quality of care transition

Two studies compared quality of care transitions to a comparator population using a version of the Care Transitions Measure (CTM).^{60, 68} A study using the three item measure (CTM-3) found an improvement in quality of care transitions in the intervention group (mean difference 6.16).⁶⁸ Another study identified improvement in care transitions in patients and caregivers three days after discharge using the 15 item tool (CTM-15) (mean in intervention 74.7 vs. 65.3, 95% CI 1.08 to 1.24).⁶⁰

Caregiver burden

Two studies found a small improvement in caregiver burden.^{52, 72} One study found improvements disappeared after three months. Additionally, the improvements were not captured with objective assessment tools used in the same population.⁵² The other study found that reduced caregiver burden was evident one year after the intervention.⁷² Results for caregiver burden are presented in Appendix 2, Table 39.

Healthcare professionals' experience

Two studies considered the healthcare professionals experiences in informal caregiver inclusive transitions of care through satisfaction-based outcome measures.^{60, 71} One study reported that 81.3% of healthcare respondents felt that the intervention was useful and 96.9% felt that it was a good idea to continue the intervention.⁶⁰ The remaining study found there was no difference in GP satisfaction with communication with the intervention.⁷¹

Cost

Resource use

Patient readmission

Four studies investigated the cost of patient readmission.⁵⁴⁻⁵⁷ Two of these studies found a decrease in readmission costs. These studies were similar interventions and designed by the same primary author.^{55, 56} The results are displayed in Appendix 2, Table 40.

Emergency department use

The cost of ED use was presented independently in one study. The total cost of ED use was lower in the intervention group but not statistically different to the control ($p=0.78$).⁵⁶

Outpatient resource use

Generally, each resource (e.g. doctors' appointment, home visits etc.) was poorly defined in the studies. Caregiver resource use was only considered by one study, where no difference was found.⁶⁶ Three^{57, 58, 70} out of seven^{54-58, 66, 70} studies found an increase in outpatient resource use. For two of these studies there was an increase in subcomponents of the measure, occupational therapy and home nursing use, but no difference in overall resource use.^{57, 70}

Increased outpatient resource use occurred most notably in a study which had a high proportion of a disadvantaged cohort. In this study, over 88% of participants were African American, and resided in a socioeconomically deprived area.⁵⁸ Outpatient resource use definition, data collection and reporting methods differ significantly between studies as demonstrated in Appendix 2, Table 41.

Intervention resource use

Cost of the intervention varied significantly between studies. The cost-saving studies achieved this lower cost through implementing care pathways and short interventions.^{52, 55, 66} More expensive interventions included follow up home nursing.^{53, 57} The cost of intervention is summarised in Appendix 2, Table 42.

Unit Cost

One study included a utility analysis. The authors concluded that the intervention was less likely to be cost-effective for patients and caregivers because the intervention was more expensive and there was no difference in QALYs.⁶⁶

A further six studies estimated costs. These studies were not designed to encompass an economic analysis.^{54-57, 63, 65} There was significant variability in resources used to calculate these costs. Two^{63, 65} of the five^{55-57, 63, 65} studies which reported an improvement in healthcare expenditure did not consider community costs. The remaining studies which reported an improvement were produced by the same author.⁵⁵⁻⁵⁷ Cost estimates from non-formal economic analyses are displayed in Appendix 2, Table 43.

2.3. Discussion

Thematic appraisal

The review encompassed many different outcomes and invention designs. The diversity in the pooled data may obscure trends in the results. Therefore, this next section of the discussion evaluates studies by themes in order to evaluate patterns in the literature. The themes explore study design and evaluation.

Study design

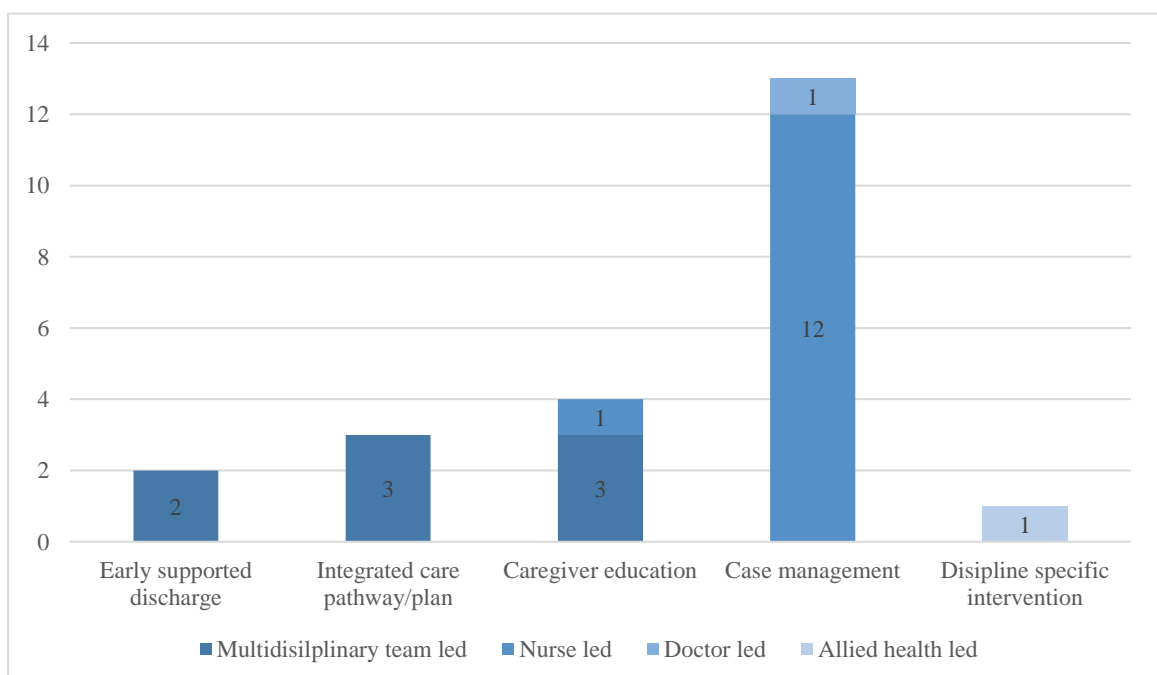
By location

All studies commenced in the inpatient setting, whilst 15 continued to the community. Previous literature suggests that integrating caregivers in acute care settings may not be ideal as they are more likely to be stressed and have a poorer ability to process decisions and new information.⁷⁵ Location of caregiver integration was also highly related to model of care. All interventions which continued into the community were either case management or early supported discharge models.

By delivery model

In this review there were five different methods of caregiver integration, as illustrated in the graph below. Each delivery model was examined to determine whether the method of caregiver integration affects the results.

Figure 6: Studies stratified by delivery model and leadership



Three studies designed and investigated integrated care pathways. Two of these three studies measured outcomes within a week of discharge.^{60, 71} They found that preparedness for discharge improved⁶⁰ as did patient satisfaction.⁷¹ The remaining study measured outcomes at three and nine months and found a transient improvement in function at three months and reduced institutionalisation at nine months.⁵²

Two studies used early supported discharge intervention models. Early supported discharge provides community support in exchange for shorter admissions. One study found improvement in discharge destination and function at 26 weeks.⁵³ Conversely, the remaining study found no difference in patient function and no change in LOS.⁶⁴

Four studies included education-only methods of caregiver engagement.^{66, 72-74} One study investigated outcomes one month after discharge⁷⁴ whilst all remaining three measured outcomes up to 12 months post discharge.^{66, 72, 73} Within education studies there was no difference in patient function,^{66, 72, 73} yet results favoured the intervention in two studies of stroke specific populations.^{66, 72} Anxiety and depression was statistically improved in patients and caregivers in one study.⁷² However, there was no difference in caregiver depression in another.⁷⁴ QoL tended to be better for patients, but was statistically improved for caregivers.⁷²

Case management was the most common model of integrated care delivery and caregiver engagement. There was inconsistency in results across 32 different outcome measurements within this delivery model. Commonly measured outcomes were readmission, cost and patient function. Some studies found that readmissions decreased, at least transiently,^{56, 57, 61, 65, 68} others found no difference.^{54, 55, 58, 69} Two out of three studies who investigated costs reported decreased cost in informal economic analyses, largely due to decreased readmissions.^{55-57, 65} No difference was found relatively consistently in patient function, several months after discharge.^{57, 69, 70}

One discipline specific intervention found improvements in patient confusion and function at discharge with an occupational therapy intervention that emphasised independence strategies.⁶²

It is difficult to compare outcomes across different models of integrated care, due to variability in outcome measurements. Additionally, the delivery model may be associated with the intensity of the intervention and caregiver integration.

By leadership in caregiver integration or discharge planning

Multidisciplinary interventions are frequently considered the gold standard in healthcare.⁷⁶ It is unclear what effect multidisciplinary team-led intervention has on caregiver integration. As viewed in Figure 6 (above), multidisciplinary team led interventions are more likely to use caregiver education, integrated care plans and early supported discharge models of care, whilst single discipline led interventions were almost exclusively case management delivery models. It is possible that if a difference exists between models of care, some of may be attributed to single discipline versus multidisciplinary team leadership. Additionally, multidisciplinary team led interventions were generally of lower intensity.

By intensity of the intervention and caregiver engagement

The degree to which caregivers were engaged, or intended to be engaged, may have impacted the results. However, adherence to caregiver integration was either poor or unreported. This is because in all papers, caregiver integration was not the primary aim, despite many being titled *family-centred* interventions. In this theme caregiver integration intensity considers caregiver contact, frequency and duration of the intervention. It was difficult to differentiate between intensity of overall intervention and of caregiver engagement as they are often intertwined and vaguely described. Therefore, this examination considered both simultaneously. This may mean, in some cases, that results are due to an intense care transition service rather than caregiver engagement.

Four studies were considered high intensity. Only two of these studies found significant improvements in outcomes. These were in cost and readmission.^{57, 65} The remaining two studies trended towards improvements in readmission,⁶⁹ LOS,⁵⁴ and cost.^{54, 69} However, they were not significant. This may be due to remarkably long interventions and potentially associated high dropout rates. One high intensity study found a significant increase in outpatient resource use.⁵⁷ There was no difference in patient function and results trended in either direction.^{57, 69} Patient satisfaction did not significantly improve on overall scales. However, results favoured the intervention groups.^{54, 57} The four high

intensity studies were led by a single discipline, nursing, and ranged from 1–6 months in duration.

Mixed results were found in low intensity studies. Positive trends were found in patient function,^{52, 72} caregiver QoL,^{72, 74} caregiver burden⁵² and institutionalisation.⁵² There was no difference in fourteen population health outcomes collected from four studies. This included outcomes such as QoL patient function,^{66, 71} ED use and readmission.^{55, 58}

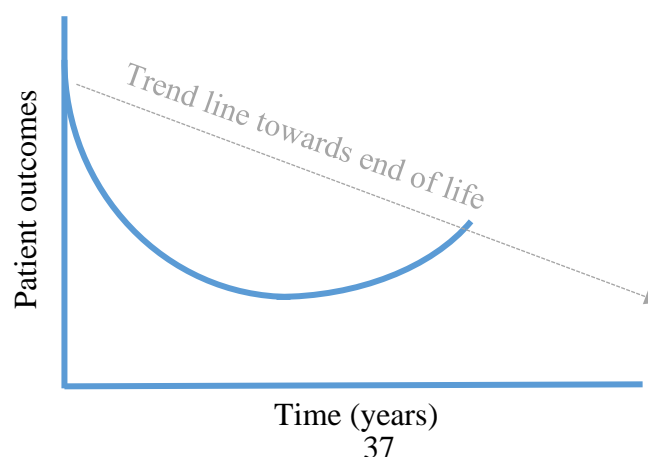
A comparison between both extremes of caregiver and intervention intensity indicates that intensity of intervention or caregiver engagement may not be related to the presence of a positive result. However, this may be limited by the quality and evaluation design, as discussed later.

Evaluation design

By timing of follow up assessment

Transient caregiver integration is likely to only have a small effect on population health outcomes if at all. Theoretically, an integrated caregiver may act as a safeguard during care transitions and maybe better equipped to maintain the patient at home.¹³ Therefore, logically, improvement in patient outcomes is most likely to occur shortly after discharge and potentially years later due to reduced institutionalisation. Several months following a transient, low intensity intervention, there is likely to be a regression to the mean in patient outcomes. This initial improvement, followed by regression and then, possible future improvement is illustrated in the figure below. It is possible no results were found because studies did not investigate the most appropriate follow up time points. This theme investigates studies which had a follow up point within one month and over a year of discharge to determine if this influences the results.

Figure 7: U-hypothesis model



Thirteen studies followed up a patient health outcome during and inclusive of one month after the patient was discharged home. Seven studies^{55, 58, 61, 65, 67-69} measured patient readmission within one month of discharge. Of these studies, two found significant reductions in readmission rates,^{61, 65} whilst three had trends towards decreased readmission^{55, 58, 67} and two trended towards an increase in readmissions.^{68, 69} Four studies investigated ED use in the same time frame^{58, 61, 67, 68} two found significant reduction in readmission^{61, 68} one trended towards decreased ED use⁶⁷ whilst one found a trend towards increased use.⁵⁸ There was no significant difference in other patient health outcome measures such as patient function,⁵⁷ and QoL.⁷¹

Three studies investigated patient outcomes one-year post discharge. They found there was no improvement in patient function.^{66, 72, 73} However, results favoured the intervention in two studies.^{66, 72} Patient QoL improved in one study,⁷² but no difference was found in another.⁶⁶ Anxiety and depression was reduced, in two studies, one significantly,⁷² the other trended towards improvement.⁶⁶ Institutionalisation tended to improve in the intervention group, but this was not significant.⁷² Similarly, two follow-up studies of included papers reported that institutionalisation was significantly less 2.5 years⁷⁷ and five years after discharge.⁷⁸

Population health outcomes trends were inconsistent at one month and tended to improve with the intervention at twelve months. Whilst there is no consistent statistical difference in long term outcomes, it is possible the impact extends beyond evaluation period.

Does caregiver integration into transitions of care provide better value care for people with geriatric syndrome?

This section places this research into the context of evidence from excluded literature and other fields. It explores the findings in comparison to other fields, for example stroke, and develops further insight and hypotheses surrounding caregiver integration into transitions of care. Throughout this section it becomes increasingly clear that despite evidence of trends, there is insufficient evidence to draw conclusions regarding the effect of caregiver integration for the quadruple aim.

Population health

Patients

A recent meta-analysis found that 90 day readmissions decreased by 25% and 24% at 180 days in transitional care interventions as a result of caregiver integration.⁶ The same trend was not replicated in this study despite six of the same studies being included. This may be due to the size of the meta-analysis and the higher vulnerability of the pooled sample in this review.

Caregiver inclusive practices have previously demonstrated improvement in patient function.⁷⁹ These studies had greater focus of function by recruiting caregivers to perform exercises in addition to regular care. The studies in this review may not have focused on function sufficiently to generate improvement. Additionally, it may be difficult for vulnerable and elderly populations to gain significant functional improvement.

Two included studies had follow-up publications which investigated patient QoL using QALYs.^{52, 72} These additional studies continue to demonstrate inconsistent results. One found a small yet significant difference in QALYs (mean difference 0.01) at nine months using the EQ-5D-3L⁸⁰ whilst the other found no difference and used the EQ-5D.⁸¹

Generally, this review may not align with other positive findings in evidence surrounding patient outcomes due to the vulnerable nature of the population and focus of the included studies. This may also be due to difference in intensity of care models, the hypothesis, or timing of follow up measurements, discussed earlier.

Caregivers

There are few studies that focus on caregiver outcomes in transitions of care. In geriatric care there is weak evidence that increased communication with caregivers during discharge planning may improve caregiver satisfaction⁸² and preparedness for caregiving.⁸³

Patient/caregiver experience

Subjective caregiver burden is modifiable, as it is dependent on perception of stress and method of management, and therefore may be increased or decreased with intervention.⁸⁴ Subjective caregiver burden has previously been significantly reduced in community programs targeted to caregivers.⁸⁵ However, this review's findings of no difference in caregiver burden is in line with other integrated care reviews.³⁷

In this review, all studies that investigated preparedness for discharge found an improvement in the intervention. Previous research has identified a relationship between poor scores in preparedness for discharge assessment tools and readmission.^{86, 87} It is believed that improving quality of discharge and patient preparedness will affect patient outcomes.

The potential benefits of caregiver integration on patient and caregiver experience is frequently discussed in excluded literature. However, solid evidence of its benefits is scarce in transitional care interventions.

Healthcare professional experience

This review has insufficient outcome measures assessing healthcare professionals' experience to draw conclusions. Non-interventional research regarding healthcare professionals' experiences with caregiver engagement in transitions of care suggests that healthcare professionals have both positive and negative experiences. It is frequently reported that caregiver engagement was beneficial to patient care, yet under-practised.⁸⁸⁻⁹² Healthcare professionals themselves report that caregiver integration is overwhelmingly good for their experience of caregiver. However, they also encounter negative experiences that affect their 'joy in work'.⁸⁹

Cost

Two studies had formal economic analyses performed in follow up studies.^{80, 81} Including these was not in the scope of this systematic review. One of these concluded that the intervention, an integrated pathway in a geriatric facility, was more likely to be cost

effective than the control.⁸⁰ The other study also found the intervention, a caregiver training program, to be cost effective largely due to reduced length of stay as there was no difference in patient QALYs.⁸¹

An informal economic analysis was performed on another included study. It found no difference in costs during follow-up, and that early supported discharge was more expensive than routine care in independent populations.⁵³

Overall, cost results were inconsistent within included literature and excluded follow up studies. However, regardless of the direction, the effect size of the intervention appears to be small.

Applicability of the evidence

It is impossible to determine the direct effect of including caregivers on the outcomes as it was not implemented independent of integrated care models, and methods of engagement and adherence were poorly described. However, trends indicate that there may be improvements in institutionalisation, readmissions, ED use and caregiver preparedness for discharge. Other reviews of transitional caregiver intervention have reported the same limitations.^{6, 93, 94} This makes the interventions hard to replicate.

The representativeness of this patient population and applicability of findings is context-dependent and may further limit applicability. Whilst the definition of geriatric syndrome used in this review is consistent with other literature,^{21, 22, 46} it may be overly inclusive in comparison to other definitions of geriatric syndrome. The pooled populations' representativeness of geriatric syndrome may be further affected by six of the included studies excluding participants with cognitive decline. The data provided for caregivers is limited and therefore the representativeness of the pooled caregiver populations is unknown.

The pooled studies are predominantly nurse-led and use case management integrated care models. Outcomes of this review may be impacted by this skewed distribution. The thematic appraisal confirmed it was not possible, with the current body of evidence, to compare studies across different delivery models, intensity of intervention and leaders in care. Therefore, it is unknown if one of these models is more appropriate than another.

Of the twenty-three included studies; eight were performed in the USA, two in China (Taiwan and Hong Kong), Germany and England and one in Australia, Spain, Singapore, Portugal, Poland, Norway, France, The Netherlands and Canada. Each of these countries' health system structures may have influenced the size of the outcome result and the interventions delivered may not be reproducible in another setting.

The U-hypothesis introduced in the thematic appraisal, suggests that caregiver integration may be a long-term investment in outcomes such as decreased institutionalisation.^{72, 77, 78} Additionally, outcomes testing is likely to require a period of latency after application of the intervention as increasing caregiver engagement requires large cultural shifts in healthcare organisations.

The result, including informal caregivers may increase outpatient service use, may be perceived as a negative outcome as public policy emphasises cost containment and policymakers are accustomed to receiving family care for free.¹³ However, when applying caregiver integration policymakers may need to consider this increase in resource use as an investment in the long-term societal goal, to shift care to the community and create a sustainable healthcare system. After all, literature suggests that including caregivers may delay institutionalisation of the patient.^{78, 95, 96} Commentary assert that increasing cost in order to support informal caregivers is the price of equity.¹³ Informal caregiving, whilst rewarding, can increase the carers risk of experiencing financial difficulty, mental health problems and poorer QoL.³⁶ The negative effects are compounded by social determinants of health, for example, cultural background, population density and gender.^{34, 36} Theoretically, supporting caregivers may improve their wellbeing and equity, achieve population health, and hence, the quadruple aims of healthcare. But few studies consider these aspects. Whilst this remains a theory, equity is frequently considered a precursor to achieving the IHI's healthcare aim.^{97, 98} The lack of an equitable foundation for caregivers may also be part of the reason caregiver engagement interventions had minimal effect on the quadruple aims in this review.

As this review draws inconclusive findings, the applicability of the current body of research is limited. Regardless, this review is beneficial as it shapes the current status of caregiver engagement and highlights evidence gaps.

Quality of included literature

Overview

The results of this review may be limited by study design. It may have been affected by appropriateness of outcome measurements, size of study and retention of participants, as discussed below. Secondly, the interpretation of results is limited by the credibility of the data. This is discussed in risk of bias. The risk of bias of all 116 collected outcomes is presented in the appendix. In brief, the key measures obtained were readmissions, resource use, QoL, caregiver burden and discharge destination.

Validity

The Functional Independence Measure (FIM), Barthel Index (BI) and EQ-5D are valid methods of collecting population health outcomes. However, they may not be sensitive enough to detect small changes at chronically poor baselines.^{99, 100}

Reduction in ED use was only found in two studies. Both utilised a large sample population (population size 8,264 and 2,494).^{61, 68} These results had small effects sizes (e.g. odds ratio 0.81 and 0.90).⁶¹ Other, smaller, studies demonstrated similar effect sizes and trends towards a reduction in readmission rates. However, these were not significant. The smaller studies may have been insufficiently powered, and therefore able to find significant results.

In this review, patient satisfaction was the predominant outcome used to inform the aim ‘patient experience’. Whilst these have been used interchangeably there are distinct differences. Patient satisfaction is subjective and may not be modifiable as it compares experience to expectation.¹⁰¹ Meanwhile experience is an objective assessment of aspects of care such as wait times and communication.¹⁰² Included studies utilised unvalidated satisfaction surveys that were unavailable for review. It is possible that using patient satisfaction as a proxy for patient experience in this review creates false result, as poor health status negatively affects satisfaction scores.^{103, 104}

Healthcare professionals regularly report there is little guidance and training regarding how best to manage caregiver inclusion and interactions,⁸⁸⁻⁹⁰ as reflected in included and follow-up studies of included papers.^{66, 94} It seems as though, in the study design for included studies, researchers assume that healthcare professionals know how

best to include caregivers, where this may not be the case. This assumption may mean that caregiver integration was insufficiently delivered.

Dropout rates of included studies frequently exceeded 20%. The challenges of recruiting and retaining patient-caregiver dyads is well documented.¹⁰⁵ This is further complicated by the high mortality rate experienced in the recruited population. As a result, some studies were underpowered to find a difference in primary outcomes.^{64, 71}

Risk of bias

The ROBINS-I and Rob 2 tool advises that overall risk of bias assessment for each outcome is based on the lowest score across the domains. As nearly all included studies scored poorly in at least one domain there was an overwhelming tendency for outcomes to be rated critical or high risk. The tables below display a summary of risk assessment. Only 11.5% of collected outcomes were considered to have low or some bias concerns, the remainder were graded at high or critical risk of bias. Generally, studies scored most poorly in bias due to deviations from intention to treat and missing data due to poor follow up. In addition to poor follow-up, many researchers did not present information regarding the distribution or analysis of missing data. The full risk of bias assessment for each outcome is presented in Appendix 3, Table 44 and Table 45.

Table 3: Overview of risk of bias assessment by severity in quasi-experimental studies using ROBINS-I

	Low	Moderate	Serious	Critical	No information
Bias due to confounding N=35 n(%)	0 (0)	10 (28.6)	18 (51.4)	7 (20)	0 (0)
Bias due to selection of participants N=35 n(%)	2 (5.7)	13 (37.1)	15 (42.9)	5 (14.3)	0 (0)
Bias in classification of intervention N=35 n(%)	11 (31.4)	14 (40)	8 (22.9)	2 (5.7)	0 (0)
Bias due to deviations from intended intervention N=35 n(%)	2 (5.7)	18 (51.4)	0 (0)	5 (14.3)	10 (28.6)
Bias due to missing data (N=35)	13 (37.1)	10 (28.6)	1 (2.9)	8 (22.9)	3 (8.6)
Bias due to measurement of outcome N=35 n(%)	14 (40)	16 (45.7)	4 (11.4)	1 (2.9)	0 (0)
Bias in selection of reported results N=35 n(%)	31 (33.6)	0 (0)	4 (11.4)	0 (0)	0 (0)

Table 4: Overview of risk of bias assessment by severity in randomised control trials using Rob 2

	Low	Some concerns	High risk
Bias due to randomisation N=78 n(%)	75 (96.2)	3 (3.8)	0 (0)
Bias in deviation from intended to treat N=78 n(%)	18 (23.1)	8 (10.3)	52 (66.7)
Bias due to missing data N=78 n(%)	47 (60.3)	0 (0)	31 (39.7)
Bias due to measurement of outcome N=78 n(%)	60 (76.9)	11 (14.1)	7 (9)
Bias due to selection of reported results N=78 n(%)	69 (88.5)	3 (3.8)	6 (7.7)

As many of the outcomes were at high risk of bias, the few low risk outcomes were investigated for trends, and summarised in the table below. Generally, outcomes improved with the intervention. However, they were rarely significant.

Table 5: Trend summary of outcomes considered low risk in bias assessment

Study	Outcome	Trend	Statistical difference
Laramée, 2003	Length of stay	Decreased	No
	Length of stay on readmission	Decreased	No
	Readmission	No difference	No
Legrain, 2011	Emergency department use	Decreased	No
	Mortality	Decreased	No
	Readmission	Decreased	Yes at 3 months and not at 6
Indredavik, 2000	Discharge destination (home)	Improved	Yes at 6 weeks but not at 26
	Mortality	Decreased	No

2.4. Limitations

Despite a rigorous search strategy, seven of the included studies were sourced through hand searching. Therefore, it is possible that some interventions, particularly those in grey literature, were missed.

During the search and screening phase, a poor representation of pharmacist-led interventions was noted. Additional searches were conducted in order to represent caregiver inclusive interventions from a range of disciplines. However, no pharmacist-led interventions met the inclusion criteria, because patient groups were too young, and others did not provide enough information on caregiver engagement.

To meet the criterion for caregiver participation, studies needed to describe proactive and routine caregiver engagement. This subjective assessment may have introduced bias. To mitigate this, all synonyms were included in this assessment. However, assessment was complicated by short, poor descriptions of caregiver integration in the broader evidence. Therefore, this assessment may have unintentionally screened the language choice rather than true caregiver integration.

During screening, twenty-four studies had insufficient information to determine the presence of geriatric syndromes. Further investigation was outside the scope of this review. Therefore, studies that did include a geriatric population may have been falsely excluded.

2.5. Future research

Further high-quality research in caregiver integration is needed to answer the research question: does caregiver integration into transitions of care provide *better value* care? Prior to answering the original research question, future research needs to address a more basic question: what *should* caregiver integration look like? To achieve this future research needs to consider the following:

Firstly, at the system level, patient and caregiver roles need to be clarified as the current interchangeable terminology of ‘patient/caregiver’ that is used, is ambiguous and also suggests that the caregiver is a co-patient. This clarification needs to be extended to research. Here, clarity should also include transparent fidelity of caregiver engagement.

Secondly, future research needs to investigate how caregiver integration is best achieved. For example, what is the effect of different integrated care models (e.g. case management or integrated care pathways), what intensity of care during transition and what leadership is best (e.g. multidisciplinary or single discipline-led). However, it is likely that ‘best’ practice is highly contextual.

Thirdly, future interventions to increase caregiver integration need to address the barriers faced by healthcare professionals. This was left unaddressed in all included studies. Further research needs to investigate barriers, facilitators and perceived solutions to caregiver integration on the front lines of healthcare.

2.6. Conclusion

Of the 113 collected outcomes, no difference was found between intervention and comparator in 64% of the studies. Most outcome measures addressed population health (73%), followed by cost of care (37%), patient and caregiver experience (19%) and notably, least frequently healthcare professional experience (<2%). Synthesis is complicated by diverse methodology and outcome measures. The collected evidence was of poor quality and the relevance of results is limited. Currently, there is insufficient good quality evidence to determine whether caregiver engagement provides better quality care using the quadruple aims. In addition to finding no result, the systematic review did not identify trends in best practice to guide health professionals in integrating informal caregivers into discharge planning for transitions of care.

3. INTRODUCTION TO MIXED METHODS STUDY

3.1. Overview

The systematic review highlighted that there is insufficient evidence that integrating informal caregivers into transitions of care provides better value care. Regardless, caregiver integration is recommended in domestic and international policy, is common practice and remains logical.

Common themes from policy and guidelines are summarised in the table below. In this format, guidelines for caregiver integration seem clear. However, extensive searching was required for this summary and is still likely to be ambiguous to a clinician. The same ambiguity is displayed in innovative transitional care models,¹³ as seen in the earlier systematic review.

Table 6: State (S), national (N) and international (I) caregiver integration recommendations for transitions of care

Time point	Recommendation	Source
Prior to admission	Have a caregiver policy that is communicated to staff ^{106, 107}	N, I
At admission	Identify caregiver contact details, name and role at admission ^{107, 108}	N, I
During admission	Ensure estimated date of discharge is visible to patient and caregivers ¹⁰⁹	S
	Establish the caregiver's willingness to continue care on discharge ¹¹⁰	N
	Include patients and caregivers in shared decision making ^{14, 106, 107, 109-115}	S, N, I
	Include caregivers and patients in any communication regarding care plans ^{107, 109-117}	S, N, I
	Educate the patient and caregiver throughout admission on care plan, follow up, self-management and symptoms of deterioration ^{14, 106, 109, 110, 113-115}	S, N, I
At discharge	Reinforce patient and caregiver education at discharge, this should not be new information and should be provided in verbal and written format ^{109, 110}	S, N
	Clarify with patients and caregivers who is responsible for ongoing care ^{109, 111, 112}	S, N
	Document what discharge information was provided to patient and informal caregiver, their understanding and health literacy ¹¹⁸	N
	Ensure there are communication/support channels in place for the patient and caregiver after discharge ^{110, 115}	N

In practice, caregiver integration in transitions of care is reported to be suboptimal by caregivers and healthcare professionals.^{119, 120} Much of the current literature in this space identifies barriers such as time and patient privacy.^{89, 119} Current policies do little to address the barriers faced by healthcare professionals.

A mixed methods study was designed to explore caregiver integration from the healthcare professional's perspective through a pilot of physiotherapists who predominately provide discharge care at a large private hospital in Sydney. It compared their experiences and their perception of ideal discharge to formulate some initial solutions to 'bridge the gap' between top down policy recommendations and the realities faced by healthcare professionals, carers and patients during discharge. This study addresses some of the most significant gaps identified in the systematic review: what *should* caregiver integration look like from the healthcare professional's perspective?

3.2. Concepts

Physiotherapists

Physiotherapists are likely healthcare professionals to encounter geriatric syndrome in the acute and rehabilitation setting due to patients' functional decline.¹²¹ Whilst part of the broader multidisciplinary team they are highly likely to interact with caregivers in transitions of care, as their care delivery investigates community social support, emphasises person-centred care and their skills are essential to transitional care, specifically discharge planning and are thus excellent representatives for healthcare perspectives.

The earlier systematic review demonstrates that many care models tend to focus on the nurse or case manager's role in discharge planning. However, policy consistently identifies including informal caregivers as the responsibility of every healthcare professional.^{14, 111, 112} Physiotherapists, and their focus on function, are essential to successful transitional multidisciplinary care of an older person as poor muscular strength and functional independence are predictors of readmission and poor health outcomes.^{122, 123} The absence of, or divergence from, a physiotherapy plan at discharge has been associated with a three-fold increase in 30 day readmissions.^{124, 125} Physiotherapists can augment discharge planning by expert assessment of social situation, functional status, falls risk, safety and enhance communication, follow-up plan, medication safety, education and self-management in order to manage identified risks.¹²¹

Physiotherapy workforce

In Australia, 66% of the physiotherapy workforce is female and is on average 38.1 years old. The average working week is 34.8 hours, split between genders as 31.8 hours for women and 40.6 hours for men.¹²⁶ 27% of physiotherapists are employed between two and four workplaces.¹²⁷ Approximately 27% plan on leaving the profession in the next 5 years and 74% plan to change their role within the profession in the same time frame. This attrition rate is caused by the perception of poor career progression and high workload pressures.¹²⁷ However, for every physiotherapist who discontinues their professional registration there are 2.4 new graduates¹²⁶ suggesting that there is high turnover in physiotherapy staffing.

Private hospitals

In Australia geriatric syndromes are increasing at a rate disproportionately greater than ageing,¹²⁸ so there is a need to investigate quality improvements in transition of care between hospital and community. A third of admissions for people aged over 65, 1.7 million, are treated in the private sector¹²⁹ and this sector is growing at a greater rate than the public sector for elective, same-day and overnight admissions.^{128, 130} Several large private hospitals have recently opened emergency departments¹²⁹ further increasing the likelihood of geriatric medical admissions in the future.

