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Transitional Care for Older Adults with Dementia: Variation Across Patients and Providers

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WASHINGTON UNIVERSITY IN ST. LOUIS

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Transitional Care for Older Adults with Dementia: Variation Across Patients and Providers

by
Patricia Elizabeth Prusaczyk

A dissertation presented to
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"If A equals success, then the formula is A = X + Y + Z, with X being work, Y play, and Z keeping your mouth shut." – Albert Einstein

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"To laugh often and much; to win the respect of intelligent people and the affection of children…to leave the world a better place…to know even one life has breathed easier because you have lived. This is to have succeeded." -Ralph Waldo Emerson

Beth Prusaczyk

Washington University in St. Louis

May 2017

Nevertheless, she persisted.

Dedicated to Hillary Rodham Clinton.

ABSTRACT OF THE DISSERTATION

Transitional Care for Older Adults with Dementia: Variation Across Patients and Providers

by

Patricia Elizabeth Prusaczyk

Doctor of Philosophy in Social Work

Brown School of Social Work

Washington University in St. Louis, 2017

Professor Enola Proctor, Chair

Older adults with dementia are particularly vulnerable to negative outcomes and adverse events when they transition between healthcare settings such as being discharged from the hospital. However, little is known about how healthcare providers help patients prepare for a care transition – known as transitional care – among older adults with dementia. Therefore, this study sought to understand the transitional care currently delivered by hospital healthcare providers to older adults with dementia, how it compared to that received by older adults without dementia, and how it varied across different patient and provider characteristics. Guided by key provider/informant interviews and theory, a medical chart review of older adults with dementia was conducted. Results revealed that while some transitional care actions, such as discharge planning, are delivered to a majority of patients other actions such as patient education are delivered only to a minority. Future research should assess whether this variation is associated with outcomes such as hospital readmission and patient and caregiver satisfaction.

Chapter 1: Introduction

1.1 Background

Older adults pose a complex and significant challenge to the US healthcare system. They are high users of healthcare [1], present with greater clinical complexity [2, 3], and bring considerable costs to the system [4, 5]. These patterns are even more apparent among older adults with dementia [6-8]. It is estimated that older adults with dementia cost the healthcare system between $159 and $215 billion annually with this estimate excepted to double by 2040 [8].

Older adults with dementia experience significantly more hospitalizations and care transitions – when a patient transitions between levels of care – than older adults without dementia [7, 9-11]. (This and other key constructs are defined in Table 1 for the sake of clarity and consistency throughout this dissertation).

Table 1.1 Glossary of Key Concepts and Definitions

Table 1.1 Glossary of Key Concepts and Definitions	
Care Transition	When a patient transitions between two different locations of care [12].
Transitional Care	A generic name for a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care in the same location [13].
Transitional Care Interventions	Named interventions such as the Transitional Care Model [14], Care Transitions Intervention [15], Project RED [16], and Project BOOST [17] that each include various combinations of transitional care actions.
Ideal Transition in Care Framework	A framework that conceptualizing the "ideal" transitional care intervention by identifying the ten domains that are the "structural supports" for the "bridge" that

	patients must cross from one care environment to another [18].	
Action	One of 10 “structural supports” of the framework	E.g. Discharge planning, Complete Communication of Information
Subaction	For some Actions, there are distinct components of the Action, henceforth called subactions.	E.g. For the Advance Care Planning Action, there are three subactions: • Establishing goals of care • Establishing health care proxies • Engaging palliative or hospice care if appropriate
Implementation features	Based on the Template for Intervention Description and Replication (TIDieR) checklist and guide [19] they include:	
What	Any physical or informational materials, or procedures, activities, and/or processes, used in the intervention delivery.	
Who	Intervention provider	
When	Timing of intervention	
Care Transition Outcomes **(not studied)**	Readmissions, patient satisfaction, adverse events, medication errors, quality of life [20-24]	

Care transitions are complicated by the older adult’s cognitive impairment [25-27] and compared to their counterparts older adults with dementia have higher mortality rates [28, 29] and are at an increased risk for adverse events [30] and hospital readmissions [31]. In response to this, researchers have developed numerous transitional care interventions for older adults [14-17, 32-34]. Transitional care is a set of actions designed to ensure the coordination and continuity of healthcare as patients transition between different locations or levels of care [13] and often includes actions such as early assessment of needs for follow-up resources, medication reconciliation, discharge planning, providing education and support to the patient and caregivers, and coordination among healthcare professionals [20-24, 35]. These interventions have been shown to reduce readmissions, shorten length of stay, improve quality of life, improve patient satisfaction, and lower costs [20-24, 35]. However, little is known about how the healthcare system provides transitional care for older adults with dementia. This dissertation examined this process, a key first step to improving care transitions and reducing the associated negative outcomes for older adults with dementia.

1.1.1 Care Transitions Among Older Adults with Dementia

Compared to older adults without dementia, older adults with dementia are more likely to be hospitalized and more likely to transition between care settings. Callahan and colleagues found that over the course of one year between 86-76% of older adults with dementia are hospitalized compared to only 51% of older adults without dementia [7]. Care transitions are not limited to when patients enter or leave the hospital. Patients transition between nursing homes and rehabilitation facilities and their homes without passing through the hospital [36]. Patients can also visit the emergency room and return home without being admitted to the hospital [36]. Taking all of these types of care transitions into account, Callahan et al. found that on average older adults with dementia experience between 9.2 and 11.2 care transitions in a year compared to only 3.8 for older adults without dementia [7]. These patterns were also found in a nationally representative sample over a ten-year time period [9].

Transitions to and from the hospital, however, are the most frequent type of care transition with hospitals serving as the “front door” to nursing homes [9, 36]. This type of transition is also important given the increasing emphasis placed on reducing hospital readmission rates by hospital administrators and policymakers. Due to recent policies by the Centers for Medicaid and Medicare (CMS) penalizing hospitals for excessive readmission rates [37], a great deal of attention has been placed on hospitals improving care transitions for all patients so that they and their caregivers receive the necessary information and support to prevent an unplanned readmission. Older adults with dementia are 20% more likely to be readmitted than their counterparts [31]. While the direct costs associated with the care transitions and readmissions of older adults with dementia has not been studied, hospital readmissions for all patients cost the US healthcare system between \$24 and \$45 billion per year[38, 39] and medication errors cost an estimated \$3.5 billon annually [40] with an estimated 76% of medication errors occurring during care transitions [41]. Given that older adults with dementia are more likely to experience readmissions [31] and care transitions [7, 9] than older adults without dementia the proportion of these costs that could be attributed to older adults with dementia is likely significant.

Readmissions and medication errors are only two of the many negative outcomes associated with poorly facilitated care transitions for older adults with dementia. Other consequences include patients having unmet needs post-discharge [42], decreased functional status [43], patient and caregiver stress [44, 45], and a decrease in patient and caregiver satisfaction [46] and quality of life [44, 47]. Older adults with dementia are at an increased risk for poor care transitions and negative outcomes due to a variety of factors such as poor comprehension of discharge instructions [28], dementia-related behavioral disturbances that can make arranging and implementing aftercare services difficult [48], discharge instructions and aftercare services that only address the acute reason for hospitalization and not the cognitive impairment [25], under-utilized and under-prepared caregivers [26], and comorbidities that often require specialty consultations [48]. Providers note distinct challenges to providing transitional care to older adults with dementia such as pressure to discharge older adults with dementia quickly and a demand for aftercare services that exceeds supply [49]. These factors are in addition to the factors that contribute to poor care transitions for all older adults such as failed communication between providers [50], complex medical problems and medication regimens [13, 51], a failure to obtain a comprehensive patient history upon admission leading to incomplete discharge plans [52], and a healthcare system that generally operates in silos inhibiting provider and information flow [51].

1.1.2 Transitional Care Interventions

Numerous interventions exist to improve care transitions for older adult patients [14-17, 32-34, 53]. These interventions target different points of a care transition, from pre-discharge interventions such as discharge planning and medication reconciliation, to post-discharge interventions such as follow-up phone calls and ensuring timely follow up with primary care, to interventions that bridge the continuum such as patient-centered discharge instructions and provider continuity [20]. Interventions can also target different mechanisms in the care system including technologic (e.g., emailed discharge summary, computerized medication reconciliation tool), pharmacy (e.g., clinical pharmacist consultation, community liaison pharmacy service), and discharge planning (e.g., geriatric floating interdisciplinary team, nurse-supported planning) [35]. A more recent systematic review of 24 randomized controlled trials of hospital discharge planning interventions found trials focused on reconciling medications, consulting pharmacists, utilizing standardized forms or assessments, following clinical practice guidelines, or comparing comprehensive discharge planning to the standard of care [22]. The interventions have been shown to reduce readmissions [22-24], shorten index and readmission hospital length of stay [14, 22, 32], lengthen time to readmission [32-34], reduce ED visits [16, 34], lower costs [14, 15, 32, 33], and improve patient satisfaction [22] and quality of life [23].

However, transitional care evidence for older adults with dementia is limited. Numerous systematic reviews have identified a dearth of information on how best to provide transitional care to older adults with dementia [23, 28, 54, 55]. Additionally, a 2013 report by Agency for Healthcare Research and Quality (AHRQ) found that one of the most common reasons individuals were excluded from transitional care intervention studies was the presence of cognitive impairment [56]. Given that older adults with dementia experience frequent care transitions that are costly to the US healthcare system and are associated with numerous adverse outcomes due to various patient- and provider-level barriers in providing high quality transitional care, the limited amount of evidence for this population represents a critical gap that must be addressed.

Therefore, the purpose of this dissertation was to address the following aims:

Aim 1: To characterize and compare the transitional care provided to older adults with and without dementia transitioning from the hospital.

RQ1: What specific transitional care actions are being provided?

RQ2: Who provides transitional care to patients?

RQ3: When is transitional care provided during a patient's hospitalization?

Aim 2: To identify patient and provider characteristics associated with variation in the transitional care provided. Using the information gained in Aim 1, variation in transitional care provided to older adults with dementia will be assessed across patient characteristics (e.g., age, reason for hospitalization) and type of provider (e.g., nurse, social worker, physician).

1.2 Theoretical Foundation

This work was guided broadly by the Care Transitions Framework (CTF) (Figure 1.1), which was developed by Dy et al [57] as part of a larger project conducted by AHRQ on creating contextual frameworks for research on the implementation of complex system interventions [58]. The CTF was adapted from the well-known Consolidated Framework for Implementation Research (CFIR) [59] for the purpose of guiding "research and evaluation of care transitions implementation to address *how, why,* and *where* these interventions succeed or fail to achieve intended outcomes and how their components can be disseminated. [57]" The CTF includes domains on the Intervention Characteristics, External Context, Organizational Characteristics, Characteristics and Roles of Providers, Characteristics and Roles of Patients and Caregivers, Process of Implementation, Measures of Implementation, and Outcomes.

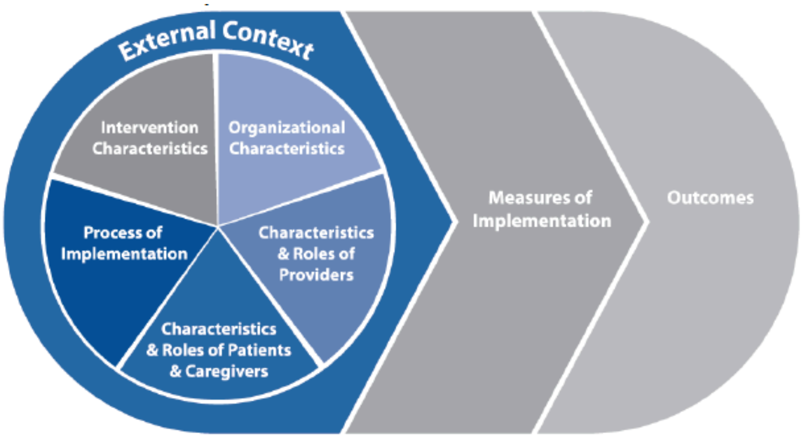

Figure 1.1 The Care Transitions Framework by Dy et al. 2015

All of these domains are important in the effective implementation of transitional care interventions and the results of the proposed study will provide insight into a number of these domains. For example, the results of the study will capture the *characteristics of patients* (demographics, clinical, etc.), *the characteristics and roles of providers* (who provides transitional care for older adults with dementia), *organizational characteristics* (hospital bed size, admitting service, etc.), as well as the *process of implementation* (at what time points do transitional care actions take place). As stated earlier, this information can be used in the future in conjunction with specific intervention characteristics to test and evaluate how, why, and where the intervention is effective.

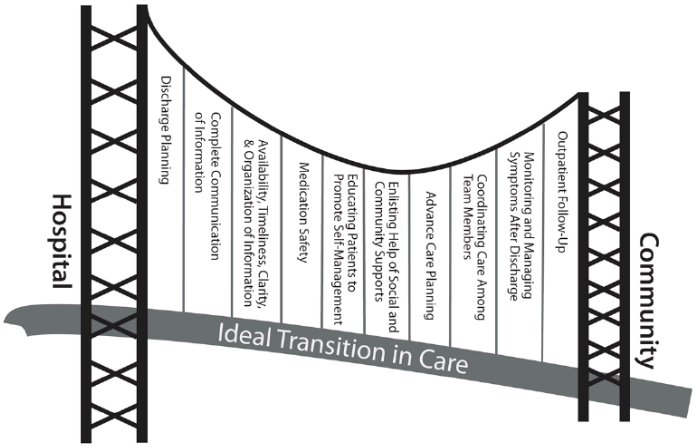

Figure 1.2 The Ideal Transition in Care by Burke et al. 2013.

Additionally, this study drew from the Ideal Transitions in Care framework [18], which was created as a way for hospital and healthcare leadership, policymakers, researchers, clinicians, and educators to improve transitions in care and reduce hospital readmissions. The Ideal Transitions in Care framework conceptualizes the ideal care transition by identifying ten domains that are the “structural supports” for the “bridge” that patients must cross from one care environment to another (Figure 1.2). The more domains missing the weaker and more prone to gaps the bridge becomes. The ten domains include: Discharge Planning; Complete Communication of Information; Availability, Timeliness, Clarity, and Organization of Information; Medication Safety; Patient Education and Promotion of Self-Management; Social and Community Supports; Advance Care Planning; Coordinating Care Among Team Members; Monitoring and Managing Symptoms After Discharge; and Outpatient Follow-up.

1.3 Methodology

While a much more detailed description of the methods used in this study is presented in the following chapters/papers, in summary, this study analyzed the existing electronic medical record (EMR) data of 210 patients hospitalized at Barnes-Jewish Hospital in St. Louis who were ≥70 years old at the time of discharge with a discharge date between January 1, 2015 and

December 31, 2015. Patients with and without dementia were included in the sample and dementia diagnoses were determined via ICD-9 codes. Key informant interviews were conducted with hospital providers prior to data collection to inform data abstraction and again after data collection to contextualize the analytic results and act as a validity check to the EMR data.

