ENGAGEMENT OF PRIMARY STAKEHOLDERS TO TAILOR A
COMPREHENSIVE TRANSITIONAL CARE MODEL FOR PERSONS WHO HAVE
EXPERIENCED A STROKE AND THEIR CAREGIVERS

by

Lorre Ann Laws

Copyright © Lorre Ann Laws 2018

A Dissertation Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF PHILOSOPHY

In the Graduate College

THE UNIVERSITY OF ARIZONA

2018
THE UNIVERSITY OF ARIZONA
GRADUATE COLLEGE

As members of the Dissertation Committee, we certify that we have read the dissertation
prepared by Lorre Ann Laws, titled Engagement of Primary Stakeholders to Tailor a
Comprehensive Transitional Care Model for Persons Who Have Experienced a Stroke and Their
Caregivers and recommend that it be accepted as fulfilling the dissertation requirement for the
Degree of Doctor of Philosophy.

Lois J. Loescher, PhD, RN, FAAN

Date: August 6th, 2018

Leslie Ritter, PhD, RN, FAAN, FAHA

Date: August 6th, 2018

Marylyn M. McEwen, PhD, FAAN

Date: August 6th, 2018

Final approval and acceptance of this dissertation is contingent upon the candidate's submission
of the final copies of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend
that it be accepted as fulfilling the dissertation requirement.

Dissertation Director: Lois J. Loescher, PhD, RN, FAAN

Date: August 6th, 2018
STATEMENT BY AUTHOR

This dissertation has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this dissertation are allowable without special permission, provided that accurate acknowledgment of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the copyright holder.

SIGNED: Lorre Ann Laws
ACKNOWLEDGMENTS

Above all, I thank Life, my greatest teacher. Through form and formless dimensions, and through all ways of knowing, I remain Life’s devout and humble student. I am blessed by and enriched from the many people who have, are, or will appear in this lifetime. May we continue to learn, grow, and serve others; and cherish the process of so doing.

I offer profound gratitude to my parents, Don and Sharon Laws, who taught me how to be my own person, transcend internal limitations, and overcome external challenges; all while laughing and enjoying the ride. To my incredible children, Cory, Kathlyn, and Ellie, I offer my unconditional love and gratitude. May you know that when adversity knocks, as it does for all of us, to respond with resilience, purpose, and grace. Live your best life, every day; in every way.

To Drs. Loescher, Ritter, and McEwen, thank you for your leadership. I am a better person, scholar, and educator because of our time together. Dr. Lois Loescher, thank you for patiently and persistently challenging and guiding me. Perhaps, one day, my middle name will also be Parsimony! Dr. Leslie Ritter, your selfless work with the stroke community inspired me to study this topic. Thank you for sharing your vast stroke knowledge while I conceptualized this dissertation study. May we continue to study and serve this population for many years to follow. Dr. Marylyn McEwen, your overall guidance and support - particularly with methods, are so sincerely appreciated. I think of you fondly each time I encourage a student with a BRAVO! To each of you, and the many others who are not specifically named, I offer my most sincere gratitude. My heart is full.
DEDICATION

This dissertation study is dedicated to all who experienced suffering because of the fragmented and ineffective US healthcare system. In response to my own suffering, and that of my loved ones, I decided to become educated and empowered – so I could do my part to transform healthcare delivery. This decision led me to pursue a doctoral degree in nursing, to teach healthcare quality improvement classes, and to complete this dissertation study. I remain committed to doing my part.

*It's not necessarily how I make a difference, I just want to be certain that I do.*
# TABLE OF CONTENTS

LIST OF FIGURES .................................................................................................................................11  
LIST OF TABLES ...................................................................................................................................12  
ABSTRACT .........................................................................................................................................13  

CHAPTER 1: INTRODUCTION TO STROKE AND TRANSITIONAL CARE ..........................15  
Risk Factors and Burden of Stroke ........................................................................................................16  
Arizona Stroke Epidemiology and Aging ..............................................................................................17  
Clinical Management of Stroke ...............................................................................................................18  
Stroke Hospital Discharge Disposition .................................................................................................19  
Discharge Planning, Continuity of Care, Care Coordination and Transitional Care ......................20  
Healthcare Policy Influencing Transitional Care ................................................................................22  
Problem Statement ............................................................................................................................24  
Purpose and Significance of Study .........................................................................................................24  
Research Question ...............................................................................................................................25  
  Aim 1 ...............................................................................................................................................25  
  Aim 2 ...............................................................................................................................................25  
Conceptual Framework Underpinning Study .....................................................................................25  
Summary .............................................................................................................................................28  