There are similarities and differences between the public and private sector. The majority of diverse rehabilitation and palliative care services are private¹²⁹ and people admitted to private hospitals historically tend to be more socioeconomically advantaged. Activity trends in both sectors are increasing however, at a greater rate in private hospitals. On average LOS is 5.2 days in each sector. However, LOS is longer by more than a day in the private sector for age associated conditions such as chronic obstructive pulmonary disease, respiratory infections and heart failure.¹²⁸

4. MIXED METHOD STUDY

4.1. Methods

This chapter describes the design and analysis of a mixed method study that explores experiences of physiotherapists with informal caregiver integration, perceived solutions to barriers and lessons learned. It details the research questions, definition and size of the study population, development of research tools and analysis methods.

Research questions

- How do physiotherapists engage caregiver integration in acute and subacute care during transitions of care in current practice for patients with geriatric syndrome?
- What challenges do they perceive in caregiver engagement, should they exist?
- What lessons can be learned from current practice of caregiver engagement?

Study design summary and rationale

This study utilises a mixed method design for conceptual data triangulation to evaluate the research question. The study design followed the convergence model, where data are analysed separately and then combined and contrasted in interpretation.¹³¹ Comprehensive solutions require rich qualitative data to explore experiences and lived realities by healthcare professionals. A quantitative questionnaire and semi-structured interview were conducted with each participant.

Population

Potential participants were made aware of the study through department meetings, informally during shared break times and in a department flyer. Recruitment was performed by the primary researcher (student). Participants were included if they met the following criteria:

- Consenting level 1–2 physiotherapists working full or part time
- Employed at the Sydney Adventist Hospital allied health department
- Have experience in including carers into transitions of care for patients with geriatric syndrome

And excluded if they:

- Did not consent,

- Had not included informal carers in transitions of care
- Were > level 2 physiotherapist

A level 1–2 physiotherapist, in New South Wales (NSW), practices physiotherapy in a range of sub-fields e.g. rehabilitation, neurological, cardio-respiratory etc. In hospital settings they frequently rotate between wards.

The Sydney Adventist Hospital, located in Wahroonga NSW, is a 700-bed not-for-profit private hospital with an ED, surgical and medical wards, intensive care and rehabilitation unit. The hospital employs approximately 2,400 staff and 1,100 doctors to treat 63,000 in patients and 120,000 outpatients annually.¹³² At the time of this study, this facility employed no eligible full time staff and 26 eligible part time or casual physiotherapists.

All participants provided informed consent and to ensure research did not interfere with their normal work and to preserve participant anonymity, participants were encouraged to organise a time and location that was most convenient for them. Emphasis was placed on their being no consequence of declining to participate.

The research was designed to recruit a minimum sample size of ten physiotherapists. This sample size was chosen as it is likely to be sufficient to reach data saturation in interviews in a homogeneous population.¹³³ In addition to this theoretical sample size calculation, a stopping criteria was applied. Data saturation was assumed when the interviewer identified no new concepts in two consecutive interviews.¹³³ Concepts were reflected on after each interview and documented in a journal by the interviewer. The stopping criteria was applied during the study as interviewee 9 introduced new concepts. As a result, two more interviews were performed to make 11, with no new concepts identified in interview 10 and 11. The decision to apply the stopping criteria was made in collaboration with supervisors.

Development of research tools

Consent form

The consent form, provided in Appendix 4, used the participating institution's pre-existing standardised form as per the request of the ethics committee.

Demographics form

The demographics form collected information on gender, age, experience and employment history, in particular, years of experience. An ad hoc decision was made to include the number of participants with more than one current place of employment, as an incidental finding was that many participants had more than one source of employment. Whilst limited to feasibility, the study was not designed to confine its findings to experiences within a single facility, rather to the perspective of the healthcare professional.

Questionnaire

A quantitative questionnaire was used to provide a granular understanding of whether there is a difference between caregiver integration in practice and policy for physiotherapists, and if so, what aspects of care transitions are most affected. The questions were designed by the primary author, informed by current discharge guidelines and incorporated feedback from a presentation to staff in the Macquarie University Centre for the Health Economy (MUCHE). The questionnaire is presented in Appendix 4. The questionnaire was distributed to participants in Google Forms via tablet immediately prior to interview.

The questionnaire used a combination of multiple choice and visual analogue rulers (VAR) for response selection. Multiple choice responses investigated frequency of specific activities in current practice. The participant was able to select one of eight closed range quantified labels e.g. never, once a week etc. Binary questions in the questionnaire used a VAR to measure responses, e.g. agree/disagree. Each VARs was labelled at extremes, had symmetrical distribution around neutral and ten buttons on the ruler. The questionnaire did not have pre-selected buttons to minimise preselection bias.¹³⁴

Semi-structured interview

Semi-structured interviews were chosen because they provide a context for in-depth investigation. The interviews were designed to be an exploratory, inductive search caregiver integration as experienced by physiotherapists. The interview was piloted twice prior to data collection with two physiotherapists, not from the study population. Minor grammatical errors were corrected in response to feedback. The interview guide included a standardised introduction and nine primary questions.

Questions were designed to funnel from participants' overall experiences of caregiver integration, to reflections on their experiences and articulation of gold-standard

policy driven practice. The interview schedule is presented in Appendix 4 and key questions are listed below:

- What is your experience engaging informal caregivers in transitions of care?
- What is an example/s of a positive experience you have had whilst including caregivers?
- What is an example/s of a negative experience you have had whilst including informal caregivers?
- Do you feel that the physiotherapists should be including informal caregivers in discharge planning/transitions of care?
- Do supports need to be established for successful discharge planning?
- Should informal carers be included at patient admission/preadmission?
- Should discharge planning take place during the inpatient stay?
- What actions or steps do you think are necessary for a well performed patient discharge when patients are ready to leave the facility?
- Should informal caregivers be involved in organising patient follow-up or treatment plan?
- Is there anything we have missed?

Ethics application

Ethics approval was granted by Adventist Healthcare Limited, and additionally granted by the Macquarie University. Ethics approval reference is 2019-018 (Appendix 4).

Data collection

At commencement all participants received an information sheet, completed a consent and demographics form. These documents are displayed in Appendix 4. Following the completion of the consent forms, participants completed the questionnaire on a tablet provided by the interviewer.

Each interview followed the primary questions in the interview schedule. Follow up questions were selected either from the interview schedule or spontaneously in response to participants' experiences. All prompts were phrased neutrally and encouraged a mix of positive and negative responses.

Following each interview, the interviewer maintained a reflective journal to assist in determining saturation, and to improve the quality of successive interviews.

The iterative process of interviewing was conducted at the same time as data analysis. All interviews were voice recorded and manually transcribed. Orthographic transcripts were produced at an average rate of 15 minutes' audio to 1 hour of transcription, the transcripts utilised semantic, non-semantic sounds and paralinguistic features in order to maximise truthful representation of the interview. All data collected from a single participant was deidentified and coded using a numerical figure.

The deidentification code was documented and only available to the primary researcher. All data was securely stored on the Macquarie University server. Paper-based forms were also securely stored at the university.

Thematic analysis

Reflexive thematic analysis, as outlined by Braun and Clarke,¹³⁵ was used because it is theoretically flexible, reliable and perceptive when applied with rigour. It is well suited to researchers with little experience in qualitative analysis.¹³⁶ Braun and Clarke argue that researchers adopt theoretical frameworks, often unwittingly, to suit their research and make decisions accordingly. These decisions need to be acknowledged and explicitly considered throughout the study as their reflexivity influences the results. Braun and Clarke highlight three theoretical framework continuums for thematic analysis that require choice and definition prior to commencement.

The first continuum is between inductive and deductive analysis. The analysis of this study used an inductive approach to thematic analysis, this is also known as a ground up or data driven approach to thematic analysis.^{135, 137, 138} This method was adopted in order to create themes that are strongly embedded in the data itself. However, as analysis is a subjective activity it is likely that some aspects of deductive reasoning were utilised through analysis. Deductive analysis is determined by the researcher's theoretical interest. It tends to be less rich in data and is considered a top down approach.

The second is between semantic and latent themes. Semantic themes are interpretations of a description whilst latent themes are shaped from underlying assumptions and concepts.¹³⁷ Initial coding tended to be more semantic but the themes became increasingly latent as they were refined through the thematic analysis process.

The third is an epistemological continuum between constructionism and essentialism. Epistemology is the theory of acquiring knowledge. Qualitative researchers construct results through their own reasoning. The method of reasoning, or epistemological approach can therefore influence the research. Essentialism focuses on individual experiences and their attached meanings whilst constructionism focus on the greater social context and conditions which create these experiences.^{137, 138} This analysis utilised constructionist epistemology, as it was appropriate for the research questions, to find potential solutions to barriers for caregivers.

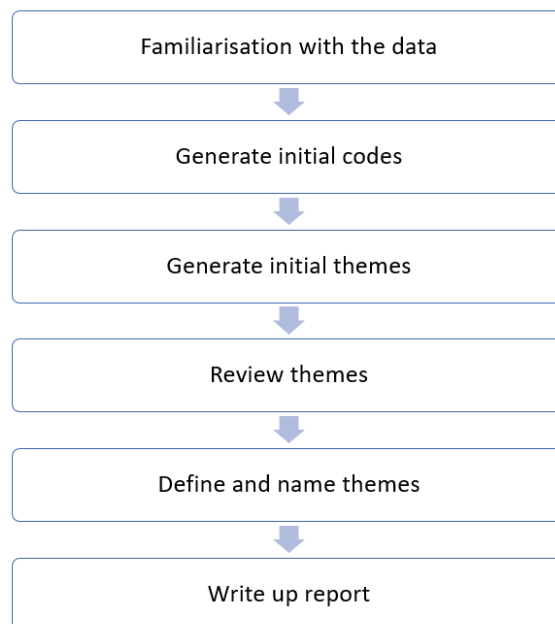
Lastly, it is important to define the primary researcher's own predispositions to the research question as the researcher is a tool in qualitative analysis. The author is a practising physiotherapist and may draw implicit or premature meaning from results.

Additionally, the author completed a systematic review and literature review on caregiver integration prior to commencing the study. This previous research led the author to believe that caregiver integration is likely to be best practice compared to caregiver exclusion.

Data interpretation

Thematic analysis followed the steps shown in the figure below. As Braun and Clarke suggest, this was not conducted in a linear fashion but rather iteratively, and in some cases simultaneously.¹³⁸ The thematic analysis was performed by the author and supported by two secondary coders (supervisors) in order to mitigate some subjectivity in coding and theme development.

Figure 8: Phases of reflexive thematic analysis as defined by Braun and Clarke¹³⁵



Familiarisation with the data

The author became familiar with the data by performing all interviews, transcribing them and reading through transcripts prior to coding. The secondary coders became familiar with the data by reading the transcripts.

Generate initial codes

Line by line coding was conducted by the primary researcher using NVivo 12. The primary researcher kept detailed memos during the development of codes and themes as well as a reflexive journal in order to maintain transparency and acknowledge the researcher's role as a tool in analysis.¹³⁶ Additionally, the first four interviews were coded

independently by the two secondary coders. Weekly meetings were held to discuss code development. The primary researcher maintained a detailed log of these review sessions in order to document code refinement. Inter-coder reliability was not assessed between coders, as advocated in Clarke and Braun's thematic analysis methods as it is seen as too positivist a method that does not fit within epistemology of thematic analysis.¹³⁸

Generate initial themes

Initial themes were developed by all coders during the coding process and were discussed at weekly meetings. Again, this process was documented by the primary researcher. The primary researcher continued theme development when coding the remaining data set.

Review themes

Themes were reviewed collaboratively by entire research team following coding of entire data set. In this step, data collected to support this theme was reviewed by the primary researcher as well as the prevalence of the theme within the data.

Define and name themes

At this point a final refinement of themes was conducted by the primary researcher. Themes were discussed at regular meetings and had 100% approval from the research team.

Write-up

Write up of the report was conducted by the primary researcher. The report was shared with the research team and received a round of feedback to ensure that the story told reflected the data. The report was not shared with participants prior to submission. However, the participating facility will have the opportunity to review any reports prior to publication.

Analysis of questionnaire

The analysis of the questionnaire was conducted using summary statistics. Questions which utilised a VAR provided answers in numerical figures between 1 and 10. Questions investigating frequency, e.g. never, monthly etc., were assigned figures as indicated in the key below to allow for summary statistic calculation. Summary statistics

were calculated using excel. All results are presented in Appendix 5 and notable findings are discussed in the results chapter.

Table 7: Frequency to numerical figure key

Frequency	Assigned value
Never	1
Monthly	2
Fortnightly	3
Weekly	4
Multiple times a week	5
Daily	6
Multiple times a day	7
Every patient encounter	8

4.2. Results

This chapter describes first the participant demographics, the questionnaire results then themes developed in qualitative data analysis.

Participant demographics

Eleven physiotherapists from a single private hospital were recruited into the study. Participants were mostly female and middle aged. Both age and number of female participants was higher than national physiotherapy demographic. Participants, on average, had a significant number of years of experience in a variety of areas. All participants were part-time or casually employed by the facility.

Table 8: Participant demographics

	Mean (range)
Gender (number)	
Female	10
Male	1
Age (years)	42 (31–51)
Years of experience	18(4–30)
Number of previous workplaces	5(2–10)
Number of current workplaces	1.36 (1–2)
Field of most experience (number) (participants could select more than one)	
Neurology	6
Orthopaedic	5
General medicine	5
Rehabilitation	5
Intensive care	2
Other	3
Length of interview (min)	47.40 (28.25–69.58)

Questionnaire results

Questionnaire results are described, displayed as summary statistics or graphs as appropriate. The tables are split to provide narrative and interpretation. The remaining sections used VAR and responses are displayed in tables or graphs. All responses summary statistics and graphs are provided in Appendix 5.

Responses to section one: Frequency of patient and caregiver engagement by the physiotherapist

As seen in table 9, participants indicated that they treated patients with geriatric syndrome multiple times a day. Participants most frequently communicated with caregivers indirectly.

Table 9: Noteworthy responses to section one, part one

Question	Mean	Standard deviation	Meaning
2. How often do you communicate directly with informal caregivers (in person or over the phone) for patients with geriatric syndrome?	4.55	1.29	Between Weekly (4) and multiple times a week (5)
3. How often do you communicate indirectly (handouts, whiteboards etc.) with informal caregivers for patients with geriatric syndrome?	6.00	1.79	Daily (6)

Participants most frequently addressed mobility level and aids when preparing patients for discharge (between multiple times a week and daily). Medications were the least frequently discussed (multiple times per week). The relatively low frequency of patient preparation for discharge may be because participants did not perform it at every patient encounter, rather this was discussed at final meetings with patients or a few times prior to discharge.

Participants discussed discharge plans more often with patients than caregivers. Discharge mobility level and aids were most frequently discussed; medications were relatively less frequently addressed (fortnightly).

Table 10: Noteworthy responses to section one, part two

Question	Mean	Standard deviation	Meaning
19. How often do you discuss/educate informal caregivers (directly or indirectly) about discharge mobility aids?	5.27	1.68	Closer to multiple times a week (5) than daily (6)

Responses to section two: Frequency of caregiver engagement by the multidisciplinary team

Participants indicated that they asked about the presence and welfare of the caregiver approximately weekly. They expected that someone else within the multidisciplinary team would be performing these tasks more often than themselves, as seen in table 11.

Table 11: Noteworthy responses to section two, part one

Question	Mean	Standard deviation	Meaning
22. How often do you ask about the presence of an informal caregiver in your initial assessment?	4.64	2.34	Closer to multiple times a week (5) than weekly (4)
23. How often do you expect someone else in the multidisciplinary team would ask about the presence of an informal caregiver?	5.64	2.16	Closer to daily (6) than multiple times a week (5)
25. How often do you expect someone else in the multidisciplinary team would ask if the informal caregiver is prepared to return to caregiving at discharge?	5.36	1.43	Closer to multiple times a week (5) than daily (6)

As seen in table 12, participants consistently responded that patients and caregivers were rarely included in team discussions. Both patient and caregivers were informed of team meeting outcomes weekly. This may be because team meetings are, on most wards, held weekly.

Table 12: Noteworthy responses to section two, part two

Question	Mean	Standard deviation	Meaning
28. How often do you discuss the estimated of discharge and/or destination with informal caregivers?	4.45	1.69	Between weekly (4) and multiple times a week (5)
31. How often are informal caregivers included in multidisciplinary team meetings?	2.64	2.01	Closer to fortnightly (3) than monthly (2)
33. How often do you inform informal caregivers of multidisciplinary team meeting outcomes?	4.09	2.30	weekly (4)
34. From your perspective, how often would someone else within the multidisciplinary team report team meeting outcomes to patients and/or informal caregivers?	5.18	1.54	Closer to multiple times a week (5) than daily (6)

Responses to section three: Perception of caregiver engagement

The following responses, in section three and four, were collected using a VAR. Therefore, responses in the remaining tables indicate the proximity to never (1) and always (10). Participants indicated, relatively consistently, that caregivers should always be included by physiotherapists and the team. They also perceived that most caregivers wanted to be included. Participants seemed to be relatively confident in their patient-centred care, and slightly less so in family-centred care, with significant variation between participants.

Table 13: Responses regarding perceptions of caregiver engagement

Questions	Mean	Standard deviation
35. In your opinion, how often should informal caregivers be included into discharge planning by the multidisciplinary team?	9.73	0.47

Responses to section four: Reflection of personal practice and knowledge

In this section the ten-point VAR rates proximity to strongly disagree (1) and strongly agree (10). This section of the questionnaire evoked the largest inconsistency in responses. Generally, participants believed they had not received training for caregiver engagement and were not aware of laws and policies. Despite this, participants seemed relatively confident that they knew when and how to include caregivers.

Table 14: Responses regarding reflection of personal practice and knowledge

Statement	Mean	Standard deviation
42. I have received training about caregiver engagement	4.73	2.76
43. I am aware of institutional policies regarding caregivers	4.09	2.47
44. I am aware of professional code of conduct and Australian laws which mandate caregiver inclusion, where appropriate	4.09	1.92

Statements 48 and 49 had binomial distributions, as illustrated in Figure 9 and 10.

Participants who scored lower in these tended to have higher expectations, as uncovered during the interview. The binomial distribution may reflect the separation between positive and negative perceptions of current caregiver integration practice.

Figure 9: Q48. I feel that physiotherapists at my institution include informal caregivers as often as is appropriate

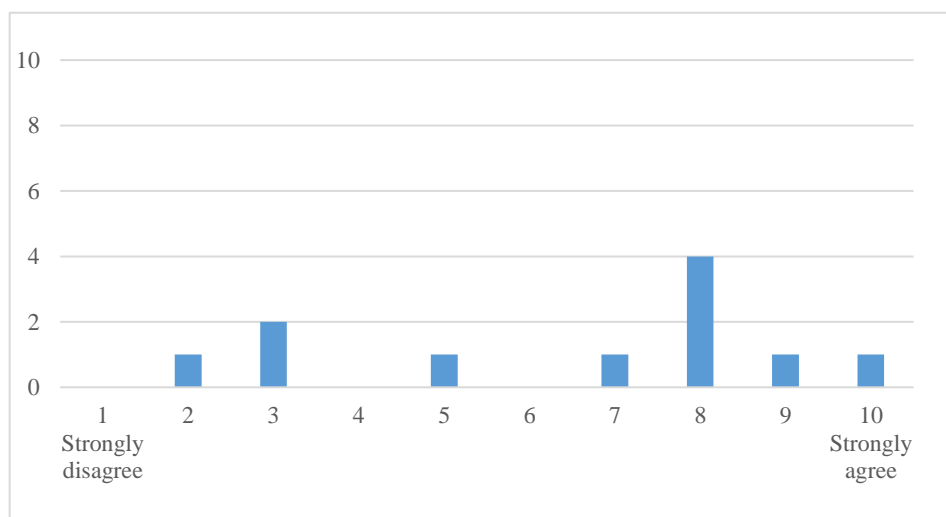
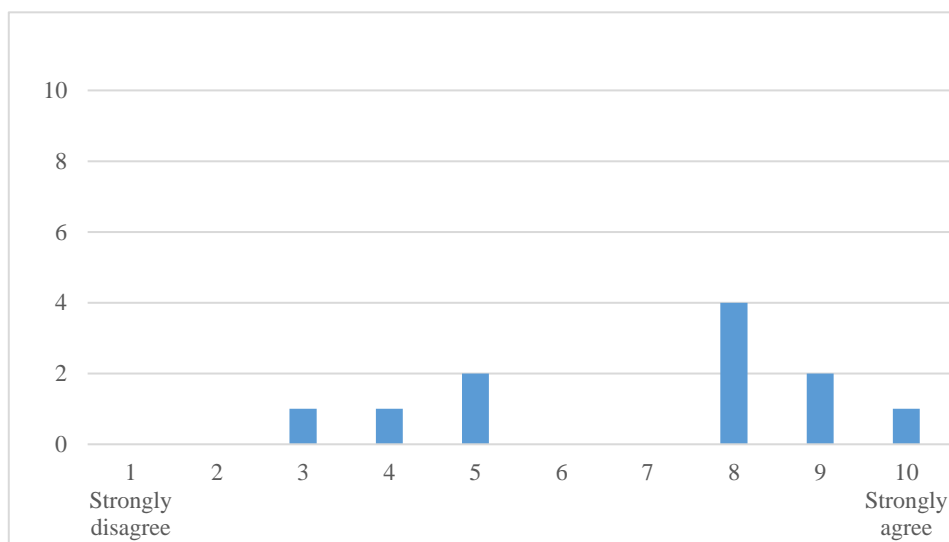


Figure 10: Q49. I feel that the multidisciplinary team includes informal caregivers as often as is appropriate



Qualitative results: Themes

This section describes five themes shaped during thematic analysis. The final coding structure that led to theme development is displayed in Appendix 5, Table 49. The themes are supported in text by quotes.

Theme one: Variability in caregiver engagement

Summary

This theme describes how initiation of caregiver engagement, as experienced by physiotherapists, depends on four factors: caregiver characteristics, patient and physiotherapist characteristics and social complexity. The relationship, once formed, is also variable.

Caregiver characteristics: The 3P's; pleasant, proactive and present

Early contact with informal caregivers was most frequently enabled by the caregiver's presence on the ward.

"Um one way would be just chance on the ward and it might be that I walk in and they are there or I walk past the room and they're there and I make an effort to go into the room and speak to them."
(participant 1, 20 years of experience)

Sometimes caregivers were proactive in seeking out healthcare professionals. Some participants expected the caregiver to come forward if they wanted to be included.

"at the end of the day usually the caregiver who is really concerned because they know that the person who is in hospital the condition is very severe they will be the one who is contact constantly"
(participant 3, 15 years of experience)

Caregivers that were described as pleasant or compliant were more likely to be engaged in treatment sessions and conversation with the staff.

"I think again it depends on the personality of of the person [laughter] so in this case the wife was absolutely lovely so it was absolutely fine having her there and including them" (participant 1, 20 years of experience)

All descriptions of negative experiences were associated with unfavourable

perceptions of caregiver characteristics for example, ‘too involved’ or ‘difficult’.

“uhm I think unrealistic expectations from caregiver often makes it harder yeah and high demanding caregivers too” (participant 5, 20 years of experience)

Overall, caregiver engagement seemed to be dependent on the physiotherapist’s perception of three caregiver characteristics; present, pleasant and proactive.

Patient characteristics

Poor cognition triggered participants to contact caregivers regarding social history. Milder dependency due to physical or cognitive ability, for example, assistance for community access, did not trigger caregiver integration without further prompts.

Patients from non-English speaking backgrounds were more likely to have their caregiver included as they could be used as a proxy translator during treatment sessions. As several participants suggested, this patient characteristic may overlap with cultural background of filial caring and increased presence on the ward.

“usually the family if they know that the patient can’t really speak English well they usually are a lot more present to try and help communicate like between the staff and patient” (participant 7, 4 years of experience)

Participant characteristics

Participant characteristics seemed to make the least impact on the likelihood of caregiver engagement. Some participants indicated that they got better at interacting with informal caregivers with experience.

“you’ve got to be empathetic as well and uhm because that comes with experience you know and like what’s the way to say that and how do you support the caregiver it’s not something you learn uh so it’s very very hard” (participant 9, 30 years of experience)

However, these years of experience did not seem to increase the likelihood of caregiver engagement.

Participants frequently identified that empathy was essential for successful caregiver integration.

“Trying to see it from the caregiver’s perspective, you know, being aware there is a lot of stressors in their life and you know really trying to understand where they are coming from” (participant 5)

All participants described caregiver engagement through a lens of patient safety and altruistic motivation for the caregiver and the patient.

*“hopefully make everybody’s job a little bit easier and safer.”
(participant 2, 20 years of experience)*

Social complexity

The relationship between the patient and the caregiver influences the caregiver’s inclusion, with complicated relationships creating adverse environments for caregiver engagement.

“depending on the relationship between the client and the caregivers and if its if its straightforward healthy relationship it’s definitely makes things [easier]” (participant 3, 15 years of experience)

Physiotherapists may also face ethical dilemmas in social context when a caregiver appears to struggle with the demands of caregiving.

“I think a lot of caregiver just feel that they have to do it and maybe that they are forced into doing it” (participant 10, 16 years of experience)

Type of relationship formed

Good relationships seemed to be shaped by the healthcare professional having a good rapport with the caregiver, and a collaborative relationship.

“gently establish the rapport and gaining their insight about about they feel about the situation that how I would usually approach these things and once you gain their trust you’ve got a better standing with them” (participant 11, 16 years of experience)

Collaborative relationships were rarely described and when prompted participants often felt *“I don’t think it happens enough” (participant 9, 30 years of experience)*. Conversely, poor relationships were caregiver dominated, or had misaligned goals between professionals, caregivers and/or patients. In response to poor relationships, participants

sometimes avoided caregivers or were guarded during discussions. Participants acknowledged that this reaction is likely to further reduce caregiver engagement.

“I think its bad [laughter] ‘cause I think sometimes then you feel like you want to avoid them and time your treatment so they aren’t there which isn’t good” (participant 9, 30 years of experience)

Theme two: Individuals working in a system

Summary

From the participants' perspective, caregiver engagement was largely influenced by patient and caregiver factors. The factors within the physiotherapist's locus of control, by comparison, had little effect. Physiotherapists' perception of the healthcare system was that it was under stress from rising demands and low resources. This was particularly clear when discussing time constraints. This theme disentangles team, hospital and system factors that influence caregiver engagement.

The system

Participants frequently identified incentivisation for activity-based care rather than quality high fidelity treatment.

"I'm weighing up if a patient could be seen but they are at baseline if they could be seen maybe to help potentially reduce the risk of falls in the future and give them exercise and work with the caregiver in that regard or see another patient who is not at their baseline and.. could benefit more at that present moment to be seen then I'll see the patient who is not at the baseline yet who would benefit more at that moment" (participant 7, 4 years of experience)

Additionally, nearly all participants described inconsistent staffing as a cause of poor caregiver integration and transitions of care. A frequently cited reason for this is that a good rapport is required with the patient and the caregiver.

"but I don't feel like yeah too much of a rapport and from being on different wards sometimes and only seeing them you know like twenty minutes and twice a week and then they have somebody else you know three days a week and then I'll come back in the next week and if they are still there then its uhm like it's me again but like it is hard to kind of like kind of form a relationship" (participant 10, 16 years of experience)

Every participant mentioned time as being a limitation in caregiver engagement and transitions of care. Participants also described resource poverty in other areas such as a lack of respite beds and community care to assist caregivers.

Participants felt the reimbursement structure of the healthcare system affected how

participants included or interacted with the informal caregivers.

“somebody said at SCRUM [approximates daily meeting] that the wife wants him to go to rehab rather than respite because it was.. because it was free, whereas respite was it costs money” (participant 10, 16 years of experience)

Some participants felt that the traditional physiotherapy staffed hours affected the physiotherapist’s ability to lead caregiver engagement as it may, by default, exclude caregivers who work.

Participants rarely mentioned care outside of the hospital (theme 3). However, some found community care difficult to navigate as it may require *“Googling it and making a recommendation” (participant 1, 20 years experience)* for patients and caregivers. One also mentioned that the system may be difficult for caregivers to navigate and the default may be to come to hospital.

“they don’t know who to phone or what to do to get the steps initiated to get an ACAT[Aged Care Assessment Tool] or get a social worker to get any kind of help so maybe sometimes feel like coming into hospital gets those in motion so that they can get that care where as whenever they are at home they don’t know where who to phone so they might go to GP and access it that way” (participant 10, 16 years of experience)

Generally, participants identified more barriers than facilitators at the system level than any other sphere of influence. The focus on barriers, particularly resource poverty, indicates that participants feel the system is under stress. Some participants felt caregivers responded to the stressed system by establishing themselves as patient advocates, and staff responded by using caregivers as resources for additional patient care in the inpatient setting.

“I think that if they are there for a patient like that they would be expected to feed their relative and and see if the the AIN or the RN on on the ward looking after that patient it would be one less thing for them to do.” (participant 10, 16 years of experience)

The hospital

The participants seemed to have incomplete understanding of how their practice is influenced by factors at a hospital level. Participants indirectly described many institutional factors that influenced their ability to integrate care and caregivers. Participants were most positive about the daily morning meetings with the team as they could allow for communication regarding the caregiver and the discharge plan. However, some participants felt that these meetings were too fast and further informal communication was necessary.

“it’s very quick and even when you have a MDT [approximates weekly meeting] it’s also quite quick so sometimes it could be like informal catch ups or chats with the team that sometimes may help but sometimes you don’t have the chance” (participant 9)

Generally, participants were less positive about longer weekly meetings with the team, case conference. This was reflected in their language choice. For example when asking if the participants found these meetings helpful some replies were uncertain, “Um.. um... I’m sure it helps” (participant 11, 16 years of experience), and contained doubt “sometimes” (participant 2, 20 years of experience).

Participants found other hospital structures such as communication with family members through patient whiteboards helpful to their practice. However, some admitted that they used this indirect communication infrequently.

“They do want us to communicate with caregiver like on the boards and everything about what the discharge plan is and what the date is and that sort of thing it probably could be done better” (participant 4, 16 years of experience)

Formal discussion with caregivers, family meetings, were described as having potential to be beneficial for caregiver engagement and empowerment. However, the participants interviewed reported they rarely attended family meetings.

“it will only include them if there is a family conference and often I haven’t been involved in a lot of those I think in the two years I’ve been here I’ve probably attended two or three” (participant 9, 30 years of experience)

Some believed that this was a missed opportunity. Other participants felt that holding meetings late in the patient's stay and conflict within the team were additional factors impeding the potential positive outcomes from family meetings. Participants who encountered these situations emphasised that teamwork and a consistent message was required by the team when handling complex social situations.

“definitely give conflicting information if you have someone who is really pushing for something and other people who are saying well that's not really appropriate or that's not possible and that's, yeah it gives uh it gives I guess hope to patients or caregivers that might not always be realistic and may not be sustainable in the long term either”
(participant 10, 16 years of experience)

All participants emphasised the importance of verbal communication within the team for care transitions and caregiver integration. Multiple participants pointed out that good documentation within the team was essential. However, many expressed frustrations over the time spent writing notes and the possible redundancy of some of the content.

“I think we are too repetitive with some of the notes and I think we don't, I think the communication part is still the downfall the verbal stuff.” (participant 2, 20 years of experience)

Some participants felt that their documentation was rarely read, particularly by the medical staff. Participants speculated this was due to several factors such as laziness, time poverty and the interface of the electronic medical record system (eMR). Additionally, some felt that medical professionals did not value the opinion of the physiotherapist. Participants had mixed responses regarding the ease of finding caregiver information in the hospital's eMR. Many found that it was difficult as the next of kin contact was not always the caregiver and it might not be clear if the caregiver wanted to be contacted. When this was clear participants found it assisted their practice.

“I think just making me aware through the notes that there was a definite need and a definite person who would be you know contacted at this particular time or available at this particular time to make it happen so yeah knowing that definitely made it a lot easier.” (participant 5, 20 years of experience)

Some participants felt that the physical set of the hospital, such as open space gyms, were beneficial for teamwork within the multidisciplinary team. However, they may be uncomfortable for the caregivers and infringe on patient privacy.

“I just think that getting the carer in and getting to explain stuff in an open gym is not ideal. Unless there is specific things you are showing them but you’ve got a crowd of people watching which is uncomfortable.” (participant 2, 20 years experience)

Participants acknowledged there were spaces they could use for private sessions, however, time constraints and seeing multiple people simultaneously limited their ability to use these.

Multiple participants indicated that longer length of stays negatively impacted patient caregiver integration.

“people are have busy lives in terms of caregivers and when it’s a really long protracted length of stay its its uh its hard for them to be involved yeah” (participant 8, 30 years of experience)

However, they simultaneously acknowledged some of the factors that caused an extended length of stay were outside the hospital’s control.

Participants felt that system economic pressures and the hospital running as a business negatively impacted the multidisciplinary team. These pressures encourage professionals to strictly keep to their professional guidelines, but participants felt that the multidisciplinary team would function better with higher levels of informal communication and interaction.

The multidisciplinary team

Participants had mixed views of the supportiveness of the multidisciplinary team and its members when including informal caregivers. These ranged from positive responses, *“They are, they are of um yeah I do find them helpful” (participant 1, 20 years of experience)* to uncertain, *“Uhhh yeah to some extent” (participant 6, 14 years of experience)*.