1.4 Significance

The knowledge gained from this work is important for multiple reasons. First, before transitional care interventions for older adults with dementia can be developed and tested, a clear understanding of the current state of transitional care delivery for these patients was needed. Among transitional care interventions for older adults *without* dementia, evidence suggests that multiple transitional care actions are performed [20, 24] and advanced practice nurses provide a majority of the transitional care, including discharge planning, patient education, and providing follow-up care, [14-16, 32-34]. It was not known if these patterns applied to transitional care for older adults *with* dementia. Second, before one can design and test an intervention, the problem and the mechanisms that favor or suppress the problem must be clearly specified [60]. Fraser and colleagues state that the problem must be understood on a variety of levels including identifying prevalence and incidence rates, specifying mediating mechanisms such as demographics, and detecting leverage points for change [60]. In the context of this study, this meant understanding how many older adults with dementia receive transitional care (prevalence) and the variation across different patients and providers (mediating and moderating mechanisms), which could inform future interventions (leverage points).

Once a problem is understood and the intervention designed and tested, the next challenge is implementing the intervention into routine practice. Again, this process can be improved when the intervention is “designed for dissemination” [61], meaning the intervention is designed in ways that match the needs and abilities of the providers, the system, and the patients [62]. For example, a key construct in many implementation conceptual frameworks is the characteristics of the intervention such as design quality and packaging [59], adaptability [59], and relative advantage [59]. According to these frameworks, if an intervention is designed without knowledge of the current processes and systems in which providers and patients operate, it may not be feasible [57] or acceptable [57] to real-world adopters.

For example, many of the transitional care interventions for patients without dementia come from the fields of nursing or medicine [12, 13, 19-26] while a smaller number come from the field of social work [63]. Therefore it is natural for these interventions to utilize their respective providers to deliver these interventions. However, without assessing the current delivery of transitional care to older adults with dementia, interventions and implementation strategies may not be successful because they may prove disruptive to the accepted norms of current practice. For example, if social workers are not currently involved in providing patient education to this population, an intervention or implementation strategy that utilizes social workers in this activity may not prove acceptable or feasible. Additionally, knowledge on the variation found in current practice can provide guidance on how an intervention may need to be adapted when rolled out across different settings. The results of this study can now be used to improve the dissemination and implementation of transitional care in this population and setting.

This dissertation is comprised of this introduction chapter, three publishable manuscripts, followed by a conclusion chapter. The three papers are all based on this dissertation study but have distinct content differences.

Paper One discusses in-depth the methodology used in this study. The goal of this paper is to serve as a guide for future researchers who wish to use chart review methodology to study the implementation of complex, psychosocial interventions. This paper does not focus on the research questions related to dementia but instead focuses on the methodology as the point of interest. Paper Two covers the differences in transitional care received by patients with and without dementia. Paper Three covers the variation found in transitional care received only by patients with dementia.

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Chapter 2: Measuring the delivery of complex interventions through chart review

2.1 Background

The Medical Research Council's framework for the development and evaluation of complex interventions emphasizes the importance of evaluating the process of implementing complex interventions [1]. However, the framework does not discuss *how* to evaluate the process nor does it discuss the challenges researchers and evaluators might encounter when measuring the process.

Medical chart review is a type of methodology "in which prerecorded, patient-centered data are used to answer one or more research questions" [2]. Despite known challenges to using medical chart review methodology including evidence of poor documentation by providers and poor sensitivity and specificity of results, it remains a commonly used methodology in clinical and health services research [3-7]. The availability of medical charts, the ability to collect data from a large sample, and the relatively low cost are just a few reasons researchers may choose to use this methodology [7-10].

Therefore, in this study we aimed to use this common methodology (medical chart review) to measure the delivery of a complex, psychosocial intervention including its implementation features and document the challenges and lessons learned in doing so.

2.1.1 The Intervention

This study focuses on transitional care for older adults discharging from the hospital. Older adults frequently transition between two different locations or levels of health care [11-14]. These *care transitions* are complicated by the complex needs of older adults such as multiple comorbidities, chronic conditions, and medications, cognitive issues, limited mobility, poor health literacy and lack of caregiver support [15-21]. Poorly facilitated care transitions have been shown to increase hospital readmission rates, medication errors, and patients' stress levels, and decrease patients' satisfaction and quality of life [14, 22-24].

Generically, *transitional care* is a set of actions designed to ensure the coordination and continuity of health care as patients transition between different locations or levels of care [25] and often includes actions such as early assessment of needs for follow-up resources, medication reconciliation, discharge planning, providing education and support to the patient and caregivers, and coordination among healthcare professionals [26-31].

Numerous specific *transitional care interventions* exist and utilize different combinations of transitional care actions [32-39]. In an effort to catalog and prioritize all of the transitional care actions utilized in the interventions, Burke et al. [40] created the Ideal Transitions in Care framework. The Ideal Transitions in Care framework conceptualizes the ideal transitional care intervention by identifying ten actions that support patients during a care transition. The ten actions include: Discharge Planning; Complete Communication of Information; Availability, Timeliness, Clarity, and Organization of Information; Medication Safety; Patient Education and Promotion of Self-Management; Social and Community Supports; Advance Care Planning; Coordinating Care Among Team Members; Monitoring and Managing Symptoms After Discharge; and Outpatient Follow-up. Because this framework conceptualizes the ideal transitional care intervention, and can be thought of as a bundled intervention, it is the intervention we measured in this study.

The Ideal Transitions in Care framework meets the Institute of Medicine's definition of a psychosocial intervention because it includes "interpersonal or information activities, techniques, or strategies that target biological, behavioral, cognitive, emotional, interpersonal, social, or environmental factors with the aim of improving health functioning and well-being" [41]. It also meets the Medical Research Council's definition of a complex intervention because it has numerous interacting components, involve a number of groups or organizational levels, and have a number of outcomes [1]. This, along with the critical and practical need to improve this healthcare process for older adults, makes it an ideal intervention to use to understand how to measure through medical chart review.

2.1.2 Medical Chart Review

Medical chart review is a commonly used methodology in fields such as epidemiology and clinical research [2]. As stated earlier, there are many reasons investigators use chart review methodology [7-10] but several studies have identified limitations with this method including poor sensitivity and specificity that vary significantly by the specific information being extracted, in addition to the general issue of inadequate documentation by providers' in the first place [3, 42, 43].

The words "extraction" and "abstraction" are often used interchangeably when describing the medical chart review process but their definitions illustrate a subtle but important difference that is we believe especially pertinent to measuring complex interventions with this methodology.

Extracted data are exact, word-for-word copies that can often be extracted automatically from the original information using software, while abstracted data are the important or general points that are usually manually recorded from the original information [44]. This distinction has been shown to affect the validity of chart review with extracted data significantly underestimating the delivery of services due to providers often documenting the services they provide in non-structured fields (which are not amenable to extraction) such as free-text fields [45]. Therefore, in measuring complex interventions, per the Medical Research Council's framework, abstraction instead of extraction may mitigate some of the limitations investigators have noted with chart review methodology because it will allow for a more comprehensive and nuanced review to capture the complexity of the intervention.

2.2 Methods

2.2.1 Sample

To achieve the study aim, an electronic medical chart review of a random sample of 210 patients admitted Barnes-Jewish Hospital, a large, urban teaching hospital in St. Louis, Missouri was conducted. The patients were ≥70 years old at the time of discharge with a discharge date between January 1, 2015 and December 31, 2015.

A sample size of 210 was needed for a separate statistical analysis that is not presented here; however, we believe this sample size is more than adequate for the exploratory purpose of this study because theoretical saturation, meaning when no new information or themes were emerging from the data, was also reached with the 210 charts. We chose a one-year time frame in an effort to minimize any institutional changes that may have occurred at the hospital that would have influenced the transitional care provided. All charts were reviewed by a single coder (author BP).

2.2.2 Operationalization

We used the transitional care actions from the Ideal Transitions in Care framework as the variables to extract and abstract from the charts. Because the definitions were not intended for chart review purposes, some had to be adapted. For example, "Monitoring and Managing Symptoms After Discharge" is an action that takes place after the patient leaves the hospital and thus would not be captured in the inpatient medical record. Therefore, we defined this action as whether or not there was evidence in the record that the patient or caregiver received information in the hospital about how to monitor and manage symptoms after discharge. This adaptation process was done prior to beginning data collection and then revised and refined after pilot testing the data collection form with a review of 20 charts not included in analysis. A full description of the adaptation and operationalization of these variables can be found in Appendix A.

We also collected, when available, information on the intervention's implementation features including who provided each action of the intervention, when the action was provided, and details on the action (i.e., what specific community or social supports were arranged) [46].

2.2.3 Process to assess validity

After data collection and analysis, we assessed the validity of the chart review methodology for measuring a complex intervention including its implementation features. To do this, we interviewed nine hospital providers about our results. We interviewed a physician, registered nurse, case manager, and pharmacist. We also interviewed two advanced practice nurses and two social workers because these are the two types of providers most often used to deliver transitional care interventions in the literature [32, 36, 47, 48, 38] and we wanted to gain multiple perspectives from these roles. For these two roles we interviewed one provider from a surgical unit and one from a non-surgical unit because we anticipated there being differences in the transitional care needs of patients who had received surgery compared to patients who had not. Lastly, we interviewed one case manager from the emergency department to ensure we captured the perspective of providers in this unique setting.

Providers were asked a number of open-ended questions to elicit their thoughts on the results including “What are your initial thoughts about the results?” and “Did you find anything surprising about the results?” Every provider was asked specifically “Do these results match what you see in your day-to-day practice?” Their responses allowed us to assess the validity and accuracy of the data obtained in the chart review and add context to the results.

A single interviewer conducted all interviews (author BP). The interviews were not recorded because they were often conducted in the hospital where there was the potential for patients’ information to be discussed and inadvertently recorded. The interviewer used a structured interview guide, however, and took detailed notes.

2.3 Results

This methodology was effective at measuring the chosen complex psychosocial intervention, transitional care. We found that some transitional care actions were delivered a majority of patients while other actions were delivered only to a minority. For example, 100% of patients received discharge planning and providers reconciled medications for over 95% of patients. Patients’ discharge summaries were only sent to patients’ primary care physicians less than 30%

of the time and social and community supports were discussed with patients less than 5% of the time. These results are presented in the following chapters.

Table 2.1 summarizes the results of the chart review. We noted which of the transitional care actions were amenable to *extraction, abstraction,* or both. We also noted for which actions additional implementation factors were collected and for which actions providers verified the accuracy of the chart review results.

Table 2.1 Effectiveness of Chart Review Methodology

Transitional Care Action	**Information was able to be extracted**	**Information needed to be abstracted**	**Implementation Features**	**Chart data validated through provider interviews**
Discharge Planning	Yes	Yes	• Who provided the action • When was it initiated	Yes
Complete Communication of Information	Yes	No	• Who created, completed, and signed off on the discharge summary	NA
Availability, Timeliness, Clarity, and Organization of Information	No	Yes	• Who created the discharge summary • Who sent it to outside providers	Partially
Medication Safety	No	Yes	• Who provided these actions • When did these actions happen	Partially
Patient Education & Promotion of Self-Management	Yes	Yes	• Who provided these actions • Was it provided to patients and/or caregivers	Yes
Social and Community Supports	No	Yes	• Who provided this action • What supports were used	Yes
Advance Care Planning	No	Yes	• Who provided this action	Partially
Coordinating Care Among Team Members	No	Yes	• Who in the hospital communicated with providers outside of the hospital • What providers outside of the hospital were contacted	Yes
Monitoring and Managing Symptoms	No	Yes	• Who provided this action	Yes

after Discharge				
Outpatient Follow-up	No	Yes	• Who provided this action	Yes

“Complete communication of information” was the only one transitional care action able to be captured completely through extraction because it is solely concerned with the information contained in the discharge summary. Discharge planning and patient education were amenable to both extraction and abstraction. For example, the presence of a discharge summary in the chart was an easily extractable data point and the existence of this summary indicates that discharge planning has occurred. However, to document the other actions involved in discharge planning, data had to be abstracted from providers’ notes. Data on all other transitional care actions were not amenable to extraction and were only amenable to the more nuanced, detailed abstraction method.

Providers confirmed the accuracy and validity of the chart review data for a majority of transitional care actions. For example, the chart review data suggested that registered nurses were most often the ones providing education to patients while social workers were almost always involved in facilitating a patient’s discharge to a facility. During their interviews both registered nurses and social workers confirmed these roles. Furthermore, we not only asked providers to confirm their own roles but also the roles of other providers. In the previous example we asked social workers if nurses are the ones primarily providing education to patients, for example, and they confirmed. Providers partially confirmed all but one of the remaining actions – meaning they confirmed what the chart review data revealed. However, they said there were additional transitional care actions and implementation features that were not captured in the chart review data. For example, a nurse practitioner said that they, along with social workers, were often the ones describing hospice and palliative care to patients and their families. This was not found in the chart data but the nurse practitioner said they do not often document this activity.

Only one transitional care action – complete communication of information – did not need a validity check by providers because it was strictly the presence of absence of key pieces of information in the discharge summary thus there was no uncertainty on the validity of the chart data.

2.4 Discussion

The results above suggest that chart review methodology is a valid way to measure a complex, psychosocial intervention including its implementation features. However, there are many challenges to using this methodology for this purpose. We discuss these challenges and the lessons we learned through this study below (and summarized in Table 2.2) and highlight key implications for future researchers who use this methodology.

2.4.1 Challenge One: Electronic chart spread across multiple software platforms

The first challenge was working across an electronic medical chart spread across three different software platforms. Hospital administrators told us that two of the three platforms funneled into a third, main platform, thus we would only need access to the third platform because all of the information in the chart would be available there. In our pre-data collection interviews with providers we learned that the providers were documenting their actions directly into one of the platforms that was supposed to funnel into the main one. The providers were not routinely entering data into the main platform, though they also acknowledged the data were supposed to funnel into that main platform.

Because of this, we decided that we would take the extra step of gaining access to all three platforms so that we could not only ensure access to all information but also so we could see where and how providers directly document their actions. Taking this extra step proved extremely valuable for multiple reasons.

First, we periodically discovered information in these other two platforms that did not actually filter into the main platform. It was not clear why this occasionally happened but if we had not gained access to these other platforms we would have missed a significant amount of data for some patients. In particular, the platform where providers primarily documented their activities also happened to be the platform where documents such as discharge paperwork, advanced directives, and other hardcopy scanned documents were stored. For charts where the data were not funneled, we would have missed these key data points, many of which were directly related to transitional care.