CHAPTER 2: REVIEW OF LITERATURE .................................................................................30  
Methods for Literature Review .............................................................................................................30  
Challenges for Individuals and Caregivers Affected by Stroke ............................................................54  
Social Determinants of Health ..............................................................................................................56  
Healthcare Policy .................................................................................................................................57  
Clinical Management of Stroke ...........................................................................................................59  
  Stroke Care Pathway Stage 4: Care and Rehabilitation in Community Settings .........................60  
  Stroke Care Pathway Stage 5: Longer Term Support in the Community Setting .........................62  
Transitional Care Models, Programs and Interventions .......................................................................63  
  Characteristics of Transitional Care Models and Interventions ...............................................64  
  Transitional Care Evidence Base .....................................................................................................66  
  General Transitional Care Models and Interventions .................................................................66  
  Transitional Care Models and Interventions Evaluated in Stroke Populations .........................70  
  Stroke TC Factors ...........................................................................................................................72  
  The Bridge Model and Bridge Organizations ..............................................................................73  
Summary ..............................................................................................................................................74  

CHAPTER 3: METHODOLOGY ...............................................................................................76  
Research Question and Aims .............................................................................................................76  
  Research Question ..........................................................................................................................76  
  Aim 1 .............................................................................................................................................76
<table>
<thead>
<tr>
<th>Aim 2.</th>
<th>77</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>77</td>
</tr>
<tr>
<td>Setting and Sample</td>
<td>77</td>
</tr>
<tr>
<td>Setting</td>
<td>77</td>
</tr>
<tr>
<td>Sample</td>
<td>78</td>
</tr>
<tr>
<td>Individuals Affected by Stroke – Inclusion Criteria</td>
<td>79</td>
</tr>
<tr>
<td>Individuals Affected by Stroke – Exclusion Criteria</td>
<td>80</td>
</tr>
<tr>
<td>Rationale for Individual Affected by Stroke Inclusion and Exclusion Criteria</td>
<td>80</td>
</tr>
<tr>
<td>Caregiver Inclusion Criteria</td>
<td>82</td>
</tr>
<tr>
<td>Caregiver Exclusion Criteria</td>
<td>82</td>
</tr>
<tr>
<td>Rationale for Caregiver Inclusion and Exclusion Criteria</td>
<td>82</td>
</tr>
<tr>
<td>Participant Recruitment and Enrollment</td>
<td>83</td>
</tr>
<tr>
<td>Telephone Recruitment</td>
<td>83</td>
</tr>
<tr>
<td>Email Recruitment</td>
<td>85</td>
</tr>
<tr>
<td>Enrollment</td>
<td>85</td>
</tr>
<tr>
<td>Data Collection Procedures</td>
<td>85</td>
</tr>
<tr>
<td>Focus Groups</td>
<td>85</td>
</tr>
<tr>
<td>Demographic Data Collection Tool</td>
<td>86</td>
</tr>
<tr>
<td>Focus Group Procedure</td>
<td>86</td>
</tr>
<tr>
<td>Data Management and Analysis</td>
<td>87</td>
</tr>
<tr>
<td>Data Management</td>
<td>87</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>89</td>
</tr>
<tr>
<td>Rigor and Trustworthiness</td>
<td>92</td>
</tr>
<tr>
<td>Establishing Credibility</td>
<td>92</td>
</tr>
<tr>
<td>Establishing Transferability</td>
<td>93</td>
</tr>
<tr>
<td>Establishing Dependability</td>
<td>93</td>
</tr>
<tr>
<td>Establishing Confirmability</td>
<td>93</td>
</tr>
<tr>
<td>Procedures to Protect Human Subjects</td>
<td>94</td>
</tr>
<tr>
<td>Beneficence</td>
<td>94</td>
</tr>
<tr>
<td>Respect for Human Dignity</td>
<td>94</td>
</tr>
<tr>
<td>Justice</td>
<td>95</td>
</tr>
<tr>
<td>CHAPTER 4: RESULTS</td>
<td>96</td>
</tr>
<tr>
<td>Sample Characteristics</td>
<td>96</td>
</tr>
<tr>
<td>Deductive Content Analysis: Naylor et al. (2017) Essential TC Components</td>
<td>98</td>
</tr>
<tr>
<td>Category 1: Patient Engagement</td>
<td>98</td>
</tr>
<tr>
<td>Category 2: Caregiver Engagement</td>
<td>99</td>
</tr>
<tr>
<td>Outcomes of care most important to caregivers related to caregiving role</td>
<td>99</td>
</tr>
<tr>
<td>Caregiver engagement facilitators</td>
<td>100</td>
</tr>
<tr>
<td>Caregiver engagement barriers</td>
<td>100</td>
</tr>
</tbody>
</table>
# TABLE OF CONTENTS – Continued