Other participants had more negative views of individual team members when it came to caregiver integration. In these instances, the participants felt that other members of

the team were not being proactive in their interaction with caregiver or communication within the team. Despite the mixed reactions to the multidisciplinary team, physiotherapists strongly perceived that caregiver integration and their practice was influenced by the team. In some cases, the roles of the team were and overlapping and/or symbiotic:

“I think it’s a two way thing it is somewhere where where we definitely have clear guidelines as to which is each uhm say each professions area of expertise but at the same time having a flexible mindset as sometimes we do have to you know go a little bit out of our, not out of our, you know, work criteria so with requisites and you know lend a hand whenever needed or you know, I sort of think, in that way it is kind of a mutual thing whenever possible.” (participant 5, 20 years of experience)

Notably when there was conflict within the team, this affected caregiver integration and patient outcomes (e.g. longer LOS).

The participants described informal communication within the team as a facilitator for transitions of care and caregiver engagement. The likelihood of informal communication was often influenced by teamwork and continuity of staffing.

Participants identified that language used to describe caregivers in their communication, both formal and informal, can negatively affect how other healthcare professionals’ approach or include caregivers. For example, labelling caregivers as ‘difficult’ or ‘unrealistic’.

Participants identified it was beneficial for integrated care to have a leader in discharge planning and caregiver engagement. However, in both instances, there was no consistency regarding whose job it was to lead. Participants frequently identified that both leadership tasks were everybody’s job, yet rarely described themselves as leaders.

Theme three: Yesterday's medical model

Summary

This theme explores the focus of the current model of care, and how caregivers fit into this. Overall, participants described care of patients as episodic, as care focused on the hospital stay with little consideration for integration into the community. The separation of a person's life course into numerous transitions raises the question: who coordinates the patient's care for the acute inpatient episode? This theme also investigates how healthcare professionals' perceptions of caregivers maybe dated. This theme extends care beyond the care of the patient and family to the healthcare professional, as healthcare professional wellbeing may affect patient care.

Inconsistent communication aims

The aims of ongoing caregiver communication varied. Some participants engaged with caregiver to update them. This was frequently described as last-minute with caregivers.

"we could involve them at the start, in the middle and maybe at the end. So it's continual and not all bombarding at the end. So I think we probably bombard carers family more towards discharge very in a rushed sort of fashion." (participant 2, 20 years of experience)

Other participants used caregiver communication for shared decision making and goal setting. Some communication included education and self-management, however, there was inconsistency in responses. This was even raised by participants.

"but I think probably consistency across the professionals needs to be addressed too" (participant 8, 30 years of experience)

Inconsistent self-management and education within the system may cause caregivers to be poorly prepared for the future. This was something professionals encountered for themselves.

"I'm thinking particularly in progressive type issues where there's um a lack of foresight into what their needs might then be in the future" (participant 9, 30 years of experience)

Episodic delivery of care

Participants identified that generally, they focused on returning “back to baseline” (participant 7). With this emphasis on baseline mobility, many participants identified there was little incentive to refer on, even when it was necessary.

“I don’t think we do I think we probably speak about it with them and as a general thing say, you know, balance reconditioning needs to be an ongoing thing because it does deteriorate as we get older but I think in actually specifically pushing them to... to um.. to actually book in or actually sign up we are actually probably a little bit slack”
(participant 8, 30 years of experience)

This focus on hospital stay was evident in the participants, as many knew little about available community services. Additionally, many reported that this limits the number of community referrals.

“I think part of it is because we don’t know what’s available”
(participant 9, 30 years of experience)

The participants’ description of transitions of care indicates that currently, acute and community care is delivered in silos. Furthermore, once ‘baseline’ is achieved in the acute setting, community supports for ongoing self-management, for example falls prevention, are rarely established.

Who coordinates patient care?

Some participants assumed that including the caregiver was in lieu of patient capacity, rather than an adjunct. In some instances, patient dependence necessitated caregiver inclusion as a proxy patient.

“If they are independent and active and cognitively well and I feel like and I feel quite confident uh in my clinical judgement that they would be okay at home. Then I probably wouldn’t go down that territory” (participant 5, 20 years of experience)

This is interrelated with patient characteristics as described in theme 1. However, it also introduces the concept that the physiotherapists perceive themselves to be the sole

coordinators of care and information during admission.

“if the patient was a poor historian or if it affected our discharge planning so if we weren’t sure what was going to happen, I would probably clue them how they could help us get the person home”
(participant 2, 20 years of experience)

‘Healthcare professionals as sole coordinators or care’ was further reflected in participant behaviour during initial assessment, as some participants neglected to ask about the presence of an informal caregiver. In other cases, caregiver’s wishes were considered at the same as patient wishes and at times caregiver wishes were recognised yet discounted.

“So I guess we don’t always involve the patients so much as telling so much as what they should do so it’s not it’s not a choose your own adventure for the carer and the patient” (participant 2, 20 years of experience)

Some participants did not consider caregiver welfare and its impact on the patient. Several participants reported that they would not ask or did not ask often enough if caregivers were prepared to take the patient back.

“No we don’t ask that often. We should ask them if they are too stressed” (participant 6, 14 years of experience)

Nearly all participants described carer stress, and some considered ways they could assist in treating carer stress.

“Yeah you can see it some are more outspoken some really say you know offer support as to what they are happy to accept.... Sometimes all they need is a listening ear it keeps them going yeah but thinking about always thinking about what is also what what is what we are capable of offering as well, we don’t have time to sit with them for two hours you know but we can at least in a small way you can offer support by acknowledging they are doing good job” (participant 11, 16 years of experience)

The acknowledgement of carer stress was aligned with perceptions that the

caregiver was the coordinator of care for the foreseeable future and therefore was a relevant person regarding the patient's hospital care. Some participants went on to make a connection between caregiver welfare and patient outcomes.

"I think it can depend on how long the patients here and how obvious it is that they are needing that extra help if the carer comes in and says everything is fine we are good we are good then I think, I think it can get overlooked you can't I think sometimes it can get missed that they are sort of stressed that when someone ends up in hospital again a few weeks later" (participant 4, 16 years of experience)

Static perception of changing demographics

Throughout the interview's participants frequently inferred that the caregiver was assumed to be female and younger.

"say a patient is being visited by a daughter" (participant 6, 14 years of experience)

"the daughter of so and so wants to speak to you" (participant 9, 30 years of experience)

"I would generally tell the patient that I'm calling the daughter" (participant 1, 20 years of experience)

Many participants (9) misinterpreted the concept of co-dependency during the interview. Some recognised the concept, however, did not know how to interact with it. Whilst others then deferred back to engaging the younger, often female, family member as opposed to the co-dependent partner.

"Yeah so, I wouldn't be going to the [co-dependent caregiver], because, I'd be going to the daughter who lives down the road but yeah." (participant 1, 20 years of experience)

How caregiver integration affects staff

Participants described positive and negative effects on their personal wellbeing from caregiver integration. Participants felt that they had positive experiences more frequently than negative experiences. Many of these interactions were altruistically motivated.

“You feel like you are actually helping the caregiver as well as the patient and they are both very appreciative yeah and you can see that you are making a difference” (participant 4, 16 years of experience)

And gave the participant a sense of purpose and recognition.

*“The fact the caregiver um asked questions, was interested, and then responded positively to the information that I gave her.”
(participant 1, 20 years of experience)*

This was juxtaposed in negative experiences where professionals felt they were not listened to.

“Just the inability of the carer to listen what changes we wanted to make and just the amount of supervision that the patient required and trying get to give certain prompts” (participant 2, 20 years of experience)

And experienced discomfort in conflict situations.

“I felt so uncomfortable about it because the daughter was so upset” (participant 9, 30 years of experience)

In the long-term, participants developed resilience to negative situations and resource limitations. All participants reported that they did not receive assistance in coping with negative effects of caregiver integration, aside from informal communication with friends at work. Multiple participants (6) described this as being something learned informally on the job.

“I guess so it’s just kind of something that you learn as you engage in it a bit more” (participant 7, 4 years of experience)

Some participants reported they felt confident in these situations, whilst others (5) used avoidance and remained guarded, as described in theme 1. The reality described by participants assumes that their wellbeing is frequently not considered in the current model of care.

Theme four: Invisible gaps

Summary

Participants, in their responses, seemed not to have considered caregiver engagement consciously prior to the interview. There was evidence during the interview of progressive realisation of gaps in care, some of which were prompted or co-created by the interviewer. These are the invisible gaps.

Caregivers falling through the cracks

Participants, when prompted, were unsure about including informal caregivers who did not provide help inside the home multiple times a day. The language and lengthy pauses in participants' responses suggests that this was the first-time participants considered these 'invisible' caregivers.

Some participants believed that someone else within the multidisciplinary was performing caregiver integration. However, there was a lack of confirmation that this was performed, as evident in language choice of participants. Therefore, some caregivers may be missed.

“the nurses or the case managers will speak to them if they need like nursing or any other health, they'll give them information that's what I believe I'm not 100% sure” (participant 7, 4 years of experience)

Participants described that, at times, assessment of patient cognition was inaccurate due to continuity of care, subjective methods of assessment and subtle cognitive decline. This may create gaps in caregiver engagement, as patient cognition is a trigger for caregiver engagement.

Integrated care gaps

Numerous participants (9) reported they would rarely refer on, even when it may be needed.

“I've never really referred on” (participant 7, 4 years of experience)

This illustrates that care emphasises acute admissions over prevention and empowerment of patients and caregivers. Participants (2) who referred to the community reported they would discuss it verbally to the patient.

“Because I feel physical fitness doesn’t end with the hospital and we do our best to you know optimise their health even once they leave and equip them with enough information to do follow through”
(participant 5, 20 years of experience)

The verbal discussion may create gaps in care as it depends on accurate assessment of patient cognition and health literacy.

Invisibility and realisation

The language choice of the participants suggested it was the first-time participants had considered informal caregivers consciously. This was demonstrated throughout interviews in paralinguistic features.

“Uhm.... Okay okay well uhm uhm..... just today” (participant 11, 16 years of experience)

It was common for participants to misinterpret concepts and questions. Participants found it difficult to consider barriers and facilitators in reflection of their experiences. Therefore, barriers, facilitators and gaps in practice, in some cases, are co-created with the interviewer and the participant. The following co-created example discusses eMR generated discharge letters.

“just generally speaking do you think that’s[discharge letter] written in a way that patients and caregivers could understand?”
(interviewer)

“I don’t think so no” (participant 9, 30 years of experience)

Overall, the ‘invisibility’ of caregivers limits the participants’ ability to find gaps in practice. However, their experiences indirectly provided a valuable description of current caregiver engagement.

Theme five: How can you think of solutions to invisible care gaps?

Summary

During the interviews, participants were asked to think of solutions to problems in caregiver engagement. However, they often struggled with this.

What should caregiver integration into transitions of care look like?

Participants often advocated for caregiver integration in the treatment of people with geriatric syndrome.

“I think with any patient that has informal caregivers involved yeah we should” (participant 8, 30 years of experience)

However, many reiterated it should be applied within limits.

“The limit is like once a week just to just to know if if at least during the first meeting like when the patients first come in we should contact the caregiver and know all the information and the expectation and after a week or so to see the progress and let them know the progress uhh like what they think and we are on the same page the goals, setting up goals” (participant 6, 14 years of experience)

Other participants suggested that caregiver integration should be encouraged but flexibility is needed as not all caregivers are appropriate, want to be included, and all have different needs. When asking participants, when should informal caregivers be included? participants consistently identified, as needed and from the beginning.

“Whenever its necessary, so ideally as so as possible if you think that’s its uh... if they are very involved” (participant 7, 4 years of experience)

The focus on early integration is a deviation, and potential improvement, on current practice described in theme three, where integration was often last minute. Participants were asked: how should caregivers be included? The responses highlighted increased communication between staff and caregivers.

Some participants identified that caregiver integration could be achieved indirectly, particularly for uncomplicated admissions.

“a typical protocol patient where you know in a week this patients going to be going home regardless because they are progressing well then the caregiver can be notified not from the beginning but throughout the process whenever possible where as if it’s a difficult patient” (participant 3, 15 years of experience)

What should transitions of care look like?

Participants were asked to discuss discharge planning in an ideal world. Participants struggled to identify pre-existing structures for successful discharge planning.

“No I’m just trying to get my head around.....

..... I guess uhm.....” (participant 8, 30 years of experience)

At admission, participants focused on getting an accurate social history, initial assessment and commencing discharge planning. During the admission, participants consistently identified it was important to update the patient goals, communicate with the team, caregiver and patient and acquire equipment long before discharge.

At discharge from the hospital, in an ideal world, participants described a final round of checks by all staff. Some participants mentioned that they would ask if the caregiver was able to take the patient back home.

The description of an ideal patient journey differed significantly to current practice at the point of organising follow up. Here participants identified follow up was often required. They believed that someone should be assisting patients to plan follow-up. However, there was inconsistency regarding whose role this was. This ranged from it being the physiotherapist’s role, if it was related to physiotherapy, to being the nursing staff or caregiver’s role.

“ideally yes you want to do it in the hospital and it’s not necessarily the physios job I think at the end of the day in discharge it’s the nursing staff can give them the information to call so if they need another home care physio” (participant 3, 15 years of experience)

Should we include informal caregivers?

Generally, participants were supportive of caregiver integration. Some participants

felt that some degree of poor caregiver integration was inevitable because of social complexities surrounding the patient and their caregiver.

“I don’t think there is anything I could have changed these two family members were very difficult to deal with, like quite aggressive to deal with” (participant 8, 30 years of experience)

Other participants alluded that in a stressed healthcare system, caregiver engagement is not a priority.

“I think.....I’m just seeing that there is a lot of pressure on the staff that things just like the patient care their struggling with so how are they going to be on the phones talking to caregivers” (participant 9, 30 years of experience)

A few participants believed that the caregiver integration was not necessary for effective patient care.

Lessons learnt from current practice

Participants provided relatively consistent information regarding what assisted and hindered their current practice of integrated care between hospital and the community. This is summarised in the table below and experiences described in earlier theme.

Table 15: Lessons learnt about health professional led caregiver integration

	Barrier or ‘not required’	Facilitator
Patient	<ul style="list-style-type: none"> • Healthy straight forward patient 	<ul style="list-style-type: none"> • Poor cognition • Requires high level care • Actively asks for caregivers to be involved • Non-English-speaking background
Caregiver	<ul style="list-style-type: none"> • Perceived as unrealistic by staff • Not present on the ward 	<ul style="list-style-type: none"> • Proactive • Pleasant • Present on the ward • Culture of family caregiving

Physiotherapist	<ul style="list-style-type: none"> • Does not feel including caregivers is worthwhile • Assumes another staff member will connect • Individual reaction to difficult situations • Time management/time poverty • Not trained • Short shifts/part-time employment 	<ul style="list-style-type: none"> • Listening • Empathy • Experience • Communication skills • Teamwork • Good documentation • Contextual knowledge e.g. services
Multidisciplinary team	<ul style="list-style-type: none"> • Conflict within the team • Poor communication • Personalities within the team • Overlapping roles • Overly siloed roles • Language used to describe the caregiver and patient 	<ul style="list-style-type: none"> • Teamwork • Communication • Strong leadership • Support/comradery in the team • documentation
Facility	<ul style="list-style-type: none"> • Physical environment • Ambiguous visitor policy • Healthcare as a business • Private patient mentality • eMR system design • Unclear privacy policy 	<ul style="list-style-type: none"> • Structured communication for within the team • Structured communication between caregivers and • White board communication • Quick involvement of appropriate disciplines
Healthcare system	<ul style="list-style-type: none"> • Incentives numbers of people treated • Resource poor • Work not suited to casual work force • Poor integration between hospital and community • Hospitals staffed hours • Time constraints • Delayed discharges 	<ul style="list-style-type: none"> • Transitional care services

Solutions

Physiotherapists overwhelming felt that the solution to caregiver engagement was to increase individual ownership of the role in their work.

“encouraging ownership of the clients and not just you know getting through the day” (participant 11, 16 years of experience)

Whilst this maybe appropriate, to some degree, it does not consider the other factors which affect caregiver engagement outside the physiotherapist’s locus of control.

Overall, participants struggled to think of solutions to gaps in practice and defaulted to responding with pre-existing models of care or with band aid solutions, where the participant fills the gap with a new role.

“I think that’s why a case manager was good.” (participant 2, 20 years of experience)

Often participants suggested changes without knowing if their suggestion already existed in care. Other participants demonstrated uncertainty in creation of solution through their language, for example repetitions of *“Umm... ..”* (participants 1,4, 6,8,9), or repeating prompts delivered by the interviewer *“Yeah education and some policy”* (participant 6). Many of the solutions were co-created between the interviewer and participant.

“Do you think it’s something [empathetic caregiver engagement] people can learn to do?” (interviewer)

“Definitely” (participant 9)

“What do you think would help them to be better at that?” (interviewer)

“I think everybody should just do some sort of training” (participant 9, 30 years of experience)

Generally, few participants described new innovations, either with or without assistance. Interestingly, despite their emphasis on the caregiver characteristics and its influence on initiation of caregiver integration, participants did not feel that caregivers could be part of the solution.

4.3. Discussion

This section discusses explores the research questions outlined in the methods section using concepts exposed during the thematic analysis and questionnaires.

How do physiotherapists engage with informal caregivers in current practice?

Participants indicated that admission and discharge were key moments in caregiver integration. Current practice is described under each of these subheadings below.

Following this, gaps and patterns in current practice are discussed.

Initiation of caregiver engagement

Establishing a relationship between the caregiver and the physiotherapist is the biggest hurdle in current caregiver integration. Participants described a reliance on their perception of caregiver characteristics (the 3P's: pleasant, present and proactive) and patient characteristics such as poor cognition and function for caregiver integration.

A reliance on caregiver presence and proactiveness corresponds with other literature.^{119, 139} Healthcare professionals often describe these as 'chance meetings'. However, 'chance' meetings require orchestration by the informal caregivers, depend on availability of the caregiver during traditional working hours¹⁴⁰ and may be limited by the caregiver's internal inhibition.⁹⁰

Interviewees highlighted that caregiver integration, whilst not always performed, was particularly important at admission and discharge, to serve as a handover between the patient and caregiver.

Caregiver engagement during the inpatient stay

Regular engagement during the inpatient stay was either caregiver driven, or in cases where it was healthcare professional driven, it was reserved for patients with high care needs. Positive caregiver integration during the inpatient stay was dependent on good rapport. Relationship types are described in the sub-headings below. These mediate how caregivers were engaged during the inpatient stay. Many described caregiver engagements starting as professional-assistant relationship and developed as rapport built. Healthcare professionals may integrate caregivers and distribute power in this way to balance resource poverty and time constraints.¹⁴¹ The maturity of the staff-caregiver relationship formed may depend on continuity of staffing. Discontinuity, in this study, may be caused by the

part-time employment status of interviewees; however, this is the norm for physiotherapists in Australia.^{126, 127}

Professional- assistant relationship

Caregivers were, at times, an additional resource on the ward. For example, being a translator, continuing exercises, getting equipment and assisting with nursing duties. This professional-assistant relationship may ease the pressure on a stressed system and may reduce cost.¹⁴² However, caution needs to be taken, as one participant pointed out, caregivers are unpaid and untrained agents and are not obliged to perform this care.

Professional-student relationship

This relationship was characterised by the healthcare professional up-skilling the caregiver in order to self-manage on transition to the community. In this study, this relationship was associated with infrequent communication as education was often once-off. Despite the rarity of this relationship, many identified it would be ideal. This has elements of gold standard practice in transitions of care, as defined by policy. However, it suggests that information transfer is unidirectional.¹⁴³

Co-worker relationship

Participants discussed that their practice was, at times, collaborative with caregivers. Theoretically, in these relationships' caregivers are considered an extension of the multidisciplinary team. Other research is more pessimistic and suggests that healthcare professionals make poor judgements on the collaborative nature of the relationship, as often even perceived 'collaborative' relationships are still healthcare professional dominated.¹⁴¹ Therefore, it is likely that current collaborative caregiver relationships are more provider led than the participants thought.

Caregiver integration at discharge

Some participants reported that handover back to the caregiver would be achieved through indirect communication, such as discharge letters and information sheets. Indirect communication was largely ignored by participants during the interview stage. However, in the questionnaire responses participants indicated that they were mostly likely to perform indirect communication. It is unknown how effective indirect communication is for caregiver integration. Its effectiveness may depend on the delivery method and health literacy.

Last-minute communication was common and often described as unideal for patient care. Last-minute interactions were caused by poor planning, discontinuity in care and fluctuating patient function. Generally, participants felt that caregiver integration at the point of discharge could be improved.

Gaps and patterns in current practice

Interviewees frequently described caregivers as a replacement voice when the patient lacked capacity, rather than an adjunct. This shift away from patient-centred care has been observed in accompanied patients at primary care settings.¹⁴⁴ The emphasis on patient autonomy, and resultant caregiver exclusion, ignores that patients often want to take their family's opinions into consideration when making a care decision. Respecting patient autonomy requires recognition of the patients' decisions and the decision making process, even if the result is that the patient favours the family's preference over their own.^{145, 146}

Caregivers were commonly assumed to be younger women. Whilst this assumption is statistically true, this demographic is declining and older, spousal and co-dependent informal caregivers are almost equally represented and increasing proportionately.¹⁴⁷ The interviews suggest that this older demographic may be invisible to participants as corroborated by older informal caregivers' current experiences of acute care.¹⁴⁸ Additionally, interviewees discussed foregoing older caregiver's integration due to poor health. Literature supports this observation, where older informal caregivers are frequently pre-frail themselves.¹⁴⁹ This is a gap in practice and policy, as there are few guidelines to address challenges in integrating this caregiver demographic effectively.

Infrequent caregivers, for example those who provide care once a week for community access or heavy housework, were also invisible to participants. This raises the question, what informal caregivers should we be including? Currently, it is up to the professional's discretion. Recommendations to reconcile this gap are discussed later.

Healthcare professionals may miss caregivers as they rely on caregivers speaking up if there is an issue. However, few then made the connection between barriers, such as stress and other commitments, and limited integration. This illustrates an environment where systematic expectations are set higher than caregivers can achieve as they are held back by personal and societal barriers. The misalignment may cause some caregivers to be missed.

What solutions do physiotherapists perceive to barrier to caregiver engagement?

Table 16 summaries all solutions suggested by participants during the interviews. Key concepts discussed in interviews are included in sub-headings below and compared to current literature.

Table 16: Summary of solutions to caregiver integration, as perceived by participants

	Summary of solutions perceived by participants
Physiotherapy led solutions	<ul style="list-style-type: none"> • Physiotherapists need to take ownership of their own caseload, discharge planning and caregiver integration.
Team led solutions	<ul style="list-style-type: none"> • Education between team members about roles within the team • Value other healthcare professionals' opinions • Increased informal communication • Deliver cohesive messages between the team and the caregiver • Earlier referrals for services and facilities (e.g. rehab)
Hospital led solutions	<ul style="list-style-type: none"> • Provide a specific privacy policy about disclosing information to caregivers • Private spaces in physical environment • Provide a policy that describes how caregivers fit in • Provide education on informal caregivers and how to handle social complexity • Have an accessible information source about community services for patients, caregivers and staff • Clarify follow up care policy • Flag complex patients early • Have a systematic method of identifying caregivers and communicating this information to the team • Provide health literacy appropriate discharge summaries for patients and caregivers • Have a designated person for discharge planning and caregiver engagement • Ensure staff deployment maximises continuity of care
System led solutions	<ul style="list-style-type: none"> • Have an accessible information source about community services for patients, caregivers and healthcare workers • Provide specific guidance about where the caregiver fits into discharge planning • Increase community support for caregivers • Provide caregiver education workshops • Decrease healthcare professionals' caseload

Teamwork

A consistent plan, clear roles, frequent communication and goodwill between team members assisted with transitions of care and engaging the informal caregiver. Participants believed that the traditional hierarchical structure between healthcare professionals may negatively impact teamwork goodwill between professionals. This has been confirmed in other multidisciplinary studies.¹⁵⁰ Participants suggested that this lack of respect may be caused by misinterpretation of roles within the team, and this could be overcome by role education within the team. This is supported in other literature.¹⁵¹ Education is an interpersonal element that affects role development in the multidisciplinary team. Other factors are the workplace and individual attributes.¹⁵² Effective teamwork solutions may need to address these factors, too.

A single contact

Participants indicated that it would be useful to have a single person, a case manager, to consistently plan discharge and hold responsibility for caregiver engagement. This suggestion often arose in the context of lack of time. Evidence suggests that caregivers find having a single contact person beneficial for integration.⁹⁰ However, there is mixed evidence to support case management. The simple introduction of a new role in the multidisciplinary team is unlikely to affect underlying system issues and poor teamwork.¹⁵³

Individual ownership

Interviewees felt that improved caregiver integration requires healthcare professionals to have pride and individual ownership of their daily caseload. Whilst individual responsibility may be part of the solution, it is unlikely professionals will self-initiate this consistently and independently. Improving transitions of care may require system-wide culture change to emphasise family-centred and community care. Paradoxically, this cultural change is likely to require individual buy-in by the professional, as the presence of even a few disillusioned staff members may impede the uptake of family-centred care.¹⁵⁴ Therefore, successful implementation of individual ownership to improve caregiver integration may require a meeting of a top down and bottom up approaches.

Unmentioned by participants, individual ownership may be limited by the discontinuity of care they described. Evidence suggests that discontinuity doesn't decrease the individual ownership of patient experience but rather changes the definition to include

a thorough handover.¹⁵⁵ In future, solutions may need to address including caregivers into handover, as recommended in nursing handovers,¹⁵⁶ or increase continuity of care.

Education

Questionnaire responses indicated that participants had received no training, this was confirmed in interviews. To address this, caregiver integration could be interwoven into all healthcare professional training, and that this could overlap with the education described in teamwork.

Policy

Introducing or changing policies such as visitor policy, patient privacy and discharge planning was suggested by several participants. However, none could discuss specific pre-existing policies. The contradiction suggests that policy is unlikely to change caregiver integration on the front lines. This is reiterated in other systems-change literature, where Braithwaite et al (2018) caution against adding more policies.¹⁵⁷ This is not say that all policies are unsuccessful, but they require other mechanisms to allow permeability to the front lines of healthcare.

Supportive IT solutions

Participants reported a high administrative burden and dissatisfaction with the effectiveness of communicating through the eMR. There is broad agreement in the literature that eMR systems design can increase the workload of the clinician administrative workload and impacts patient outcomes.¹⁵⁸ To reduce ‘missed’ notes, participants recommended changes to the interface. Participants also recommended structured documentation at admission regarding the presence of a caregiver and their willingness to be included. Information surrounding the caregiver’s willingness for engagement is an addition to current minimum caregiver information documentation recommendations.¹¹⁸

Lastly, participants suggested that the discharge summary autogenerated by the eMR was not suitable for patients and caregivers as it contains acronyms and an irrelevant structure. However, these discharge summaries are not intended for the patient. This unintended use of discharge summaries may mean that the summaries need to be re-designed to suit the general public. This has been implemented successfully at a local hospital, where patient-centred discharge letters increased patient understanding of post-discharge instructions.¹⁵⁹

Navigating healthcare

All participants reported that they had limited knowledge of community services. In turn, inadequate knowledge limited their ability to refer to the community. Professionals reported they often directed patients to use Google to self-navigate their care. However, 78% of Australian adults aged 64–74 have inadequate health literacy³⁰ and only 0.4% of online health information is suitable for the average Australian comprehension.¹⁶⁰ Patients require both health literacy and an appropriate health literacy environment to navigate and make effective decisions and appropriate use of healthcare.¹⁶¹ Participants who identified health literacy as a barrier requested appropriate resources to direct patients and caregivers to for ongoing care, for example information fliers or a website. This aspect of care navigation could be assisted by the facility through increasing bonds locally between hospital and community care.¹⁶² Participants also requested education on community services for themselves. These recommendations have already been advised by leading health research institutes.^{163, 164} It is also recommended that healthcare professionals know how to recognise and manage healthcare literacy and pay particularly close attention to it during transitions of care.¹⁶³

‘Give us more time’

Participants experienced stress due to emphasis on volume of treatments. The resultant call for a decreased workload or increased time is consistent internationally and across different settings. However, this is a reductive solution as it does not consider the cause for demand. The workload experienced by the participants may be driven by Australia’s fee-for-service reimbursement model.¹⁶⁵ Funding reform, for example, incentivisation of patient and caregiver outcomes, may be required to give healthcare professionals more time.

Systematic definition of where caregivers fit in

Participants described a reliance on caregivers for organisation of follow-up care. This practice may work for healthcare professionals in a time scarce environment. However, inappropriate handover to caregivers and subsequent caregiver action or inaction may cause safety and health issues for the caregiver and patient.^{3, 166} At other times, participants reported that caregivers were not asked to perform these tasks as they appeared disinterested in patient care or could not assist. This introduces concern whether caregiver engagement, in a professional-assistant relationship is true caregiver integration.¹⁶⁷

‘Caregivers as a resource’ perception is extensive in nursing and physiotherapy literature,

for example, caregiver-mediated exercises.^{79, 168} Some caregivers argue that they do not want to be considered as care facilitators, as they have their own needs.¹⁶⁹ In future, the system and local facilities need to provide clear guidance in family-centred care, this requires clarity regarding appropriate caregiver engagement and the delineation of caregiver inclusion and provision of care.

What lessons can be learned from facilitators of caregiver engagement?

Braithwaite et al (2018) advocates that too much time is spent focusing on what went wrong in care, rather than learning from the positive feedback loops, which occur far more frequently.¹⁵⁷ Key lessons learnt from these positive feedback loops are discussed in the subheadings below.

Participant satisfaction with current practice was the only divergent information between qualitative and quantitative results. In the questionnaires, participants indicated relatively high satisfaction with current caregiver engagement. However, participants were relatively negative during interviews.

Local solutions

Interviewees did not recognise how the healthcare system influences their practice of caregiver integration. Other literature agrees that care on the front lines is more dependent on local structures such as the team and hospital.¹⁵⁷ It is clear that mandating caregiver integration at a system level, as currently done in policy, is unlikely to reach the front lines of care. Therefore, successful improvement in caregiver engagement and transitions of care requires local innovation.

Flexibility on the front lines of healthcare

Patient care and caregiver integration was assisted by team members being flexible, and when needed, working outside their routine role. The dynamic between flexibility and defined roles within the team has been identified as a facilitator to effective teamwork.¹⁷⁰ Participants described further flexibility in roles when ‘trading’ patients to ensure continuity of care. Participants suggested that they conducted this practice to enhance patient experience despite discouragement caused by reimbursement models. This tug of war between the local reflexivity to care needs and the rigidity of funding arrangements demonstrates the current model is not always appropriate for addressing patient needs. Locally implemented person-centred models of care may deliver better patient outcomes and cost-effective care.^{171, 172} In future, funding models with outcome-based payment should be considered.

Flexibility needs to extend to how caregivers are integrated, as some participants point out, not all caregivers want to be included. Additionally, very independent patients may require substantially less caregiver involvement, depending on patient preference. In

future, caregiver integration is likely to need a great deal of flexibility to respect caregiver and patient autonomy.

Leadership

Effective teamwork^{173, 174} and caregiver integration requires a leader. Interviewees reported diffuse and inconsistent distribution of leadership in the team, which was beneficial. However, interview and questionnaire responses indicated that the participants rarely led. This may reflect role ambiguity¹⁷⁵ and could impact the benefits of physiotherapy participation in discharge planning. Empowering team members to develop autonomy may enhance equal distribution of leadership.¹⁵²

Resilience

Participants described emotional distress as a result of negative experiences of caregiver engagement. Over time, some developed jaded perceptions of caregiver engagement and tended to avoid caregiver interaction. However, others felt that they got better at addressing and coping with negative situations, suggesting resilience. Healthcare professionals have a high rate of burnout and it is hypothesised that difficult interactions with family and caregivers may contribute to this.⁸⁹ Harnessing resilience may benefit staff wellbeing and in turn cost, patient and caregiver experience. Literature suggests that resilience can be taught during healthcare professional university degrees¹⁷⁶ and positively supported in the workplace.¹⁷⁷

Informal communication

Informal communication was the most effective method of communication within the team, and the primary method of communication with the informal caregiver. Evidence suggests that informal communication enhances healthcare professionals perception of patient- and family-centred care and supports teamwork.¹⁴⁰ Healthcare facilities could improve patient safety and family-centred care by fostering a physical and social environment which encourages informal communication within the team and between caregivers, patients and the team.

Activated caregivers

Throughout the interviews, participants disregarded caregivers as being part of the solution in gaps in caregiver integration. The healthcare system could benefit from mobilising caregivers to facilitate caregiver integration. Caregivers require social support to overcome barriers to integration. The healthcare system may need to modify these

barriers, for example the expectation that the caregiver will speak up if there is an issue. This solution is not to ‘employ’ caregivers into a stressed healthcare system but to create an environment where they feel as partners in care and have the skills and support to make informed decisions.

4.4. Limitations

Firstly, this study was conducted as a single department of a private hospital in a homogenous social demographic. Therefore, the transferability of these results to the system may be limited.

Secondly, some of the findings regarding fractured delivering of care may be due to the participants' part-time employment. However, the participating facility did not have any eligible full-time employees at the time of recruitment. Furthermore, this is reflective of the Australian physiotherapy demographic.

The study received a high response rate to participation, likely due to the pre-existing relationship between the participants and the interviewer. It is possible that participants who responded hold similar views to the interviewer, and/or have views that are different to non-respondents. Equally, the overall effect of selection bias is likely to be small as over 40% of eligible employed staff were interviewed. The pre-existing relationship is also likely to have affected the responses and may have made the discussion more open.¹⁷⁸

The interview responses may have been influenced by completing the quantitative survey first. The most likely impact is that the interview captured 'second thought' perceptions of caregiver integration.