Second, even when the three platforms did funnel together, we learned that implementation features were often found only in one platform. For example, copies of patients' discharge paperwork were found in the main platform. Reviewing this paperwork gave us numerous data points including the mere presence or absence of the paperwork, the clinical information included in it, and the providers who completed and signed the paperwork (e.g., a physician and a nurse practitioner). However, upon further investigation, we could see in another platform that the discharge paperwork was actually created and populated with information by a registered nurse and then reviewed and "signed off" on by a physician and nurse practitioner. We were able to see how these different providers worked together for this one action because of the automated documentation in one of the platforms that logged the name, credentials, and timestamp of every action. Thus we were able to see, for example, that “Jane Doe, RN, 07-25-15, 14:25” created and updated the discharge paperwork in one software platform and then at a later date and time the paperwork was reviewed and signed by “John Doe, NP, 07-27-15, 08:12”.

This nuanced process might not be important for clinical chart review, but it is critical for measuring complex interventions. Thus the first lesson learned is that researchers should review the entire medical chart in all available software platforms and not rely on the availability of the entire chart in one place even if that is what procedure dictates is supposed to happen.

2.4.2 Challenge Two: Inconsistencies in the data

The second challenge was inconsistencies found in the data and how to make sense of them. It is true that single providers authored many of the “notes” or documentation in the charts. For example, a “Social Work Assessment” was solely completed by a social worker. A “Case Management Note” captured a single episode of care provided by a single case manager. This may lead one to make the assumption that the providers are working in silos. However, we learned that by taking the time to read through these notes we gained a much clearer picture of how the providers are working together.

For example, we saw a pattern emerge in the chart that suggested that case managers were evaluating every patient within 24 hours of admission and then social workers were often – but not always – evaluating patients after that. A further inspection of both the case managers’ and social workers’ documentation revealed that they were working together to provide discharge planning to patients. The case manager would determine if there was a need to involve social work (common reasons included the patient being likely to discharge to a facility or the patient needing advanced directive and power of attorney assistance) and then the case manager would initiate a referral to social work. A social worker would receive the referral and then evaluate the patient. The referral was not separately documented in the chart. It was only through reading the text in these providers' notes did we see this collaboration and process. Both the case manager and social workers confirmed this collaboration and process in our post-analysis interviews, thus highlighting the importance of these interviews as a validity check.

Related to this, it is important to pay attention to the timestamp of not only the documentation or notes themselves but also the timing of the providers' signatures on those documents. While the notes in the chart are supposed to be listed in chronological order there were occasions when they were out of order and we did not notice this until we were reading the notes and noticed discrepancies. For example, a patient was originally supposed to be discharged to a nursing facility but was later deemed stable enough to be discharged back home with their caregiver. We then discovered a later note from a case manager discussing the patients' pending nursing home transfer. At first we thought the case manager had the wrong information or may be confused but upon further inspection of the timestamp of the case manager's signature on her note, we discovered that the information in that note was actually entered prior to the change in discharge plans, but the note was later updated so a new, more recent timestamp was ultimately given to the note. We would have mistakenly assumed an error on the case manager's part had we not read the note and paid close attention to the information that was automatically entered into the note, such as the timestamp.

Thus our second lesson learned is the importance of reading through all available information, including the seemingly unimportant administrative details in the charts. This will provide a better understanding of an intervention's implementation features.

2.4.3 Challenge Three: Wide variation in time needed to review charts

The third challenge we faced was the uncertainty of how long it would take to review each chart. As we discussed earlier, clinical chart review is often looking for discrete data extraction with it taking on average 10 minutes to review a chart with most charts being reviewed in less than 30 minutes [3]. The inclusion criteria for patients in these studies are often based on whether they have had a specific procedure or have a specific diagnostic code in their chart. Investigators may purposefully try to reduce the amount of variation in their sample for a clinical chart review. Variation is of interest to implementation researchers, however, and the sample for a chart review in implementation research may be more diverse which will lead to greater variation in the amount of time it takes to review any given chart. Thus we were not able to estimate how long it would take to review any given chart or how long it would take to complete data collection entirely.

For example, the main clinical differences we accounted for were whether the patient had dementia or not and whether they had surgery in the hospital or not. We did not restrict our sample based on any clinical criteria. This was important since our research questions were about the implementation of transitional care and not patient-level outcomes. Therefore our sample included patients with a wide range of primary diagnoses, comorbidities, and social circumstances. These differences may not influence the amount of time it takes to review a chart when the purpose is to extract clinical data but it does influence the time when abstracting a complex intervention and its implementation features.

For example, a patient’s length of stay obviously influences how much information is in their chart for their hospitalization; the longer the stay, the more associated documentation and notes in the chart. This would likely not influence how long it would take a clinical researcher to access the chart and extract the patient’s blood pressure reading, for example. Length of stay would, however, greatly influence how long it would take an implementation researcher to abstract all of the transitional care provided to the patient simply because there is more data to review and abstract. We timed the review of a random sample of charts and it took on average 44 minutes to review one chart with a range of 34 to 97 minutes.

The literature on the time it takes to review charts is limited but is still primarily from the clinical research field but we learned that researchers measuring complex interventions using chart review would be wise to allow for more variation in the time it takes to review charts for this purpose.

2.4.4 Challenge Four: Seeing the forest through the trees

The final challenge is more overarching than the previous ones but we feel it is perhaps more important. When conducting a chart review to abstract a complex, psychosocial intervention including its implementation features from the data, it is critical to remember to “see the forest through the trees”. In other words, to remember that you are attempting to gain insight into a complex intervention *and* its implementation features, not pinpoint specific data points that you can quantitatively analyze. Chart reviewers must remain open to seeing and documenting new relevant data and patterns beyond what is recorded the data collection form.

It is useful to have training in qualitative methods including content analysis before embarking on a chart review of this nature. Qualitative methodology often allows for the results to emerge from the data without preconception rather than collecting data that will create a dataset to analyze for specific answers. This concept is useful for conducting a chart review in implementation research because it allows the researcher to gather a more holistic and rich picture of an intervention's implementation features.

That is not to say that operationalizing specific data points is not important (as noted earlier, we spent a great deal of time on this). But the importance of balancing focused, well-defined data collection with broad aims when conducting this type of chart review is the most important lesson we learned.

Table 2.2. Challenges and Lessons Learned when Measuring a Complex Intervention with Chart Review

Challenge	**Lesson Learned**
Electronic chart spread across three software platforms	It is critical to gain access to the full chart in order to review all possible data
Inconsistencies in the data	It is important to read through all available information, including the seemingly unimportant administrative details in the charts, to gain an accurate understanding of implementation factors of complex interventions.
Wide variation in time needed to review charts	Allott additional time to complete data collection when measuring complex interventions with chart review.
Failing to see the forest through the trees	Chart reviewers must remain open to seeing and documenting new relevant data and patterns beyond what is recorded the data collection form.

2.5 Limitations

There are of course limitations that still exist with this method regardless of the field in which it is used. The data abstracted from the chart is still reliant upon providers documenting their activities. Other limitations can be addressed with future research. Our study was conducted at a single hospital and more studies are needed that look at the applicability of this methodology across multiple hospitals, outpatient settings, and different EMR systems. Our study was also conducted with only one data abstractor (author BP) and future studies should use multiple data abstractors then refine and revise the methodology appropriately. Despite these limitations, we feel confident that our results accurately depict the implementation of transitional care by hospital providers, a feeling shared by the hospital providers themselves.

Related to these interviews, we recognize that what is found documented in a chart and what a provider believes he or she does in practice may still not accurately reflect what truly happens [43, 42]. Providers may subconsciously misrepresent their roles because they have an existing concept of their roles and are motivated to improve or confirm this concept due to the self-evaluation process. The self-evaluation process is one in which an individual negotiates and modifies their self-concept based on motives including self-enhancement (improve one's self-concept) or self-verification (the need to verify previously formed self-concepts) [49]. However, if this process did lead to a misrepresentation of providers' roles in our results, it may not be problematic in the context of implementation research. For example, if social workers see themselves as the primary discharge planners and they are presented with an intervention or implementation strategy where they are asked to take the lead on discharge planning, they will view that intervention or implementation strategy as acceptable whether or not they actually do the majority of the discharge planning. This is just another example of how traditional chart review limitations may not apply in the context of implementation research.

2.6 Conclusion

Measuring the implementation of complex interventions is a cornerstone in implementation research and chart review remains a frequently used methodology for clinical research. We believe we have demonstrated the value in this methodology for this purpose. Through our study we learned numerous lessons that proved key to our success including gathering input from providers, going the extra step to gain access to the full electronic medical record, and allowing for findings that stemmed from the data itself instead of limiting our data collection and results to those that were identified in the literature ahead of time. We believe there are numerous benefits to using this methodology in implementation research and with more use and refinement could emerge as a valuable and widely used method in the field.

2.7 References

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Chapter 3: Transitional Care for Older Adults With and Without Dementia

3.1 Introduction

Older adults with dementia experience more care transitions – when a patient transitions between levels of care – than older adults without dementia [1-4]. Callahan et al. found that on average older adults with dementia experience between 9.2 and 11.2 care transitions in a year compared to only 3.8 for older adults without dementia [1]. These patterns were also found in a nationally representative sample over a ten-year time period [2]. Transitions to and from the hospital are the most frequent type of care transition with hospitals serving as the "front door" to nursing homes [2, 5]. This type of transition is also important given the increasing emphasis placed on reducing hospital readmission rates by hospital administrators and policymakers. Older adults with dementia are 20% more likely to be readmitted than their counterparts [6].

Older adults with dementia are at an increased risk for poorly facilitated care transitions and negative outcomes due to a variety of factors such as poor comprehension of discharge instructions [7], dementia-related behavioral disturbances that can make arranging and implementing aftercare services difficult [8], discharge instructions and aftercare services that only address the acute reason for hospitalization and not the cognitive impairment [9], under-utilized and under-prepared caregivers [10], and comorbidities that often require specialty consultations [8].

Poorly facilitated care transitions can result in numerous negative outcomes for patients, caregivers, and the healthcare system. After a care transition patients report having unmet needs

[11], decreased functional status [12], stress [13, 14], and a decrease in patient and caregiver satisfaction [15] and quality of life [13, 16]. While the direct costs associated with the care transitions and readmissions of older adults with dementia has not been studied, hospital readmissions for all patients cost the US healthcare system between $24 and $45 billion per year [17, 18] and medication errors cost an estimated $3.5 billon annually [19] with an estimated 76% of medication errors occurring during care transitions [20]. Given that older adults with dementia are more likely to experience readmissions [6] and care transitions [1, 2] than older adults without dementia, the proportion of these costs that could be attributed to older adults with dementia is likely significant.

Transitional care is a set of actions designed to ensure the coordination and continuity of health care as patients transition between different locations or levels of care [21] and often includes actions such as early assessment of needs for follow-up resources, medication reconciliation, discharge planning, providing education and support to the patient and caregivers, and coordination among healthcare professionals [22-27]. Providers note distinct challenges to providing transitional care to older adults with dementia such as pressure to discharge older adults with dementia quickly and a demand for aftercare services that exceeds supply [28]. These factors are in addition to the factors that contribute to poor care transitions for all older adults such as failed communication between providers [29], complex medical problems and medication regimens [21, 30], a failure to obtain a comprehensive patient history upon admission leading to incomplete discharge plans [31], and a healthcare system that generally operates in silos inhibiting provider and information flow [30].

Numerous transitional care interventions have been shown to be effective at improving care transitions for older adult patients [32-39]. However, the majority of these intervention studies excluded older adults with dementia and as a result there is very little evidence on how to improve care transitions for this important population [7, 25, 40, 41]. A 2013 report by the Agency for Healthcare Research and Quality found that one of the most common reasons individuals were excluded from transitional care intervention studies was the presence of cognitive impairment [42]. Given that older adults with dementia experience frequent care transitions that are costly to the US healthcare system and are associated with numerous adverse outcomes due to various patient- and provider-level barriers in providing high quality transitional care, the limited amount of evidence for this population represents a critical gap that must be addressed. Therefore, this study aimed to characterize and compare the transitional care provided to older adults with and without dementia transitioning from the hospital.

3.2 Methods

3.2.1 Data Source and Sample

The data were obtained from the medical charts of patients at Barnes-Jewish Hospital in St. Louis, Missouri, a large, urban teaching hospital with 1,158 beds and 1,800 medical staff. The Institutional Review Board for Washington University in St. Louis approved this study.

The study cohort consisted of patients ≥70 years old at the time of discharge with a discharge date between January 1, 2015 and December 31, 2015. The sample was stratified based on dementia and whether the patient was hospitalized for a surgical procedure or not, resulting in four strata: (1) Surgical patients with dementia, (2) non-surgical patients with dementia, (3) surgical patients without dementia, and (4) non-surgical patients without dementia. Dementia was identified using International Classification of Diseases (ICD) codes previously used in the literature [43, 44] (see Appendix B for codes).

Using these parameters, a repository of administrative health data for the hospital was queried twice (once for patients with dementia and once for patients without dementia) and the medical record numbers of matching patients were returned. The full medical records of these patients were then accessed in order to further assess eligibility. In this phase, patients were excluded if they were discharged directly from the emergency department or if they did not have at least one overnight stay in the hospital upon admission. Patients were also excluded if they died in the emergency department or hospital.

The query returned 458 patients with dementia: 66 who had a surgical procedure and 392 who did not. Given the large number of patients, to adequately address the study aims and for feasibility purposes, the surgical dementia patients were assessed for eligibility first then the resulting number of patients in this stratum was used to determine the sizes of the other strata. Of the 66 surgical dementia patient charts reviewed for eligibility, 42 were included in the sample (five were excluded because they died in the hospital, 11 were discharged directly from the emergency department, and eight were not admitted overnight). Of the 392 non-surgical dementia patients, the decision was made to include a random sample of 84 eligible patients to reflect the overall larger size of this stratum compared to the surgical dementia stratum. After all dementia patients were included and analyzed, a random sample of patients without dementia were included that matched the proportions of surgical and non-surgical patients in the dementia strata.

This ultimately yielded a final sample for analysis of 210 patients: 126 with dementia (42 [33.3%] surgical, 84 [66.7%] non-surgical) and 84 without dementia (28 [33.3%] surgical, 56 [66.7%] non-surgical).

3.2.2 Transitional Care

To operationalize transitional care, we began with a thorough review of the literature to understand the existing transitional care evidence. After this review, we chose to use the Ideal Transitions in Care framework to operationalize our transitional care variables. The Ideal Transitions in Care framework [45] was created as a way for hospital and healthcare leadership, policymakers, researchers, clinicians, and educators to improve transitions in care and reduce hospital readmissions. The Ideal Transitions in Care framework conceptualizes the ideal care transition by identifying ten domains that are the "structural supports" for the "bridge" that patients must cross from one care environment to another. The more domains missing the weaker and more prone to gaps the bridge becomes. The ten domains include: Discharge Planning; Complete Communication of Information; Availability, Timeliness, Clarity, and Organization of Information; Medication Safety; Patient Education and Promotion of Self-Management; Social and Community Supports; Advance Care Planning; Coordinating Care Among Team Members; Monitoring and Managing Symptoms After Discharge; and Outpatient Follow-up.