<table>
<thead>
<tr>
<th>Category 3: Complexity Management</th>
<th>.........................................................................</th>
<th>101</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipating problems and holistic person-centered care.</td>
<td>..................................................</td>
<td>101</td>
</tr>
<tr>
<td>Managing complex physical needs.</td>
<td>..........................................................</td>
<td>102</td>
</tr>
<tr>
<td>Managing complex emotional needs.</td>
<td>..................................................................</td>
<td>103</td>
</tr>
<tr>
<td>Managing complex social needs.</td>
<td>.......................................................................</td>
<td>103</td>
</tr>
<tr>
<td>Managing medications.</td>
<td>......................................................................................</td>
<td>104</td>
</tr>
<tr>
<td>Category 4: Patient Education</td>
<td>.........................................................................</td>
<td>106</td>
</tr>
<tr>
<td>Continuous interactive teaching and learning.</td>
<td>...............................................</td>
<td>106</td>
</tr>
<tr>
<td>Education delivery and participation.</td>
<td>......................................................................</td>
<td>106</td>
</tr>
<tr>
<td>Promote independence in activities of daily living.</td>
<td>...........................................</td>
<td>107</td>
</tr>
<tr>
<td>Category 5: Caregiver Education</td>
<td>.........................................................................</td>
<td>107</td>
</tr>
<tr>
<td>Efforts to involve caregivers with patient care decision-making.</td>
<td>........................................</td>
<td>107</td>
</tr>
<tr>
<td>Caregiver skill preparation and managing worsening symptoms.</td>
<td>..................................</td>
<td>109</td>
</tr>
<tr>
<td>Community resources and caregiver competencies.</td>
<td>.........................................</td>
<td>110</td>
</tr>
<tr>
<td>Category 6: Patient and Caregiver Well-Being</td>
<td>..................................................................................</td>
<td>112</td>
</tr>
<tr>
<td>Emotional reactions to stressful experiences.</td>
<td>................................................</td>
<td>112</td>
</tr>
<tr>
<td>Coping skills.</td>
<td>......................................................................................................</td>
<td>112</td>
</tr>
<tr>
<td>Quality of life.</td>
<td>..................................................................................................</td>
<td>113</td>
</tr>
<tr>
<td>Category 7: Care Continuity</td>
<td>...................................................................................</td>
<td>114</td>
</tr>
<tr>
<td>Management continuity.</td>
<td>.................................................................</td>
<td>114</td>
</tr>
<tr>
<td>Informational continuity.</td>
<td>...............................................................</td>
<td>115</td>
</tr>
<tr>
<td>Relational continuity.</td>
<td>.........................................................................................</td>
<td>116</td>
</tr>
<tr>
<td>Category 8: Accountability</td>
<td>........................................................................................</td>
<td>117</td>
</tr>
<tr>
<td>Clinician accountability.</td>
<td>..................................................................................</td>
<td>118</td>
</tr>
<tr>
<td>Organizational accountability.</td>
<td>..................................................................................</td>
<td>118</td>
</tr>
<tr>
<td>Inductive Content Analysis and Emerging Categories</td>
<td>.....................................................................</td>
<td>119</td>
</tr>
<tr>
<td>Psychological Stuff</td>
<td>........................................................................</td>
<td>119</td>
</tr>
<tr>
<td>I Don’t Want it to be My New Normal</td>
<td>.....................................................................</td>
<td>119</td>
</tr>
<tr>
<td>Fearful and Absolutely Overwhelmed</td>
<td>..................................................................................</td>
<td>121</td>
</tr>
<tr>
<td>Determination</td>
<td>.............................................................................................................</td>
<td>122</td>
</tr>
<tr>
<td>What’s Next?</td>
<td>........................................................................................................</td>
<td>123</td>
</tr>
<tr>
<td>Transportation Challenges</td>
<td>..................................................................................</td>
<td>123</td>
</tr>
<tr>
<td>Information Seeking</td>
<td>..................................................................................</td>
<td>124</td>
</tr>
<tr>
<td>Summary</td>
<td>..................................................................................................................</td>
<td>125</td>
</tr>
</tbody>
</table>

# CHAPTER 5: DISCUSSION

Refinement of Naylor’s Essential TC Components and Stroke-Specific Exemplars | .......... | 126 |
| Complexity Management | ........................................................................... | 126 |
| Accountability | ........................................................................................ | 128 |
| Patient Education | ........................................................................................ | 130 |
| Caregiver Education | ........................................................................................ | 131 |
# TABLE OF CONTENTS – Continued