It is unclear how accurately participants identified and recalled patients with geriatric syndrome, and it is likely that they defaulted to talking about the most severe cases.

Lastly, a questionnaire was constructed and piloted by the author as no validated questionnaires relevant to the research question exist. Hence, the validity of these pilot interview results is uncertain.

4.5. Future research

Further research is required to investigate caregiver integration into current transitions of care for geriatric syndrome. To ensure future high-quality research in this space, methods to measure caregiver integration into care transitions need to be validated.

Solutions to caregiver integration need to be realistic to front line healthcare professionals. Therefore, future research needs to recruit multiple stakeholders, particularly the multidisciplinary team.

Many of the solutions discussed indicate system re-design. Further evidence is required surrounding the large- and small-scale solutions to system design and its effects on transitions of care and caregiver engagement. For example, large-scale changes such as incentivisation of patient reported outcomes, or smaller-scale changes, such as improvement in suitability of local eMR systems and information sources.

4.6. Conclusion

Integrating informal caregiver into care transitions was largely unconsidered by participants prior to this interview. Currently caregiver integration is initiated when caregivers are perceived as present, pleasant and proactive, or when the patient does not have the capacity to manage at home independently.

This study identified fractured transitions of care and inconsistent caregiver engagement likely to result in missed caregivers. Many of these gaps in practice were influenced by factors outside of the participants' control. Nearly all participants felt that caregiver integration and transitions of care could be improved. Improvement requires system change, and a shift in perspective to put patients and their communities first.

5. POLICY RECOMMENDATIONS

The results from the systematic review and pilot mixed methods study were used to inform the following policy recommendations for caregiver integration. These policy recommendations should be confirmed in further investigations.

Flexible structures that define caregiver integration

Flexibility in caregiver engagement may be necessary to meet the needs of caregivers and patients. However, flexibility without bounds leads to variation in practice and missed caregivers. In future, facilities need to implement structures that enable caregiver integration which include options for caregivers and patients to opt-out. At minimum, it requires a handoff at admission and discharge to the caregiver.

Back end solutions

Participants described caregiver integration as a task beyond their time constraints. Back-end solutions, such as changes to the physical environment, eMR or scheduling can enhance ‘passive’ caregiver integration and transitions of care without increasing workloads. In future, caregiver integration may be enhanced by technological support. However, further innovation and research is required in this space.

Cultural shift to family-centred and community care

The current model of care is episodic, acute care focused and at times lacks caregiver or even patient-centred care. This model’s structure and ethos are barriers to caregiver integration. To overcome this, all future system design and practices need to emphasise and value family and community-centred care. This cultural shift needs to extend beyond healthcare to other systems such as workplaces to boost caregiver capacity.

Reimbursement model

Australia’s reimbursement structure encourages volume of treatments rather than quality. This underlying structure affects how healthcare professionals prioritise quality transitions of care. Caregiver integration and transitions of care may benefit from restructuring the funding model or remuneration related to patient outcome measures.

6. ORIGINAL RESEARCH CONTRIBUTION

As best as can be determined, this systematic review is the first to examine caregiver integration using the quadruple aim. The mixed methods study was also unique compared to previous research as it asked participants to consider gaps and potential solutions. Both studies build on a limited body of previous literature regarding caregiver integration into transitions of care. These studies highlighted current variability in caregiver integration in research and practice. Both need to be addressed to improve integrated care.

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Appendix 1 Systematic review methods

1. Inclusion and exclusion material

1.1. Detailed population inclusion criteria

The following table details the specific population inclusion criteria utilised in the systematic review.

Table 17: population inclusion criteria

Criteria	Specific measures
Functional decline	<ul style="list-style-type: none"> • Barthel Index (0–100) ≤ 75 • Modified Barthel Index (0–20) ≤ 14 • ≤ 65 on the functional components of the FIM, or ≤ 90 in total FIM categories, or • Comparable dependency or worse on another functional scale
Frailty	<ul style="list-style-type: none"> • ≥ 4 on Canadian Study of Health and Ageing (CHSA) frailty scale
Cognitive decline	<ul style="list-style-type: none"> • A population average of <24 on Mini Mental State Examination (MMSE), or • A population average of <26 on Montreal Cognitive Assessment (MOCA) • Greater than 50% of the population as a diagnosis of cognitive decline (e.g. dementia, delirium)
Falls	<ul style="list-style-type: none"> • A population average of two or more falls in six months prior to admission.
Incontinence	<ul style="list-style-type: none"> • Greater than 50% of the included population had a diagnosis of urinary incontinence (defined as at least one episode of urinary incontinence per week)
Comorbidity	<ul style="list-style-type: none"> • Greater than 3 chronic co-morbidities • Charlson Co-morbidity Index (CCI) ≥ 5 or similar score on another scale
Poly pharmacy	<ul style="list-style-type: none"> • The average number of daily prescribed medications in the included population ≥ 5
Undernutrition	<ul style="list-style-type: none"> • Undernourished on a validated nutrition screening tool (and not Body Mass Index, BMI, alone)
Recurrent admissions	<ul style="list-style-type: none"> • one or more unplanned readmission in the last six months • two or more ED visits in the last six months

1.2. Extended population inclusion rationale

The following section describes the inclusion criteria rationale into the systematic review.

Functional decline

Functional decline, in this review, was considered moderate dependency or greater on patient mobility/activities of daily living measures. For example,

- Barthel index ≤ 75
- Modified Barthel Index ≤ 14
- ≤ 65 on the functional components of the Functional Independence Measure (FIM), or ≤ 90 in total FIM categories

Many scales do not have a consistent cut off score to define moderate dependency. The definition for moderate dependency on the Barthel scale range from 75¹⁷⁹ to 90.^{100, 180} The lower value, 75, was selected as the inclusion criteria as previous literature has demonstrated this lower value can accurately predict longer length of stay in acute admissions.¹⁷⁹ Therefore, the lower value may be more reflective of high-end geriatric syndrome.

A score of less than 14 in the modified Barthel index is similar to scores of less than 75 in the original Barthel index, as demonstrated in previous literature. The modified Barthel index does not have nominal dependency categories.¹⁸¹ Therefore, this is an approximation based off previous literature and may be a limitation of the study.

All other cut offs of functional scales, such as the FIM, were identified to match the score on the Barthel Index.¹⁸²

Frailty

Identified as frail or vulnerable on frailty scales. For example,

- ≥ 4 on Canadian Study of Health and Ageing (CSHA) frailty scale

This is because those with moderate and severe frailty both show significantly higher rates of readmission and length of stay on the CHSA frailty scale.¹⁸³ This level of frailty also demonstrates overlap between our other definitions of cognitive and functional decline.¹⁸⁴

Cognitive decline

The average score on cognitive assessment represents mildly cognitively impaired or worse. For example,

- A population average of <24 on Mini Mental State Examination (MMSE)
- A population average of <26 on Montreal Cognitive Assessment (MOCA)
- Greater than 50% of the population as a diagnosis of cognitive decline and/or dementia

Cognitive decline is frequently cited as a geriatric syndrome. It was selected for the inclusion criteria as the presence of cognitive decline, in any severity, significantly increases the risk of adverse patient events and readmission.¹⁸⁵

Falls

- A population average of two or more falls in six months prior to admission.

A history of two or more falls in the past six months is a strong predictor of risk for future falls.¹⁸⁶ This particular cut off is also frequently used in screening tools,¹⁸⁷ and is higher than the number of falls in the average geriatric population.¹⁸⁶

Incontinence

- Greater than 30% of the included population had a diagnosis of urinary incontinence (defined as at least one episode of urinary incontinence per week)

Incontinence is frequently recognised as a geriatric syndrome and it is associated with increased dependence. Previous cohort studies indicate that urinary incontinence increases dramatically with frailty and a prevalence of >30% may reflect the high-risk geriatric syndrome defined in this study.¹⁸⁴ This criterion is higher than the prevalence of urinary incontinence in community dwelling older adults.¹⁸⁸

Comorbidity

- Greater than 3 chronic co-morbidities
- Charlson co-morbidity index (CCI) of five or more

Comorbidity causes the development of geriatric syndrome, for this reason some researchers use comorbidity within their definition.²¹ The incidence of geriatric syndrome is significantly more likely with comorbidity and, risk increases with increasing number of chronic diseases.¹⁸⁹ Three chronic co-morbidities is the average number of co-morbidities at the time of death.¹⁹⁰ As this review looks at a population with a proximity to death, three chronic comorbidities was selected as the inclusion criterion.

The CCI is a frequently used measure which calculate the chance of ten-year survival in a ten year follow up period. In this calculation, more points reflect lower odds of ten-year

survival. Points are allocated by age, condition and in some cases severity of condition.¹⁹¹ Having a CCI of three or more significantly increases the risk of frequent hospital admissions.^{192, 193} To continue capturing a high-risk population the ‘severe’ preassigned category was used as the inclusion criterion, this is a CCI of five or greater. The CCI gives up to four points for age alone (for people aged 80+). Therefore, the higher value was chosen so that a healthy population of elderly people are not falsely included.

Polypharmacy

- Population average of ≥ 5 daily prescribed medications

Previous literature has demonstrated that a presence of five prescribed daily medications is associated with the presence of one or more geriatric syndromes.¹⁹⁴ Polypharmacy is not traditionally considered a geriatric syndrome within the literature. However, this systematic review aims to capture transitional care efforts across and within disciplines. Pharmacological studies are unlikely to measure more traditional geriatric syndrome symptoms at baseline (e.g. functional status and falls). In order to capture these pharmacological interventions polypharmacy was added as an inclusion criterion.

Undernutrition

Undernourished on a validated nutrition screening tool (and not BMI alone). For example:

- <7 on mini nutritional assessment

Undernutrition was added to capture dietitian led transitional care interventions that may otherwise have been excluded. Undernutrition is not recognised as a geriatric syndrome on its own. However, undernutrition has a strong association with recurrent falls and sarcopenia, recognised symptoms geriatric syndrome.^{195, 196}

Recurrent readmission

- An average of one or more unplanned readmissions in the last six months.

Whilst recurrent readmission is not a geriatric syndrome it is a characteristic of this high-risk population. This cut off was chosen as previous literature suggests this rate has a similar risk of readmission to the polypharmacy criterion selected.¹⁹²

2. Search strategies

2.1. Medline search strategy

(last run 23/06/2019)

1. Transitional care/ OR patient discharge/ OR patient transfer/
2. Family care* OR caregivers/
3. (care* adj (participation OR integration OR collaboration OR engagement)).mp.
4. 2 OR 3
5. (Care* adj (satisfaction OR experience)).mp.
6. Patient* adj (satisfaction OR experience)).mp.
7. Health personnel/
8. (experience OR perspective OR satisfaction).mp.
9. 7 AND 8
10. (Carer outcome OR caregiver outcome).mp.
11. Health resources/
12. Mortality/
13. Emergency service, Hospital/
14. (Patient OR care*) adj quality of life
15. Quality-adjusted life years/
16. Length of stay/
17. Patient readmission/
18. Quality of life/
19. (Care* adj (burden OR prepare* OR stress)).mp.
20. Treatment outcome/
21. OR/ 5,6,9–20
22. 1 AND 4 AND 21
23. Limit 22 to (English language and (“all aged(65 and over) OR “aged(80 and over)”))

2.2. CINAHL search strategy

(last run 23/06/2019)

1. (MM “Transfer, Discharge”) OR “patient discharge”
2. “family care” OR “carer” OR “caregiver” OR (MH family centred care+)
3. “(care* n#(participation OR integration OR collaboration OR engagement))”
4. 2 OR 3

5. “(care* n#(satisfaction OR experience))”
6. (MH “patient satisfaction+”) OR “(patient n#(satisfaction OR experience))”
7. “carer outcome” OR “caregiver outcome”
8. (MH “health resource utilisation”)
9. (MH “Mortality+”)
10. (MH “emergency service+”)
11. (MH “quality of life+”) OR (MH “quality-adjusted Life years”)
12. (MH “length of stay”)
13. (MH “readmission”)
14. (MH “caregiver burden”) OR “(care* n#(burden OR prepare* OR stress))”
15. (MH “treatment outcomes+”)
16. “health personnel experience” OR “health professional experience”
17. 1 AND 4
18. OR/5–16
19. 17 AND 18 limiters – Aged: 65+ years; English language

2.3. EMBASE

(Last run 23/06/2019)

1. Patient discharge.mp. or hospital discharge/
2. Care* NEAR/5(participation OR integration OR collaboration OR engagement)
3. 1 AND 2
4. Care* NEAR/3(satisfaction OR experience).mp.
5. Health personnel/ AND experience OR perspective OR satisfaction .mp.
6. Health resources/
7. Mortality/
8. Emergency service, hospital/
9. (patient or care*) NEAR/3 quality of life .mp.
10. Quality-adjusted life years/
11. Length of stay/
12. Patient readmission/
13. Care* NEAR/3(burden OR prepare* OR stress) .mp.
14. Treatment outcome/
15. Care* NEAR (satisfaction OR experience)
16. Patient NEAR/3(satisfaction OR experience)

17. OR/4–16

18. 3 AND 17

19. Limit 18 to (English language and aged <65+ years>)

2.4. Proquest search strategy

(Last run 23/06/2019)

SU(transitional care OR discharge plan* OR patient discharge OR discharge) AND ((carer* OR caregiver*) NEAR/5(education OR participation OR collaboration OR integration)) AND ("quality of life" OR ((patient OR carer* OR caregiver) NEAR/3 (satisfaction OR experience OR "preparedness for discharge"))) OR ((carer* OR caregiver) NEAR/3(strain OR burden)) OR readmission OR "emergency service" OR ((resource) NEAR/3 (use OR utilisation)) OR mortality OR "length of stay" OR "quality adjusted life years" OR (("health personnel" OR "health professional") NEAR/3(satisfaction OR experience)) OR "treatment outcome")

Filter applied: English language

2.5. Scopus search strategy

(Last run 23/06/2019)

TITLE-ABS-KEY (transitional AND care OR discharge AND plan* OR patient AND discharge OR discharge) AND ((carer* OR caregiver*) AND (education OR participation or collaboration OR integration)) AND ("quality of life" OR ((patient or carer* OR caregiver) PRE/3 (satisfaction OR experience OR "preparedness for discharge"))) OR ((carer* OR caregiver) PRE/3 (strain OR burden)) OR readmission OR "emergency service" OR "resource use" OR mortality OR "length of stay" OR "quality adjusted life years" OR (("health personnel" OR "health professional") PRE/3 (satisfaction OR experience)) OR "treatment outcome") LANGUAGE (english)

3. Screening tools

This section displays the screening tools used in abstract and full text screening. These are presented as tables, however, during the review they were implemented in Microsoft Access as forms.

Table 18: Abstract screening tool

Assessor		
Instructions: if YES or UNSURE continue screening process. If NO, stop and exclude as described		
question	Response	instructions
Did the study have a transition care intervention?	Yes/No/Unclear	If NO exclude as study does not have a transitional care intervention
Did the intervention routinely include informal caregivers?	Yes/No/Unclear	If NO exclude as study does not include informal caregivers
Was the patient population over 65?	Yes/No/Unclear	If No exclude as population does not have geriatric syndrome
Did the patient population have geriatric syndrome as defined by the inclusion criteria?	Yes/No/Unclear	
Did the intervention commence during the patient admission to an acute/sub-acute facility OR within one week of discharge from an acute facility?	Yes/No/Unclear	If NO, exclude as “other”
Does the intervention have a comparison?	Yes/No/Unclear	
Inclusion/exclusion assessment	Included/excluded/unsure	
Reason for exclusion	Does not have a transitional care intervention/ did not include informal caregivers/ was not performed in a population with geriatric syndrome/ other	
Does the full text need to be read to determine inclusion/exclusion?	Yes/No	
Date assessed		
Comments		

Table 19: Full text screening tool

Assessor		
Instructions: if YES continue screening process. If NO or UNCLEAR, stop and exclude as described		
Question	Response	Instructions
Did the study have a transition care intervention?	Yes/No/Unclear	If NO exclude as study does not have a transitional care intervention
Did the intervention routinely include informal caregivers?	Yes/No/Unclear	If NO exclude as study does not include informal caregivers
Was the patient population over 65?	Yes/No/Unclear	If No exclude as population does not have geriatric syndrome
Did the patient population have geriatric syndrome as defined by the inclusion criteria?	Yes/No/Unclear	
Did the intervention commence during the patient admission to an acute/sub-acute facility OR within one week of discharge from an acute facility?	Yes/No/Unclear	If NO, exclude as “other”
Does the intervention have a comparison?	Yes/No/Unclear	
Inclusion/exclusion assessment	Included/excluded/unsure	
Reason for exclusion	Does not have a transitional care intervention/ did not include informal caregivers/ was not performed in a population with geriatric syndrome/ other	
Date assessed		
Comments		

4. Data extraction tool

The tables below represent the data extraction tool used in the systematic review. These were implemented as forms in Microsoft Access.

Table 20: Data extraction tool: general information

Date form completed	
Name of researcher performing extraction	
Report title	
Publication type	
Type of study	e.g. RCT quasi experimental etc.
Study ID	(last name of first author, year)
Country in which the study was conducted	
Economic level of the country in which the study was conducted	
Study funding source	
Possible conflicts of interest	
Notes	

Table 21: Data extraction tool: population and setting

Inclusion criteria	
Exclusion criteria	
Population description	
Focused condition and severity of focused condition	
Setting description	
Notes	

Table 22: Data extraction tool- study methods

Aim of study	
Methods of recruitment	
Was there randomisation?	Yes/no
If yes, how was randomisation achieved?	
If no randomisation, how were group allocated?	
Were participants and/or personnel blinded to allocation of groups?	Yes/no
Comment on blinding during allocation	
Start date	
End date	
Duration of participation	
Notes	

Table 23: Data extraction tool: description of intervention, control and caregiver engagement

Type of intervention	e.g. nurse delivered, integrated care pathway etc.
Description of intervention	
Type of control	

Description of control	
Cost of intervention	
Resources needed for intervention	
When were caregivers included?	Design/development, at admission, during stay, at discharge, at follow-up or other
Which staff member included informal caregivers?	
What activities were informal caregivers included in?	e.g. education, co-design, goal setting etc.
Notes	

Table 24: Data extraction tool: participants

Data for each arm of study and total if available	
Study arm	
Participant population	Patients, informal caregivers or healthcare professionals
Number of participants	
Age (mean and SD)	
Gender (number of M and F and %)	
Ethnicity	
Primary diagnosis/most frequently illness	
Co-morbidities (mean, SD, range)	
Comment on co-morbidities	
Function/dependence scale used and mean and SD on this scale	
Number and % living alone	
Number and % who have an informal caregiver	
Comment on social situation	e.g. how much care is provided by informal caregivers
Number and % with cognitive impairment	
Comment on SES	
Number and % finished high school and/or number and % of people finished tertiary education	
Mean and SD of daily prescribed medications	
notes	
Data for overall baseline demographics	
How many arms of the study were there?	
How many people were eligible for the study?	
How many people were recruited?	
Number and % of deaths during the study?	
How many people were loss to follow up at the end of study?	Number and %
Notes	

Table 25: Data extraction tool: outcome measures

Summary of outcome measures			
Primary outcome measures			
Secondary outcome measures			
How were outcome measures collected? (brief summary)			
To be completed for each relevant outcome measure			
Outcome name			
Outcome definition			
Which population is the outcome being assessed in?		Patient/informal caregiver/healthcare professionals	
Tool used			
For scales, indicate whether upper or lower limit is good			
Is this tool validated?		Yes/no/ unclear comment:	
Person measuring/reporting		Patient/ informal caregiver/healthcare professional/researcher	
Comment on how the tool was administered			
Which quadruple aim/s does this tool/outcome relate to?		Population health/ patient/caregiver experience/ health professional experience/ cost of care	
Time points reported			
Time points measured			
Is outcome data complete?		Yes/No	
Comment on completeness of outcome data			
Is a reason provided for missing participants?		Yes/no	
Reason for missing participants			
Statistical methods and appropriateness			
Power			
Where participants and researchers blinded to allocation?		Yes/No/Unclear	
Was there blinding of assessors?		Yes/No/unclear	
Were any measurements made by proxy?		Yes/No/Unclear	
Comment on measurement by proxy			
Was subgroup analysis performed?		Yes/no	
If yes, details of sub-group analysis			
Potential confounders	confounder	Is this confounder controlled for?	Description of how confounder is controlled for
		Yes/No	

Notes	
Additional information for economic studies	
What method was used to extrapolate QoL?	
Justification of extrapolation of QoL	
What method was used to extrapolate costs?	
Justification of extrapolation of costs	
Notes	
Additional information for qualitative outcomes	
Describe data collection	
Describe method of analysis	
Notes	

Table 26: Data extraction tool: data and analysis

This form needs to be completed for each outcome. However, not all sections are appropriate for each outcome

Outcome						
Population	Patient/caregiver/healthcare professional					
Comparison						
Time point						
Results for continuous outcomes	Intervention			Control		
	Number of participants	Mean	SD or other variance	Number of participants	mean	SD or other variance
Results for dichotomous outcomes	Intervention			Control		
	Total in group	Number with event		Total in group	Number with event	
OR						
RR						
Mean difference						
Are values adjusted? E.g. baseline differences etc.	Yes/No	Comment:				
p-value						
Is p-value significant	Yes/no/borderline					
Comment on confidence intervals						
Number of missing participants						
Unit of analysis						

Any other results reported	
Notes	
Additional information for qualitative outcomes	
Themes displayed in results	
Theme discussed	
Direction of themes/experiences	e.g. positive/negative/neutral
Description of themes and experiences	
Notes	

Table 27: Data extraction tool: conclusion, summary and other information

Key conclusion of the study authors	
Was there selective reporting of outcome measures	Yes/No/Unclear
Which outcome measure improved in this study, in the intervention group when compared to the control?	
Which outcome measures did not change in this study, in the intervention group when compared to the control?	
Which outcomes got worse, in the intervention group when compared to the control?	
Generalisability of results	
Notes	

Appendix 2 Systematic review results

Throughout this appendix significant results are indicated in bold text. Where outcomes use a scale, the range is indicated and the healthier, or more desirable side of the range is signalled by an underline.

Table 28: Study characteristics

First Author, year published	Setting	Study design	Participants (n=intervention + comparator)	Disease area	Eligibility criteria addressed	Intervention duration, Follow-up period	Country	Intervention	Comparator
Multidisciplinary led interventions									
Everink 2018 ⁵²	A single rehabilitation unit	Quasi experimental	162 patients with and 54 caregivers (mean age 80.4 and 60.2 years respectively)	Multimorbidity	Comorbidity (mean 3.5 conditions) and poor function (KATZ15=5.96)	Length of rehabilitation admission, 9 months	The Netherlands	Integrated care pathway in a rehabilitation unit.	Comparator group receiving routine care
Forster 2013 ⁶⁶	36 stroke rehabilitation units	Cluster RCT	930 caregiver patient dyads (mean age of patients 71.2 years, caregivers 61 years).	Stroke	Poor function (BI 0–20 mean score 12.39 post stroke)	Duration of rehabilitation admission, 12 months	England	Multidisciplinary led caregiver training program consisting of 14 competencies.	Comparator group receiving routine care
Hebel 2014 ⁷³	specialist neurological ward	Quasi experimental	157 patient caregiver dyads (patient mean age 72.2 years, unknown caregiver mean age)	Stroke	Poor function (mean BI 0–100, 66.05)	Inpatient admission, 12 months	Poland	Caregiver education program delivered by a nurse and psychologist in 2, 2 hour sessions	Comparator group receiving routine care
Preen 2005 ⁷¹	two acute hospitals	RCT	189 elderly patients admitted with chronic	Chronic Cardiore	Comorbidity (mean 6.1 conditions)	Length of acute admission,	Australia	A multidisciplinary program that identified patient problems, collaboratively set	Comparator group

			cardiorespiratory diseases (mean age 75.1 years)	spiratory disease		7 days after discharge		goals and connected patients with appropriate community providers. Additional efforts were made to ensure timely transfer of an automated discharge summary.	receiving routine care
Toles 2017 ⁶⁰	specialist nursing facility chain with three separate locations	Quasi experimental	175 patient dyads (mean of patients 80 years, caregivers 63.4 years)	Multimorbidity	CCI >5 (mean 6.14)	Admission until 3 days after discharge, 3 days after discharge	USA	Multidisciplinary intervention which included a protocol for transition to the community and routine patient and caregiver engagement.	Historically enrolled comparator group
Kalra 2004 ⁷²	a single rehabilitation facility	RCT	300 patients (mean age 76 years)	Stroke	Poor function (mean BI 0–20, 8)	During inpatient admission, 12 months	England	Caregivers received manual handling training and education in individualised sessions by members of the multidisciplinary team.	Comparator group receiving routine care
Multidisciplinary led interventions. Subgroup: Early supported discharge interventions									
Indredavik 2000 ⁵³	acute stroke ward, inpatient rehabilitation and the community	RCT	320 patients (mean age 73.9 years)	Stroke	Poor function (mean BI 0–100, 59.5)	Inpatient admission to 4 weeks after discharge, 6 months	Norway	Patients were discharged to the community as soon as possible with community follow up for four weeks.	Comparator group, both intervention and comparator received high quality acute stroke care
Santana 2017 ⁶⁴	stroke unit, rehabilitation and the community	RCT	190 patients (mean age 67 years)	Stroke	Poor function (mean FIM 69.6)	One month after discharge, 6 months	Portugal	In the acute phase multidisciplinary meetings with the patient and the caregiver were held to assess, educate and establish goals. Patients were followed up in the community by a case manager and members of the multidisciplinary team.	Comparator group receiving routine stroke care

Interventions led by nurses/case managers									
Coleman 2006 ⁶⁵	non-profit large group model managed health care system	RCT	750 patients (mean age 76.2 years)	Multimorbidity	Comorbidity (Chronic disease scale mean 6.9)	Admission up to 24 hours after discharge, 6 months	USA	Nurses provided education to patients and caregivers on medication management, follow up, signs of deterioration and keeping a patient record.	Comparator group receiving routine care
Gräsel 2005 ⁷⁰	two rehabilitation wards and in the community	Quasi experimental	62 patient caregiver dyads (mean age of patients 72.8 years and mean age of caregivers 59.6 years)	Stroke	Poor function (mean BI 0–100, 64.6)	Admission to 3 months after discharge, 6 months	Germany	Training sessions were provided to caregivers during admission by a nurse. Prior to discharge patients and caregiver performed a practice weekend at home. Patients and caregivers were provided telephone counselling up to three months after discharge.	Comparator group receiving routine care
Hirsch 2014 ⁷⁴	single neurological rehabilitation hospital	Quasi experimental	28 patient caregiver dyads (mean age of patients 69.6 years, caregivers 69.35 years)	neurological patients, largely stroke patients	Poor function (mean BI 0–100, 38.2)	During in patient admission, 1 month	Germany	Bedside training for caregivers was offered by nurses to gain nursing and manual handling skills.	Comparator group receiving routine care
Kitzman 2017 ⁶⁷	a regional hospital and community in an economically disadvantaged area	quasi-experimental trial	30 stroke patients (mean age 65) and 12 historically matched individuals	Stroke	Co-morbidity (70% had ≥ 5 comorbidities)	Admission to 6 months after discharge, 30 days	USA	Support was provided by a case manager for patients and caregivers during acute admission and transition to the community.	Matched comparators receiving routine care
Kwok 2004 ⁶⁹	two acute hospitals in the same region	RCT	157 patients (mean age 74.7 years) and 110 caregivers	Chronic lung disease	Readmissions (mean 2.6 in last 12 months)	Admission to 6 months post discharge, 6 months	China (Hong Kong)	Nurse assessment in hospital follow up by six months of community nursing. The intervention reviewed the patients condition, provided health counselling, caregiver support, arranged social	Comparator group receiving routine care

								services and consulted with doctors.	
Laramiee 2003 ⁵⁴	an acute hospital in a semi-rural area and continued into the community setting	RCT	287 patients (mean age 70.7 years)	Heart Failure	Co-morbidity (mean >3 comorbidities)	Admission to 3 months after discharge, 3 months	USA	A case manager instigated early discharge planning, individualised patient and family intervention, follow up for 12 weeks via telephone and medication education.	Comparator group receiving routine care
Naylor 1994 ⁵⁵	A single university Hospital	RCT	364 patients (mean age 75 years) and 125 caregivers	medical and surgical causes for admission	Co-morbidity (mean 3.9 in medical group and 3.3 in surgical group)	Admission to 2 weeks after discharge, 3 months	USA	In hospital discharge planning and two weeks of follow up in the community by a nurse.	Comparator group receiving routine care
Naylor 1999 ⁵⁶	a single university hospital	RCT	363 patients (mean age 75.4 years)	Multimorbidity	Co-morbidity (mean 5.3 conditions)	Admission to 4 weeks after discharge, 6 months	USA	Nurse delivered discharge planning in hospital with four weeks of follow up in the community.	Comparator group receiving routine care
Naylor 2004 ⁵⁷	six university and community hospitals and in the community.	RCT	239 patients (mean age 76 years)	Heart failure	Co-morbidity (mean 6.4 conditions) and polypharmacy (mean 6.8 medications)	Admission to 3 months after discharge, 1 year	USA	Nurse delivered intervention which included discharge planning, collaboration with doctors and three months of community follow up.	Comparator group receiving routine care
Ohuabunwa 2013 ⁵⁸	a single hospital in a low income African American community	Quasi experimental design	104 patients (mean age 69.9 years)	Multimorbidity	Co-morbidity (mean CCI 5.4)	Admission to 4 weeks after discharge, 1 year	USA	Nurse led intervention that took place in hospital and four weeks after discharge. It aimed educated and promote self-management.	Matched comparators receiving routine care

Shyu 2008 ⁵⁹	four neurological wards in a 3,000 bed acute hospital	Quasi experimental design	201 patients and 158 caregivers (mean age 74.2 and 47.8 years respectively)	Stroke	Poor function (mean BI 0–100 49.1)	1 month after discharge, 1 month	China (Taiwan)	Nurse delivered caregiver orientated discharge planning which involved caregiver assessment, needs based consultation with caregiver, education and preparation for discharge. This occurred during the inpatient setting.	Comparator group receiving routine care
Van Spall 2019 ⁶⁸	ten acute hospitals in one city	RCT	2,650 patients (mean age 77.7 years)	Heart failure	High emergency department use (mean 2 in six months)	Inpatient admission till 6 weeks after discharge, 6 months	Canada	A nurse led intervention which included assessing patient needs, educating the caregiver and patient on heart failure, organising a doctor's appointment within 1 week of discharge, referrals to outpatient nursing services	Comparator group receiving routine care
Wee 2014 ⁶¹	five acute hospitals	Quasi experimental design	8,264 patients	Multimorbidity	Co-morbidity (56% had >3 conditions) and poly pharmacy (68% taking > 5 medications)	Admission to 2 months after discharge, 6 months	Singapore	Care coordinators (mostly nurses) educated patients and caregivers, encouraged self-management and articulation of preferences. Care co coordinators followed up patients and caregiver for approximately 1.5 months in the community.	Retrospectively matched comparator group receiving routine care
Interventions led by allied health professionals or doctors									
Abizanda 2011 ⁶²	acute geriatric unit	RCT	400 patients (mean age 83.5 years)	General medical geriatrics	Co-morbidity (mean 3.7 conditions) and poor function (mean BI 0–100, 66.6)	Length of acute admission, end of acute admission	Spain	Occupational therapy intervention including assessment, cognitive stimulation, activity retraining and a discharge talk.	Comparator group receiving routine care
Legrain 2011 ⁶³	five university hospitals	RCT	1 045 patients (mean age 86.1 years)	Multimorbidity	Co-morbidity (mean 3.4 conditions) and polypharmacy	Inpatient admission, 6 months	France	Geriatrician led program which routinely assessed and addressed depression, malnutrition and medication adherence.	Comparator group receiving routine care

					(mean 6.7 medications)				
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Key: BI=Barthel Index, CCI=Charlson comorbidity index, USA=The United States of America, RCT=Randomised Comparator Trial, FIM=functional independence measure

Table 29: Methods of caregiver integration and transitional care

Study	Method of caregiver engagement as described in the protocol						Intensity of caregiver engagement			Intensity of entire intervention	
	Development of intervention	discharge planning	Caregiver education and/or manual skills training	Goal setting (for patient and/or caregiver)	Needs assessment	Follow up sessions	Intervention (as per protocol)	Comparator (as per protocol)	Intensity of caregiver engagement delivered	Intensity of overall intervention as proposed	Intensity delivered by intervention, overall
Abizanda 2011 ⁶²			Yes	Yes	Yes		Carers could be included in 1 x 1-hour baseline assessment, daily contact/treatment and 1 discharge session	?	?	Daily inpatient support to patient/caregivers, including assessment, ongoing care and discharge meeting	?
Coleman 2006 ⁶⁵		Yes	Yes			Yes	Not specific	?	?	One visit in hospital close to discharge with patient/caregivers, a home visit and 3 follow up phone calls	67% received all components (hospital visit, home visit and 3 follow up phone calls)
Everink 2018 ⁵²	Yes	Yes	Yes	Yes	Yes		Not specific	?	?	Inpatient service only including “active involvement” of patients and caregivers, staff training*, implementation of triage instrument, evaluation meetings and timely provision of discharge summary	?
Forster 2013 ⁶⁶			Yes				Caregiver training program consisting of 14 competencies.	?	Time with caregiver was 136.5 (SD 111.12) minutes in	N/A	N/A

									intervention and 200.3 minutes in the control (SD 189.12)		
Gräsel 2005 ⁷⁰			Yes				1 x 1-hour group information session, 3 x45 – 60 min individual training sessions, a ‘therapeutic weekend’ and 3 months of telephone support	?	?	As per caregiver engagement	?
Hebel 2014 ⁷³			Yes				2 x 2-hour education sessions and provided with education materials	?	?	N/A	N/A
Hirsch 2014 ⁷⁴			Yes				Not specific	?	Mean number of training sessions in intervention group was 5.2	N/A	N/A
Indredavik 2000 ⁵³		Yes				Yes	Not specific. Family engagement describe as “a lot” in intervention group and “a little” in control.	?	?	Multiple visits in hospital by the members of the multidisciplinary team with patient/caregivers, a discharge planning meeting and outpatient home care for up to one-month post discharge*.	?
Kalra 2004 ⁷²			Yes				Not specific	?	3–5 training/education sessions for 45–60 minutes	N/A	N/A
Kitzman 2017 ⁶⁷			Yes			Yes	Not specific	?	Not specific. Of 417 follow up education sessions, 41 were for caregiver support.	Face to face contact with patient/caregivers in hospital*, follow up phone calls* and home visits*	214 encounters and 516 related services
Kwok 2004 ⁶⁹			Yes				Not specific. Included psychological support.	?	?	One hospital visit prior to discharge with patient/caregivers, weekly home visits up to four weeks and	9.9 hours of care was given to each patient.

										monthly visits up to 6 months, telephone support available 6 days a week	
Laramée 2003 ⁵⁴		Yes	Yes				Not specific	?	?	Daily contact with patient/caregivers whilst in hospital. Follow up phone calls at 1–3 days post discharge and 1,2,3,4,6,8,10 and 12 weeks post discharge.	Telephone calls ranged from 5 to 45 minutes. 6.7 hours of nurse time for each patient over 12 weeks.
Legrain 2011 ⁶³			Yes		Yes		Not specific	?	Caregivers were included 58.8% of the time	Face to face contact with patient/caregivers in hospital*	Doctors spent 231.6 minutes patient.
Naylor 1994 ⁵⁵		Yes	Yes		Yes		Not specific	?	?	Face to face contact with patient/caregivers in hospital* and at least two follow up phone calls	?
Naylor 1999 ⁵⁶		Yes	Yes		Yes		Not specific	?	?	Face to face contact with patient/caregivers in hospital*, home visits (at least two) and telephone support up to 4 weeks after discharge	?
Naylor 2004 ⁵⁷		Yes	Yes		Yes		Not specific	?	?	Face to face contact with patient/caregivers in hospital*, follow up home visits (at least 8) and telephone calls up to 3 months after discharge	6.3 home visits. Intensity of inpatient care in unknown
Ohuabunwa 2013 ⁵⁸		Yes	Yes		Yes		Not specific	?	?	Face to face contact with patient/caregivers in hospital*, phone calls at 2, 7 and 14 days and home visits when appropriate	?
Preen 2005 ⁷¹			Yes	Yes			Not specific	?	?	Face to face contact with patient/caregivers in hospital* and communication of patient discharge plan to GP	?
Santana 2017 ⁶⁴			Yes	Yes	Yes		Not specific	?	?	Face to face contact with patient/caregivers in hospital*,	Eight home visits

										home visits up to one-month post discharge*	
Shyu 2008 ⁵⁹		Yes	Yes				Not specific	?	?	Initial assessment and face to face training and communication with patient/caregivers in hospital*	4–5 visits approximately 30 min each
Toles 2017 ⁶⁰		Yes	Yes				Not specific	?	?	communication with patient/caregivers and collaborative discharge planning in hospital (detailed protocol provided) and one follow up phone call 72 hours after discharge	?
Van Spall 2019 ⁶⁸			Yes			Yes	Not specific	?	?	One education session at discharge with patient/caregivers, organisation of follow up appointments and additional referrals and face to face of telephone follow up for 4–6 weeks post discharge*	?
Wee 2014 ⁶¹		Yes	Yes				Not specific	?	?	Face to face contact with patient and caregiver in hospital* and follow up phone calls for up to 1.5 months post discharge*	?