Because the definitions were not intended for chart review purposes, some had to be adapted. For example, "Monitoring and Managing Symptoms After Discharge" is an action that takes place after the patient leaves the hospital and thus would not be captured in the inpatient medical record. Therefore, we defined this action as whether there was evidence in the record that the patient or caregiver received information in the hospital about how to monitor and manage symptoms after discharge. Furthermore, some of these 10 actions were comprised of multiple sub-actions and, when possible, these sub-actions were coded in addition to their parent action in order to provide a more detailed understanding. A full description of the adaptation and operationalization of these variables can be found in Appendix A.

In addition to the Ideal Transitions in Care framework, input was also sought from providers at the hospital. Brief, structured interviews were conducted with a range of providers who may be involved in providing transitional care. The interviews were structured around the Ideal Transitions in Care framework with two additional open-ended questions. First, providers were asked "How do you help patients with dementia prepare for discharge?". The interviewer noted each of the actions from the framework the provider listed in his or her response and any actions not included in the framework. A follow-up prompt (i.e., "Do you do anything else?") was repeated to elicit any additional actions. At this point if any actions from the framework were not discussed in the responses the interviewer asked the provider directly if he or she provided those actions. Structured interviews, as opposed to unstructured interviews or focus groups, were used because of the clear focus on eliciting information related to the framework and the ability to collect data efficiently with the busy providers [46]. We conducted a total of nine interviews including one of each of the following types of providers: physician, registered nurse, inpatient case manager, emergency department case manager, and pharmacist. Additionally, we interviewed two advanced practice nurses and two social workers. After analysis was completed, the results were presented to these same providers and their feedback was solicited. Result reports were tailored based on existing strategies for providing feedback to physicians [47] and emailed to providers prior to the second interview. The providers were asked to review the results report ahead of time and the interviewer walked providers through the results at the beginning of the interviews. Providers were asked a number of open-ended questions to elicit their thoughts on the results including "What are your initial thoughts about the results?" and "Did you find anything surprising about the results?" Every provider was asked specifically "Do these results match what you see in your day-to-day practice?" These post-analysis interviews served two purposes: 1) to serve as a validity check on the chart data and 2) to provide context to the results. A single interviewer (author BP) conducted all interviews.

3.2.3 Data Analysis

The main purpose of this study was to describe the transitional care provided to older adults with dementia. Bivariate analyses were conducted between dementia and non-dementia patients for both transitional care variables as well as demographic and clinical variables to understand how these groups differed. All statistical analyses were conducted in R 3.3.2 using the "stats" package.

3.3 RESULTS

Table 3.1 presents the demographic and clinical characteristic of the sample by patients with and without dementia.

Table 3.1 Sample Description by Patients With and Without Dementia

	Dementia (N=126)	**Non-Dementia (N=84)**	
Variable	**M(SD)** **Range**	**M(SD)** **Range**	**Significance**
Age*	83.98 (6.43) 70-101	79.07 (6.02) 70-93	t= -5.64(185.93) p<.0001
Length of Stay	5.40 (4.66) 1-30	5.49 (5.39) 1-33	
# of admissions in past 12 months	0.81 (1.19) 0-5	0.63 (1.02) 0-5	
# of ED visits in past 12 months	0.70 (1.38) 0-10	0.46 (0.96) 0-5	
	n(%)	**n(%)**	
Male	53 (42.1%)	43 (51.2%)	

Black (vs. White)*	57 (45.2%)	21 (25.0%)	$\chi^2=8.0(1)$, $p=0.004$
Married (vs. Not Married)	77 (61.1%)	40 (47.6%)	
Living Arrangement			$\chi^2=25.3(2)$, $p<.0001$
Alone	15 (11.9%)	22 (26.2%)	
With caregiver	73 (57.9%)	59 (70.2%)	
In a facility*	38 (30.2%)	3 (3.6%)	
Cognitive Impairment Severity			
Mild	36 (28.6%)	--	
Moderate to Severe	90 (71.4%)	--	
Mobility Assistance			$\chi^2=10.54(3)$, $p<.0001$
Unassisted	25 (19.8%)	31 (36.9%)	
Cane/Walker	66 (52.4%)	39 (46.4%)	
Wheelchair	21 (16.7%)	5 (6.0%)*	
Unknown	14 (11.1%)	9 (10.7%)	
Admitted for surgery	42 (33.3%)	28 (33.3%)	
Disposition			$\chi^2=36.37(5)$, $p<.0001$
Home Alone	2 (1.6%)	8 (9.5%)	
Home with Home Health	21 (16.7%)	23 (27.4%)	
Home with Caregiver	27 (21.4%)	31 (36.9%)	
Rehab Facility	8 (6.3%)	9 (10.7%)	
Skilled Nursing Facility*	66 (52.4%)	11 (13.1%)	
Short-Term Hospital	2 (1.6%)	2 (2.4%)	
Discharged to a higher level of care	62 (49.2%)	43 (51.2%)	
Readmitted within 30 days	22 (17.5%)	18 (21.4%)	
*Significant Difference with adjusted alpha of 0.004			

There was a significant difference between patients with and without dementia in terms of race, mobility status, living arrangement prior to admission, and disposition location. There were significantly more black dementia patients (45.2% vs. 25.0%, p=0.003) and dementia patients were significantly more likely to require the use of a wheelchair than patients without dementia (16.7% vs. 6.0%, p=0.0219). Patients with dementia were significantly more likely to living in a facility prior to admission (30.2% vs. 3.6%, p<.0001) and were more likely to discharge to a facility (52.4% vs. 13.1%, p<.0001).

While the proportion of surgical patients was kept the same across the dementia and non-dementia patient groups, there are other clinical characteristics worth noting across the sample and groups. Table 3.2 shows the admitting service for all patients and the difference between dementia and non-dementia patients for this characteristic. The only significant difference between the two groups was that dementia patients were significantly more likely to be admitted to the Intensive Care Unit (ICU) compared to patients without dementia (13.49% vs. 1.19%, χ^2=8.23(1) *p*=0.002). This suggests that dementia patients were clinically more seriously ill or injured than patients without dementia.

Table 3.2 Admitting Service of Patients

Variable	Dementia (N=126) n (%)	No Dementia (N=84) n (%)	Total (N=210) n(%)	Significant Difference χ^2(df) *p-value*
Orthopaedics	24 (19.05%)	16 (19.04%)	40 (19.05%)	NS
Gastrointestinal	1 (0.79%)	3 (3.57%)	4 (1.90%)	NS
Neurology	8 (6.35%)	8 (9.52%)	16 (7.62%)	NS
Medicine	49 (38.89%)	21 (25.00%)	70 (33.33%)	NS
ICU	17 (13.49%)	1 (1.19%)	18 (8.57%)	χ^2=8.23(1) *p*=0.002

Vascular	2 (1.59%)	1 (1.19%)	3 (1.43%)	NS
Urology	0 (0%)	2 (2.38%)	2 (0.95%)	NS
Cardiology	16 (12.70%)	18 (21.43%)	34 (16.19%)	NS
Other	4 (3.17%)	8 (9.52%)	12 (5.71%)	NS
Unknown	5 (3.97%)	6 (7.14%)	11 (5.24%)	NS

Significant difference with adjusted alpha of 0.005

3.3.1 Transitional Care

The provider interviews did not yield any additional transitional care actions outside of the Ideal Transitions in Care framework therefore only the actions from the framework were coded and analyzed.

Dementia patients did not differ from patients without dementia on most transitional care actions. These results are summarized in Table 3.3. Significant differences were found, however, in a few transitional care actions. Providers were significantly less likely to ensure accurate medication histories were taken from patients with dementia (60.32% vs. 85.71%, p=0.0001) compared to patients without.

Table 3.3 Difference in Transitional Care Provided to Patients With and Without Dementia

Variable	**Dementia (N=126) n(%)**	**Non-Dementia (N=84) n(%)**	**Significance**
Discharge Planning	125 (99.2%)	84 (100%)	
Discharge Summary included			
Diagnoses	125 (99.2%)	84 (100%)	
Discharge medications	126 (100%)	84 (100%)	
Procedure results	124	84 (100%)	

	(98.4%)		
Follow-up needs	122 (96.8%)	84 (100%)	
Pending test results	7 (5.6%)	0	
Discharge Summary was available to PCP	26 (20.6%)	23 (27.4%)	
Accurate medication history taken*	76 (60.3%)	72 (85.7%)	$\chi^2=14.43(1)$, $p=0.0001$
Medications were reconciled throughout hospitalization	121 (96.0%)	82 (97.6%)	
Medication changes were discussed with patient or caregiver	124 (98.4%)	83 (98.8%)	
Number who understood education*	55 (43.7%)	67 (79.8%)	$\chi^2=29.64(1)$, $p<.0001$
Patient or Caregiver educated about			
In-hospital medications*	97 (77.0%)	84 (100%)	$\chi^2=20.54(1)$, $p<.0001$
Diagnoses*	57 (45.2%)	70 (83.3%)	$\chi^2=28.41(1)$, $p<.0001$
Follow-up needs*	53 (42.1%)	68 (81.0%)	$\chi^2=29.64(1)$, $p<.0001$
Whom to contact after discharge*	51 (40.5%)	67 (79.8%)	$\chi^2=30.02(1)$, $p<.0001$
Post-discharge medication regimen*	59 (46.8%)	67 (79.8%)	$\chi^2=20.91(1)$, $p<.0001$
Post-discharge medication side effects	3 (2.4%)	3 (3.6%)	
Post-discharge symptoms*	52 (41.3%)	67 (80.0%)	$\chi^2=28.30(1)$, $p<.0001$
Post-discharge adverse events	9 (7.1%)	2 (2.4%)	
Patient or Caregiver asked about any post-discharge management challenges	7 (5.6%)	3 (3.6%)	
Teach-back used during education	122 (96.8%)	83 (98.8%)	
Printed educational materials used	66 (52.4%)	54 (64.3%)	
Patient assessed for delirium or dementia	126 (100%)	83 (98.8%)	
Arranged social or community support post-discharge	3 (2.4%)	3 (3.6%)	
Advanced Care Planning	35	18 (21.4%)	

	(27.8%)	
Coordinated with providers outside of the hospital	113 (89.7%)	69 (82.1%)
Outpatient follow-up scheduled with specialty provider	44 (34.9%)	36 (42.9%)
Outpatient follow-up scheduled with PCP	30 (23.8%)	38 (45.2%)
Significant difference with adjusted alpha of 0.002		

The remaining differences related to patient/caregiver education. Due to the limited information available in the medical chart, it was not always clear whether providers were providing education to patients, their caregivers, or both. Therefore, we counted education as having been provided if it was provided to either the patient or the caregiver. Thus in our data if a patient is recorded as not having received education then there was no indication in the chart that education was provided to the patient or the caregiver. Patients with dementia were significantly less likely to receive education related to their diagnoses (45.24% vs. 83.33%, p<.0001), follow-up needs (42.06% vs. 80.95%, p<.0001), whom to contact after discharge (40.48% vs. 79.76%, p<.0001), medication regimens after discharge (46.83% vs. 79.76%, p<.0001), and symptoms after discharge (41.27% vs. 79.96%, p<.0001) than patients without dementia. Among patients who received education about their in-hospital medications, patients with dementia were significantly less likely to understand the education (per provider assessment) they received about their medications (43.65% vs. 79.76%, p<.0001) compared to those without dementia.

3.4 DISCUSSION

This study revealed few differences in the transitional care provided to patients with and without dementia. However, key differences were found related to patient education and taking an accurate medication history.

Related to the significant differences found in the transitional care actions documented in the charts, the providers were able to provide valuable insight into why those differences may exist. For example, one registered nurse said that the location where a patient is discharging to influences the education the patient receives: “(We) always go over the discharge paperwork with patients and families. Unless they are going to long-term care, then it’s less important.”

This important distinction could help explain why patients with dementia were less likely to receive this type of education. In the sample, patients with dementia were significantly more likely to be admitted from a facility and discharged to a facility and were significantly less likely to receive education about post-discharge needs. These findings are consistent with the nurse’s explanation and suggest that perhaps instead of creating separate interventions for patients with and without dementia interventions that address the needs of specific disposition locations are needed.

The effect of patients’ living situation prior to and after discharge does not explain, however, the significant difference in obtaining accurate medication histories. For dementia patients who presented to the emergency department alone or with a caregiver from their personal residence, taking an accurate medication history was often not possible due to the patients’ dementia. If the patient had a recent (subjectively defined by the provider) visit to a medical facility in the hospital network and that record was in the chart, the provider would often use the medication list from that visit as the current medication history.

For patients who were coming from a facility, they were often sent with a list of medications from the healthcare providers at the facility. Thus one might expect that because patients with dementia were more likely to be living in a facility prior to admission they would be more likely as a group to have accurate medication histories. While this was noted in many cases, the significant difference remains.

The case manager in the emergency department was specifically asked about this process and the significant difference found in the data. While the case manager prefaced that she is not personally responsible for obtaining medication histories from patients, she is privy to the process. She stated “the physicians, social workers and nurses make an effort to contact family about medication information, so I would think the same goes for medications.” She also said that it the patient a nursing home they will contact the nursing home for information.

This may be an instance where providers’ real-world actions are not accurately being captured in the chart data therefore this result warrants further investigation in the future before practice changes are implemented. However, the lack of documentation in the chart of any efforts made to collect accurate medication information alone is important to note. A majority of medication errors happens during a care transition [20] and patients with dementia experience frequent medication errors [48], therefore the process or lack thereof should be clearly documented in an effort to reduce potential errors and adverse events.

Beyond these differences, many of the transitional care actions provided to patients without dementia are also being provided to patients with dementia. This suggests that the interventions currently shown to be effective at improving care transitions for patients without dementia may also be effective for patients with dementia. However, because there is an obligation for providers to deliver evidence-based care [49, 50], it is critical that new and existing transitional care interventions be tested with this population. Investigators often exclude patients with dementia from research due to the additional challenges faced in getting approval from institutional review boards but guidance in this area exists to help investigators navigate these challenges [51].

There are several limitations to this study. First, as with all studies utilizing medical chart review, the study data are only as reliable as the data entered into the chart. However, the interviews conducted with hospital providers suggest that the results are consistent with day-to-day practice and thus are relatively reliable and valid. Second, due to the small sample size and limited variation in the sample, multivariable analyses could not be conducted. This is especially disappointing in terms of testing the association between transitional care actions and patient outcomes such as disposition location and hospital readmission. Third, the patient and caregiver perspective was not available in the chart thus it is unclear how patient and caregiver satisfaction is associated with these results. It is imperative that transitional care interventions aim to improve not only clinical outcomes but also patient and caregiver satisfaction and this can only be done through inclusion of this as a study outcome. Lastly, these results come from only one hospital and may not be generalizable to other hospitals.