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Continuity</td>
<td>133</td>
</tr>
<tr>
<td>Patient and Caregiver Well-Being</td>
<td>134</td>
</tr>
<tr>
<td>Caregiver Engagement</td>
<td>136</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>137</td>
</tr>
<tr>
<td>Summary of Key Findings: Naylor’s TC Model</td>
<td>138</td>
</tr>
<tr>
<td>Key Inductive Analysis Findings</td>
<td>139</td>
</tr>
<tr>
<td>Psychological Stuff</td>
<td>140</td>
</tr>
<tr>
<td>I Don’t Want it to be My New Normal</td>
<td>141</td>
</tr>
<tr>
<td>Fearful and Absolutely Overwhelmed</td>
<td>142</td>
</tr>
<tr>
<td>Determination</td>
<td>142</td>
</tr>
<tr>
<td>What’s Next?</td>
<td>142</td>
</tr>
<tr>
<td>Transportation Challenges</td>
<td>143</td>
</tr>
<tr>
<td>Information Seeking</td>
<td>144</td>
</tr>
<tr>
<td>Summary of Inductive Findings</td>
<td>144</td>
</tr>
<tr>
<td>Application of Naylor’s TC Model in Stroke Population</td>
<td>145</td>
</tr>
<tr>
<td>Future Directions for a Stroke-Specific TC Model</td>
<td>147</td>
</tr>
<tr>
<td>Research Implications</td>
<td>149</td>
</tr>
<tr>
<td>Implications for Nursing Practice</td>
<td>149</td>
</tr>
<tr>
<td>Strengths and Limitations of Study</td>
<td>151</td>
</tr>
<tr>
<td>Summary</td>
<td>153</td>
</tr>
<tr>
<td>Conclusion</td>
<td>154</td>
</tr>
</tbody>
</table>

APPENDIX A: RECRUITMENT FLYER ...............................................................156
APPENDIX B: RECRUITMENT SCRIPT: TELEPHONE AND EMAIL .........................158
APPENDIX C: ENROLLMENT FORM ...................................................................162
APPENDIX D: T-MOCA SCREENING .................................................................165
APPENDIX E: DEMOGRAPHIC DATA TOOL .........................................................167
APPENDIX F: FOCUS GROUP PROCEDURE AND INTERVIEW GUIDE ......................172
APPENDIX G: INTERVIEW QUESTION DEVELOPMENT TABLE ..............................181
APPENDIX H: INFORMED CONSENT ..................................................................188
APPENDIX I: REFLEXIVITY JOURNAL ..............................................................192
APPENDIX J: THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD
APPRAVAL LETTER ......................................................................................194
TABLE OF CONTENTS – Continued

APPENDIX K: REFLEXIVITY STATEMENTS

REFERENCES

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>APPENDIX K: REFLEXIVITY STATEMENTS</td>
<td>196</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>198</td>
</tr>
</tbody>
</table>
**LIST OF FIGURES**

<table>
<thead>
<tr>
<th>FIGURE</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIGURE 1</td>
<td>Components of comprehensive and effective transitional care.</td>
<td>28</td>
</tr>
<tr>
<td>FIGURE 2</td>
<td>Literature review search strategy</td>
<td>31</td>
</tr>
<tr>
<td>FIGURE 3</td>
<td>Telephone recruitment flow chart</td>
<td>84</td>
</tr>
<tr>
<td>FIGURE 4</td>
<td>Inductive and deductive phases of content data analysis</td>
<td>90</td>
</tr>
<tr>
<td>FIGURE 5</td>
<td>Operational definition of patient engagement</td>
<td>98</td>
</tr>
<tr>
<td>FIGURE 6</td>
<td>Operational definition of caregiver engagement</td>
<td>99</td>
</tr>
<tr>
<td>FIGURE 7</td>
<td>Operational definition for complexity management</td>
<td>101</td>
</tr>
<tr>
<td>FIGURE 8</td>
<td>Operational definition for patient education</td>
<td>106</td>
</tr>
<tr>
<td>FIGURE 9</td>
<td>Operational definition for caregiver education</td>
<td>107</td>
</tr>
<tr>
<td>FIGURE 10</td>
<td>Operational definition for patient and caregiver well-being</td>
<td>112</td>
</tr>
<tr>
<td>FIGURE 11</td>
<td>Operational definition of care continuity</td>
<td>114</td>
</tr>
<tr>
<td>FIGURE 12</td>
<td>Operational definition of accountability</td>
<td>117</td>
</tr>
<tr>
<td>FIGURE 13</td>
<td>Operational definition for complexity management with stroke-specific exemplars added</td>
<td>128</td>
</tr>
<tr>
<td>FIGURE 14</td>
<td>Operational definition for accountability with stroke-specific exemplars added</td>
<td>130</td>
</tr>
<tr>
<td>FIGURE 15</td>
<td>Operational definition for patient education with stroke-specific exemplars added</td>
<td>131</td>
</tr>
<tr>
<td>FIGURE 16</td>
<td>Operational definition for caregiver education with stroke-specific exemplars added</td>
<td>133</td>
</tr>
<tr>
<td>FIGURE 17</td>
<td>Operational definition for care continuity with stroke-specific exemplars added</td>
<td>134</td>
</tr>
<tr>
<td>FIGURE 18</td>
<td>Operational definition for patient and caregiver well-being with stroke-specific exemplars added</td>
<td>135</td>
</tr>
<tr>
<td>FIGURE 19</td>
<td>Operational definition for caregiver engagement with stroke-specific exemplars</td>
<td>136</td>
</tr>
<tr>
<td>FIGURE 20</td>
<td>Operational definition for patient engagement with stroke-specific exemplars added</td>
<td>138</td>
</tr>
<tr>
<td>FIGURE 21</td>
<td>Tailoring of and stroke-specific refinements to Naylor et al.’s (2017) essential TC components</td>
<td>148</td>
</tr>
</tbody>
</table>
LIST OF TABLES