Key: N/A=where the intervention is only includes caregiver engagement components and is already described in caregiver engagement section of table *=timing and intensity unspecified, ?=unknown

Table 30: Patient readmission

Study	Definition of readmission		Subgroup of definition		Sample size	Type of measurement		Method of data collected	Results			Statistical decrease in LOS on readmission
	All cause readmission (inclusive of planned)	All unplanned readmissions	Admission related diagnoses of index hospitalisation	Readmission related to comorbidity		Dichotomous measurement	Discrete measurement		Summary of results	Time (months)	Size of effect	
Coleman 2006 ⁶⁵	No	Yes	Yes	No	750	Yes	No	Administrative records	All cause readmissions, and readmission for same diagnoses decreased with intervention at 90 and 30 days. No difference at 180 days.	1	OR for all cause readmission 0.59 (95% CI 0.35 to 1) p=0.048	N/A
										3	OR of all readmissions 0.64 (95% CI 0.42 to 0.99) p=0.04	
										3	OR of readmission for same diagnosis 0.50 (95% CI 0.26 to 0.96), p=0.04	
										6	OR for all cause readmission 0.8 (95% CI 0.54 to 1.19) p=0.28	
Kitzman 2017 ⁶⁷	?	?	No	No	42	Yes	No	Patient records and patient self-reporting	At 30 days readmission was lower in the intervention group	1	In the intervention 3% were readmitted and in the comparator 42% were readmitted	N/A
Kwok 2004 ⁶⁹	Yes	Yes	No	No	149	Yes	Yes	National database	No statistical difference in all cause or unplanned	1	37% of control group were readmitted compared to 47% of the intervention p=0.244	No

									readmission using dichotomous or discrete measurements	6	In intervention Mean number readmissions was 1.5 (SD 1.4) and in control it was 1.5 (SD 2.2) p=0.08		
Laramée 2003 ⁵⁴	Yes	No	Yes	No	256	Yes	No	Patient reported and verified with administrative records	No statistical difference	3	In the intervention and control 37% of had at least one readmission p=0.99		No
Legrain 2011 ⁶³	No	Yes	No	No	665	Yes	No	Patient interviews and administrative records of participating hospitals	There was no statistical difference in readmission at six months, at 3 months readmission was lower in the intervention group.	3	In the intervention 20.2% were readmitted compared to 28.4% in the comparator, p=0.01		N/A
										6	32.5% of the intervention group were readmitted and 38.2% of the comparator, p=0.12		
Naylor 1994 ⁵⁵	?	?	No	No	142	Yes	No	Unclear	The medical group experienced a reduction in readmission at 2 weeks. There was no statistical difference at 6 or 12 weeks. There was no difference at any time in the surgical group.	0.5	Medical group	12% reduction in readmissions at 2 weeks with intervention (95% CI −22% to −2%).	N/A
										0.5–1.5		4% difference, in favour of intervention between groups (95% CI −9 % to 7%)	
										1.5–3		1% difference, in favour of intervention between groups (95% CI −8% to 12%)	
										0.5	Surgical group	4% difference, in favour of intervention between groups (95% CI −14 to 6%)	
										0.5–1.5		diff 4% difference, in favour of intervention between groups (95% CI −16 to 8%)	
										1.5–3		3% difference in favour of the comparator between groups (95% CI −7% to 13%)	
Naylor 1999 ⁵⁶	?	?	Yes	Yes	363	Yes	Yes	Patient interviews and	Improvement at follow up (24 weeks) in	6	16.8% reduction in number of people admitted at least once, p=0.01		Yes

								administrative records	favour of the intervention for dichotomous and discrete measures	6	8.30% reduction in people readmitted at least twice, p=0.01	
										6	46.87% fewer index related readmissions, p=0.005	
Naylor 2004 ⁵⁷	?	?	Yes	Yes	239	Yes	Yes	Patient interviews and administrative records	Improvement at one year in discrete and dichotomous measures (readmissions/per patient over one year) and subgroup analysis of comorbidity related readmissions in favour of the intervention	12	23 in intervention vs 50 comorbidity related readmissions in the comparator over one-year p=0.013.	No
										12	Total readmission per patient/year was 1.18 in intervention and 1.79 in comparator p=0.001	
Oluabunwa 2013 ⁵⁸	No	Yes	No	No	104	Yes	No	Administrative records from only the participating facility	No statistical difference at any time	1	9.6% in the intervention were admitted at least once compared to 17.3% in the comparator group, p=0.27	N/A
										2	28.9% of intervention group were readmitted compared to 25% of comparator group, p=0.64	
										6	32.7% of intervention group were readmitted compared to 36.5% of comparator, p=0.68	
										12	44.2% of intervention group were readmitted compared to 53.9% in comparator group, p=0.34	
Van Spall 2019 ⁶⁸	Yes	No	No	No	2494	Yes	No	Administrative records	No statistical difference	1	At one month, 20.4% admitted at least once in intervention vs 19.10% in the comparator group, HR 1.23, p=0.12	N/A
										3	36.2 % of the intervention group were readmitted compared to 36% in the comparator group, HR 1.1, p=0.32	
Wee 2014 ⁶¹	Yes	Yes	No	No	8264	Yes	No	National database	Readmissions reduced at 15 days, 30 days and	0.5	OR of all readmissions 0.5 (95% CI 0.4 to 0.5) p<0.001	N/A

									180 days in dichotomous and discrete measures	1	OR of all readmissions 0.5 (95% CI 0.5 to 0.6) p<0.001	
										6	OR of all readmissions 0.6 (95% CI 0.6 to 0.7) p<0.001	

Key: ?=unclear, N/A=not an assessed outcome measure in the study, LOS=length of stay, HR=hazard ratio, OR=odds ratio,
CI=confidence interval

Table 31: Patient emergency department use

Study	Dichotomous outcome	Discrete outcome	Sample size	Method of data collection	Results		
					Summary of results	Time (months)	Effect size
Kitzman 2017 ⁶⁷	Yes	No	42	Patient records and patient self-reporting	ED use was higher at 30 days in the comparator group, significance was not reported	1	83% of the comparator visited ED at least once, whilst 0% in the intervention visited (unknown whether this is statistically significant)
Kwok 2004 ⁶⁹	No	Yes	149	National database	No statistical difference in ED visits	6	Intervention groups mean number of visits was 2.2 (SD 2.4) the comparator group had 2.3 (SD 3.1), p=0.997
Legrain 2011 ⁶³	Yes	No	665	Patient interviews and administrative records of participating hospitals	No statistical difference in ED visits	3	3.8% of intervention group visited ED compared to 3.4% in comparator group, p=0.86
						6	6% of intervention visited ED compared to 6.3% of comparator group, p=0.86
Naylor 1999 ⁵⁶	No	Yes	363	Patient interviews and administrative records	No statistical difference in ED visits	6	Mean number of ED visits in intervention was 0.1 (SD 0.5) compared to 0.2 (SD 0.4) in comparator group, p=0.21
Naylor 2004 ⁵⁷	No	Yes	239	Patient interviews and administrative records	No statistical difference in ED visits	12	The mean number of ED visits was 0.1 (SD 0.4) in the intervention group 0.3 (SD 1.2) in the comparator group, p=0.116
Oluabunwa 2013 ⁵⁸	Yes	No	104	Administrative records from only the participating facility	No statistical difference in ED visits at any time	1	17.3% in intervention group were admitted at least once compared to 15.4% of the comparator group, p=0.81
						2	32.7% of the intervention group were admitted at least once compared to 34.6% of the comparator group, p=0.85
						6	38.5% of the intervention group were admitted at least once compared to 40.4% of the comparator group, p=0.85
						12	50% of the intervention group were admitted at least once compared to 55.8% of the comparator group, p=0.57
Van Spall 2019 ⁶⁸	Yes	No	2 494	Administrative records	Decrease in ED visits at 30 days, no difference at 3 months	1	HR 0.65 (95% CI 0.45 to 0.95), p=0.03
						3	HR 0.88 (95% CI 0.68 to 1.15), p=0.36.
Wee 2014 ⁶¹	Yes	Yes	8 264	National database		1	OR of all ED visits 0.81 (95% CI 0.72 to 0.90) p<0.001

					ED use reduced at 30 and 180 days in dichotomous and discrete measures	6	OR of all ED visits 0.90 (95% CI 0.82 to 0.99) p=0.003
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Key: HR=hazard ratio, SD=standard deviation, ED=emergency department, OR=odds ratio

Table 32: Length of stay on index admission

Study	Method of data collection	Sample size	Result	Size of effect
Preen 2005 ⁷¹	Administrative records	189	No statistical difference	In the intervention group LOS was 11.6 days (SD 5.7) compared to 12.4 days (SD 7.4) in the comparator group
Santana 2017 ⁶⁴	Administrative records	190	No statistical difference	In the intervention group LOS in acute stroke ward was 9.8 days (SD.3) and 40.6 days (SD 11.1) in rehabilitation ward. In the comparator group LOS was 10 days (SD 5.3) in acute ward and 39 days (SD 18.3) in rehabilitation ward
Laramée 2003 ⁵⁴	Administrative records	126	No statistical difference	Intervention group had a LOS 5.5 days (SD 3.5) compared to 6.4 days (SD 5.2) in the comparator group
Gräsel 2005 ⁷⁰	Administrative records	62	Intervention group experienced an increased LOS in rehabilitation unit	Mean LOS in intervention group was 64 days (SD 20) compared to 53 days (SD 15) in the comparator group

Key: LOS=Length of stay

Table 33: Patient function

Study	Instrument used to measure outcome	Sample size of sourced outcome at final follow-up	Functional observed by researcher	Results		
				Summary of results	Time (months)	Size of effect
Everink 2018 ⁵²	FAI (15– <u>60</u>)	147	No	Improvement at 3 months, no difference at 9 months	3	The mean difference was 4.14 (95% CI 0.86 to 7.42) p=0.014
					9	The mean difference was 1.84 (95% CI -1.58 to 5.26) p=0.288
	KATZ-15 (0 to <u>8</u>)	147	No	No statistical difference at any time	3	The mean difference was -0.51 (95% CI -1.60 to 0.59) p=0.360
					9	The mean difference was -0.14 (95% CI -1.41 to 1.12) p=0.862
	IPA (<u>30</u> –155)	147	No	No statistical difference at any time	3	The mean difference was -1.20 (95% CI -4.28 to 1.88) p=0.441
					9	The mean difference was -0.27 (95% CI -4.70 to 4.16) p=0.903
Indredavik 2000 ⁵³	mRS (<u>0</u> –6)	243	Yes	No statistical difference at 6 weeks, improvement at 26 weeks	1.5	54.4% of participants in intervention group were independent (mRS≤2) compared to 45.6% in routine care p=0.118.
					6	OR of people who were independent (mRS≤2) at 26 weeks was 1.72 (95% CI 1.1 to 2.7)
	BI (0– <u>100</u>)	243	Yes	No statistical difference at 6 weeks, improvement at 26 weeks	1.5	56.3% of the intervention group were independent (BI≥95) compared to 48.8% in the comparator group p=0.179
					6	OR of people who were independent (BI≥95) at 26 weeks was 1.54 (95% CI 0.99 to 2.39)
Gräsel 2005 ⁷⁰	FIM (18– <u>128</u>)	62	Yes	No statistical difference	6	The mean change in function from baseline was 2.5 (SD 12.9) in the intervention group compared to 7.4 (SD 12.2) in the comparator group, p=0.129
	BI (0– <u>100</u>)	62	Yes	No statistical difference	6	The mean change in function from baseline was 11.4 (SD 14.1) in the intervention group and was 11.2 (SD 16.4) in the comparator group, p=0.968

Hebel 2014 ⁷³	mRS (<u>0–6</u>)	157	Yes	No statistical difference	3	The mean change in function from baseline was 0.3 (SD 0.6) in the intervention group and was 0.2 (SD 0.5) in the comparator group
					12	Median score in each group was 2, SD or p value not provided
	BI(<u>0–100</u>)	157	Yes	No statistical difference	3	The mean change in function from baseline was 11.9 (SD 13.8) in the intervention group and 8.4 (SD 10.10 in the comparator group, p=0.054
					12	The mean change in function from baseline was 20.5 (SD 18.3) in the intervention and 12.8 (SD 14.1) in the comparator group, p=0.057
	NEADL <u>0–22</u>)	157	Yes	Difference at 3 months however no difference at 12 months	3	The mean score was 7 in the intervention group and 13 in the comparator group, p=0.004
					12	The mean score was 14 in the intervention group and 14.5 in the comparator group, p value was not reported but was said to be insignificant
Naylor 1999 ⁵⁶	ESDS (<u>12–72</u>)	Not reported	No (telephone questionnaire)	No statistical difference	1	Patients reported an increase in functional decline two weeks after discharge in all groups. Groups were reported to be similar specific values are not provided.
Naylor 2004 ⁵⁷	ESDS (<u>12–72</u>)	147	No (telephone questionnaire)	No statistical difference at any time	0.5	Data was presented in quartiles in the results section of the study. Authors wrote there was no statistical difference at any time. However, little can be interrupted from the figure provided therefore they are not presented here.
					1.5	
					3	
					6	
					12	
Santana 2017 ⁶⁴	FIM (<u>18–128</u>)	152	Yes	No statistical difference at any time	Discharge	The mean score was 88.9 (SD 27.6) in the intervention group and 90.3 (SD 23.3) in the comparator group, p=0.699
					2	The mean score was 104.6 (SD 21.6) in the intervention group and 105.6 (SD 24.0) in the comparator group, p=0.798
					6	The mean score was 107.4 (SD 19.9) in the intervention group and was 106.6 (SD 25.5) in the comparator group, p=0.816
	FAI (<u>15–60</u>)	147	Yes	No statistical difference	6	The mean score was 34.6 (SD 17.6) in the intervention group and 32.2 (SD 11.4) in the comparator group, p=0.328
Kalra 2004 ⁷²	mRS (<u>0–6</u>)	299	Yes	No statistical difference at any time	3	80/150 people in the intervention group had a mRS score of 0–2 and 63/148 had this score in the comparator group, p=0.054
					12	100/151 people in the intervention group had a mRS score of 0–2 and 87/148 had this score in the comparator group, p=0.18

	BI (0– <u>20</u>)	300	Yes	No statistical difference at any time	3	77/151 people in the intervention group had a BI>18 and 52/149 had this score in the comparator group, p=0.007
					12	93/151 people in the intervention group had a BI>18 and 5/149 had this score in the comparator group, p=0.074
	FAI (15– <u>60</u>)	299	Yes	No statistical difference	12	The mean score was 15 (IQR 9 to 23) in the intervention group and 16 (IQR 8 to 22) in the comparator group, p-value not provided
Forster 2013 ⁶⁶	NEADL (0– <u>66</u>)	631	No (postal questionnaire)	No statistical difference	6	The mean score was 27.4 in the intervention group and 27.6 in the comparator group, (95% CI –3.0 to 2.5), p=0.866
					12	The mean score was 29.6 in the intervention and 29.1 in the comparator group, (95% CI – 2.2 to 3.2), p=0.70
	BI (0– <u>20</u>)	622	No (postal questionnaire)	No statistical difference	6	The mean score was 14.2 in the intervention and 14.1 in the comparator group (95% CI–0.6 to 0.7), p=0.825
					12	The mean score was 14.6 in the intervention group and 14.4 in the comparator group, (95% CI–0.5 to 0.8), p=0.60

Key: FAI=Frenchay Activities Index, FIM=Functional Independence Measure, BI=Barthel Index, mRS=Modified Rankin Scale, ESDS=Enforced Social Dependency Scale, NEADL=Nottingham extended activities of daily living, IPA=Impact on participation and autonomy, IQR=interquartile range, CI=confidence interval

Table 34: Patient mental health

Study	Instrument used to measure outcome	Sample size of sourced outcome at final follow-up	Results		
			Summary of results	Time (months)	Size of effect
Everink 2018 ⁵²	RAND-36 subscale	215	No difference at any time	3	The mean difference between groups was -1.20 (95% CI -2.61 to 1.54)
				9	The mean difference between groups was -0.91 (95% CI -3.67 to 1.94)
Forster 2013 ⁶⁶	HADS (0-21)	612	No difference at any time	6	The mean score on anxiety component was 6.7 in intervention group and 6.6 in comparator group, the mean difference was 0.1 (95% CI -0.5 to 0.7) p=0.629. In the depression component the interventions mean score was 7.3 and was 7.2 in the comparator, the mean difference was 0.1 (95% CI of difference -0.5 to 0.7) p=0.759
				12	The mean score on anxiety component was 6.4 for intervention group and 6.6 in the comparator, the difference was -0.2 (95% CI -0.9 to 0.3) p=0.355. In the depression component the interventions mean score was 6.9 and was 7.3 in the comparator, the difference was -0.4 (95% CI -1.1 to 0.3) p=0.191
Kalra 2004 ⁷²	HADS (0-21)	274	Improvement in anxiety and depression subscales at 1 year	12	Median score in anxiety subscale was 3 (IQR 2 to 4) in the intervention group and was 4.5 (IQR 4 to 6) in the comparator group, p=0.0001 The mean score in the depression subscale was 3 (IQR 2 to 4) for the intervention group and was 4 (IQR 2 to 5.5) in the comparator group, p=0.0001
Kwok 2004 ⁶⁹	GHQ (0-28)	140	No difference	6	The mean score was 7.5 (SD 5.3) in the intervention group and 7.9 (SD 5.2) in the comparator group
Naylor 1999 ⁵⁶	CESDS (0-60)	Not reported	No difference		Not reported in full

Key: HADS=hospital anxiety and depression scale, CESDS=Centre of Epidemiologic Studies Depression Scale, GHQ=general health questionnaire, IQR=interquartile range, SD=standard deviation, CI=confidence interval

Table 35: Caregiver mental health

Study	Instrument used to measure outcome	Sample size of sourced outcome at final follow-up	Results		
			Summary of results	Time (months)	Size of effect
Forster 2013 ⁶⁶	HADS (0–21)	597	No difference at any time	6	Anxiety subscale mean was 7 in the intervention group and 7.5 in the comparator group, mean difference was –0.5 (95% CI –1.2 to 0.1) p=0.084. The depression subscale mean was 5 in the intervention group and 5.2 in the comparator group, mean difference was –0.3 (95% CI –0.9 to 0.3) p=0.308
				12	Anxiety subscale mean was 6.9 in the intervention group and 7 in the control group, mean difference was –0.1 (95% CI –0.9 to 0.5) p=0.636. The depression subscale mean was 5.2 for both groups, mean difference was –0.0 (95% CI –0.6 to 0.5) p=0.889
Gräsel 2005 ⁷⁰	D-S *	62	No difference	1	The mean score was 65.3 (SD 32.5) in the intervention group and 64 (SD 29.8) in comparator group, p=0.153
Hirsch 2014 ⁷⁴	GDS (0–15)	28	No difference	1	The mean score was 2.71 (SD 2.34) in the intervention group and 1.71 (SD 1.59) in the comparator group, p=0.28
Kalra 2004 ⁷²	HADS (0–21)	284	Improvement in anxiety and depression subscales at 1 year	12	The median score in anxiety subscale was 3 (IQR 2 to 4) in the intervention group and 4 (IQR 3 to 6) in the comparator group, p=0.0001. The median score for the depression subscale was 2 (IQR 1 to 3) in the intervention group and 3 (IQR 2 to 5) in the comparator, p=0.001

Key: HADS=hospital anxiety and depression scale, GDS=geriatric depression scale, D-S=Zerssen Depression Scale * scale and ranges are in German higher scores indicate better mental health whilst lower scores indicate poorer health, SD=standard deviation, CI= confidence interval, IQR=interquartile range

Table 36: Patient quality of life

Study	Outcome measurement tool	Sample size at final follow-up	Results		
			Summary of results	time (months)	Size of effect
Everink ⁵²	CSAL (0–100)	147	No statistical difference at any time	3	The mean difference between groups was 4.95 (95% CI 2.17 to 12.08), p=0.170
				9	The mean difference between groups was 1.54 (95% CI –7.29 to 10.37), p=0.730
Gräsel 2005 ⁷⁰	SF-36 (0–100)	62	No statistical difference	6	The mean score was 30.5 (SD 6.9) in the intervention group and 31.7 (SD 8.1) in the comparator group, p=0.561
Naylor 2004 ⁵⁷	MLHF (0–105)	149	Greater quality of life at 12 weeks, no difference at 2,6,26 and 52 weeks. P values were not provided	0.5	In the intervention group the mean total score was 3 (SD 1.2) and was 2.9 (SD 1.4) in the comparator group
				1.5	In the intervention group the mean total score was 3.1 (SD 1.3) and was 2.9 (SD 1.4) in the comparator group
				3	In the intervention group the mean total score 3.2 (SD 1.5) and was 2.7 (SD 1.5) in the comparator group
				6	In the intervention group the mean total score 2.9 SD 1.6 and was 2.6 SD 1.5) in the comparator group
				52	In group intervention the mean total score was 2.8 (SD 1.8) and was 2.6 (SD 1.7) in the comparator group
Preen 2005 ⁷¹	SF-12 (0–100)	128	No statistical difference	0.5	Mental components mean score was 42.4 (SD 5.6) and was 40.9 (SD 5.7) in the comparator group, in the physical component the intervention mean was 27.2 (SD 4.5) and 27.2 (SD 4.1) in the comparator group
Van Spall 2019 ⁶⁸	EQ-5D-5L (0–1)	986	Improved with intervention at all follow up measures. However, no difference in QALY at 6 months.	Discharge	The mean difference between groups was 0.18 (95% CI 0.14 to 0.23), p<0.001
				1.5	The mean difference between groups was 0.06 (95% CI 0.01 to 0.11), p=0.02
				6	The mean difference between groups was 0.06 (95% CI 0.01 to 0.12), p=0.02 The mean difference between groups in QALYs was 0, p=0.9800.
Kwok 2004 ⁶⁹	LHD (each subscale ranges 1–6)	140	No difference in overall score. There was an improvement in social subscale at 6 months.	6	Intervention mean in social subscale was 2.2 (SD 1.0) and in the comparator 2.5 (SD 1.0)

Kalra 2004 ⁷²	EuroQol VAS (0–100)	256	Improved with intervention at all follow up measures	3	The median score in the intervention group 60 (IQR 42 to 70) and was 50 (IQR 40 to 90) in the comparator group, p=0.019
				12	The median score in the intervention group was 65 (IQR 55 to 80) and was 60 (IQR 41 to 80) in the comparator group, p=0.009
Forster 2013 ⁶⁶	EQ-5D (–0.59–1)	598	No statistical difference and no statistical difference in QALY	12	The mean difference between groups in QALYs was 0.01 (95% CI –0.02 to 0.05), p=0.5200
	SIS (functional ability and quality of life) (0–100)	615	No statistical difference	12	Presented in subscales, in results p values ranged from 0.121 to 0.7

Key: CSAL=Cantril's Self Anchoring Ladder, SF-36=Short form 36, SF-12=Short form 12, LHD=London health scale, MLHF=Minnesota Living with Heart Failure questionnaire, SIS=Stroke impact scale, SD=standard deviation, IQR=interquartile range, QALY=quality adjusted life years, CI=confidence interval

Table 37: Caregiver quality of life

Study	Instrument used to measure outcome	Sample size of sourced outcome at final follow-up	Results		
			Summary of results	Time (months)	Size of effect
Everink 2018 ⁵²	CSAL (0–100)	30	No statistical difference at any time	3	The mean difference between groups was 3.11 (95% CI –3.8 to 10.01), p=0.371
				9	The mean difference between groups was 1.54 (95% CI –7.29 to 10.37), p=0.730
Forster 2013 ⁶⁶	EQ-5D (–0.59–1)	596	No statistical difference	12	The mean difference between groups was 0 (95% CI –0.02 to 0.02), p=0.674
Kalra 2004 ⁷²	EuroQol VAS (0–100)	264	Improvement in quality of life at 3 months and one year	3	The median score was 80 (IQR 71 to 90) in the intervention group and 70 (IQR 60 to 80) in the comparator group, p=0.0001
				12	The median score was 80 (IQR 70 to 90) in the intervention group and 70 (IQR 60 to 80) in the comparator group, p=0.0001

Key: CSAL=Cantril's Self Anchoring Ladder, EuroQol VAS=EuroQol visual analogue scale, IQR=interquartile range, CI=confidence interval

Table 38: Patient satisfaction

Study	investigator developed questionnaire	Tool validated	Sample size	Results		
				Summary of results	Time (months)	Size of effect
Preen 2005 ⁷¹	Yes	No	128	There was an improvement in 4 questionnaire items. There was no statistical difference in the remaining 10 items	0.25	The percentage difference between intervention and comparator in satisfaction scores was 36.5% for satisfaction with level of patient input (p=0.02), 22.8% in comparison with prior discharge experiences (p=0.04), 10.1% in practicality of discharge plans (p=0.038) and 13.6% in importance of coordinating with GP (p=0.02). The p values of the remaining 10 items of the questionnaires ranged from 0.054 to 0.34
Laramie 2003 ⁵⁴	Yes	No	240	Improvement in satisfaction in 13 out of 16 questionnaire items	1	The mean satisfaction of total score questionnaire was 4.2 in intervention group and 3.8 in the comparator, p=0.003
Naylor 1999 ⁵⁶	Yes	No	262	No statistical difference	1	Only detail provided was p=0.92
Naylor 2004 ⁵⁷	Yes	No	181	Improvement in patient satisfaction at 2 and 6 weeks of follow up	0.5	The mean satisfaction score in the intervention was 83 (SD 10.3) and was 74.6 (SD 10.4) in the comparator group
					1.5	The mean satisfaction score in the intervention was 83.1 (SD 9.6) and was 77.8 (SD 11.2) in the comparator group

Key: GP= general practitioner, SD= standard deviation

Table 39: Caregiver burden

Study	Assessment tool	Self-rated assessme	Sample size	Result		
				Summary of result	Time (months)	Size of effect
Everink 2018 ⁵²	SRB-VAS (0–10)	Yes	30	Decrease in self rated burden at 3 months. No difference at 9 months	3	The mean difference between groups was –1.54 (95% CI –3.08 to 0) p=0.05
					9	The mean difference between groups was –1.54 (95% CI –3.25 to 0.17) p=0.077
	Erasmus iBMG	No	30	No statistical difference at any time	3	The mean difference between groups in hours spent performing domestic duties, personal care moving outside the house and number of hours spent providing informal care was –3.15, 0.54, –0.72, 0.67 and p values; 0.53, 0.65, 0.58, 0.5 respectively
					9	The mean difference between groups in hours spent performing domestic duties, personal care moving outside the house and number of hours spent providing informal care was –4.54, 2.99, 1.65, –1.92 and p values; 0.36, 0.47, 0.51, 0.68 respectively
Kalra 2004 ⁷²	CBS (22–88)	Yes	283	Improvement in caregiver burden at 3 and 12 months	3	The median score was 43 (IQR 36 to 54) in the intervention group and 51 (IQR 41 to 62) in the comparator group, p=0.0001
					12	The median score was 32 (IQR 27 to 41) in the intervention group and 41 (IQR 36 to 50) in the comparator group, p=0.0001
Kwok 2004 ⁶⁹	CCI (0–20)	Yes	110	No statistical difference	6	The mean score in the intervention was 0.20 (SD 5.30) and was 0.40 (SD 3.7) in the comparator group, p=0.794
Hirsch 2014 ⁷⁴	CBS FC (28–112)	Yes	28	No statistical difference	1	The mean score in the intervention group was 22.1 (SD 14.9) and was 16.1 (SD 10.6) in the comparator group, p=0.41
Forster 2013 ⁶⁶	CBS (22–88)	yes	665	No statistical difference at any time	6	The mean score in the intervention group was 45.5 and 45 in the comparator group, (95% CI –1.7 to 2.7), p=0.660
					12	The mean score in the intervention group was 44.4 and 43.8 in comparator group, (95% CI –1.6 to 3.6), p=0.435

Key: CBS=caregiver burden scale, CBSFC=burden scale for family caregivers, CCI=cost of care index, SRB- VAS=self-rated burden visual analogue scale, CI=confidence interval

Table 40: Readmission cost

Study	Calculated for all patient readmissions?	Results	Currency	Year	Time (months)	Size of effect	
Laramée 2003 ⁵⁴	Yes	No statistical difference	USD	2000	3	Total readmission cost per patient was \$15,417 in the intervention group and \$16,395 in the comparison group, p=0.82	
Naylor 1994 ⁵⁵	No. First readmission only	No statistical difference in surgical group. Improvement in readmission cost at 2 and 6 weeks. There was no difference at 12 weeks	USD	Not reported	0.5	Medical group	Total readmissions costs were \$170 248 less in the intervention group (95%CI –253 000 to –87 000)
					0.5–1.5		Total readmissions costs were \$137 508 less in the intervention group (95%CI –210 000 to –67 000)
					1.5–3		Total readmissions costs were \$130 960 more in the intervention group (95% CI –205 to 467)
					0.5	Surgical group	Total readmissions costs were \$6 548 more in the intervention (95% CI–43 to 56)
					0.5–1.5		Total readmissions costs were \$39 288 more in the intervention group (95% CI–66 to 144)
					1.5 - 3		Total readmissions costs were \$85 124 more in the intervention group (95% CI–28 to 198)
Naylor 1999 ⁵⁶	Yes	Decrease in total cost at six months	USD	1998	6	Total readmissions cost was \$427 217 in the intervention group and \$1 024 218 in the comparator group, p<0.001	
Naylor 2004 ⁵⁷	Yes	No statistical difference in total cost	USD	Not reported	12	Total cost of readmission in the intervention group was \$587 253 and \$1 065 927 in the comparator group, p=0.088	