To address these limitations, future research is needed that collects data from a larger sample and from multiple hospitals including rural hospitals. This will yield more generalizable knowledge and allow for the testing of outcome variables include disposition and readmission. Additionally, future research should include more patient and caregiver variables and perspectives whether it is through conjunctive satisfaction surveys or qualitative interviews.

3.5 Conclusion

There is a critical need to add to the limited evidence base related to transitional care for patients with dementia. The results of this study suggest that patients with dementia receive many of the same transitional care actions as patients without dementia. Perhaps more important than whether the patient has dementia or not is whether the patient is living alone/with caregivers or whether the patient is living in a facility. Yet the transitional care evidence base excludes this population, leaving clinicians and providers with little evidence to draw from. In the future, investigators must include patients with dementia in new transitional care studies and test the effectiveness of existing interventions within this population, as well as better understand the relationship between living arrangement and transitional care needs.

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Chapter 4: Current Implementation of Transitional Care for Older Adults with Dementia

4.1 BACKGROUND AND OBJECTIVES

4.1.1 Care Transitions among Older Adults with Dementia

On average older adults with dementia experience between 9.2 and 11.2 care transitions – when a patient transitions between levels of care – in a year compared to only 3.8 for older adults without dementia [1]. This pattern was also found in a nationally representative sample over a ten-year time period [2]. Poor care transitions can result in numerous negative outcomes for patients and caregivers including patients having unmet needs [3], decreased functional status [4], stress [5, 6], and a decrease in patient and caregiver satisfaction [7] and quality of life [5, 8].

Older adults with dementia are at an increased risk for poor care transitions and negative outcomes due to a variety of factors such as poor comprehension of discharge instructions [9], dementia-related behavioral disturbances that can make arranging and implementing aftercare services difficult [10], discharge instructions and aftercare services that only address the acute reason for hospitalization and not the cognitive impairment [11], under-utilized and under-prepared caregivers [12], and comorbidities that often require specialty consultations [10].

4.1.2 Transitional Care Evidence Base

Transitional care is a generic term for a set of actions designed to ensure the coordination and continuity of health care as patients transition between different locations or levels of care [13].

Numerous transitional care interventions, that are comprised of various combinations of transitional care actions, have been shown to be effective at improving care transitions for older adult patients [14-21] and often includes actions such as early assessment of needs for follow-up resources, medication reconciliation, discharge planning, providing education and support to the patient and caregivers, and coordination among healthcare professionals [22-27].

However, the majority of these intervention studies excluded older adults with dementia and as a result there is very little evidence on how to improve care transitions for this important population [9, 25, 28, 29]. A 2013 report by the Agency for Healthcare Research and Quality found that one of the most common reasons individuals were excluded from transitional care intervention studies was the presence of cognitive impairment [30]. Additionally, providers note distinct challenges to providing transitional care to older adults with dementia such as pressure to discharge older adults with dementia quickly and a demand for aftercare services that exceeds supply [31].

4.1.3 Consideration of Future Implementation Efforts

Given that older adults with dementia experience frequent care transitions and are at an increased risk for experiencing poor care transitions, and that providers have difficulty providing transitional care to patients with dementia, the lack of evidence-based interventions and current implementation of transitional care for this population represents a critical gap. However, before interventions can be developed and tested, a clear understanding of the transitional care provided to older adults with dementia is needed including the features of implementing this care.

Understanding the implementation features, such as who implements what and when, [32] of transitional care in this population will improve the design of future interventions, a process known as “designing for dissemination” [33]. This concept posits that interventions designed in ways that match the needs and abilities of the providers, the system, and the patients are more suitable for implementation in routine practice [34]. For example, in many implementation conceptual frameworks a key construct is the characteristics of the intervention, which include feasibility [35], acceptability [35], design quality and packaging [36], adaptability [36], and relative advantage [36]. Therefore, according to these frameworks, if an intervention is designed without knowledge of the current processes and systems in which providers and patients operate, it may not be feasible [37] or acceptable [37] to real-world adopters. Additionally, knowledge on the variation found in current practice can provide guidance on how an intervention may need to be adapted when rolled out across different settings.

An example of this concept within the context of transitional care relates to who provides transitional care to patients. Current interventions often utilize advanced practice nurses to provide a majority of transitional care actions including discharge planning, patient education, and providing follow-up care, [14-18, 20] but it is not known if advanced practice nurses are routinely providing this care already. If other providers – not advanced practice nurses – are the primary providers of these transitional care actions then any effort to implement an intervention using advanced practice nurses could be met with resistance because it would be incongruent with current practice. Advanced practice nurses might not be able nor want to provide transitional care because they have other duties to fulfill or may feel it is not within the purview of their job description. In other words, the advanced practice nurses may not find the intervention appropriate, acceptable, or feasible for them to implement.

Therefore, it was the purpose of this study to understand the transitional care actions provided to older adults with dementia and the features of implementing this transitional care including what transitional care actions are provided, which types of hospital providers are providing these actions, and any variation found across patient and clinical characteristics. The results will inform the development of future interventions and implementation strategies.

4.2 RESEARCH DESIGN AND METHODS

4.2.1 Conceptual Framework

This study was guided broadly by the Care Transitions Framework (Figure 1), which was developed by Dy et al. [37] as part of a larger project conducted by AHRQ on creating contextual frameworks for research on the implementation of complex system interventions [38]. The Care Transitions Framework was adapted from the well-known Consolidated Framework for Implementation Research [36] for the purpose of guiding "research and evaluation of care transitions implementation to address *how, why,* and *where* these interventions succeed or fail to achieve intended outcomes and how their components can be disseminated," [37]. The Care Transitions Framework includes domains on the Intervention Characteristics, External Context, Organizational Characteristics, Characteristics and Roles of Providers, Characteristics and Roles of Patients and Caregivers, Process of Implementation, Measures of Implementation, and Outcomes. All of these domains are important in the effective implementation of transitional care interventions and this study aimed to capture the *characteristics of patients* (demographics, clinical, etc.), *the characteristics and roles of providers* (who provides transitional care for older adults with dementia), as well as the *process of implementation* (at what time points do transitional care actions take place). This information can be used in the future in conjunction with specific intervention characteristics to test and evaluate how, why, and where the intervention is effective.

4.3 Methods and Sample

This study utilized two methods: a medical chart review and structured interviews. The chart review was used to abstract data on the transitional care provided to patients in the hospital and the interviews were used to gain information on the hospital providers' perspectives on providing transitional care to this population.

The data were obtained from the medical charts of patients at Barnes-Jewish Hospital in St. Louis, Missouri, a large, urban teaching hospital with 1,158 beds and 1,800 medical staff. The Institutional Review Board for Washington University in St. Louis approved this study.

The study cohort for chart review consisted of patients ≥70 years old at the time of discharge with a discharge date between January 1, 2015 and December 31, 2015. The sample was stratified based on whether the patient was hospitalized for a surgical procedure or not. Dementia was identified using ninth revision International Classification of Diseases (ICD) codes previously used in the literature [39, 40] (see Appendix B for codes).

Using these parameters, a repository of administrative health data for the hospital was queried and the medical record numbers of matching patients were returned. The full medical records of these patients were then accessed in order to further assess eligibility. In this phase, patients were excluded if they were discharged directly from the emergency department or if they did not have at least one overnight stay in the hospital upon admission. Patients were also excluded if they died in the emergency department or hospital.

The query returned 458 patients: 66 who had a surgical procedure and 392 who did not. Given the large number of patients, to adequately address the study aims and for feasibility purposes, the surgical dementia patients were assessed for eligibility first then the resulting number of patients in this stratum was used to determine the size of the non-surgical stratum. Of the 66 surgical dementia patients whose charts were reviewed for eligibility, 42 were included in the sample (five were excluded because they died in the hospital, 11 were discharged directly from the emergency department, and eight were not admitted overnight). Of the 392 non-surgical dementia patients, the decision was made to include a random sample of 84 eligible patients to reflect the overall larger size of this stratum compared to the surgical dementia stratum. This ultimately yielded a final sample for analysis of 126 patients with dementia: 42 (33.3%) surgical and 84 (66.7%) non-surgical).

The sample for the brief, structured interviews consisted of a range of providers who may be involved in providing transitional care. We conducted a total of nine interviews including one of each of the following types of providers: physician, registered nurse, inpatient case manager, emergency department case manager, and pharmacist. Additionally, we interviewed two advanced practice nurses and two social workers. Structured interviews, as opposed to unstructured interviews or focus groups, were used because of the clear focus on eliciting information related to transitional care [41]. Two rounds of interviews were conducted: one before data collection to guide the selection and operationalization of constructs and one after data analysis.

The interviews prior to data collection were structured around the Ideal Transitions in Care framework. Providers were asked an open-ended question related to how they help prepare patients for discharge with follow-up prompts to elicit additional information on this. Their responses were recorded and if any actions from the framework were not spontaneously given the providers were then specifically asked if they provided those actions. This was done to capture captured not only research-based transitional care evidence but also practice-based evidence.

The interviews after data analysis were based on result reports given to providers that were tailored based on existing strategies for providing feedback to physicians [42]. These reports were sent to providers prior to the interview for their review. Providers were then interviewed and asked a number of open-ended questions to elicit their thoughts on the results including "What are your initial thoughts about the results?" and "Did you find anything surprising about the results?" Every provider was asked specifically "Do these results match what you see in your day-to-day practice?" This was done to serve as a validity check on the chart data and to provide context to the results.

4.3.1 Variables and Data

To operationalize transitional care, we began with a thorough review of the literature to understand the existing transitional care evidence. After this review, we chose to use the Ideal Transitions in Care framework to operationalize our transitional care variables. The Ideal Transitions in Care framework [43] was created as a way for hospital and healthcare leadership, policymakers, researchers, clinicians, and educators to improve transitions in care and reduce hospital readmissions. The Ideal Transitions in Care framework conceptualizes the ideal care transition by identifying ten domains that are the "structural supports" for the "bridge" that patients must cross from one care environment to another. The more domains missing the weaker and more prone to gaps the bridge becomes. The ten domains include: Discharge Planning; Complete Communication of Information; Availability, Timeliness, Clarity, and Organization of Information; Medication Safety; Patient Education and Promotion of Self-Management; Social and Community Supports; Advance Care Planning; Coordinating Care Among Team Members; Monitoring and Managing Symptoms After Discharge; and Outpatient Follow-up. Because the definitions were not intended for chart review purposes, some had to be adapted. Furthermore, some of these 10 actions were comprised of multiple sub-actions and, when possible, these sub-actions were coded in addition to their parent action in order to provide a more detailed understanding.

As stated earlier, we interviewed providers to obtain information on the transitional care they provided not captured in the framework as a way to ensure our results were based not only in evidence but also practice. However, the providers did not identify any additional transitional care actions outside of the framework thus only the 10 actions in the framework were used for data collection. A full description of the adaptation and operationalization of the transitional care variables from the framework can be found in Appendix A.

4.3.2 Data Analysis

The main purpose of this study was to describe the transitional care provided to older adults with dementia. Descriptive and bivariate analyses were to understand the variation in transitional care (including transitional care actions and the providers who deliver them) provided to patients based on different clinical and demographic characteristics. Specifically, tests of association were conducted between the transitional care actions and the key demographic variables of gender, race, dementia severity, surgical or non-surgical visit, and disposition location.

All statistical analyses were conducted in R 3.3.2 using the “stats” package.

4.4 RESULTS

4.4.1 Sample Characteristics

The demographic and clinical description of the sample can be found in Table 4.1. On average the sample was 84 years old. The majority of the sample was female, white, and married. Almost three-fourths of the sample had moderate to severe dementia and over half of the sample required a cane or walker for mobility assistance. The majority of the sample was living with a caregiver or in a facility prior to admission and a majority discharged to a facility or home with a caregiver.

Table 4.1 Demographic and Clinical Characteristics of Patients with Dementia

Variable	**M (SD)** **Range**
Age	83.98 (6.43) 70-101
LOS	5.40 (4.66) 1-30
# of past admissions in 12m	0.81 (1.19) 0-5
# of past ED visits in 12m	0.70 (1.38) 0-10

Table 1 Continued **Variable**	**n (%)**
Male	53 (42.1%)
Black (vs. White)	57 (45.2%)
Married (vs. Not Married)	77 (61.1%)
Living arrangement before hospitalization	
Alone	15 (11.9%)
With a caregiver	73 (57.9%)
In a facility	38 (30.2%)
Severity of Cognitive Impairment	
Mild	36 (28.6%)
Moderate to Severe	90 (71.4%)
Mobility Status	
Unassisted	25 (19.8%)
Cane/Walker	66 (52.4%)
Wheelchair	21 (16.7%)
Unknown	14 (11.1%)
Admitted for surgery	42 (33.3%)
Readmitted within 30 days	22 (17.5%)
Disposition	
Home Alone	2 (1.6%)
Home with Home Health	21 (16.7%)
With a caregiver	27 (21.4%)
Rehab Facility	8 (6.3%)
Skilled Nursing Facility	66 (52.4%)
Short Term Hospital	2 (1.6%)
Discharged to higher level of care than pre-admission	62 (49.2%)

4.4.2 Transitional Care

The transitional care provided to the sample is summarized in Table 4.2. As stated earlier, some of the 10 transitional care actions in the Ideal Transitions in Care framework had sub-actions and for this analysis these sub-actions, when present, were coded and analyzed. The majority of patients received discharge planning (99.21%) and had the required pieces of information in their discharge summaries (96.83-100%). All patients were assessed for delirium with the Richmond Agitation-Sedation Scale (RASS) and for a majority of patients providers used teach-back (96.83%) and coordinated care without other providers outside of the hospital (89.68%). Furthermore, providers took accurate medication histories (60.32%), reconciled medications during the hospitalization (96.03%), provided education about medication changes (98.41%), and generally educated patients about their medications (76.98%) for a majority of patients.