TABLE 1. Characteristics of prominent evidence-based transitional care models and interventions. .................................................................32

TABLE 2. Representative transitional care efficacy studies (excluding stroke studies), quality improvement projects and systematic reviews. ........................................33

TABLE 3. TC models and interventions studied in stroke populations. ........................................43

TABLE 4. Bridging intervention summary of studies, quality improvement projects and clinical trial registrations. .................................................................49

TABLE 5. Focus group characteristics. ..................................................................................97

TABLE 6. Sample characteristics. ........................................................................................97
ABSTRACT

**Background:** Stroke is the leading cause of disability in the US, affecting approximately 795,000 persons annually. Stroke care is delivered across multiple settings from hyperacute care in a hospital through chronic stroke management in the community. Considerable advancements have been made in the delivery of hyperacute and acute stroke care. Science and practice gaps exist in providing stroke transitional care across multiple providers and settings once an individual is discharged from an in-patient care facility to home.

**Purpose:** Using a qualitative descriptive design, this study engaged and elicited descriptions from stroke survivors and caregivers affected by stroke to inform the refinement and tailoring of a stroke-specific model of transitional care.

**Sample:** A purposeful sample of 19 individuals affected by stroke and their caregivers was required to attain data saturation. Participants provided rich descriptions regarding the postacute stroke transition from an inpatient care facility to home.

**Methods:** The investigator conducted five focus group discussions using a semi-structured interview format to elicit participant descriptions of their stroke transitional care experience. Interviews were audio-recorded, transcribed, organized using Atlas.ti 8.1 software, and analyzed using the content analysis method.

**Findings:** Stroke transitional care is generally not provided, and a host of unmet survivor and caregiver needs persist. The findings of this study inform stroke-specific exemplars for essential transitional care components. Stroke-specific findings emerged from the data that could not be explained in the context of the transitional care model, such as self-determination and self-efficacy, transportation challenges, and neuropsychiatric management. There is considerable
healthcare system passivity in delivering postacute and transitional stroke care, leaving stroke survivors and their caregivers feeling abandoned and marginalized. The findings from this dissertation study and the literature inform refined, stroke-specific components and a stroke transitional care model.

**Conclusion:** This dissertation study is the first of its kind to engage primary stakeholders in developing stroke-specific refinements to and exemplars of stroke transitional care components. Study findings describe an urgent need for *active* stroke transitional care delivery, discusses stroke-specific exemplars of core transitional care components, and identifies refinements for a stroke transitional care model. The findings of this study are innovative in describing a community stroke nurse-led transitional care model that “reaches back” to the hospital. The unique findings from this study can inform a community-centric, stroke-specific transitional care model that aligns with the American Heart Association/American Stroke Association’s guidelines for adult stroke rehabilitation and recovery, from which community stroke nurse-led interventions can be developed and examined.
CHAPTER 1: INTRODUCTION TO STROKE AND TRANSITIONAL CARE

The cardiovascular disease stroke, or “brain attack,” imposes a major healthcare and financial burden for the US. Every 40 seconds, one person living in the United States (US) experiences a “brain attack” or stroke (Mozaffarian et al., 2016), which subsequently leaves approximately 665,000 persons disabled annually (Centers for Disease Control and Prevention [CDC], 2016c; Meschia et al., 2014). As of 2017, approximately 7.2 million American adults have experienced stroke (American Heart Association American Stroke Association [AHAASA], 2017; Benjamin et al., 2017), placing stroke as the leading cause of long-term disability, the leading cause of preventable disability, and the fifth-leading cause of death (AHAASA, 2017b). Projections indicate that by 2030, approximately 3.4 million Americans will have experienced a stroke, representing a 20.5% increase from 2012 (CDC, 2016c). Of the approximately 795,000 US persons affected by stroke annually, 25% of those will experience a stroke recurrence (Mozaffarian et al., 2015).