Key: USD= United States Dollar, CI=confidence interval

Table 41: Outpatient resource use

Study	Doctors apt.	Allied health apt.	Home visits	Home equipment	Medication	Caregivers resource use	Comment	Sample size for sourced outcome	Instrument used to measure outcome	Method of reporting outcome	Results		
											Summary of results	Time (months)	Size of effect
Laramée 2003 ⁵⁴	Yes	Yes	Yes	No	No	No		234	Patients recorded outpatient resource in a self-kept logbook	Displayed as cost	No statistical difference	3	In the intervention, outpatient costs were \$1,552 vs \$1,307 USD in the control, p=0.28
Naylor 1994 ⁵⁵	Yes	Yes	Yes	No	No	No	Data includes ED visits and rehospitalisation as it is unable to be separated.	276	Actual patient charges and the documented visits by healthcare professionals in the intervention group	Displayed as cost	No statistical difference at any time	3	Unclear as data cannot be separated and authors stratified results by groups despite not recruiting participants this way
Naylor 1999 ⁵⁶	Yes	Yes	Yes	No	No	No		363	Self-reported by patient and collected by a research assistant over the phone	Displayed as visits and cost	No statistical difference at any time	6	There were 16.6 outpatient visits (SD 22.9) in the intervention 6 to 15.9 (SD 25.9) in the comparator group, p=0.77
Naylor 2004 ⁵⁷	Yes	Yes	Yes	No	No	No		239	Collected by research assistance by telephone interview with patients. This was confirmed with billing records	Displayed results as visits and cost (visit data is incomplete)	Increased home nursing use. No difference in other subgroups.	12	total difference in home visit cost was \$40,766 USD more in the intervention, p<0.01 , doctors' appointments were \$620 in the intervention p=0.64
Ohuabunwa 2013 ⁵⁸	Yes	?	?	No	No	No	Only outpatient primary care	104		Percentage of people	Significantly higher use	1	21.2% more people attended outpatient

							delivered by index hospital. It is unclear whether this include allied health and nursing services.		Patient bills incurred at index facility	who attended	up to 180 days following discharge. There was no difference at 1 year.		resources in the intervention group, $p<0.001$
												3	44.2% more people attended outpatient resources in the intervention group, $p<0.001$
												6	32.7% more people attended outpatient resources in the intervention group $p<0.001$
												12	17.3% more people attended outpatient resources in the intervention group, $p=0.07$
Gräsel 2005 ⁷⁰	Yes	Yes	Yes	No	Yes	No		62	Unclear whether it is self-reported or collected from patient records	Number and % of people who used the resource	Greater occupational therapy use at 6 months in the intervention group. No overall difference in outpatient care	6	28% more people in the intervention group uses OT compared to the comparator group
Forster 2013 ⁶⁶	Yes	Yes	Yes	Yes	Yes	Yes		928 dyads	Self-reported by patients and caregivers in diaries	Number of uses and cost	No difference at any time	0–6	Mean number of outpatient services was 3 (SD 4) in the intervention and 3 (SD 5) in the comparator
												6–12	Mean number of outpatient services was 3 (SD 2) in intervention and 3 (SD 3) in the comparator group

Key: SD=standard deviation, USD= United States Dollar

Table 42: Cost of intervention

Study	Currency	Year priced	Price/per person intended to treat	Real resource use by the intervention, if available
Abizanda 2011 ⁶²			unknown	
Gräsel 2005 ⁷⁰			unknown	
Hebel 2014 ⁷³			unknown	
Kitzman 2017 ⁶⁷			unknown	There were 7.13 encounters per patient, most performed over the phone
Ohuabunwa 2013 ⁵⁸			unknown	
Preen 2005 ⁷¹			unknown	
Santana 2017 ⁶⁴			unknown	
Shyu 2008 ⁵⁹			unknown	
Toles 2017 ⁶⁰			unknown	
Van Spall 2019 ⁶⁸			unknown	
Kwok 2004 ⁶⁹			unknown	Mean home visits 11.8 (SD 3.9, range 2–24) Mean nurse time per patient was 9.9 hours (SD 3.3, range 2.3–17.1 hours)
Hirsch 2014 ⁷⁴			unknown	The mean number of bedside training sessions was 5.2
Kalra 2004 ⁷²	Pounds	2001	150–285 ⁸¹	
Forster 2013 ⁶⁶	Pounds	2009	39	
Everink 2018 ⁵²	Euro	2014	77.60 ⁸⁰	
Naylor 1994 ⁵⁵	USD	Not reported	93.30	Patients received 4.8 personal visits and 2.5 telephone contacts
Coleman 2006 ⁶⁵	USD	Not reported	197.63	
Laramée 2003 ⁵⁴	USD	2000	228.52	Case managers spent an average of 6.7 hours per patient
Legrain 2011 ⁶³	Euro	2009	278	On average, doctors spent 231.6 minutes on each patient
Naylor 1999 ⁵⁶	USD	Not reported	348.02	
Wee 2014 ⁶¹	SGD	2010	469.51	This model of care required 16 care coordinators and 4 clinician leaders
Indredavik 2000 ⁵³	Euro	Not reported	569 ¹⁹⁷	
Naylor 2004 ⁵⁷	USD	Not reported. Used prices were indexed in 1998	981	

Key: USD=United States Dollar, SD=standard deviation, SGD=Singapore dollar

Table 43: Total cost estimates derived from non-formal cost analysis methods

Study	Resources considered				Comment	Data collection method						Results		
	Hospitalisation costs	Community care costs	Doctors apt	Informal care		Patient/caregiver logbook	HCP logbook	Patient interview	Self-reported data verified	Real cost data	Patient/administrative records	Summary of results	Time (months)	Effect size
Coleman 2006 ⁶⁵	Yes	No	No	No		No	Yes	No	No	No	Yes	180 day hospital data suggested decrease in cost in favour of intervention	6	Estimated total cost saving was \$295,594 USD over one year
Laramée 2003 ⁵⁴	Yes	Yes	Yes	No	Did not include specialist appointments	Yes	No	No	O	Yes	No	No statistical difference	3	Total cost per patient was \$23,054 in the intervention group and \$25,536 USD in the comparator group, p=0.39
Legrain 2011 ⁶³	Yes	No	No	No		No	No	Yes	Yes	No	No	Tertiary care was lower in intervention group at 6 months	6	€797 lower per patient in intervention group
Naylor 1994 ⁵⁵	Yes	Yes	Yes	No		No	Yes	Yes	No	Yes	No	No difference in surgical group. In medical group there is no difference at 2 and 12 weeks. At six weeks there was a decrease in total cost in the intervention group.	1.5	Total costs were \$295,598 USD less in the intervention in the medical group p=0.02 , total costs are not present for other point points or groups
Naylor 1999 ⁵⁶	Yes	Yes	Yes	No		No	No	Yes	?	Yes	Yes	Decrease in total cost of care over 24 weeks, largely due to decrease cost of readmissions	6	Total reimbursement costs were \$6 661 per patient in comparator and \$3,630 USD in intervention group, p<0.001
Naylor 2004 ⁵⁷	Yes	Yes	Yes	No		No	Yes	Yes	?	No	Yes	A decrease in total costs over one year in favour of the intervention. Largely caused by decreased readmission	52	Cost saving \$4,845 USD per patient over one year, p=0.002

												within first six months of indexed admission.		
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Key: Community care=allied health, nursing services and home services, HCP=healthcare professional, O=only when patient was recorded to be a poor historian, ?=unclear, USD=United States Dollar

Appendix 3 Risk of bias assessment

Table 44: Results of risk of bias assessment using ROBINS-I

Study	Outcome	Overall score	Bias due to confounding	Bias in selection of participants	Bias in classification of interventions	Bias due to deviations from intended intervention	Bias due to missing data	Bias in measurement of outcome	Bias in selection of reported result
Everink ⁵²	Caregiver quality of life	Serious risk	●	●	●	●	●	●	●
	Patient dependence in ADLs	Serious risk	●	●	●	●	●	●	●
	discharge destination	Serious risk	●	●	●	●	●	●	●
	Objective burden of caregiving	Serious risk	●	●	●	●	●	●	●
	Patient quality of life	Serious risk	●	●	●	●	●	●	●
	Performance in extended ADLs	Serious risk	●	●	●	●	●	●	●
	Patient Psychological wellbeing	Serious risk	●	●	●	●	●	●	●
	Self-rated burden of informal caregiving	Serious risk	●	●	●	●	●	●	●
Gräsel ⁷⁰	Patient care related complications	Serious risk	●	●	●	●	●	●	●
	Gait disturbance	Serious risk	●	●	●	●	●	●	●
	Gait speed/falls risk	Serious risk	●	●	●	●	●	●	●
	Health related quality of life	Serious risk	●	●	●	●	●	●	●
	Caregiver depression	Serious risk	●	●	●	●	●	●	●
	Length of stay	Serious risk	●	●	●	●	●	●	●

	Patient deterioration	Serious risk	●	●	●	●	●	●
	Patient function	Serious risk	●	●	●	●	●	●
	Outpatient resource use	Serious risk	●	●	●	●	●	●
	Subjective health complaints	Serious risk	●	●	●	●	●	●
Hebel ⁷³	Patient function	Critical risk	●	●	●	○	●	●
Hirsch ⁷⁴	Caregiver burden	Critical risk	●	●	●	○	●	●
	Caregiver depression	Critical risk	●	●	●	○	●	●
	Caregiver prostration	Critical risk	●	●	●	○	●	●
Kitzman ⁶⁷	Emergency department use	Critical risk	●	●	●	●	○	●
	Readmission	Critical risk	●	●	●	●	○	●
Oluabunwa ⁵⁸	Emergency department use	Critical risk	●	●	●	●	●	●
	Readmission	Critical risk	●	●	●	●	●	●
	Outpatient resource use	Critical risk	●	●	●	●	●	●
Shyu ⁵⁹	Caregiver discharge needs	Serious risk	●	●	●	○	●	●
	Objective caregiver preparedness	Serious risk	●	●	●	○	●	●
	Subjective caregiver preparedness	Serious risk	●	●	●	○	●	●
	Caregiver degree of perceived balance	Serious risk	●	●	●	○	●	●
Toles ⁶⁰	Quality of care transitions	Critical risk	●	●	●	●	●	●
	Healthcare professional satisfaction	Critical risk	●	●	●	●	○	●
Wee ⁶¹	Emergency department use	No information	●	●	●	○	●	●
	Readmission	No information	●	●	●	○	●	●

Table 45: Results of risk of bias assessment using Rob 2

Study	Outcome	Overall score	Bias due to randomisation	Bias in deviation from intended treatment	Bias due to missing data	Bias due to measurement of outcome	Bias in selection of reported results
Abizanda ⁶²	Patient confusion	Some concerns	●	●	●	●	●
	Patient function	Some concerns	●	●	●	●	●
Coleman ⁶⁵	Hospital costs	High risk	●	●	●	●	●
	Readmission	High risk	●	●	●	●	●
Forster ⁶⁶	Caregiver burden	High risk	●	●	●	●	●
	Caregiver quality of life	High risk	●	●	●	●	●
	Caregiver mood	High risk	●	●	●	●	●
	Cost to informal caregivers	High risk	●	●	●	●	●
	Patient function	High risk	●	●	●	●	●
	Patient independence	High risk	●	●	●	●	●
	Patient quality of life	High risk	●	●	●	●	●
	Patient quality adjusted life years	High risk	●	●	●	●	●
	Caregiver Quality adjusted life years	High risk	●	●	●	●	●
	Patient total costs	High risk	●	●	●	●	●
	Resource use	High risk	●	●	●	●	●
	Caregiver social restriction	High risk	●	●	●	●	●
Kwok ⁶⁹	Caregiver burden	High risk	●	●	●	●	●
	Patient disability	High risk	●	●	●	●	●
	Emergency department use	High risk	●	●	●	●	●
	Hospital days	High risk	●	●	●	●	●
	Patient psychological status	High risk	●	●	●	●	●
	Readmission	High risk	●	●	●	●	●
	Patient psychology	High risk	●	●	●	●	●
Laramée ⁵⁴	Patient adherence to medication	High risk	●	●	●	●	●

	Patient adherence to treatment	High risk	●	●	●	●	●
	Cost	High risk	●	●	●	●	●
	Patient satisfaction	High risk	●	●	●	●	●
	Length of stay	Low risk	●	●	●	●	●
	Length of stay on readmission	Low risk	●	●	●	●	●
	Readmission	Low risk	●	●	●	●	●
Legrain ⁶³	Cost	Low risk	●	●	●	●	●
	Emergency department use	Low risk	●	●	●	●	●
	Mortality	Low risk	●	●	●	●	●
	Readmission	Low risk	●	●	●	●	●
Naylor 1994 ⁵⁵	Hospital cost	High risk	●	●	●	●	●
	Length of stay	High risk	●	●	●	●	●
	Readmission	High risk	●	●	●	●	●
Naylor 1999 ⁵⁶	Hospitalisation cost	High risk	●	●	●	●	●
	Patient depression	High risk	●	●	●	●	●
	Acute service use	High risk	●	●	●	●	●
	Length of stay on readmission	High risk	●	●	●	●	●
	Readmission	High risk	●	●	●	●	●
	Patient function	High risk	●	●	●	●	●
	Patient satisfaction	High risk	●	●	●	●	●
	Time to first readmission	High risk	●	●	●	●	●
	Total cost	High risk	●	●	●	●	●
Naylor 2004 ⁵⁷	Patient quality of life	High risk	●	●	●	●	●
	Patient satisfaction	High risk	●	●	●	●	●
	Functional status	High risk	●	●	●	●	●
	Outpatient resource use	High risk	●	●	●	●	●
	Acute service use	High risk	●	●	●	●	●
	Readmission	High risk	●	●	●	●	●
	Time to readmission	High risk	●	●	●	●	●
	Total cost	High risk	●	●	●	●	●
Preen ⁷¹	General practitioner satisfaction	High risk	●	●	●	●	●
	Length of stay	High risk	●	●	●	●	●
	Patient satisfaction	High risk	●	●	●	●	●
	Patient quality of life	High risk	●	●	●	●	●
Santana ⁶⁴	Patient function	High risk	●	●	●	●	●
	Patient length of stay	High risk	●	●	●	●	●
Van spall ⁶⁸	Emergency department use	Some concerns	●	●	●	●	●

	Patient preparedness for discharge	High risk	●	●	●	●	●
	Quality of care transitions	High risk	●	●	●	●	●
	Patient quality of life	High risk	●	●	●	●	●
	Quality adjusted life years	High risk	●	●	●	●	●
	Readmission	Some concerns	●	●	●	●	●
Kalra ⁷²	Caregiver burden	High risk	●	●	●	●	●
	Caregiver function	High risk	●	●	●	●	●
	Caregiver mental health	High risk	●	●	●	●	●
	Caregiver quality of life	High risk	●	●	●	●	●
	Patient function	High risk	●	●	●	●	●
	Institutionalisation	High risk	●	●	●	●	●
	Patient mental health	High risk	●	●	●	●	●
	Mortality	High risk	●	●	●	●	●
	Patient quality of life	High risk	●	●	●	●	●
Indredavik ⁵³	Discharge destination	Low risk	●	●	●	●	●
	Patient function	High risk	●	●	●	●	●
	Mortality	Low risk	●	●	●	●	●

Appendix 4 Mixed methods study material

This appendix displays the tools and forms used for data collection in the mixed methods study. This includes consent form, questions, interview schedule and ethics approval. All documents here have received ethics approval for use and are presented here in the same format in which they received approval.



Participant information sheet

Bridging the Gap

Invitation

You are invited to participate in a research study at the Sydney Adventist Hospital. This involves a short questionnaire of approximately 15 minutes duration and one face-to-face interview, of approximately 40 minutes duration at a location of your choosing. The study is being conducted by Isabelle Meulenbroeks, under the supervision of an academic team at Macquarie University.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. 'What is the purpose of this study?'

To explore health professionals' (physiotherapists) experiences and perspectives when including informal caregivers into transitions for care for patients with geriatric syndrome.

2. 'Why have I been invited to participate in this study?'

You are eligible to participate in this study because you are a level 1-2 physiotherapist who has experience in including informal caregivers for patients with geriatric syndrome.

3. 'What if I don't want to take part in this study, or if I want to withdraw later?'

Participation in this study is entirely voluntary. It is completely up to you whether or not you participate. There are no consequences for non-participation. If you wish to withdraw from the study once it has started, you can do so within one week of the interview taking place.

4. 'What does this study involve?'

If you agree to participate in this study, you will be asked to complete an online questionnaire directly prior to an audio recorded, face-to-face interview lasting approximately forty minutes.



5. ‘How is this study being paid for?’

There is no funding for this study. It is being undertaken as part of an Master’s of Public Health project at Macquarie University.

6. ‘Are there risks to me in taking part in this study?’

There are no medical risks to participating in this study, it is simply an interview collecting information about your professional perspectives. Additionally, in order to safeguard your privacy, your name, address, or date of birth will not be included in the study.

7. ‘What happens if I suffer injury or complications as a result of the study?’

It is highly unlikely that you would suffer any injuries or complications as a result of this study

8. ‘Will I benefit from the study?’

This study aims to further knowledge of healthcare and may improve future implementation of new policies, guidelines to indirectly inform healthcare goals. However, at this stage it will not directly benefit you.

9. ‘Will taking part in this study cost me anything, and will I be paid?’

Participation in this study will not cost you anything, nor will you be reimbursed for participating in the study.

10. ‘How will my confidentiality be protected?’

Any personally identifiable information, such as your name and contact details will not be included in the study. The research database will be compiled without the use of personal identifiers. The database will be held securely at Macquarie University.

11. ‘What happens with the results?’

If you give us your permission by signing the consent document, we plan to publish collated themes in a peer reviewed journal article. In any publication, information will be analysed and presented in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

12. ‘What should I do if I want to discuss this study further before I decide?’

When you have read this information, the researcher Isabelle Meulenbroeks will be available to discuss with you any queries you might have. If you would like to know more at any stage, please do not hesitate to contact Isabelle Meulenbroeks at, Isabelle.Meulenbroeks@hdr.mq.edu.au.



14. 'Who should I contact if I have concerns about the conduct of this study?'

This study has been approved by Adventist HealthCare Limited HREC.

Any person with concerns or complaints about the conduct of this study should contact the Research Officer who is the person nominated to receive complaints from research participants. You should contact them on and quote the HREC project number IM0014.

Research Officer

Research Ethics & Governance Office

Adventist HealthCare Limited

Phone: (02) 94879604 or Email: ethics@sah.org.au

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.



Consent Form

Title:	Bridging the Gap
HREC Number:	IM0014
Coordinating Principal Investigator:	Dr Liz Schroeder
Student Researcher:	Isabelle Meulenbroeks
Location:	Sydney Adventist Hospital

Declaration by Participant

- I have read the Participant Information Sheet or someone has read it to me in a language that I understand.
- I understand the purposes, procedures and risks of the research described in the project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.
- I understand that I will be given a signed copy of this document to keep.

Do you wish to be contacted with details when research results are published?

Yes

No

Name of Participant (please print) _____	
Signature _____	Date _____
Witness _____	Date _____

Declaration by Study Doctor/Senior Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher [†] (please print) _____	
Signature _____	Date _____

[†] A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature



Demographics form for questionnaire

Demographics form	
Gender	Male/Female
Age	
Years of experience as a physiotherapist	
Number of previous workplaces	
Field of most experience	Orthopaedic/ general medicine/ rehabilitation/ ICU/ neurological/ other specify:_____

This form was given to participants on paper prior to the intervention. Participants could choose more than one field of most experience.

Questionnaire

The follow section displays the introduction provided to participants prior to the questionnaire, followed by the questions asked. The questionnaire and introduction were entered in Google Forms and participants responded using a tablet provided to them by the researcher immediately prior to the interview.

Introduction to questionnaire

The following questionnaire relates to patients with geriatric syndrome and their informal caregivers.

Patients with geriatric syndrome are typically characterised by cognitive and functional decline, falls, pressure ulcers and incontinence. These patients are frail and are at high risk of frequent readmissions, poor health outcomes and have a high mortality rate. Please answer the following questions within the context of this high-risk population.

Informal caregivers are people who provide aid without payment. This may be as infrequent as providing transport to providing twenty-four-hour care. These people are frequently family, but they may also be friends or neighbours. The terms caregiver and or informal caregiver in the questionnaire relate to this group of people.

Questionnaire								
Section one: Frequency of patient and caregiver engagement by you, the physiotherapist								
	Never	Monthly	Fortnightly	Weekly	Multiple times a week	Daily	Multiple times a day	Every patient
How often do you treat patients with geriatric syndrome?	1	2	3	4	5	6	7	8
How often do you communicate directly with informal caregivers for patients with geriatric syndrome? (e.g. in person or over the phone)	1	2	3	4	5	6	7	8
How often do you communicate indirectly with informal caregivers for patients? E.g. handouts or on white boards	1	2	3	4	5	6	7	8
How often do you set patient goals during the admission?	1	2	3	4	5	6	7	8
How often do you set goals in collaboration with the patient during the admission?	1	2	3	4	5	6	7	8
How often do you set goals in collaboration with the caregiver during the admission?	1	2	3	4	5	6	7	8
How often do you discuss/educate patients (directly or indirectly) about discharge, with regard to:								
Medications (e.g. timing with exercise or side effects such as orthostatic hypotension)	1	2	3	4	5	6		8
Exercises	1	2	3	4	5	6		8
Precautions/prevention (e.g. hip and sternal precautions, falls prevention)	1	2	3	4	5	6		8
Mobility status/assistance level	1	2	3	4	5	6		8
Mobility aids	1	2	3	4	5	6		8
Home exercise program/physiotherapy plan on discharge	1	2	3	4	5	6		8
Follow up	1	2	3	4	5	6		8
How often do you discuss/educate informal caregivers (directly or indirectly) about discharge, with regard to:								
Medications (e.g. timing with exercise or side effects such as orthostatic hypotension)	1	2	3	4	5	6	7	8
Exercises	1	2	3	4	5	6	7	8

Manual handling	1	2	3	4	5	6	7	8
Mobility status/assistance level	1	2	3	4	5	6	7	8
Mobility aids	1	2	3	4	5	6	7	8
Precautions/prevention	1	2	3	4	5	6	7	8
Home exercise program/physiotherapy plan on discharge	1	2	3	4	5	6	7	8
Follow up	1	2	3	4	5	6	7	8

Section two: How often does the multidisciplinary team include informal caregivers								
	Never	Monthly	Fortnightly	Weekly	Multiple times a week	Daily	Multiple times a day	Every patient encounter
How often do you ask about the presence of an informal caregiver in your initial assessment?	1	2	3	4	5	6	7	8
How often do you expect someone else in the multidisciplinary team would ask about the presence of an informal caregiver?	1	2	3	4	5	6	7	8
How often would you ask if the informal caregiver is prepared to return to caregiving after discharge?	1	2	3	4	5	6	7	8
How often do you expect someone else in the multidisciplinary team would ask if the informal caregiver is prepared to return to caregiving at discharge?	1	2	3	4	5	6	7	8
How often is the estimated date of discharge and destination visible for patients and caregivers?	1	2	3	4	5	6	7	8
How often do you discuss the estimate of discharge and/or destination with patients?	1	2	3	4	5	6	7	8
How often do you discuss the estimated date of discharge and/or destination with caregivers?	1	2	3	4	5	6	7	8
From your perspective, how often does someone else in the multidisciplinary team discuss estimated date of discharge and destination with the patient and/or caregiver?	1	2	3	4	5	6	7	8
How often are patients included in multidisciplinary team meetings?	1	2	3	4	5	6	7	8
How often are informal caregivers included in multidisciplinary team meetings?	1	2	3	4	5	6	7	8
How often do you inform patients of multidisciplinary team meeting outcomes?	1	2	3	4	5	6	7	8
How often do you report of multidisciplinary team meeting outcomes to informal caregivers?	1	2	3	4	5	6	7	8
From your perspective, how often would someone else within the multidisciplinary team report team meeting outcomes to patients and/or informal caregivers?	1	2	3	4	5	6	7	8

Section three: your perceptions of caregiver engagement in your practice and by the multidisciplinary team									
	Never			Sometimes			Always		
How often do you feel that informal caregivers want to be included in discharge planning for patients with geriatric syndrome?	1	2	3	4	5	6	7	9	10
In your opinion, how often should informal caregivers be included into discharge planning by the multidisciplinary team?	1	2	3	4	5	6	7	9	10
In your opinion, how often should physiotherapists include the informal caregiver into discharge planning?	1	2	3	4	5	6	7	9	10
How often do you feel patient engagement in discharge planning by the multidisciplinary team meets the patient's expectation?	1	2	3	4	5	6	7	9	10
How often do you feel caregiver engagement in discharge planning by the multidisciplinary meets the caregiver's expectation?	1	2	3	4	5	6	7	9	10
Do you feel that you include the patient in discharge planning sufficiently to meet your definition of good practice? How often?	1	2	3	4	5	6	7	9	10
Do you feel that you include the informal caregiver in discharge planning sufficiently to meet your definition of good practice? How often?	1	2	3	4	5	6	7	9	10

Section four: Your perceptions and knowledge									
	Strongly disagree			Neutral			Strongly agree		
I have received training about caregiver engagement	1	2	3	4	5	6	7	9	10
I am aware of institutional policies regarding caregivers	1	2	3	4	5	6	7	9	10

I am aware of professional code of conduct and Australian laws which mandate caregiver inclusion, where appropriate	1	2	3	4	5	6	7	9	10
I am confident I know when it is appropriate to include caregivers into discharge planning	1	2	3	4	5	6	7	9	10
I am confident I know how best to include caregivers into discharge planning	1	2	3	4	5	6	7	9	10
I feel that I include informal caregivers in discharge planning as often as is appropriate	1	2	3	4	5	6	7	9	10
I feel that physiotherapists at my institution include informal caregivers as often as is appropriate	1	2	3	4	5	6	7	9	10
I feel that the multidisciplinary team includes informal caregivers in discharge planning as often as is appropriate	1	2	3	4	5	6	7	9	10

Interview schedule

Interview schedule	
Introduction	
<p>Thank you for agreeing to participate in this survey. This survey aims to collect information on factors that impact on including family caregivers into transitions of care for people with geriatric syndrome. Your responses will provide us with a greater understanding of ways to improve care transitions. All of your responses will be kept confidential on a secure server and you will not be identified based on the information you provide.</p> <p>In this interview, I would like you to consider a population of people with geriatric syndrome. In this context I define Geriatric syndrome as the term used to describe symptoms that are related to ageing and which do not fit under a specific disease. Some of the symptoms included in this syndrome are cognitive decline, functional decline, falls and urinary incontinence. This patient group often has frequent readmissions, falls, poor health outcomes and can be dependent and frail with many patients considered high risk, or at the high-end spectrum for geriatric syndrome. Before I continue, would you like any further clarification about the patient group we are discussing?</p> <p>Throughout this interview I will be asking questions about the informal caregivers of patients with geriatric syndrome. Informal caregivers or family caregivers are people who aid these patients without payment. This may be as infrequent as assisting the patient with groceries to as frequent as providing twenty-four-hour care. This may include activities such as assisting with community access, medication management, wound dressing or with activities of daily living.</p> <p>Today I would like to talk about informal caregiver engagement in transitions of care, in particular discharge planning between hospital and community for patients with high risk geriatric syndrome. As you will be aware, preparation for patient discharge may include education, equipment prescription, exercise program, prevention etc.</p> <p>Do you have any questions before we begin?</p>	
Questions	Leading questions to ensure consistency (number and selection of prompts is based on the participants answer)
What is your experience engaging informal caregivers in transitions of care?	<ul style="list-style-type: none"> • Have you had much experience including caregivers into transitions of care? • When would you include caregivers into transitions of care? <ul style="list-style-type: none"> ○ If yes, how would you include caregivers into transitions of care? • Do you feel that you include caregivers often enough to meet the caregivers needs? <ul style="list-style-type: none"> ○ Why? Or why not?

	<ul style="list-style-type: none"> What do you think the informal carers want? Are they included according to their preferences? too much or too little?
What is an example/s of a positive experience you have had whilst including caregivers?	<ul style="list-style-type: none"> What made this situation go well? Would you use/have you used this factor again? Do you feel there is anything you do well in your practice which influences a positive experience/outcome? Do you feel that there is anything the institution does that influences/causes your positive experience/outcome? Do you feel that is anything the health system does that influences/causes your positive experience?
What is an example/s of a negative experience you have had whilst including informal caregivers?	<ul style="list-style-type: none"> What made this situation go badly? Could anything be done to change the bad experience of carer integration into transitions of care? For example, system changes, institutional changes or personal changes Do you feel there is anything you do poorly in your practice which influences a negative experience/outcome? Do you feel that there is anything the institution does that influences/causes your negative experience/outcome? Do you feel that is anything the health system does that influences/causes your negative experience?
Do you feel that the physiotherapists should be including informal caregivers in discharge planning/transitions of care?	Prompts in response to positive themes: <ul style="list-style-type: none"> Why? How should physiotherapists include caregivers? When and how often should this occur?
	Prompts in response to negative themes: <ul style="list-style-type: none"> Why? Should including the caregiver be someone else's responsibility?
For the final section of our interview, I want to get your opinion on what you think discharge planning should look like for patients with high end geriatric syndrome.	
Do supports need to be established for successful discharge planning?	<ul style="list-style-type: none"> For example, policy or education What supports need to be established? And who should be responsible for this? Should these supports consider informal caregivers? Are you aware of any pre-existing policy, guidelines or education regarding discharge planning? <ul style="list-style-type: none"> Do you know if these structures consider the caregiver?
	In response to positive themes:

Should informal carers be included at patient admission/preadmission?	<ul style="list-style-type: none"> • What should be happening at this point to prepare for transition of care/discharge? • What is the role of the physiotherapist at this stage? • Should caregivers be included in this stage of discharge planning? • How should caregivers be included in discharge planning at this stage?
Prompt: if yes, how? And by whom?	<p>In response to negative themes:</p> <ul style="list-style-type: none"> • What should the multi-disciplinary team be doing at patient admission? • What should physiotherapists be doing at patient admission?
Should discharge planning take place during the inpatient stay?	<ul style="list-style-type: none"> • What should the multi-disciplinary team be doing to conduct discharge planning? • Does the physiotherapists role in discharge planning? <ul style="list-style-type: none"> ○ If yes, <ul style="list-style-type: none"> ▪ What does this role look like? ○ If no: <ul style="list-style-type: none"> ▪ Why? • Should informal caregivers be included in this process? <ul style="list-style-type: none"> ○ Why or Why not? ○ If yes: <ul style="list-style-type: none"> ▪ How should informal caregivers be included in this process by the multidisciplinary team? ▪ What role do you feel you have, as a physiotherapist, in informal caregiver engagement? ○ If no: <ul style="list-style-type: none"> ▪ Is it ever appropriate to include informal caregivers into discharge planning? ▪ Whose role is it to include informal caregivers? ▪ What role do you feel you have, as a physiotherapist, in including informal caregivers?
What actions or steps do you think are necessary for a well performed patient discharge when patients are ready to leave the facility?	<ul style="list-style-type: none"> • What steps/actions are appropriate/performed by the multidisciplinary team? • What actions/steps do you feel are appropriate, as a physiotherapist, prior to patient discharge? • Should informal caregivers be included in these steps? <ul style="list-style-type: none"> ○ Who do you think should be including the informal caregiver?

	<ul style="list-style-type: none"> ○ Do you feel, as a physiotherapist, you have a role in including informal caregivers? ▪ If yes; how?
Should informal caregivers be involved in organising patient follow-up or treatment plan?	<ul style="list-style-type: none"> • Why or why not? • If yes; <ul style="list-style-type: none"> ○ whose responsibility is it to include informal caregivers? ○ Do you feel that you have a responsibility to include informal caregivers in follow-up plans? <ul style="list-style-type: none"> ▪ How would you as a physiotherapist, include informal caregivers in this process
Is there anything we have missed?	<ul style="list-style-type: none"> • Do you have any final comments or thoughts about what we have discussed?