Table 4.2 Transitional Care Provided to Patients with Dementia (N=126)

Variable	n (%)
Discharge Planning	125 (99.21%)
Discharge Summary included	
Diagnoses	125 (99.21%)
Discharge medications	126 (100%)
Procedure results	124 (98.41%)
Follow-up needs	122 (96.83%)
Pending test results	7 (5.56%)
Discharge Summary was available to PCP	26 (20.63%)
Accurate medication history taken	76 (60.32%)
Medications were reconciled throughout hospitalization	121 (96.03%)
Medication changes were discussed with patient or caregiver	124 (98.41%)
Number who understood education	55 (43.65%)
Patient or Caregiver educated about	
In-hospital medications	97 (76.98%)
Number who understood education	28 (22.22%)
Diagnoses	57 (45.24%)
Follow-up needs	53 (42.06%)
Whom to contact after discharge	51 (40.48%)
Post-discharge medication regimen	59 (46.83%)
Post-discharge medication side effects	3 (2.38%)
Post-discharge symptoms	52 (41.27%)
Post-discharge adverse events	9 (7.14%)
Patient or Caregiver asked about any post-discharge management challenges	7 (5.56%)
Teach-back used during education	122 (96.83%)
Printed educational materials used	66 (52.38%)
Patient assessed for delirium or dementia	126 (100%)
Arranged social or community support post-discharge	3 (2.38%)
Advanced Care Planning	35 (27.78%)
Coordinated with providers outside of the hospital	113 (89.68%)
Outpatient follow-up scheduled with specialty provider	44 (34.92%)
Outpatient follow-up scheduled with PCP	30 (23.81%)

However, while a majority of patients received education about their medication changes and in-hospital medications, only 22.22 - 43.65% understood this education, according to the results of the teach-back providers recorded in the charts. Other areas of education that were also not routinely provided to patients included education on diagnoses (45.25%), follow-up needs (42.06%), whom to contact after discharge if problems arise (40.48%), post-discharge medication regimen (46.83%), post-discharge medication side effects (2.38%) and symptoms (41.27%) to be aware of, and possible post-discharge adverse events (7.14%).

Providers sent patients' discharge summaries to their primary care providers for 20.63% of patients and follow-up appointments were scheduled prior to discharge with primary care providers for 23.81% patients. Follow-up appointments were scheduled with specialty providers for 34.92% of patients and advanced care planning was provided to 27.78% of patients.

4.4.3 Variation in Transitional Care

All transitional care actions were tested for their association with five key demographic variables: gender, race, severity of dementia, surgical vs. non-surgical visit, and dispositions. The results of these analyses are presented in Appendices C-G.

Patients who were admitted for a surgical procedure differed from patients admitted for a non-surgical reason on a number of transitional care actions. Providers were significantly less likely to send patients' discharge summaries to primary care physicians for surgical patients compared to non-surgical patients (4.9% vs. 28.6%; χ^2 (1,N=125)=8.01, *p*=0.03). Providers were significantly more likely to make follow-up appointments with specialty providers for surgical patients compared to non-surgical patients (92.6% vs. 43.2%; χ^2 (1,N=71)=15.30, *p*<.0001). Conversely, providers were significantly less likely to make follow-up appointments with primary care providers for surgical patients compared to non-surgical patients (3.7% vs. 65.9%, χ^2 (1,N=71)=24.05, *p*<.0001).

Follow-up appointments also differed significantly between black and white patients and patients with different dispositions. Providers were significantly less likely to make follow-up appointments with *specialty* providers for black patients compared to white patients (42.9% vs. 80.6%, χ^2 (1,N=71)=9.16, *p*=0.013). Providers were also significantly less likely to make follow-up appointments with *primary care* providers for patients discharging to a facility compared to patients discharged home with caregivers or home health (11.8% vs. 41.7%, χ^2 (2,N=71)=13.26, *p*=0.012).

Numerous other differences were found between patients discharged to a facility compared to patients discharged home with caregivers or home health. Patients discharged to a facility were also less likely to understand the medication education provided to them (72.4% vs. 37.5%, χ^2 (2,N=126)=17.48, *p* <.0001) and have social or community supports discussed with them (7.9% vs. 45.8%, χ^2 (2,N=126)=25.08, *p* <.0001). Providers in the hospital were more likely to communicate with providers outside the hospital for patients discharged to a facility compared to those discharged home with caregivers or home health (97.4% vs. 77.1%, χ^2 (2,N=126)=13.32, *p* =0.03).

Patients with moderate to severe dementia were also less likely to understand the education they received compared to patients with mild dementia (31.1% vs. 69.4%, χ^2=13.97(1), p=0.0002).

None of the other comparisons were significantly associated.

4.4.4 Transitional Care Providers

The providers delivering transitional care were also studied. While the above analysis included any transitional care sub-actions of the 10 parent actions in the Ideal Transitions in Care framework, for this analysis only the 10 parent actions were analyzed. These results can be found in Table 4.3 and are summarized below.

Table 4.3. The percent of patients with whom providers were involved for transitional care

Transitional Care Action	Provider				
	SW	CM	APRN	RN	MD
Discharge Planning	78.4	96.0	0.80	7.20	4.00
Complete Communication of Information	0.79	0.00	36.51	90.48	100.00
Availability, Timeliness, Clarity, and Organization of Information	4.80	14.4	36.0	90.40	100.00
Medication Safety	0.00	0.00	33.33	95.24	92.86
Patient Education and Promotion of Self-Management	7.94	3.97	11.11	99.21	14.29
Social and Community Supports	28.57	82.14	0.00	0.00	3.57
Advanced Care Planning	97.14	20.00	0.00	11.43	2.86
Coordinating Care Among Team Members	69.03	46.90	0.88	38.94	3.54
Monitoring and Managing Symptoms After Discharge	2.40	1.60	16.00	90.40	32.80
Outpatient Follow-up	2.74	39.73	15.07	23.29	4.11

Percent based on total number of patients who received that transitional care action

Case managers and social workers were the primary providers of discharge planning, with case managers being involved in the discharge planning for 96% of patients and social workers for 78.4%. Case managers and social workers were also the primary providers to coordinate care with providers outside of the hospital (case managers in 46.9% of patients, social workers in 69.03% of patients), discuss or utilize social or community supports (case managers in 82.14% of patients who received it, social workers in 28.57%), and provide advanced care planning (case managers in 20% of patients who received it, social workers in 97.14%).

Registered nurses were the primary providers for a number of transitional care actions including medication safety (RNs involved in 95.24% of patients), patient education and promotion of self-management (RNs involved in 99.21% of patients), and monitoring and managing symptoms after discharge (RNs involved in 90.40% of patients). Physicians were the primary providers of the action of complete communication of information (physicians involved in 100% of patients) and ensuring the availability, timeliness, clarity, and organization of the information (physicians involved in 100% of patients).

These results are contextualized by the feedback from providers. All of the same providers who were interviewed before data collection were interviewed after analyses were completed except for the physician who was lost to follow-up.

The providers all agreed that the results of the chart review were consistent with what they saw in their day-to-day clinical practice. This consistency was quantified by comparing what providers said they did or did not do routinely in their first interviews and what they were found to do or not do in the chart data. Specifically, each provider was asked about each transitional care action from the Ideal Transition in Care Framework and whether or not they routinely provided that action. Then each type of provider involved in each transitional care action was extracted from the chart data. Because there were some instances where a provider type was involved in only a few patients for certain transitional care actions, we used a cutoff of the top two most frequent provider types for each action. Therefore, for a provider type to count as having provided a transitional care action for the purposes of comparing interview data to chart data that provider type had to be one of the top two primary providers for that transitional care action. For example, both social workers interviewed said they routinely provide discharge planning to patients and social workers were one of the top two provider types routinely providing discharge planning according to the chart data. Therefore, this was counted as a match between the interview data and the chart data. Similarly, the nurse interviewed said she did not routinely discuss social and community supports with patients and nurses were not in the top two provider types for this transitional care action therefore this was also counted as a match. An example of a mismatch is how both nurse practitioners said they routinely provide discharge planning to patients but the chart data revealed nurse practitioners were involved in less than 1% of patients' discharge planning. Therefore this was counted as a mismatch. Overall the interview and chart data matched 62.2% of the time. The results of this comparison of interview and chart data are found in Appendix H.

4.5 DISCUSSION AND IMPLICATIONS

The primary purpose of this study was to describe and better understand the transitional care delivered to patients with dementia. The results presented above were discussed with the same hospital providers who were interviewed prior to data collection (with the exception of the physician who was lost to follow-up) and their responses offer valuable context to the results.

The main findings revealed that a majority of patients are receiving discharge planning, have the appropriate and necessary information included in their discharge summaries, are assessed for delirium, and educated about their medications. In-hospital providers are also coordinating and communicating with providers outside of the hospital for a majority of patients. Patients are less likely to receive education about their diagnoses, follow-up needs, whom to contact after discharge if problems arise, or how to manage their medications, side effects, symptoms, or adverse events after discharge. For a majority of patients, providers do not send patients' discharge summaries to their primary care physicians nor do they make follow-up appointments with primary or specialty care providers.

4.5.1 Implications for Practice

To our knowledge, transitional care provided to patients with dementia has not previously been studied thus there are no results in the literature to compare and contrast our results with. However, based on the provider interviews, the accuracy of these results are mixed. Providers stated that all results indicating the transitional care a majority of patients receive (discharge planning, education about medication, etc.) are consistent with what they see in their day-to-day practice. Where the results fall short of real-world practice, according to the providers, however, is with the education provided to patients. Providers stated that patients are educated on their diagnoses and post-discharge medications, follow-up needs, side effects, symptoms, and adverse events. One registered nurse stated they (RNs) "always" go over discharge paperwork with patients including post-discharge medications, symptoms, and adverse events. The nurse continued saying when they do this they are "especially noting any upcoming follow-up appointments".

One caveat to this, according to the same nurse, is for patients discharged to facilities. For these patients, education is "less important" because patients will be under the supervision of healthcare providers after leaving the hospital. Indeed patients who were discharged to a facility and patients who were admitted for surgery received significantly different transitional care suggesting these differences may be key points for future providers to make note of when delivering transitional care. There is a growing body of literature on how hospitals can utilize basic patient-level data to trigger different care processes [44, 45]. Whether a patient is having surgery or not, for example, could serve as an easily identifiable and available data point to trigger the delivery of specific transitional care actions such as sending the patient's discharge summary to his or her primary care physician (something that our results showed was significantly less likely to happen in this population).

The nurse also stated that for patients with severe dementia, education about follow-up needs or care was not a top priority because the patients were unable to understand the education. This distinction of whether or not patients understand the education is an important one when studying transitional care among patients with dementia. Our results showed that despite a majority of patients receiving education about their medications, at the most only 43.65% understood that education. Therefore one could argue that the patients who did not understand their education did not in effect receive any education at all. An incidental but illuminating finding related to this idea was that, out of all 126 patients, none of the discharge summaries or educational materials were assessed or tailored to patients' literacy, health literacy, or cognition levels. If providers are not prioritizing the education of patients with severe dementia perhaps an increased effort to tailor materials to cognition level would improve understanding among this population and would motivate providers to provide education to this population. This process is already called for in an existing transitional care intervention, Project Reengineering Discharge [20, 46].

4.5.2 Implications for Implementation

Understanding which transitional care actions are being provided also has implications for future implementation efforts. For example, existing transitional care interventions feature many of the transitional care actions providers are already implementing including education about post-discharge symptoms and adverse events [14] or coordinated communication with primary care physicians [18]. However, other components of existing interventions are not currently being provided including scheduling follow-up appointments [14] and making post-discharge phone calls to check in with patients [20]. Understanding which transitional care actions are already routine daily practice for providers and which actions will require a change to daily practice can prepare researchers, administrators, and other stakeholders for how acceptable, appropriate, or feasible [47] a given intervention might be to providers and what areas of an intervention may need particular attention paid to them to increase implementation. For example, if hospital administrators aim to implement a transitional care intervention that includes discharge planning, assessing patients' cognition, tailoring educational materials, providing education, making follow-up appointments with primary care physicians, and calling the patients two weeks post-discharge to check in, some of these actions may be more easily implemented than others because some of these actions are already being done and others will be new, additional actions for providers.

Related to this idea, this study aimed to understand which providers were primarily providing specific transitional care actions so that future implementation efforts could be as congruent with current practice as possible. This study found that social workers and case managers were primarily involved in discharge planning, communicating with providers outside the hospital, advanced care planning, providing social and community supports, and making follow-up appointments with primary care providers. Registered nurses were the primary providers of patient education and medication safety while physicians were primarily involved with ensuring the necessary information was available in the discharge summary and that discharge summary was available in the chart. However, the interviews conducted with providers about these results revealed many nuances to this information.

All providers interviewed agreed that social workers and case managers were the primary providers of discharge planning and coordinating patients' discharges to facilities or home with home health. The results of the chart review revealed that a case manager was meeting with every patient within 24 hours of the patient being admitted and assessing the patient's potential discharge needs. If the patient were likely to discharge to a facility, the case manager would contact the social worker who would take over facilitating this transfer. If the patient were likely to be discharged home with home health services, the case manager would facilitate this and not contact the social worker for discharge planning needs. Both the case manager and the social workers who were interviewed confirmed this "triage" method. However, the case manager and the social workers stated there were exceptions to this rule. For example, the case manager stated that on the weekends the case manager on duty is responsible for not only the initial assessments but also the discharge planning therefore the case manager does not always have the time to conduct the initial assessment with every patient. Similarly, the social workers stated that while they may not be called for discharge planning needs for those patients expected to discharge home, they might be called to see those patients for other reasons.

For example, one social worker said they receive referrals to provide advance care planning including establishing surrogate decision makers through advanced directives or durable power of attorney orders as well as to screen for various forms of abuse or neglect. The social worker said these activities are not routinely documented in the chart (indeed these actions were not found in the chart review) but are happening on a routine basis. The other social worker interviewed stated that any "family situation" that arises also falls under the responsibilities of the social worker: "If there is a situation that needs to be resolved and no one can or knows how to do it, they call us."

With regards to case managers and social workers being the ones primarily involved in communicating and coordinating with providers outside of the hospital, the case manager and social workers interviewed stated this was true for patients discharged to facilities but not always true for patients discharged home. For patients discharged home, the only outside-the-hospital provider to be contacted were patients' primary care physicians when sending discharge summaries and making follow-up appointments. In these instances, the case manager stated who does these actions depends on the particular unit or floor: "On my unit (an orthopaedic surgery unit), it's the nurse practitioner who does those things but on medicine (a medical unit), it's the case managers."

This nuanced view of how, when, and why social workers and case managers come to interact with patients is important for future implementation efforts. For example, two of the most well-known existing transitional care interventions use advanced practice registered nurses to deliver the interventions [14, 15, 17, 18] and another well-known intervention uses a nurse and pharmacist [20, 46]. This conflicts with the results of this study, which show that social workers, case managers, and registered nurses are the primary providers of all transitional care actions. Advanced practice registered nurses were not the primary provider of any transitional care action.

During the interviews, however, nurse practitioners stated that they are highly involved in medication reconciliation, medication review, and completing discharge paperwork and while these patterns did not appear in the chart review it is important to note that they may have a key role in transitional care. Nonetheless, social workers, case managers, and nurses are not commonly used to deliver existing transitional care interventions yet are the common providers of key critical transitional care actions including discharge planning. Future implementation efforts must take into account current provider roles if implementation is to be successful. For example, at most, advanced practice registered nurses are involved in the more clinically-based transitional care actions (e.g., medication review and reconciliation) and if they are asked to begin implementing discharge planning or communicating with providers outside of the hospital, in addition to their regularly provided actions, they may become overburdened or may feel unqualified to perform these actions, leading to feelings that the intervention is neither feasible nor acceptable to implement. Alternatively, if advanced practice registered nurses are asked to implement only the components of transitional care intervention that fit with their current day-to-day practice and social workers and case managers are asked to implement components such as discharge planning and making follow-up appointments, this will cause the least disruption to providers’ current roles and the intervention may be more successfully implemented.