As the leading cause of adult disability, stroke costs account for 1.7% of national health expenditures (Ovbiagele et al., 2013). Stroke is among the top 10 most expensive Medicare diagnoses, with ischemic stroke lifetime care estimated at $140,000 (Johnson, Bonafede, & Watson, 2016). The direct and indirect costs of stroke annually are $33.9 billion; $17.9 billion attributable to direct medical costs and $16 billion attributed to indirect costs (Mozaffarian et al., 2015; Ovbiagele et al., 2013). Projections for stroke direct medical costs are expected to triple by 2030, most of these costs being associated with persons aged 65-79 years (Benjamin et al., 2017). Currently, the per capita outpatient stroke cost is $11,145 per patient, per annum.
(Benjamin et al., 2017), highlighting the fiscal significance of addressing post-acute, community-based stroke care strategies.

There are unique stroke care needs when transitioning across care settings (e.g., acute care, in-patient rehabilitation, skilled nursing facility) to home. Individuals and caregivers must adjust to a post-stroke lifestyle, adapt to new medications, identify and access health and community supports, and experience changes in societal roles (Bettger et al., 2012; Puhr & Thompson, 2015). The transition of care from inpatient settings to outpatient and community settings shifts the locus of care from a hospital interprofessional team to the primary care provider, neurologist, and a team of other allied health and social professionals (Puhr & Thompson, 2015). To better understand the needs of individuals and caregivers affected by stroke, this study engages primary stakeholders in the refinement and tailoring of a stroke-specific model of transitional care.

**Risk Factors and Burden of Stroke**

A systematic review of 13 systematic review articles or meta-analyses classified stroke risk factors as uncontrollable (e.g., age, gender, race and ethnicity, family history, certain heart alterations, such as atrial fibrillation) and controllable (e.g., hypertension and diabetes management, smoking, level of physical activity, obesity, illegal drug use) (Goff et al., 2014). Stroke prevalence is higher in persons with lower educational attainment and income levels (Benjamin et al., 2017; Yang, 2017), while persons with limited English proficiency tend to have limited stroke knowledge (Benjamin et al., 2017; Mozaffarian et al., 2015).

While stroke affects persons of all ages, the risk for stroke doubles for each consecutive decade following the age of 55 (Ovbiagele et al., 2013), posing significant challenges for care
delivery in an aging US population. Aging persons often present with multiple comorbidities at stroke onset (Buttorff, Ruder, & Bauman, 2017). Persons under the age of 65 represent 34% of stroke hospital admissions (Hall, Levant, & DeFrances, 2012). Between 1995-1999 and 2010-2014, investigators found the rate of stroke more than doubled (2.47-fold increase) for persons aged 35-39 years while stroke incidence doubled in persons aged 40-44 years (Rhoads, Cheng, Cosgrove, Moreyra, & Kostis, 2016), resulting in a challenging 30-50 year post-acute care trajectory, also likely involving comorbidities. Gender differences also exist. Men are more likely to experience a stroke, while women experience greater disability and mortality rates (Gall et al., 2018; Mozaffarian et al., 2016).

**Arizona Stroke Epidemiology and Aging**

Mirroring the national median for stroke prevalence (3% of adults), Arizona residents, in 2016, experienced 200,100 strokes (2.9% of adults). As a popular retirement destination, Arizona’s population of persons over the age of 65 is projected to constitute 17.6% and 21.3% of Arizona’s general population by 2020 and 2055, respectively (AHAASA, 2014a; CDC, 2016a; United Health Foundation, 2016). As the risk for stroke doubles during each decade past 55 years of age, this aging trend suggests Arizona stroke prevalence and the cost of care provision associated therewith will continue to increase.

With nearly one-third of Arizona residents being of Hispanic ethnicity (United States Census Bureau, 2011-2015), this group experiences a 4.1% stroke prevalence rate as compared to a 3.6% national median. The Arizona Hispanic population is projected to grow 57% by 2020 (Arizona Office of Economic Opportunity, n.d.; Pew Research Center, 2014b). Further, stroke incidence is projected to increase by 29% for Hispanic males in the next 15 years (AHAASA,
2015). With 66% of Hispanics not speaking English in the home (Arizona Office of Economic Opportunity, n.d.; Pew Research Center, 2014a), and a disproportionate burden of diabetes (Go et al., 2014), and hypertension (AHAASA, 2017b), it is imperative that appropriate stroke prevention and care models are ready to meet this ‘perfect storm’ of projected stroke incidence.