Pages 184 - 185 of this thesis have been removed as
may contain sensitive/confidential content

Appendix 5 Mixed method study results

1. Summary statistics for questionnaire responses

Table 46: Summary statistics for responses to sections 1 and 2 of questionnaire

	Mean	Standard deviation	Meaning
1. How often do you treat patients with geriatric syndrome?	6.36	1.29	Closer to daily (6) than multiple times a day (7)
2. How often do you communicate directly with informal caregivers (in person or over the phone) for patients with geriatric syndrome?	4.55	1.29	Between Weekly (4) and multiple times a week (5)
3. How often do you communicate indirectly (handouts, whiteboards etc.) with informal caregivers for patients with geriatric syndrome?	6.00	1.79	Daily (6)
4. How often do you set patient goals during the admission?	6.64	1.75	Closer to multiple times a day (7) than Daily (6)
5. How often do you set goals in collaboration with the patient during the admission?	6.00	1.41	Daily (6)
6. How often do you set goals in collaboration with the informal caregiver during the admission?	3.91	1.58	Closer to weekly (4) than fortnightly (3)
7. How often do you discuss/educate patients (directly or indirectly) about discharge medications? (e.g. timing with exercise or side effects such as orthostatic hypotension)	5.00	1.95	Multiple times a week (5)
8. How often do you discuss/educate patients (directly or indirectly) about discharge exercises?	6.00	1.90	Daily (6)
9. How often do you discuss/educate patients (directly or indirectly) about discharge precautions/prevention? (e.g. hip and sternal precautions, falls prevention)	6.36	1.43	Closer to daily (6) than multiple times a day (7)
10. How often do you discuss/educate patients (directly or indirectly) about discharge mobility status/assistance level?	6.55	1.51	Between daily (6) and multiple times a day (7)
11. How often do you discuss/educate patients (directly or indirectly) about discharge mobility aids?	6.36	1.36	Closer to daily (6) than multiple times a day (7)

12. How often do you discuss/educate patients (directly or indirectly) about discharge home exercise program?	5.73	1.74	Closer to daily (6) than multiple times a week (5)
13. How often do you discuss/educate patients (directly or indirectly) about follow up?	5.27	1.79	Closer to multiple times a week (5) than daily (6)
14. How often do you discuss/educate informal caregivers (directly or indirectly) about discharge medications? (e.g. timing with exercise or side effects such as orthostatic hypotension)	3.82	1.47	Closer to weekly (4) than fortnightly (3)
15. How often do you discuss/educate informal caregivers (directly or indirectly) about discharge exercises?	5.00	1.95	Multiple times a week (5)
16. How often do you discuss/educate informal caregivers (directly or indirectly) about discharge precautions/prevention? (e.g. hip and sternal precautions, falls prevention)	5.00	1.67	Multiple times a week (5)
17. How often do you discuss/educate informal caregivers (directly or indirectly) about manual handling?	4.73	1.68	Closer to multiple times a week (5) than weekly (4)
18. How often do you discuss/educate informal caregivers (directly or indirectly) about discharge mobility status/assistance level?	5.27	1.49	Closer to multiple times a week (5) than daily (6)
19. How often do you discuss/educate informal caregivers (directly or indirectly) about discharge mobility aids?	5.27	1.68	Closer to multiple times a week (5) than daily (6)
20. How often do you discuss/educate informal caregivers (directly or indirectly) about discharge home exercise program?	5.00	1.79	Multiple times a week (5)
21. How often do you discuss/educate informal caregivers (directly or indirectly) about follow up?	4.82	1.83	Closer to Multiple times a week (5) than weekly (4)
Section two: frequency of caregiver engagement by the multidisciplinary team			
22. How often do you ask about the presence of an informal caregiver in your initial assessment?	4.64	2.34	Closer to multiple times a week (5) than weekly (4)
23. How often do you expect someone else in the multidisciplinary team would ask about the presence of an informal caregiver?	5.64	2.16	Closer to daily (6) than multiple times a week (5)
24. How often would you ask if the informal caregiver is prepared to return to caregiving after discharge?	4.09	2.17	Weekly (4)

25. How often do you expect someone else in the multidisciplinary team would ask if the informal caregiver is prepared to return to caregiving at discharge?	5.36	1.43	Closer to multiple times a week (5) than daily (6)
26. How often is the estimated date of discharge and destination visible for patients and caregivers?	6.36	1.03	Closer to daily (6) than multiple times a day (7)
27. How often do you discuss the estimated of discharge and/or destination with patients?	5.45	1.63	Between multiple times a week (5) and daily (6)
28. How often do you discuss the estimated of discharge and/or destination with informal caregivers?	4.45	1.69	Between weekly (4) and multiple times a week (5)
29. From your perspective, how often does someone else in the multidisciplinary team discuss estimated date of discharge and destination with the patient and/or caregiver?	5.55	1.51	Between multiple times a week (5) and daily (6)
30. How often are patients included in multidisciplinary team meetings?	2.73	2.10	Closer to fortnightly (3) than monthly (2)
31. How often are informal caregivers included in multidisciplinary team meetings?	2.64	2.01	Closer to fortnightly (3) than monthly (2)
32. How often do you inform patients of multidisciplinary team meeting outcomes?	4.45	1.86	Between weekly (4) and multiple times a week (5)
33. How often do you inform informal caregivers of multidisciplinary team meeting outcomes?	4.09	2.30	weekly (4)
34. From your perspective, how often would someone else within the multidisciplinary team report team meeting outcomes to patients and/or informal caregivers?	5.18	1.54	Closer to multiple times a week (5) than daily (6)

Table 47: Summary statistics for responses to section 3 of questionnaire

Questions	Mean	Standard deviation
35. In your opinion, how often should informal caregivers be included into discharge planning by the multidisciplinary team?	9.73	0.47
36. How often do you feel that informal caregivers want to be included in discharge planning for patients with geriatric syndrome?	9.18	0.87
37. In your opinion, how often should physiotherapists include the informal caregiver into discharge planning?	9.36	0.81

38. How often do you feel patient engagement in discharge planning by the multidisciplinary team meets the patient's expectation?	7.18	1.47
39. How often do you feel caregiver engagement in discharge planning by the multidisciplinary meets the caregiver's expectation?	7.00	2.05
40. Do you feel that you include the patient in discharge planning sufficiently to meet your definition of good practice? How often?	8.27	1.62
41. Do you feel that you include the informal caregiver in discharge planning sufficiently to meet your definition of good practice? How often?	7.00	2.41

Table 48: Summary statistics for responses to section 4 of questionnaire

Statement	Mean	Standard deviation
42. I have received training about caregiver engagement	4.73	2.76
43. I am aware of institutional policies regarding caregivers	4.09	2.47
44. I am aware of professional code of conduct and Australian laws which mandate caregiver inclusion, where appropriate	4.09	1.92
45. I am confident I know when it is appropriate to include caregivers into discharge planning	7.64	2.01
46. I am confident I know how best to include caregivers into discharge planning	6.73	2.28
47. I feel that I include informal caregivers in discharge planning as often as is appropriate	7.18	2.32
48. I feel that physiotherapists at my institution include informal caregivers as often as is appropriate	6.45	2.73
49. I feel that the multidisciplinary team includes informal caregivers in discharge planning as often as is appropriate	7.00	2.32

2. Graphs for questionnaire responses

Figure 11: Q1. How often do you treat patients with geriatric syndrome?

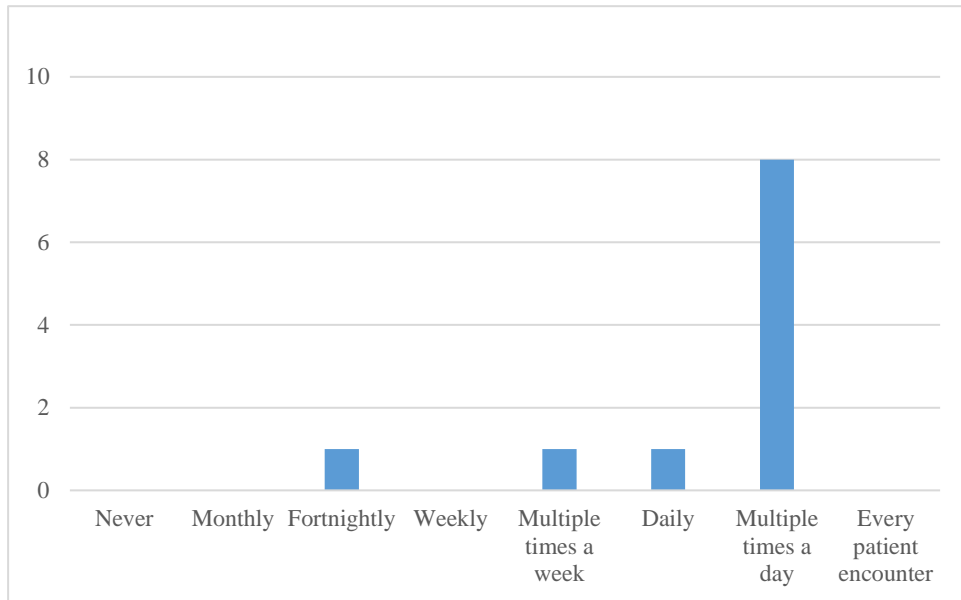


Figure 12: Q2-3. How often do you communicate with informal caregivers for patients with geriatric syndrome?

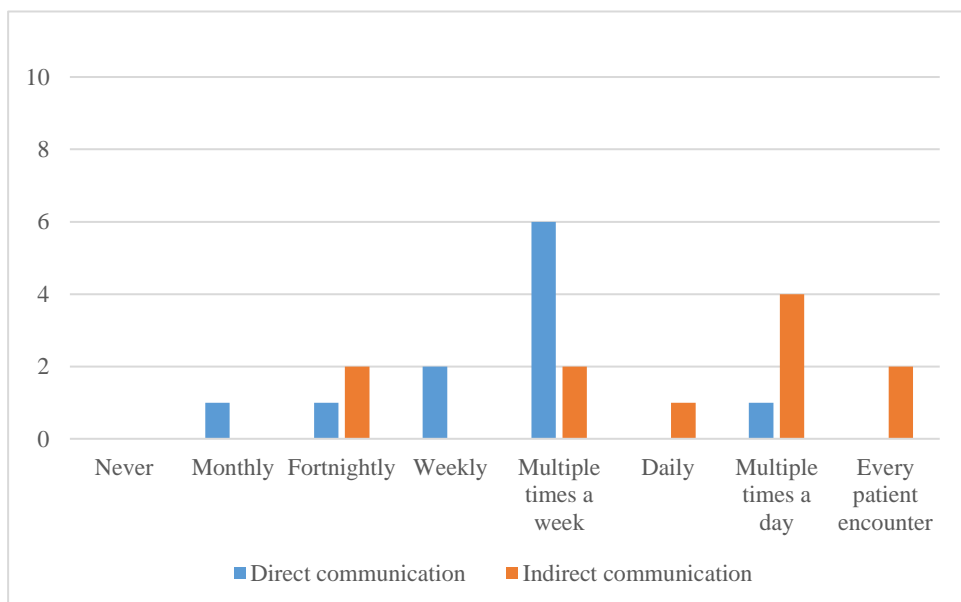


Figure 13: How often do you set patient goals during the admission?

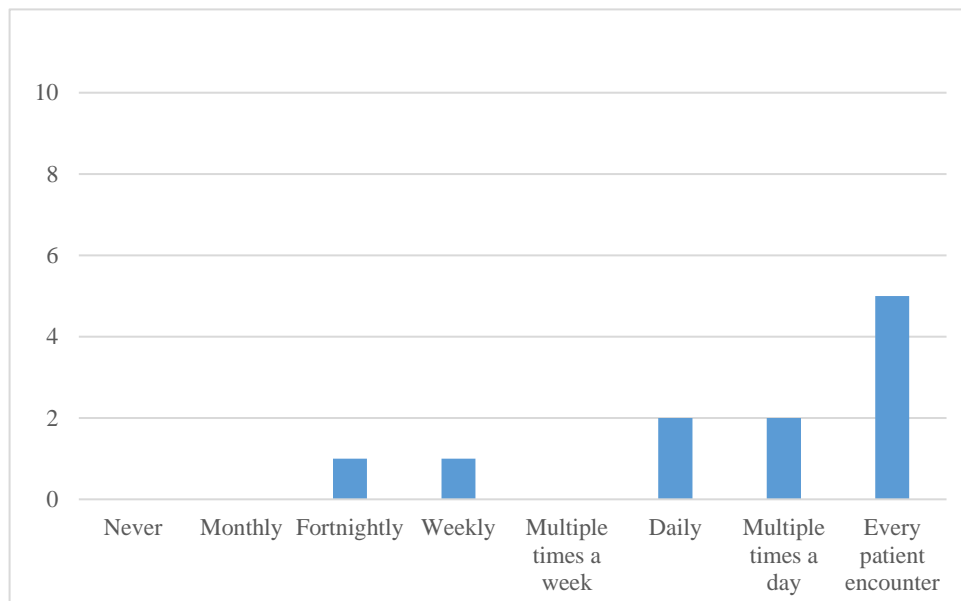


Figure 14: Q5-6. How often do you set goals with the patient or caregiver during the admission?

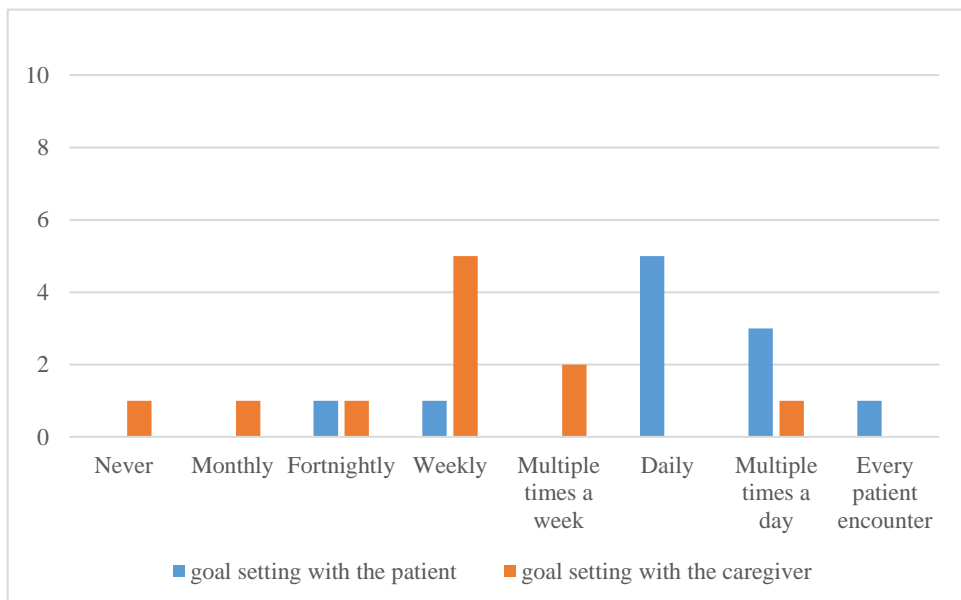


Figure 15: Q7-13. How often do you discuss/educate patients about the following? (directly and indirectly)

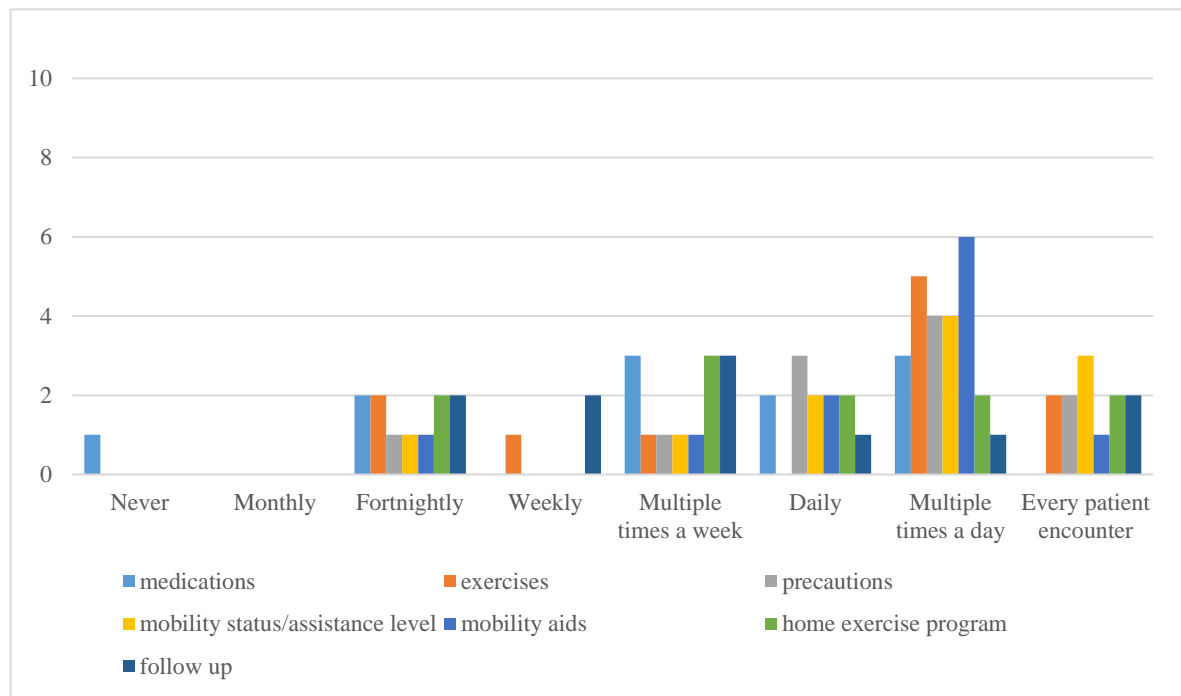


Figure 16: Q14-21. How often do you discuss educate caregivers about the following? (directly and indirectly)

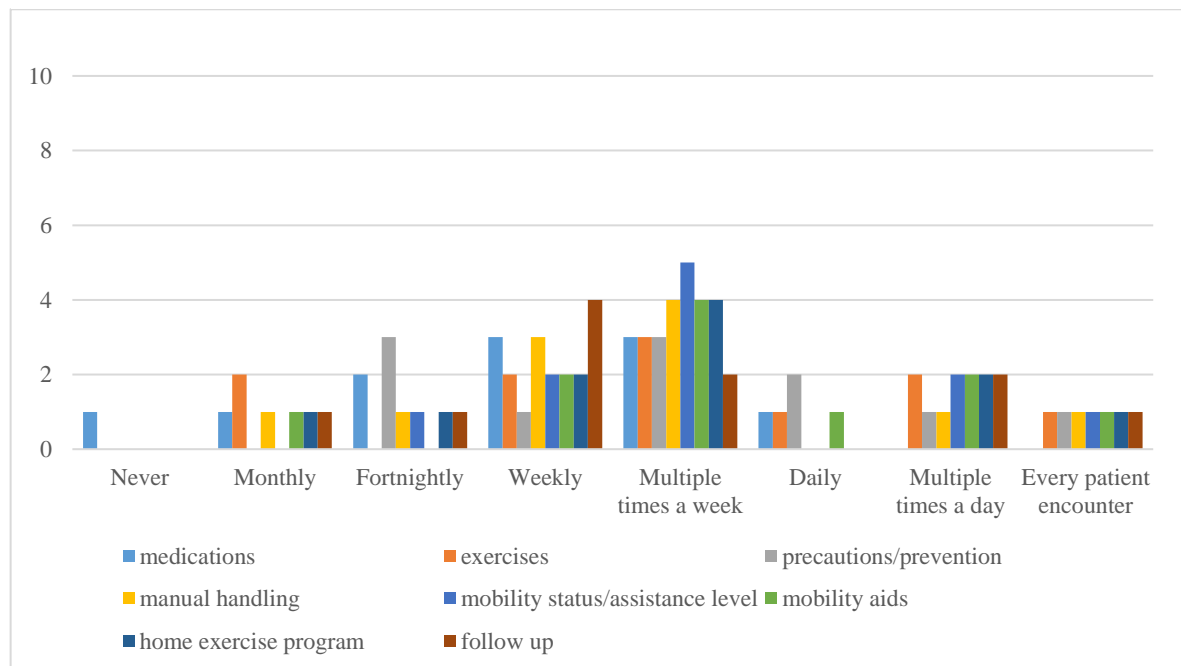


Figure 17: Q22. How often do you ask about the presence of an informal caregiver in your initial assessment?

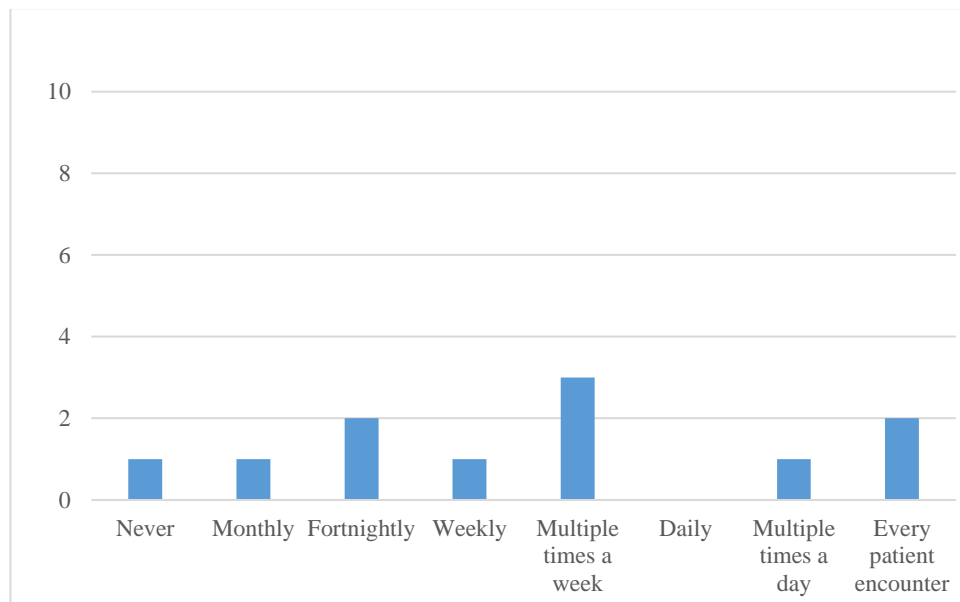


Figure 18: Q23. How often do you expect someone else in multidisciplinary team would ask about the presence of an informal caregiver?

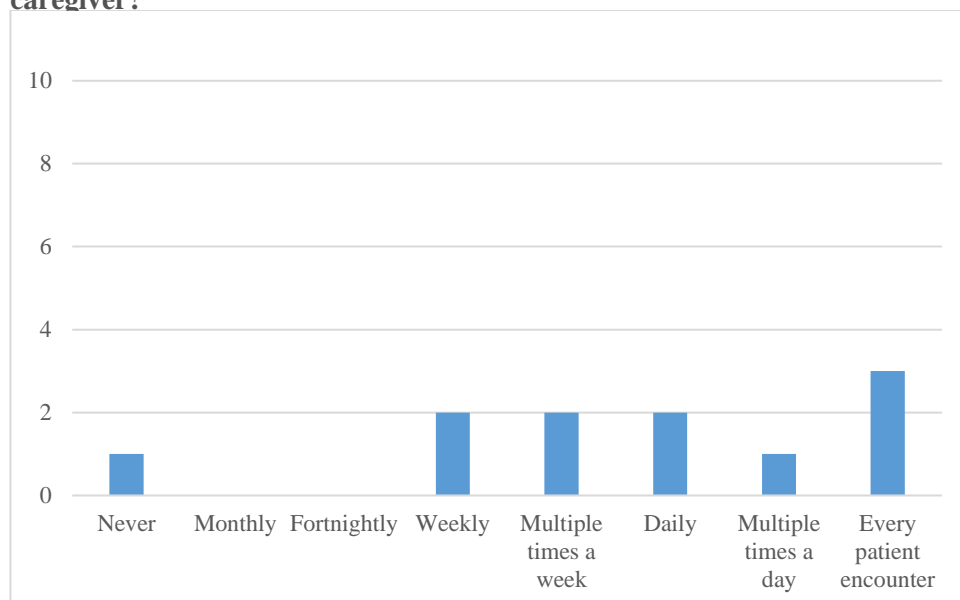


Figure 19: Q24. How often would you ask if the informal caregiver is prepared to return to caregiving after discharge?

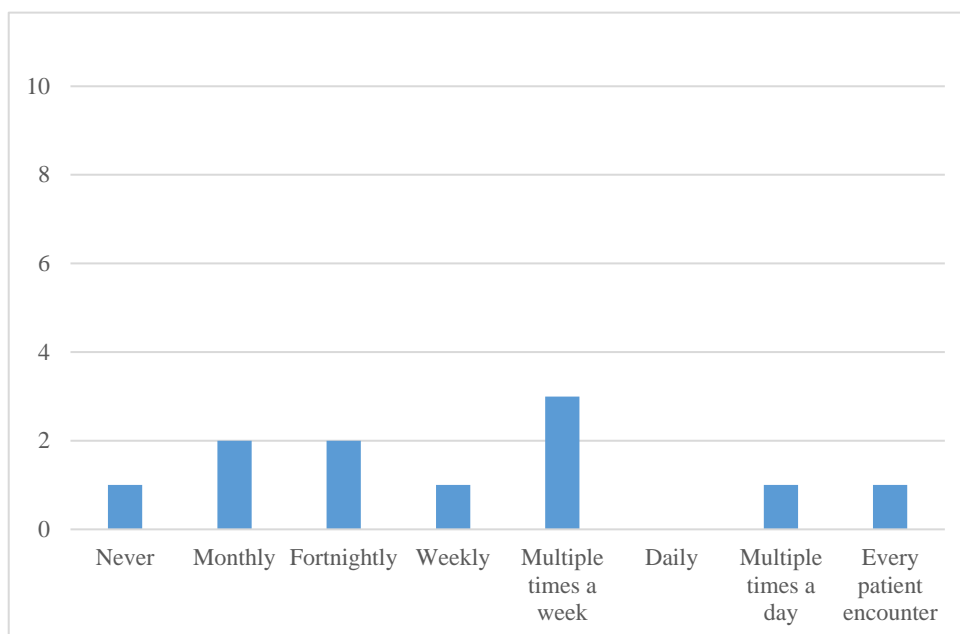


Figure 20: Q25. How often would someone else in the multidisciplinary team ask if the caregiver is prepared to return to caregiving?

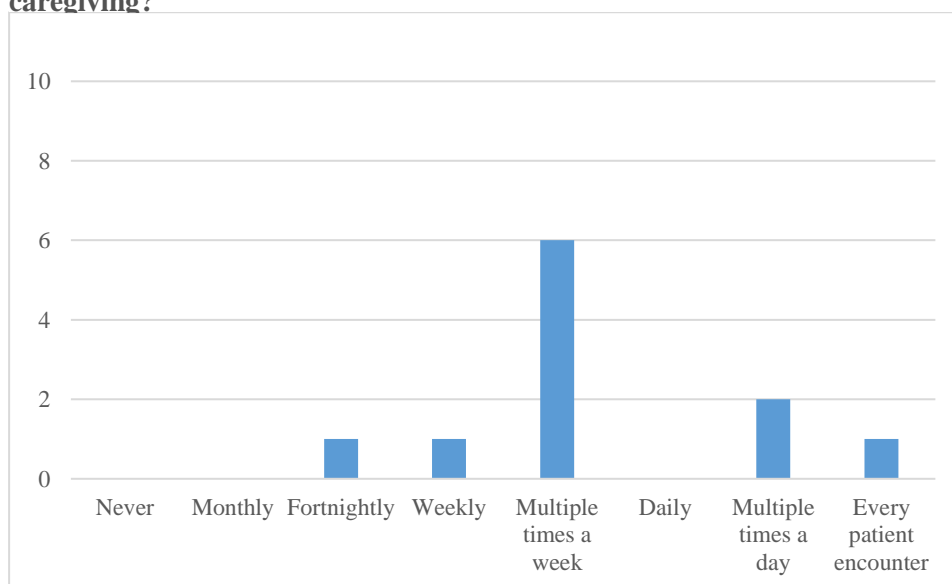


Figure 21: Q26. How often is the estimated date of discharge visible to patients and caregivers?

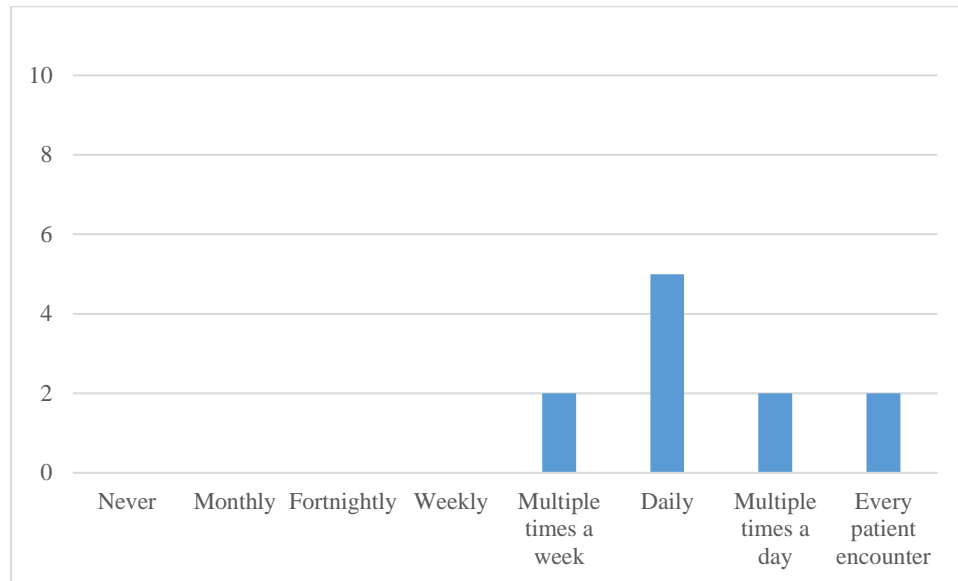


Figure 22: Q27-28. How often would you discuss the estimated date of discharge with patients and caregivers?

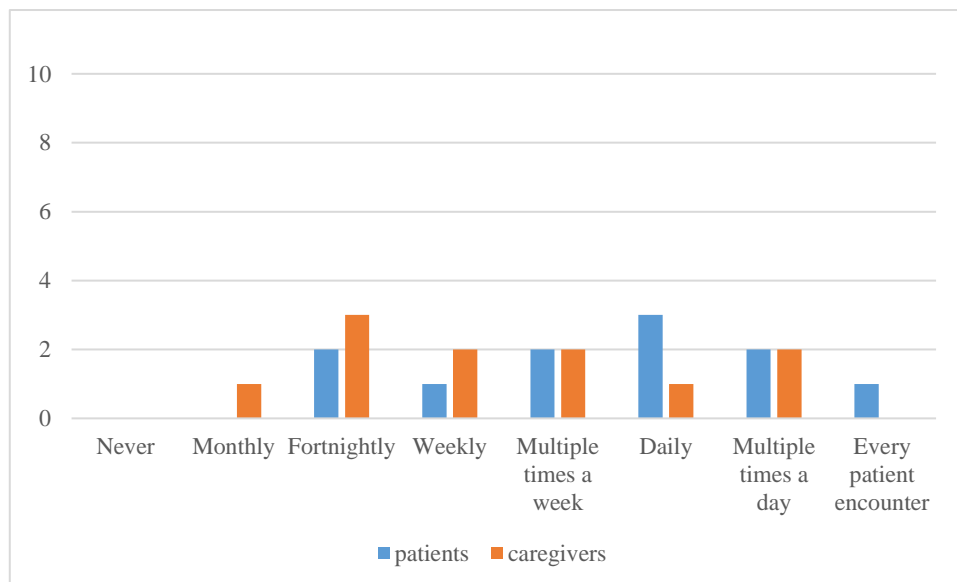


Figure 23: Q29. How often do you think someone else in the team discuss estimated date or discharge with the patient and/or caregiver?

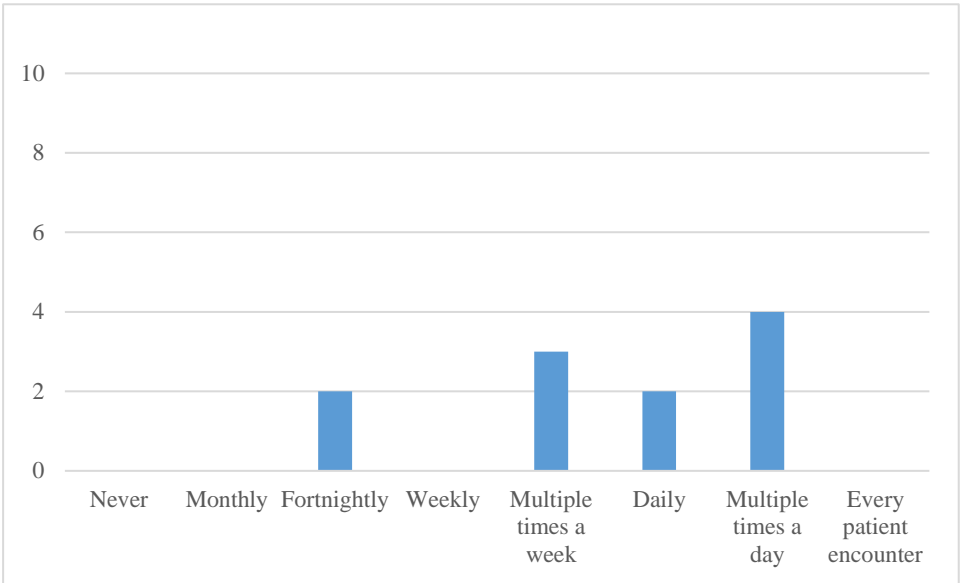


Figure 24: Q30-31. How often are patients and caregivers included in multidisciplinary team meetings?