4.6 Limitations

This study is not without its limitations. As with all studies using medical chart data, the validity and reliability of the results are dependent on the accuracy and completeness of the information providers enter into the medical chart. However, the post-analysis interviews with providers suggest that the results from the chart review are relatively accurate. Second, this study was conducted with data and providers from a single hospital and the results may not be very generalizable. The results may differ in other hospitals particularly privately owned hospitals and rural hospitals. Lastly, due to the small sample size, analysis could not be conducted on the relationship between transitional care and patient outcomes such as readmissions. Future research can address these limitations by conducting larger, multisite studies to yield more data with more variation and incorporate other forms of data (e.g., direct observation) to supplement the chart review.

4.7 Conclusion

Despite these limitations, this study has important implications for current practice and future implementation efforts. Hospital administrators and providers should immediately begin tailoring their discharge paperwork and educational materials to literacy and cognition level given there is ample evidence that this increases understanding and improves patient outcomes [48-51]. Before researchers consider whether new transitional care interventions are needed that highlight the actions found to be under-delivered in this study, immediate research is needed on whether the variation found in this study is associated with negative or poor outcomes. In other words, perhaps whether or not the patient has a scheduled follow-up appointment at the time of discharge does not impact whether or not the patient is readmitted, thus creating new interventions that seek to reinforce and increase this action may not be needed.

Once current interventions are tailored or new interventions are created, strategies to implement these interventions should be based on the information from this study related to the current delivery process of transitional care in this population. This includes which providers are leading which transitional care actions and the flow of delivery (e.g., case managers triage patients' discharge needs during first 24 hours). By tailoring the implementation strategies to the current process the interventions stand the best chance to be adopted into routine practice and improve the outcomes of older adult patients with dementia.

4.8 References

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Chapter 5: Conclusion

5.1 Introduction

This dissertation work produced a number of key findings that have important implications. Equally important is situating these findings within the current literature and future practice, policy, and implementation efforts. Furthermore, thoughtful planning of future research is necessary to ensure the efforts of this dissertation are fully realized.

5.1.1 Summary of key findings

Key transitional care differences were found between patients with and without dementia. Patients with dementia were significantly less likely to receive education about follow-up needs and were less likely to understand any education they received. Providers echoed these findings stating that they were less likely to provide education to patients with severe dementia because they would not understand it anyway. Dementia patients were also more likely to be admitted from and discharged to facilities such as a skilled nursing facility. This difference influenced the transitional care these patients received in terms of in-hospital providers coordinating with providers outside of the hospital, making follow-up appointments for patients, and whether or not social workers were involved in the discharge planning. This pattern was also found among a sample of only dementia patients. Overall, the variation in transitional care provided to patients could largely be explained by whether the patient was being discharged to a facility compared to patients discharged home alone or with assistance.

5.2 Theoretical and Empirical Implications

5.2.1 Transitions Theory

One of the most frequently cited theories in transitional care is Meleis' Transitions Theory [99, 100]. Transitions Theory provides a broad view of transitions separated into three components: (1) the nature of the transition, (2) the conditions of the transition, and (3) the pattern of response. The nature of the transition includes type of transition, patterns in transitions, and the experience of the transition. The conditions of transitions are considered the barriers and facilitators to a successful transition and include the meaning (of the transition to those involved), cultural beliefs and attitudes, socioeconomic status, and preparation and knowledge. Patterns of response to transitions include process indicators and outcome indicators.

The results of this dissertation work directly relate to the nature and conditions of the transition. Patients who were admitted from and discharged to facilities had significantly different transitional care provided to them compared to other patients. This outcome changes the nature and conditions of the transition and thus changes the transitional care needed and provided. Thus instead of tailoring interventions for patients with dementia future interventions should perhaps be tailored to patients' disposition. Specifically, in-hospital providers should identify patients upon admission who are likely to be discharged to a facility and focus on transitional care actions that have been shown in this study to be lacking in this population such as educating the patient about follow-up care and making follow-up appointments with primary care physicians.

5.2.2 Health Literacy and Cognition

An incidental but striking finding of this dissertation work is that none of the discharge paperwork or educational materials provided were tailored to patients' literacy, health literacy, or cognition levels. This is not necessarily a surprising finding given that assessing patients' literacy levels and tailoring materials accordingly is not a component of the majority of existing transitional care interventions. Health literacy is defined as, "ability to obtain, communicate, process and understand the basic health information and services needed to make appropriate health decisions" [101]. Barriers to health literacy screening and interventions have been reported, including a lack of time and knowledge of interventions [102]. Furthermore, physicians have reported that screening for health literacy levels among older adults can be hindered by cognitive issues and acuity of illness upon admission [103]. Low health literacy is a significant problem for older adults and is linked to poor health outcomes, decreased ability to self-manage chronic conditions, increased hospital and ED visits, and difficulty managing medications and understanding discharge instructions [81, 104-106]. The effects of low health literacy, once established, can be mitigated by directly changing the design and presentation of documents, numerical data, and adding pictorial representations, and more indirectly through patient education, providing oral as well as written instructions, and assessing for understanding [103, 107]. Even assessing a patient's health literacy level and recording a communication need in the medical record can have a positive effect on physicians' future communication with the patient [103].

Thus while this study's findings are consistent with the literature, it is still imperative that this oversight be noted. Future transitional care interventions should emphasize assessing literacy and cognition levels and tailoring education accordingly. This may increase improve patient outcomes and may also increase providers' willingness to provide education to patients. Providers in this study stated they did not prioritize providing education to patients with severe dementia because they would not understand that education but perhaps if the education is tailored in a way that increases understanding providers will then be more motivated to make this a routine transitional care action.

5.2.3 Transitional Care in Social Work

Social workers have been involved in transitional care – sometimes referred to as care coordination or discharge planning – for over 100 year [108-110] and this work suggests they are still integral to this process. Social workers were the primary providers to communicate and coordinate care with providers outside of the hospital and to provide advance care planning to patients and their families. Social workers were also involved in over 75% of patients' discharge planning.

This is an important point because many of the existing transitional care interventions do not utilize social workers and are instead designed around and delivered by advanced practice nurses. While advanced practice nurses were found to deliver some transitional care actions, they were not involved in the discharge planning, communicating and coordinating with providers outside of the hospital, or engaging social or community supports – key transitional care actions according to existing frameworks [18, 111]. Social work researchers have recently begun studying social-work-led transitional care interventions [63] and the results of this study should be used as evidence that this is a valuable line of research to pursue. Social work researchers should engage with investigators from related fields such as nursing and occupational therapy to ensure future transitional care interventions represent the number of different disciplines involved in delivering transitional care in routine practice. Social work practitioners should use the results of this study to advocate for their roles in hospitals and the need for reimbursement and compensation for the transitional care they provide.

The roles of transitional care providers are also an important concept with regards to future implementation efforts. As stated in earlier chapters, identifying the current providers of transitional care and using that information to design implementation strategies could increase the success of that implementation effort. Specifically, utilizing social workers and advanced practice nurses, along with registered nurses and case managers, in the roles they currently serve related to transitional care will make the intervention more acceptable and feasible.

5.3 Future Research

The need for future research has been discussed in earlier chapters but in this conclusion I will briefly discuss my personal future research plans and goals related to this specific study and beyond.

Upon the successful completion of my degree requirements and graduation, I will begin a post-doctoral fellowship at the Center for Clinical Quality and Implementation Research at Vanderbilt University's School of Medicine. Under the mentorship of Dr. Sunil Kripalani, I will have extensive support to pursue transitional care research. Dr. Kripalani was a key author of the Ideal Transitions in Care framework and has published extensively in the field of transitional care and hospital readmissions. Dr. Kripalani is also charged with increasing the capacity of implementation science research conducted at the University and the Center thus I will be encouraged to pursue implementation science research related to transitional care. Additionally, Vanderbilt's Center for Quality Aging, directed by Drs. Sandra Simmons and John Schnelle, also has a long history of conducting transitional care research and the directors have expressed interest in collaborating. Together, I will be in a rich environment to continue this line of research.

Specifically, I will begin by analyzing the data from this dissertation study related to social network analysis. While not collected for the purpose of this dissertation, data were collected on the communication or collaboration between providers and patients/caregivers when providing transitional care. These data will be analyzed with social network analysis methods and the result will be a descriptive, theoretical network of key stakeholders in transitional care. This information will be important in terms of future implementation efforts to once again ensure implementation strategies are as congruent as possible with current practice thus making the intervention more acceptable, appropriate, or feasible.

One of the limitations to this dissertation study is its single-site design. One of the first projects I would like to conduct a replication study in another large, urban teaching hospital and a rural hospital. Vanderbilt Health Affiliated Network is comprised of over 60 hospitals across Tennessee and a few in Arkansas, Mississippi, Virginia, and Kentucky. Through this powerful network I will have access to a large sample size from a variety of hospitals through which I can study the variation in transitional care provided to older adults with dementia. This larger sample would also allow me to study if and how variation in transitional care is associated with patient outcomes including disposition and hospital readmission.

The qualitative interviews conducted in this dissertation yielded rich and interesting data from real-world providers. I would like to expand upon this as well in a future study. Using the results from this dissertation as pilot data, I would like to understand more about how providers make decisions regarding which patients are “priorities” for receiving various transitional care actions, how providers view their roles and the roles of other providers, and what are the potential barriers and facilitators to implementing transitional care interventions.

Long-term as I work towards tenure, I would like to move beyond understanding the current process of delivering transitional care and into the implementation of transitional care interventions including the de-implementation of ineffective actions. This area is currently vastly understudied and given the intense focus on how to reduce healthcare costs, improve efficiency and effectiveness, and reduce hospital readmissions, implementing transitional care actions has significant potential. In tandem, I would also like to investigate transitional care policy implementation, meaning how can we disseminate findings and knowledge about transitional care to policymakers and directly influence policy change. One avenue I am interested in pursuing related to this is the Health and Aging Policy Fellows Program, which is a one-year fellowship where researchers receive the experience and skills necessary to translate research and practice evidence into sound health policy for older adults.

5.4 Conclusion

This dissertation work revealed important findings related to the delivery of transitional care to older adults with dementia and these findings have important implications for future research, practice, and policy. I will build upon these findings both in my immediate post-graduation research plans as well as long-term career goals. Ultimately, this dissertation marks the beginning of what I hope to be a lifetime of working to improve the healthcare for older adults.

5.5 References

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Appendix A

Operationalization and Adaptation of Variables

Ideal Transition in Care Framework Definition	**Operationalization**	**Action and Sub-actions**
Discharge Planning: Planning ahead for hospital discharge while the patient is still being treated in the hospital. Includes collaborating with the outpatient provider and taking the patient and caregiver's preferences for appointment scheduling into account.	This will be any indication of discharge planning either by completed Discharge Summary form or any mention of "discharge plan/planning" in the free-text documentation.	Action: 1. Discharge Planning No sub-actions
Complete Communication of Information: The content that should be included in the discharge summaries and other means of information transfer from hospital to post-discharge care.	At a minimum, the following information (coded as sub-actions) should be included in the discharge summary or documentation: (1) Primary and secondary diagnoses, (2) discharge medications, (3) results of procedures, (4) follow-up needs, and (5) Pending test results.	Action: 2. Complete Communication of Information Sub-actions are items found in discharge summary: 2.1 Diagnoses 2.2 Discharge medications 2.3 Results of procedures 2.4 Follow-up needs 2.5 Pending test results
Availability, Timeliness, Clarity, and Organization of Information: The availability, timeliness, clarity, and organization of the information above ensure post-discharge providers can access and quickly understand the information before assuming care of the patient.	All information will be considered *available* since it was by nature available in the medical record. The information will be considered *timely* if there is any indication the Discharge Summary form was provided to the PCP prior to discharge or first scheduled follow-up appointment. The *clarity and organization* of the information will be coded if the Discharge Summary or note contains sub-headings or bullet-points.	Action: 3. Availability, Timeliness, Clarity, and Organization of Information Sub-actions: 3.1 Discharge summary existed 3.2 Discharge summary sent to PCP 3.3 Discharge summary contained sub-headings or bullet points
Medication Safety: (1) Taking an accurate medication history, (2) reconciling changes throughout hospitalization, and (3) communicating the reconciled medication regimen to patients and providers across transitions of care.	One of the three sub-actions indicated either by completed Discharge Medication Report or mention of "medication history" or "medication reconciliation" or mention of discussing medications with patient or PCP in free-text documentation.	Action: 4. Medication Safety Sub-actions 4.1 Accurate medication history taken 4.2 Medications reconciled during hospitalization Changes in medications communicated to patient

Patient Education & Promotion of Self-Management: Teaching patients and their caregivers about (1) the main hospital diagnoses and instructions for self-care, including (2) medication changes, (3) appointments, and (4) whom to contact if issues arise. Confirming comprehension of instructions through (5) assessment of delirium and dementia and (6) teach-back, and (7) providing educational materials that are appropriate to the patient and caregiver's level of health literacy and preferred language are important.	One of these seven sub-actions indicated by either completed form or mention in the free-text documentation.	Action: 5. Patient Education Sub-actions: 5.1 Patient/Caregiver educated about diagnoses 5.2 Patient/Caregiver educated about medication changes 5.3 Patient/Caregiver educated about follow-up appointments 5.4 Patient/Caregiver educated about whom to contact after discharge 5.5 Patient assessed for delirium or dementia 5.6 Provider assessed patient's understanding with teach-back 5.7 Provider used educational materials with patient or gave materials to patient
Social and Community Supports: Enlisting the help of these supports is crucial for assisting patients with household activities, meals, and other necessities during recovery.	Any indication - by either completed form or mention in documentation – of contacting, enlisting, or utilizing community and social supports.	Action: 6. Social and Community Supports No sub-actions
Advance Care Planning: May begin in hospital or outpatient setting and involves (1) establishing goals of care and (2) health care proxies, as well as (3) engaging with palliative or hospice care if appropriate.	One of these sub-actions indicated by either completed form or mention in the free-text documentation.	Action: 7. Advance Care Planning Sub-actions: 7.1 Establishing goals of care 7.2 Establishing health care proxies Engage with palliative or hospice care if appropriate
Coordinating Care Among Team Members: Synchronizing efforts across settings and providers is vital as they coordinate information, assessments, and plans as a team.	This will be any indication of communication between the hospital and any outside providers either by completed form or mention in the free-text documentation.	Action: 8. Coordinating Care Among Team Members No sub-actions