**Clinical Management of Stroke**

Historically, stroke has been viewed and clinically managed as an acute condition. Key technological and pharmaceutical advancements, such as advanced brain imaging, intravenous infusion of tissue plasminogen activator and most recently, mechanical clot removal, have significantly affected the treatment of hyperacute stroke (Heit & Wintermark, 2017). In light of these advancements, stroke management became time sensitive; described as ‘time is brain’ (Saver, 2006). In response to these advancements, the AHAASA, and Brain Attack Coalition developed stroke core measures, which were subsequently endorsed by the National Quality Forum (The Joint Commission, 2017). Hospitals complying with the stroke core measures are accredited and designated by The Joint Commission as either Primary Stroke Centers or Comprehensive Stroke Centers. In 2003, the AHAASA partnered with The Joint Commission in developing a comprehensive acute stroke treatment protocol “Get with the Guidelines® - Stroke.” These guidelines include acute care treatments (e.g., early thrombolytic treatment, anticoagulation therapies), stroke risk factor education, stroke education, and assessment for rehabilitation services (AHAASA, 2017a). Absent from the hospital-centric “Get with the Guidelines® - Stroke” are guidelines for the long-term management of stroke as a chronic condition, or consideration of community-based services, resources, and supports.
Community-based stroke care has historically received less attention and funding than acute stroke care. A limited and outdated evidence base offers few US studies examining post-acute stroke care models. A recent guideline by the AHAASA asserts that stroke care models are to consider stroke as a chronic condition as opposed to a single acute incident. However, problems in post-acute care needs persist, including social reintegration, health-related quality of life, fatigue, low physical activity, high depressive symptomology, and difficulties with autonomy, engagement, or fulfilling societal roles (Winstein et al., 2016). Stroke care models are needed to support persons transitioning from a medical model to a community-based stroke model of care and support, including matching patient and caregiver to available formal and informal resources (Winstein et al., 2016). This proposed study seeks to address, in part, the AHAASA’s call for community-based stroke care models.

**Stroke Hospital Discharge Disposition**

The median length of stroke hospital stay is only four days (Winstein et al., 2016), offering little time for the patient and family to adjust to the consequences of stroke, which vary by severity. The four-day hospital stay affords little time for an interprofessional healthcare team to devise and coordinate complex individualized discharge and post-acute care plans. Hospital discharge dispositions vary. For patients requiring in-patient rehabilitation after hospital discharge, the AHAASA guideline recommends an in-patient rehabilitation facility over a skilled nursing facility (Winstein et al., 2016). Patients, however, prefer to be discharged to home (Gregory, Edwards, Faurot, Williams, & Felix, 2010). Frequently, it is the availability of care facilities (e.g., in-patient rehabilitation, skilled nursing facility), age, and insurance status driving the transition to a patient’s next care facility (Prvu Bettger et al., 2015). Approximately 42% of
all stroke patients (60.4% of persons under 65 years; 37.5% of those over 65 years) are discharged to home without services. Further, 11.7% of patients diagnosed with ‘severe stroke’ are discharged to home without services (Prvu Bettger et al., 2015; Winstein et al., 2016). In short, hospitals are discharging stroke patients to home without adequate community-based care models, services, or connection to formal or informal resources. This alarming statistic further underscores the need for community and evidence-based stroke care systems and interventions in this population.

**Discharge Planning, Continuity of Care, Care Coordination and Transitional Care**

From the point of stroke hospitalization, several care transitions occur, including discharge planning and, ideally, transitional care (TC). Discharge planning is defined as an interprofessional process that assesses post-acute care needs and arranges for those needs to be met by self-care, family care, provision of healthcare, or some combination thereof (Bull, 2000). Discharge planning aims to reduce unnecessary healthcare utilization, minimize adverse effects of interventions, and improve patient outcomes, thereby reducing overall healthcare costs and readmissions (Goncalves-Bradley, Lannin, Clemson, Cameron, & Shepperd, 2016). Continuity of care is a patient-centered care approach connecting connect care events within the hospital and across multiples settings over time (McDonald et al., 2007; Sparbel & Anderson, 2000; van Servellen, Fongwa, & D'Erro, 2006). Care coordination, similarly, is defined as the organization of patient care activities between patient and other participants involved in facilitating the delivery of appropriate healthcare services (McDonald et al., 2007).

Transitional care, by contrast, is complementary to but not the same as continuity of care, care coordination, or discharge planning. Transitional care is a comprehensive range of services
designed to ensure continuity of care, to avoid preventable poor outcomes while promoting safe and timely transfers among levels of care or from one type of setting to another (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). The key characteristics of TC include focus on critical transitions in health and healthcare, time-limited nature of TC services, and emphasis on patient and caregiver education in addressing root causes of poor health outcomes and avoidable readmissions. Internationally, the US leads developed countries in overall hospital discharge planning, but ranks lowest in care coordination (The Commonwealth Fund, 2016); care coordination being one aspect of transitional care. When transitioning from hospital to home, one in five patients experiences an adverse event, one-third of which are preventable, with another third being ameliorable (Groesbeck, Whiteman, & Stewart, 2015). Ineffective care transitions pose considerable patient safety risks, increase healthcare utilization, and contribute to poor patient outcomes and health-related quality of life.