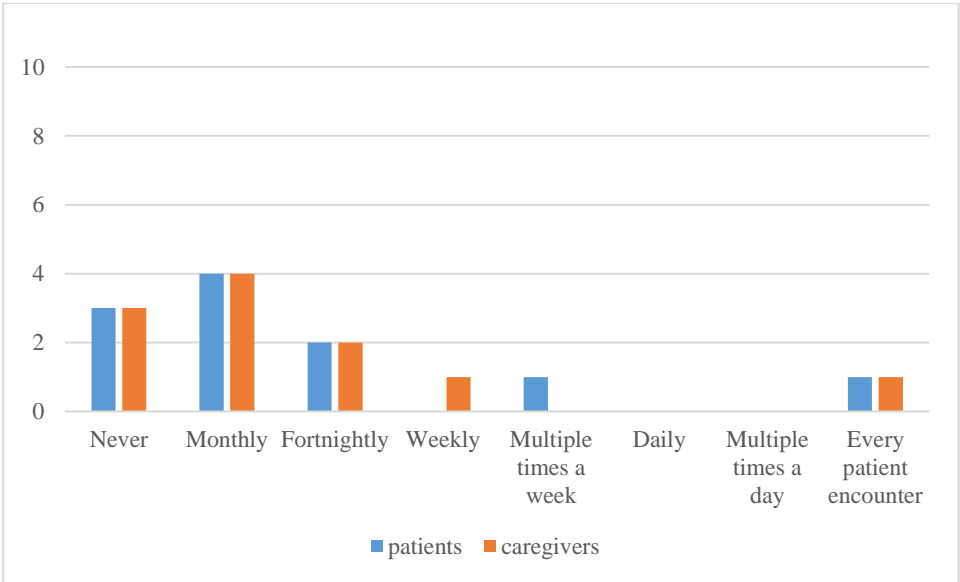


Figure 25: Q32-33. How often do you inform patients and caregivers about multidisciplinary team meeting outcomes?

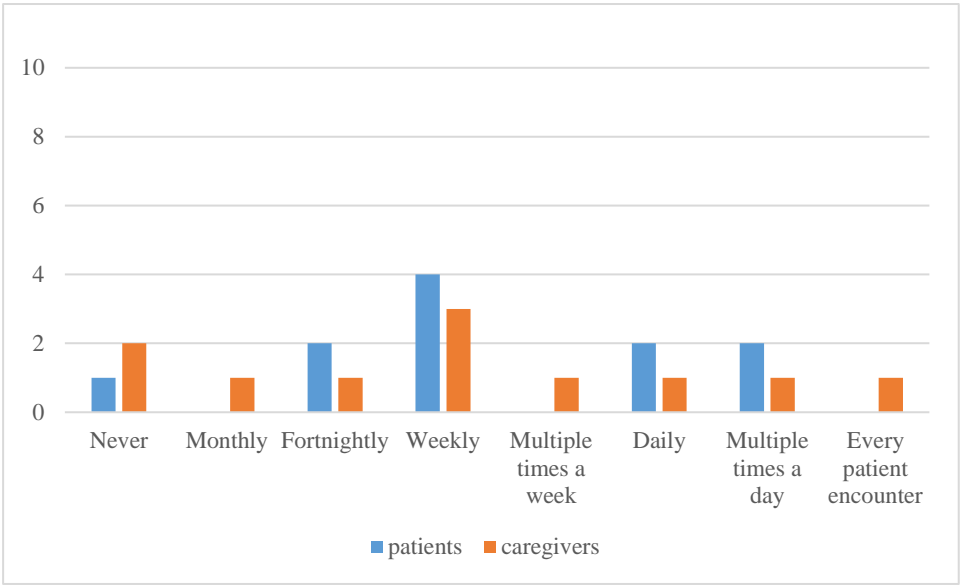


Figure 26: Q34. How often would someone else in the multidisciplinary team report team meeting outcomes to patients and caregivers?

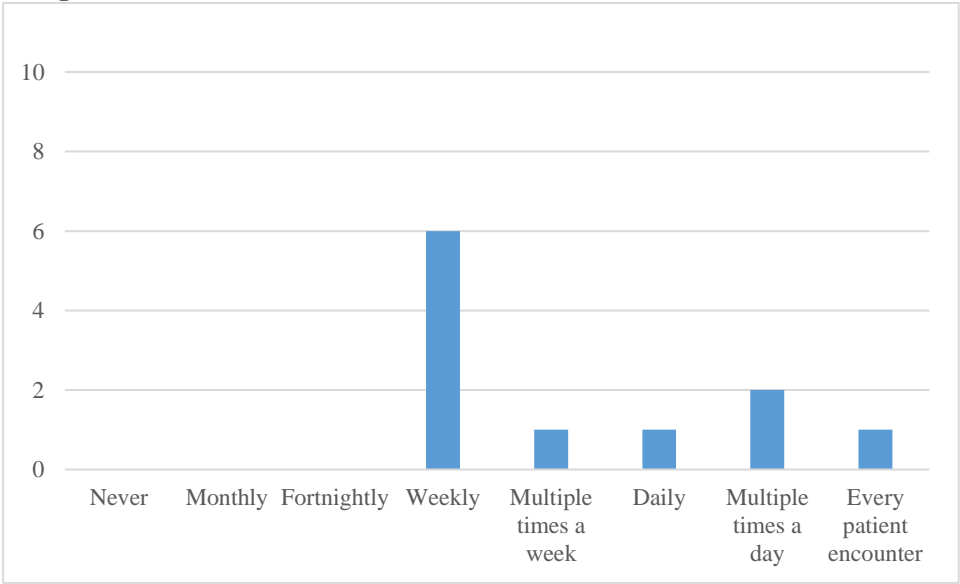


Figure 27: Q35. How often do you think informal caregivers should be included by the multidisciplinary team?

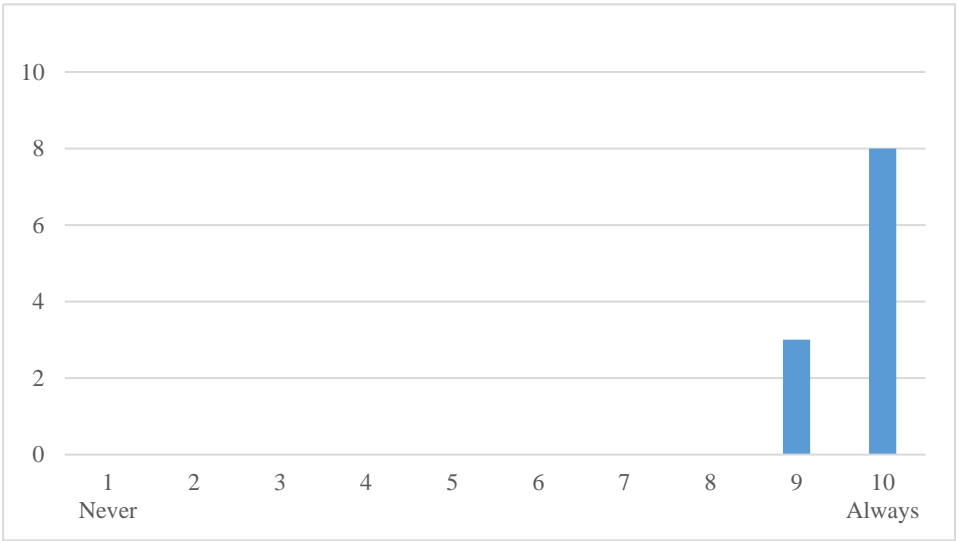


Figure 28: Q 36. How often do you feel that informal caregivers want to be included in discharge planning?

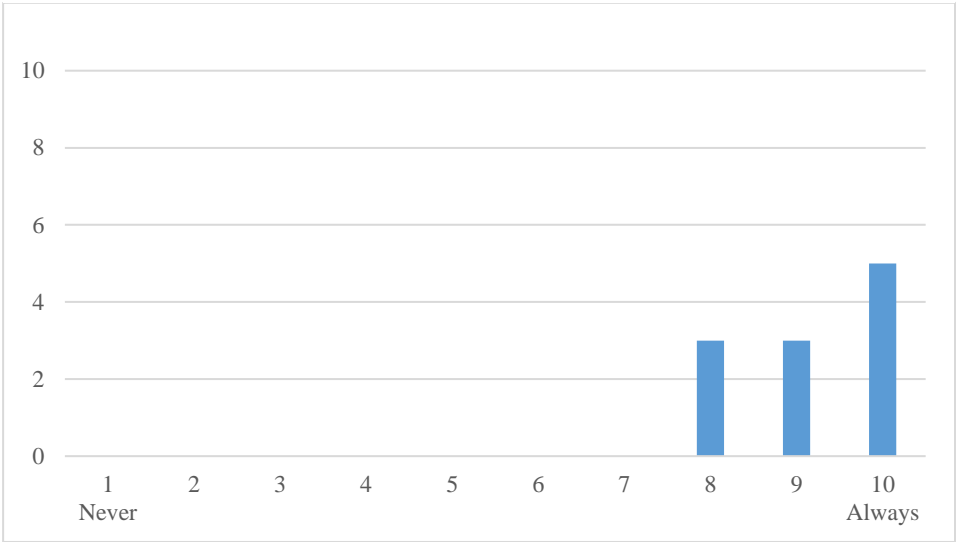


Figure 29: Q37. How often should physiotherapist include informal caregivers in discharge planning?

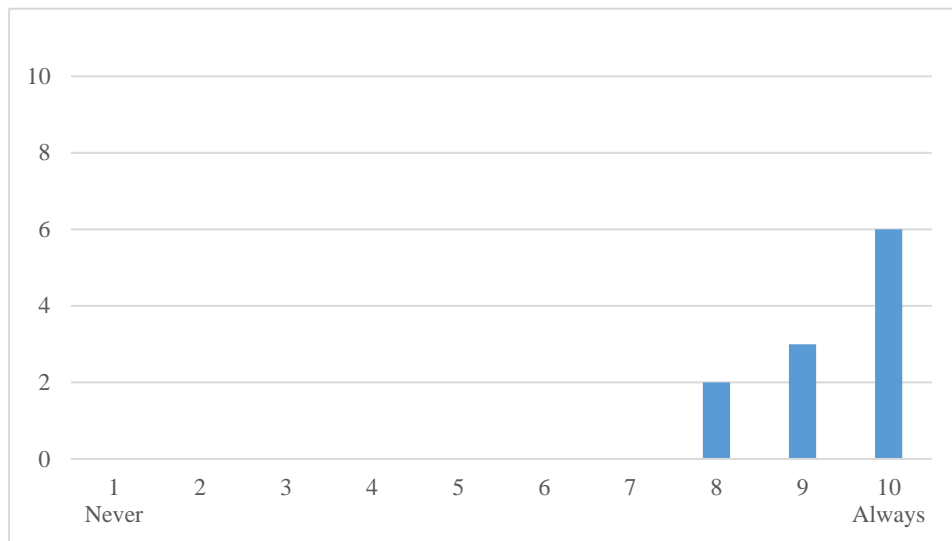


Figure 30: Q38-39. How often does patient/caregiver engagement meet patient and caregiver expectations?

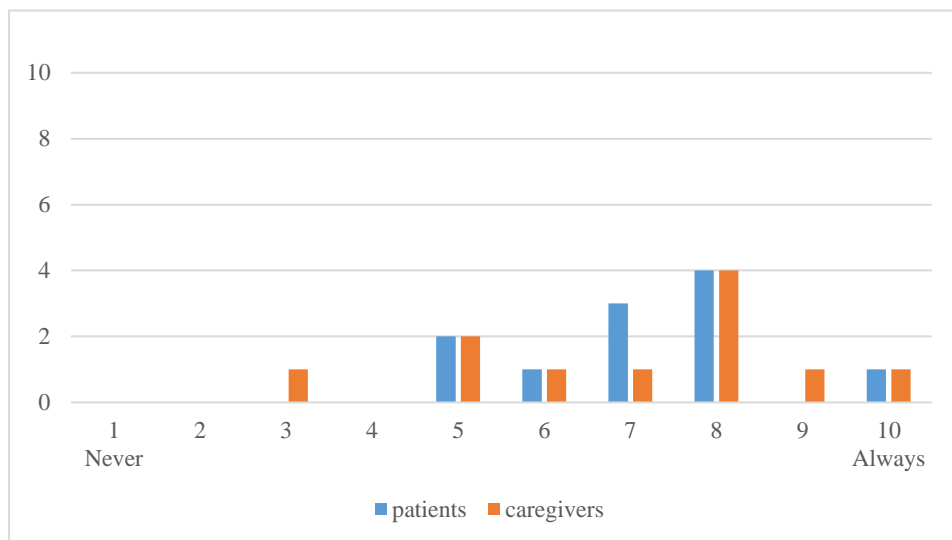


Figure 31: Q40-41. How often does patient/caregiver engagement meet your definition of good practice?

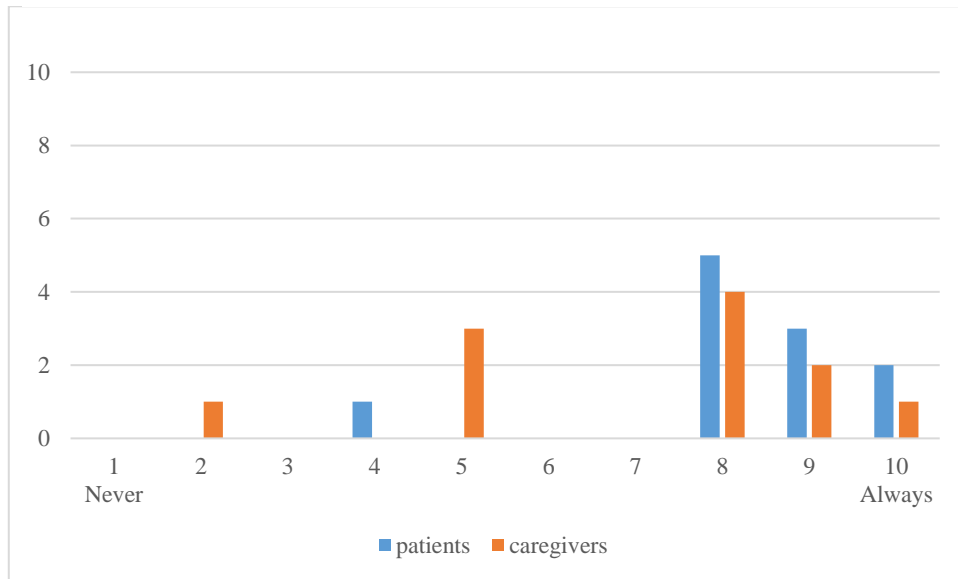


Figure 32: Q42. I have received training about caregiver engagement

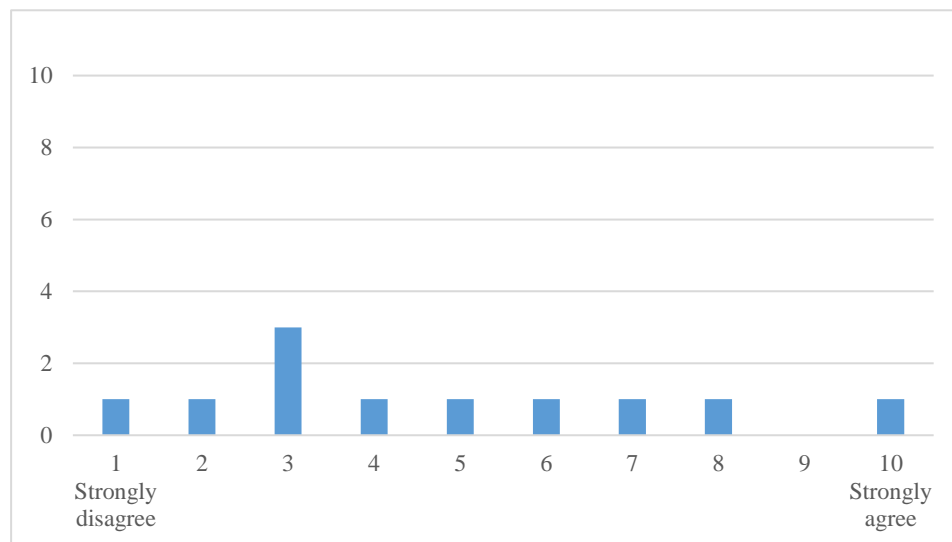


Figure 33: Q43. I am aware of institutional policies regarding caregivers

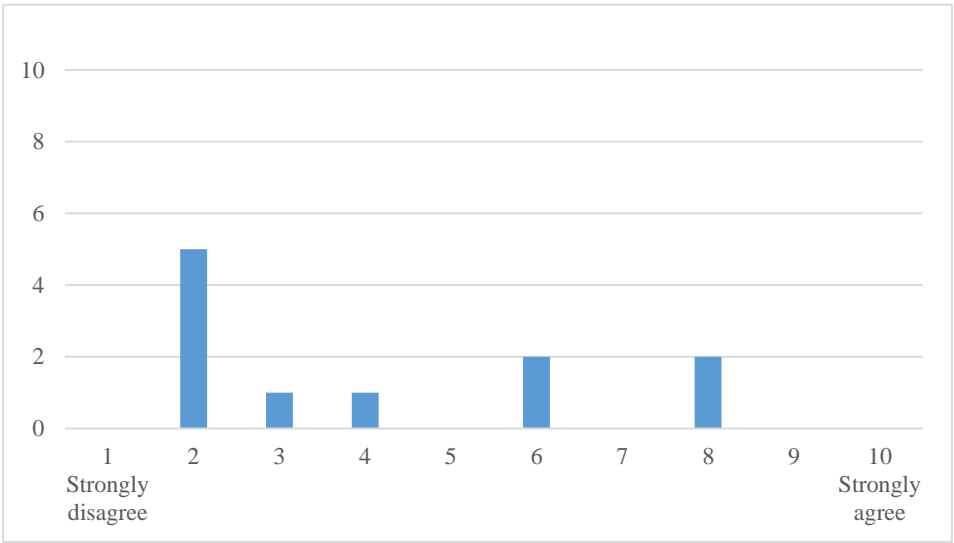


Figure 34: Q44. I am aware of professional code of conduct and Australian laws regarding caregiver inclusion

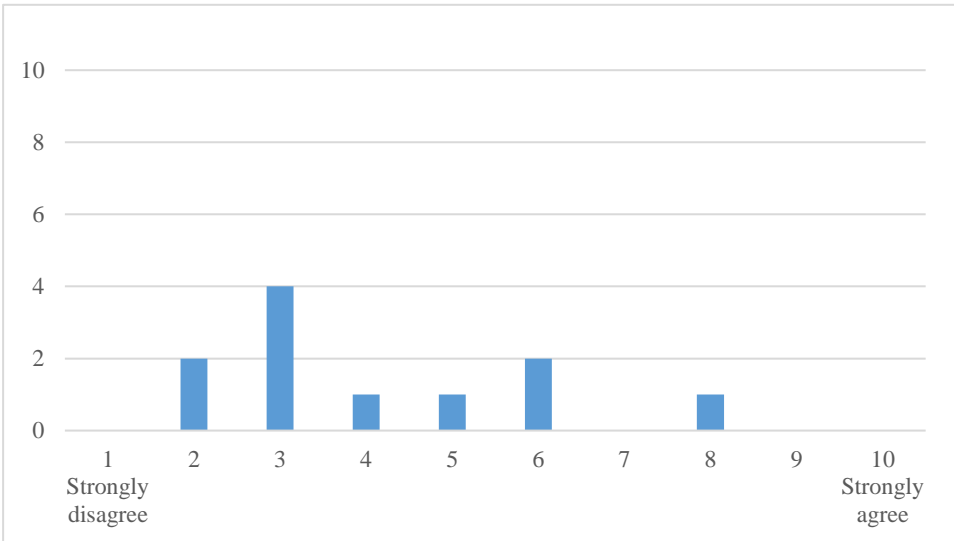


Figure 35: Q45. I am confident I know when it is appropriate to include caregivers into discharge planning

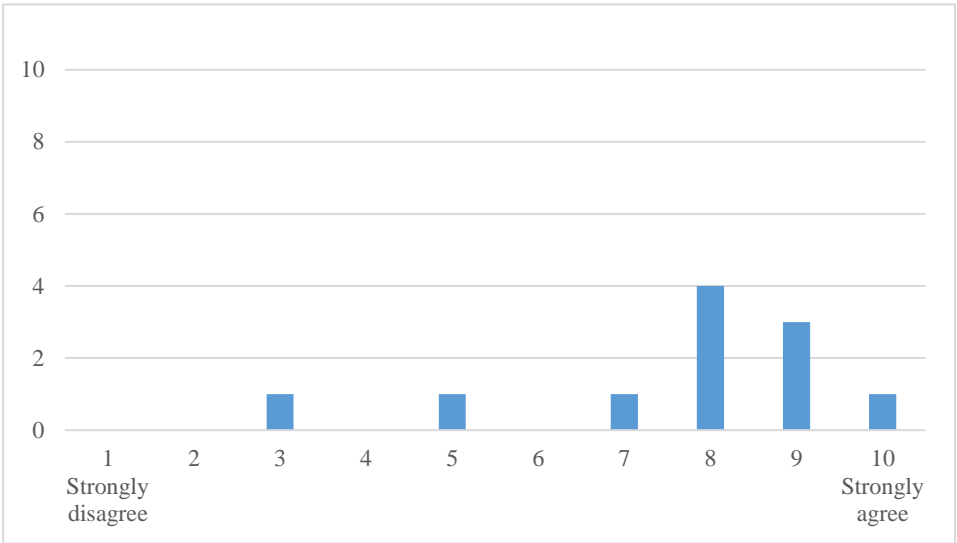


Figure 36: Q46. I am confident I know how to best include informal caregivers into discharge planning

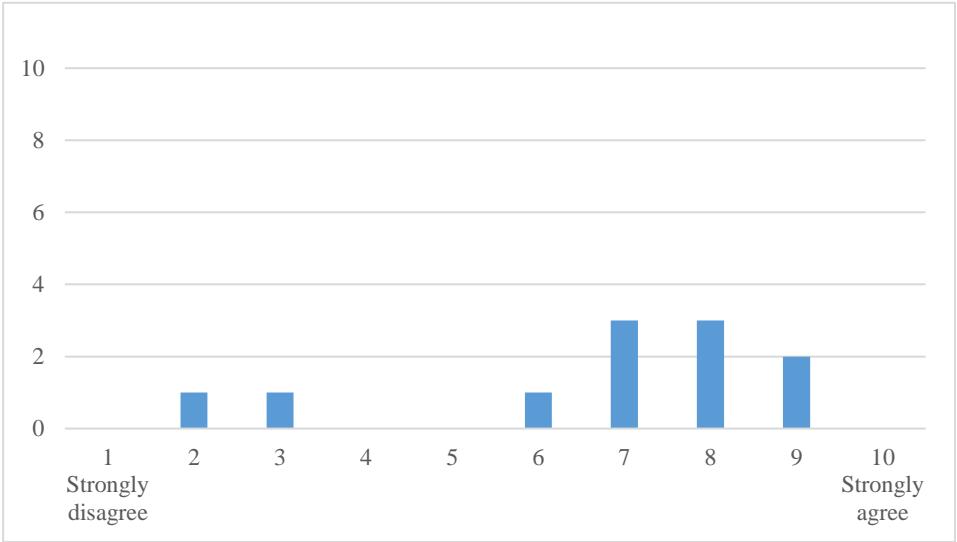
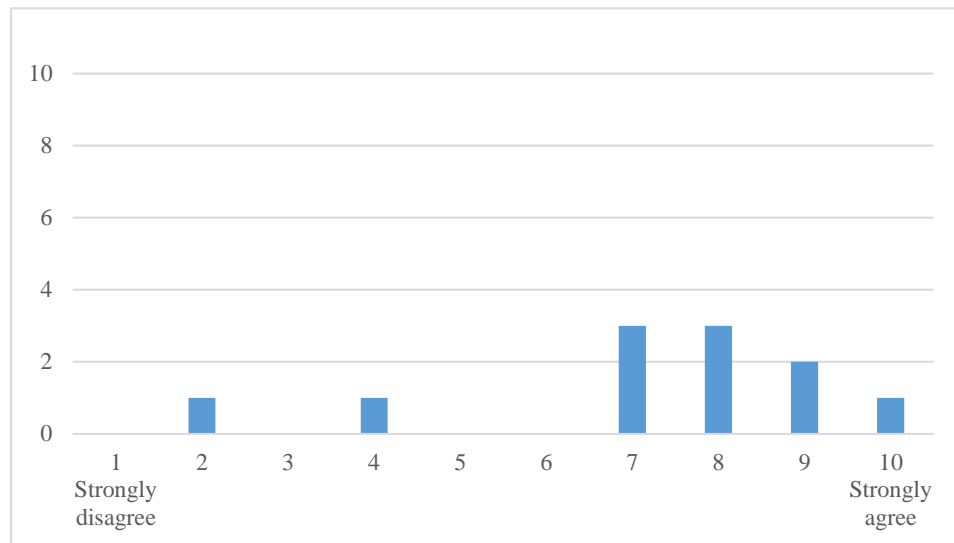


Figure 37: Q47. I feel that I include informal caregivers as often as is appropriate



3. Coding structure

Table 49: Thematic analysis coding structure

Meta-theme	Theme	Sub-theme
Variability in caregiver engagement	Caregiver characteristics	Caregivers who have other commitments
		Health literacy
		Present on the ward
		Not present on the ward
		Caregivers who value privacy
		Negative persona: obstructive
		Negative persona: too involved
		Negative persona: unrealistic/demanding
		Neutral persona: embarrassed caregiver
		Positive persona: compliant
		Positive persona: pleasant
		Positive persona: proactive
		Lives with the patient
		Doesn't live with the patient
		Stressed carers
		Carers have difficulty coping with bad news
	Patient characteristics	Fluctuating patient
		Non-compliant patient
		Patients cannot identify their caregiver
		Non-English-speaking patients
		Patients from cultures which value family caring
		Low function as a trigger for integration
		Poor cognition as a trigger for integration

Meta-theme	Theme	Sub-theme
	Physiotherapist characteristics	Confident in their practice of caregiver engagement
		Find it difficult to deliver hard news
		Emphasis on patient safety
		Listens to caregivers wishes
		Lots of experience
		Wants the best for patients and caregivers
	How the relationship between caregiver and healthcare professional forms	Chance communication
		Caregivers as a source of information
		Passive therapist: alerted to presence of caregiver by caregiver
		Passive therapist: Altered to presence of caregiver by multidisciplinary team
		Passive therapist: expects caregiver to come forward if there is problem
		Proactive physiotherapist: actively seeks out the caregiver without prompts
		Proactive physiotherapist; asks about caregiver in initial assessment
		Proactive physiotherapist: opportunistic of visiting caregivers
		Reactive to caregivers' requests
	Good relationship with caregiver	Collaborative relationship
		Good rapport
	Poor relationship with caregiver	Caregiver dominated relationship
		Healthcare professional dominated relationship
		Misaligned goals between caregivers and healthcare professionals
		Staff avoided caregivers
		Staff were guarded when talking to caregivers
	Social complexity	Caregivers pressured into caring
		Having multiple caregivers
		More than one patient per caregiver
		Good relationship between patient and caregiver
		Tension between patient and caregiver

Meta-theme	Theme	Sub-theme
Individuals working in a complex system	Caregivers as a resource	Uncertain relationship between patient and caregiver
		Caregiver as an advocate
		Caregiver as a source of additional help in hospital
	Physiotherapists perception of factors outside of their control	Does not feel that the multidisciplinary team influenced caregiver integration
		Does not think the hospital influences caregiver integration
		Does not recognise the influence of the healthcare system
		Has a negative view of the hospitals influence on practice and caregiver engagement
		Feels the multidisciplinary team is supportive of their practice and caregiver integration
		Feels that their practice is influenced by the healthcare system
		Negative view of team or team members with regards to caregiver integration
	The multidisciplinary team	Conflict within the team affects caregiver integration
		Language choice within the team: labelling caregivers
		Language choice within the team: takes caution with language when describing caregivers
		Personalities within the team
		Teamwork supports caregiver integration and transitions of care
		Difference between teams inside one facility
		Informal communication
	Leadership in discharge planning in the multidisciplinary team	The physiotherapists as the leader
		Nurses as the leader
		Doctors as the leader
		Inconsistent leadership
		Under the influence of the caregiver
		The occupational therapist as the leader
		The case manager as the leader
	Uncertainty in roles within the multidisciplinary team	Other people might already be including the caregiver
		There is an overlap in roles in discharge planning/caregiver engagement

Meta-theme	Theme	Sub-theme
		It's everyone's job to include the caregiver
		It's the occupational therapist's job to include the informal caregiver
		It's the case managers job to include the informal caregiver
		It's the doctor's job to include the informal caregiver
		It's the nurse's job to include the informal caregiver
		It's the physiotherapist's job to include the informal caregiver
		It's the social worker's job to include the informal caregiver
	The hospital	Formal communication with the caregiver; family meeting
		Siloed roles in the hospital
		Formal communication with the caregiver: white boards
		Formal communication with the team: morning meeting
		Formal communication with the team: case conference
		Healthcare as a business
		Length of stay is longer than it needs to be
		Institutionalised patients
		Poor integration within the hospital
		Private patient mentality
		Electronic medical record system: documentation process/quality of documentation
		Electronic medical record system: summary reports are complicated
		Electronic medical record system: finding caregiver details
		Hospital policy: patient privacy
		Hospital policy: discharge planning
		Hospital policy: visitors and visiting hours
		Physical environment of hospital
	The system	Community care is difficult to navigate
		Inconsistent staffing
		Healthcare as a service industry

Meta-theme	Theme	Sub-theme
Yesterday's medical model		Reimbursement structure
		Lack of respite beds
		Working hours of staff
		Time
		Translator services
	Caregivers as coordinators of care	Asks the caregivers if they are prepared to resume care
		Believes that caregiver welfare is related to patient outcomes
		Considered caregiver stress
		Considered the caregiver needs as separate to patient
		Considers the home environment
		Does not know how to address caregiver stress
		Knew how to address caregiver stress
	Communication with caregivers	Early communication
		Face to face communication
		Indirect communication
		Last minute communication
		Phone the caregivers
	Focus on care in hospital	Caregivers are not prepared for the future
		Does not consider follow up care
		Emphasis on back to baseline
		No integration from community to hospital
		No integration of follow up services
		Aware of services
		Caregivers and patients are told to negotiate google
		Not aware of services
		Comfortable with social complexity
		I'm not that sort of therapist

Meta-theme	Theme	Sub-theme
	How healthcare professionals are affected by caregiver integration	Long term effect: learning to do the best with limited resources
		Long term effect: stop caring or develop resilience
		Method of coping with negative experiences
		Refers back to professional standards
		Negative affect: feeling advice was not taken
		Negative: safety
		Negative: uncomfortable
		Positive: altruistic
		Positive: feeling of being listen to
	How caregivers are included in current practice by physiotherapists	Communication
		Did not include caregivers
		Education
		Organising ongoing care
		Home exercise program
		Goal setting
		Minimal action by physiotherapists
		Self-management
	Caregiver engagement/disengagement affects the patient	Caregiver integration affects patient outcomes
	Perceptions of care	Feels that care is currently not wholistic regarding patient and caregiver
		Feels that care is currently wholistic regarding patient and caregiver
	Professionals as custodians of care	Caregivers and patients make decisions off little information
		Did not ask if there was a caregiver
		Did not consider the caregivers wishes
		Does not ask if the caregiver is able to return to caregiving
		Did not consider caregiver welfare

Meta-theme	Theme	Sub-theme
		Did not consider caregiver stress
Invisible problem	Gaps in practice	Missed caregivers, even though they were present
		Missed opportunities to include caregivers
		Focus on hospital stay
		Uncertain judgement of cognition
		Unsure of what happens in the community
		Unsure of what the team is doing
	Physiotherapists perception of caregiver engagement	Believes it is performed well
		Does not believe it is performed well
	Uncovered through interview	Describes a recent case
		Physiotherapist misunderstood the concept
		Problem co-created with the interviewer
		Unable to think of an experience with a caregiver
How do you think of solutions to a problem you can't see?	Discharge planning involving caregivers in an ideal world	Prior to admission
		At admission
		During admission
		At discharge
		Follow up
	What should caregiver engagement look like in an ideal world?	Communication
		Education
		Exercise program
		Indirect communication
		Self-management/empowerment
	When should caregivers be included?	As needed
		From the beginning
	Flexibility	It will always be complicated due to social complexity
		Caregivers want different things

Meta-theme	Theme	Sub-theme
		Not all caregivers are appropriate
		Not all caregivers want to be included
		Patient autonomy
	Caregiver integration is necessary in a stressed system	Caregivers are secondary
		It would be nice but it's not worth it
	Lessons learnt from current practice: Barriers	The physiotherapist
		The caregiver
		The patient
		The multidisciplinary team
		The hospital
		The system
	Lessons learnt from current practice: Facilitators	The physiotherapist
		The caregiver
		The patient
		The multidisciplinary team
		The hospital
		The system
	Lessons learnt from current practice	Negative experiences
		Positive experiences
		Workarounds
	Opinions on caregiver engagement	Advocates for caregiver engagement within limits
		Advocates for frequent caregiver engagement
		Does not feel caregiver engagement is important
	Solutions perceived by physiotherapists	Fills gaps with previous models of care
		Hospital led solutions
		Not aware solution exists in the first place
		Physiotherapists need to take ownership

Meta-theme	Theme	Sub-theme
		Suggestion already exists
		System led solutions
		Team lead solutions
		Language choice in solutions: certainty
		Language choice in solutions: uncertainty
		Language choice in solutions: co-creation between participant and interviewer