Monitoring and Managing Symptoms after Discharge: Monitoring for new or worsening symptoms, medication side effects, discrepancies, or non-adherence, and other self-management challenges.	Any indication the patient/caregiver was educated on any one of these sub-actions: (1) Post-discharge symptoms, (2) Post-discharge medication side effects, (3) Medication regimen, (4) Inquired about other self-management challenges.	Action: 9. Monitoring and Managing Symptoms after Discharge Sub-actions: 9.1 Patient/Caregiver educated about post-discharge symptoms 9.2 Patient/Caregiver educated about post-discharge medication side effects 9.3 Patient/Caregiver educated about post-discharge medication regimen 9.4 Provider inquired about self-management challenges with Patient/Caregiver
Outpatient Follow-up: Appropriate and prompt post-discharge appointments with providers who have a longitudinal relationship with the patient.	This will be any indication of scheduled follow-up appointments with either the patient's PCP or a specialty provider by completed form or mention in free-text documentation.	Action: 10. Outpatient Follow-up Sub-actions: 10.1 Follow-up made with PCP 10.2 Follow-up made with Specialty Provider

Appendix B

ICD-9 Diagnosis Codes Used to Identify Sample

Name	Code
Variant Creutzfeldt-Jakob Disease	46.11
Other and Unspecified Cruetzfeldt-Jakob Disease	46.19
Senile Dementia Uncomplicated	290
Presenile Dementia Uncomplicated	290.1
Presenile Dementia with Delirium	290.11
Presenile Dementia with Delusional Features	290.12
Presenile Dementia with Depressive Features	290.13
Senile Dementia with Delusional Features	290.2
Senile Dementia with Depressive Features	290.21
Senile Dementia with Delirium	290.3
Vascular Dementia, Uncomplicated	290.4
Vascular Dementia with Delirium	290.41
Vascular Dementia with Delusions	290.42
Vascular Dementia with Depressed Mood	290.43
Alcohol-induced persisting dementia	291.2
Dementia in Conditions Classified Elsewhere Without Behavioral Disturbance	294.1
Dementia in Conditions Classified Elsewhere With Behavioral Disturbance	294.11
Alzheimer's Disease	331
Pick's Disease	331.11
Other Frontotemporal Disease	331.19
Senile Degeneration of Brain	331.2
Dementia with Lewy Bodies	331.82

Appendix C

Differences in Transitional Care by Gender Among Patients with Dementia

Transitional Care Actions and Sub-Actions	M	F
Discharge Planning	52 (98.1%)	73 (100%)
Discharge Summary included		
Diagnoses	53 (100%)	72 (98.6%)
Discharge medications	53 (100%)	73 (100%)
Procedure results	53 (100%)	71 (97.3%)
Follow-up needs	52 (98.1%)	70 (95.9%)
Pending test results	3 (5.7%)	4 (5.5%)
Discharge Summary was available to PCP	10 (18.9%)	16 (22.2%)
Accurate medication history taken	31 (58.5%)	45 (61.6%)
Medications were reconciled throughout hospitalization	50 94.3%)	71 (97.3%)
Patient or Caregiver educated about		
In-hospital medications	53 (100%)	71 (97.3%)
Number who understood education	28 (52.8%)	25 (34.2%)
Diagnoses	24 (45.3%)	33 (45.2%)
Follow-up needs	21 (39.6%)	32 (43.8%)
Whom to contact after discharge	20 (37.7%)	31 (42.5%)
Post-discharge medication regimen	41 (77.4%)	56 (76.7%)
Post-discharge medication side effects	1 (1.9%)	2 (2.7%)
Post-discharge symptoms	21 (39.6%)	31 (42.5%)
Post-discharge adverse events	5 (9.4%)	4 (5.5%)
Patient or Caregiver asked about any post-discharge management challenges	3 (5.7%)	4 (5.5%)
Teach-back used during education	51 (96.2%)	71 (97.3%)
Printed educational materials used	35 (66.0%)	31 (42.5%)
Patient assessed for delirium or dementia	53 (100%)	73 (100%)
Arranged social or community support post-discharge	15 (28.3%)	13 (17.8%)
Advanced Care Planning	18 (34.0%)	17 (23.3%)
Coordinated with providers outside of the hospital	46 (86.8%)	67 (91.8%)
Outpatient follow-up scheduled with specialty provider	17 (32.1%)	27 (37.0%)
Outpatient follow-up scheduled with PCP	10 (18.9%)	20 (27.4%)
Significant at an adjusted alpha of 0.002 No significant differences		

Appendix D

Differences in Transitional Care by Race Among Patients with Dementia

	Race		
Transitional Care Actions and Sub-Actions	**Black**	**White**	**Significance**
Discharge Planning	57 (100%)	68 (98.6%)	
Discharge Summary included			
Diagnoses	56 (98.2%)	69 (100%)	
Discharge medications	57 (100%)	69 (100%)	
Procedure results	56 (98.2%)	68 (98.6%)	
Follow-up needs	55 (96.5%)	67 (97.1%)	
Pending test results	2 (3.5%)	5 (7.2%)	
Discharge Summary was available to PCP	17 (29.8%)	9 (13.2%)	
Accurate medication history taken	31 (54.5%)	45 (65.2%)	
Medications were reconciled throughout hospitalization	56 (98.2%)	65 (94.2%)	
Patient or Caregiver educated about			
In-hospital medications	56 (98.2%)	68 (98.6%)	
Number who understood education	21 (36.8%)	32 (46.4%)	
Diagnoses	23 (40.4%)	34 (49.3%)	
Follow-up needs	18 (31.6%)	35 (50.7%)	
Whom to contact after discharge	17 (29.8%)	34 (49.3%)	
Post-discharge medication regimen	43 (75.4%)	54 (78.3%)	
Post-discharge medication side effects	0	3 (4.3%)	
Post-discharge symptoms	16 (28.1%)	36 (52.5%)	
Post-discharge adverse events	2 (3.5%)	7 (10.1%)	
Patient or Caregiver asked about any post-discharge management challenges	2 (3.5%)	5 (7.2%)	
Teach-back used during education	54 (94.7%	68 (98.6%)	
Printed educational materials used	25 (43.9%)	41 (59.4%)	
Patient assessed for delirium or dementia	57 (100%)	69 (100%)	
Arranged social or community support post-discharge	11 (19.3%)	17 (24.6%)	
Advanced Care Planning	17 (29.8%)	18 (26.1%)	

Coordinated with providers outside of the hospital	52 (91.2%)	61 (88.4%)	
Outpatient follow-up scheduled with specialty provider	15 (26.3%)	29 (42.0%)	χ^2=9.16(1), p=0.001
Outpatient follow-up scheduled with PCP	20 (35.1%)	10 (14.5%)	
Significance at an adjusted alpha level of 0.002			

Appendix E

Differences in Transitional Care by Dementia Severity Among Patients with Dementia

	Severity		
Transitional Care Actions and Sub-Actions	**Mild**	**Moderate to Severe**	**Significance**
Discharge Planning	35 (97.2%)	90 (100%)	
Discharge Summary included			
Diagnoses	36 (100%)	89 (98.9%)	
Discharge medications	36 (100%)	90 (100%)	
Procedure results	36 (100%)	88 (97.8%)	
Follow-up needs	35 (97.2%)	87 (96.7%)	
Pending test results	2 (5.6%)	5 (5.6%)	
Discharge Summary was available to PCP	8 (22.9%)	18 (20.0%)	
Accurate medication history taken	26 (72.2%)	50 (55.6%)	
Medications were reconciled throughout hospitalization	35 (97.2%)	86 (95.6%)	
Patient or Caregiver educated about			
In-hospital medications	35 (97.2%)	89 (98.9%)	
Number who understood education	25 (69.4%)	28 (31.1%)	χ^2=13.97(1), p=0.0002
Diagnoses	17 (47.2%)	40 (44.4%)	
Follow-up needs	16 (44.4%)	37 (41.1%)	
Whom to contact after discharge	15 (41.7%)	36 (40.0%)	
Post-discharge medication regimen	27 (75.0%)	70 (77.8%)	
Post-discharge medication side effects	0	3 (3.3%)	
Post-discharge symptoms	14 (38.9%)	38 (42.2%)	
Post-discharge adverse events	2 (5.6%)	7 (7.8%)	
Patient or Caregiver asked about any post-discharge management challenges	0	7 (7.8%)	
Teach-back used during education	34 (94.4%)	88 (97.8%)	
Printed educational materials used	20 (55.6%)	46 (51.1%)	
Patient assessed for delirium or dementia	36 (100%)	90 (100%)	
Arranged social or community support post-discharge	10 (27.8%)	18 (20.0%)	

Advanced Care Planning		
Coordinated with providers outside of the hospital	29 (80.6%)	84 (93.3%)
Outpatient follow-up scheduled with specialty provider	10 (27.8%)	34 (37.8%)
Outpatient follow-up scheduled with PCP	8 (22.2%)	22 (24.4%)
Significance at an adjusted alpha level of 0.002		

Appendix F

Differences in Transitional Care by Surgical Visit Among Patients with Dementia

	Surgical Visit		
Transitional Care Actions and Sub-Actions	**Y**	**N**	**Significance**
Discharge Planning	42 (100%)	83 (98.8%)	
Discharge Summary included			
Diagnoses	42 (100%)	83 (98.8%)	
Discharge medications	42 (100%)	84 (100%)	
Procedure results	41 (97.6%)	83 (98.8%)	
Follow-up needs	42 (100%)	80 (95.2%)	
Pending test results	6 (14.3%)	1 (1.2%)	
Discharge Summary was available to PCP	2 (4.9%)	24 (28.6%)	χ^2=8.01(1), p=0.002
Accurate medication history taken	23 (54.8%)	53 (63.1%)	
Medications were reconciled throughout hospitalization	37 (88.1%)	84 (100%)	
Patient or Caregiver educated about			
In-hospital medications	42 (100%)	82 (97.6%)	
Number who understood education	17 (40.5%)	36 (42.9%)	
Diagnoses	18 (42.9%)	39 (46.4%)	
Follow-up needs	18 (42.9%)	35 (41.7%)	
Whom to contact after discharge	18 (42.9%)	33 (39.3%)	
Post-discharge medication regimen	33 (78.6%)	64 (76.2%)	
Post-discharge medication side effects	2 (4.8%)	1 (1.2%)	
Post-discharge symptoms	18 (42.9%)	34 (40.5%)	
Post-discharge adverse events	1 (2.4%)	8 (9.5%)	
Patient or Caregiver asked about any post-discharge management challenges	2 (4.8%)	5 (6.0%)	
Teach-back used during education	41 (97.6%)	81 (96.4%)	
Printed educational materials used	26 (61.9%)	40 (47.6%)	

Patient assessed for delirium or dementia			
Arranged social or community support post-discharge	11 (26.2%)	17 (20.2%)	
Advanced Care Planning	11 (26.2%)	24 (28.6%)	
Coordinated with providers outside of the hospital	40 (95.2%)	73 (86.9%)	
Outpatient follow-up scheduled with specialty provider	25 (59.5%)	19 (22.6%)	χ^2=15.30(1), p<.0001
Outpatient follow-up scheduled with PCP	1 (2.4%)	29 (34.5%)	χ^2=24.05(1), p<.0001
Significance at an adjusted alpha level of 0.002			

Appendix G

Differences in Transitional Care by Surgical Visit Among Patients with Dementia

	Disposition			
Transitional Care Actions and Sub-Actions	**Home Alone**	**Home w/ Caregiver or Home Health**	**Facility**	**Significance**
Discharge Planning	2 (100%)	47 (97.9%)	76 (100%)	
Discharge Summary included				
Diagnoses	2 (100%)	48 (100%)	75 (98.7%)	
Discharge medications	2 (100%)	48 (100%)	76 (100%)	
Procedure results	2 (100%)	47 (97.9%)	75 (98.7%)	
Follow-up needs	2 (100%)	47 (97.9%)	73 (96.1%)	
Pending test results	0	1 (2.1%)	6 (7.9%)	
Discharge Summary was available to PCP	2 (100%)	48 (100%)	75 (98.7%)	
Accurate medication history taken	1 (50%)	32 (66.7%)	43 (56.5%)	
Medications were reconciled throughout hospitalization	2 (100%)	48 (100%)	71 (93.4%)	
Patient or Caregiver educated about				
In-hospital medications	2 (100%)	46 (95.8%)	76 (100%)	
Number who understood education	2 (100%)	30 (62.5%)	21 (27.6%)	χ^2=17.48(2), p<.0001
Diagnoses	2 (100%)	24 (50.0%)	31 (40.8%)	
Follow-up needs	2 (100%)	23 (47.9%)	28 (36.8%)	
Whom to contact after discharge	1 (50%)	23 (47.9%)	27 (35.5%)	
Post-discharge medication regimen	2 (100%)	41 (85.4%)	54 (71.1%)	
Post-discharge medication side effects	0	1 (2.1%)	2 (2.6%)	
Post-discharge symptoms	1 (50%)	23 (47.9%)	28 (36.8%)	

Post-discharge adverse events				
Patient or Caregiver asked about any post-discharge management challenges	0	4 (8.3%)	3 (3.9%)	
Teach-back used during education	1 (50%)	47 (97.9%)	74 (97.4%)	
Printed educational materials used	2 (100%)	26 (54.2%)	38 (50.0%)	
Patient assessed for delirium or dementia	2 (100%)	48 (100%)	76 (100%)	
Arranged social or community support post-discharge	0	22 (45.8%)	6 (7.9%)	χ^2=25.08(2), p<.0001
Advanced Care Planning	0	10 (20.8%)	25 (32.9%)	
Coordinated with providers outside of the hospital	2 (100%)	37 (77.1%)	74 (97.4%)	χ^2=13.32(2), p=0.002
Outpatient follow-up scheduled with specialty provider	1 (50%)	13 (27.1%)	30 (39.5%)	
Outpatient follow-up scheduled with PCP	1 (50%)	20 (41.7%)	9 (11.8%)	χ^2=13.26(2), p=0.0005

Appendix H

Comparison of Interview Results and Chart Review Results

	SW 1	SW 2	NP 1	NP 2	IP CM	ED CM	RN	MD	Pharm
Discharge Planning	✓	✓	✓	✓	✓	✓	✓	✓	-
Complete Communication of Information	-	-	✓	✓	✓	✓	-	-	-
Availability, Timeliness, Clarity, & Organization	-	-	✓	✓	✓	✓	-	✓	✓
Medication Safety	-	-	✓	✓	-	-	✓	✓	✓
Patient Education	✓	✓	✓	✓	✓	✓	✓	✓	✓
Social & Community Supports	✓	✓	✓	✓	✓	✓	-	✓	✓
Advance Care Planning	✓	✓	✓	-	✓	✓	-	✓	-
Coordinating Care Among Team Members	✓	✓	✓	✓	✓	✓	-	✓	-
Monitoring & Managing Symptoms After Discharge	-	-	✓	✓	-	-	-	✓	✓
Outpatient Follow-Up	-	-	✓	✓	✓	✓	-	✓	-

Gray shading indicates a match
White indicates a mismatch