Of significance for this study is that most TC services, both in general and stroke-specific, are initiated prior to hospital discharge (Agency for Healthcare Research and Quality [AHRQ], 2012; Bettger et al., 2012; Puhr & Thompson, 2015). Most TC services are led by a registered nurse (RN) or advanced practice registered nurse (APRN) (Coleman, Parry, Chalmers, & Min, 2006; Naylor et al., 1994). TC demonstrates efficacy and effectiveness in reducing all-cause readmissions, mortality, and emergency department visits (Rennke et al., 2013) in persons with heart failure (Feltner et al., 2014), myocardial infarction (Bettger et al., 2012; Dharmarajan et al., 2013), and pneumonia (Dharmarajan et al., 2013; McHugh & Ma, 2013). While the evidence base for hospital-initiated, non-stroke TC models is robust, little is known about the
effectiveness of a community-initiated TC model that ‘reaches in’ to the hospital (Kansagara et al., 2016).

With the AHAASA calling for community-based stroke care models, currently, a paucity of outdated evidence exists for stroke TC models (Bettger et al., 2012; Puhr & Thompson, 2015). Hospitals are unable to fund stroke TC programs, as described below, while TC programs in other disease-states are situated in large healthcare or academic institutions, bound by hospital readmission metrics and hospital-centric policies. Given the lack of scientific stroke, TC knowledge, and stroke TC models, this study takes a novel and evidence-based approach by engaging primary stakeholders – individuals and caregivers affected by stroke – in describing stroke-specific characteristics corresponding to the following essential TC components (Naylor et al., 2017): patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. The findings of this study will provide preliminary data to underpin the development of a future community-based TC model and intervention.

A note about terminology: Many TC models use the word ‘patient,’ while a community-based stroke ‘patient’ self-identifies as ‘survivor,’ or ‘individual who experienced a stroke.’ In this dissertation, the terms ‘patient,’ ‘survivor,’ or ‘individual,’ all refer to a person who has experienced a stroke. Further, the terms ‘persons affected by stroke’ and ‘primary stakeholders’ refer to survivors, caregivers, or both.

**Healthcare Policy Influencing Transitional Care**

Currently, TC for the stroke population is not generally integrated into hospital care, partially due to AHAASA’s opposition to the stroke 30-day readmission measures proposed for
adoption by Centers for Medicare and Medicaid Services (CMS). The AHAASA recommends stroke as an excluded diagnosis in the CMS 2014 Inpatient Prospective Payment System final rule due to a flaw in not accounting for stroke severity (AHAASA, 2014b). Presently, the CMS Hospital Readmission Reduction Program (HRRP) (McIlvennan, Eapen, & Allen, 2015) assesses hospitals with readmission penalties for the following HRRP-qualifying diagnoses: myocardial infarction, heart failure, pneumonia, chronic obstructive pulmonary disease, hip/knee arthroplasty, and coronary artery bypass graft (CMS, 2014). Accordingly, hospitals have incentives to design TC programs for these diagnoses to mitigate HRRP penalties; the expense of such a program costing significantly less than the HRRP penalty itself (Zhang et al., 2016). It is not clear when stroke will be a qualifying HRRP diagnosis as CMS is updating the risk adjustment methodology (CMS, 2017b). Thus, it makes sense that unless stroke is a qualifying HRRP diagnosis, there is little fiscal incentive for hospitals to fund, develop, and sustain TC programs for the post-acute stroke population.

In 2016, the AHAASA issued its first-ever guidelines regarding rehabilitation after stroke. Traditionally managed as an acute condition, this new scientific statement calls for an intensive, multidisciplinary approach to address the treatment and research gaps by developing effective care models moving away from the medical model, towards a community-based model to better manage the consequences of stroke as a chronic condition (Winstein et al., 2016). Hence, at the present time, science and policy for post-acute stroke care lacks congruence; there is a significant lack of science around community-based stroke care models while policy limits resources for delivering this care.
Problem Statement

The AHAASA guidelines specifically call for community-based stroke care models, while healthcare policy lacks fiscal incentives for hospitals to develop and maintain TC stroke programs. With an average hospital stay of four days (Winstein et al., 2016), the patient, their caregiver, interprofessional teams, and community service providers have scant time to develop and implement individualized, comprehensive TC services. Older adults with polypharmacy needs are frequently at risk for TC challenges; 83% experience significant post-discharge barriers, 73% of these barriers emerge within 30 days of patient resuming home living (Altfeld et al., 2013b). Additionally, 66% of stroke patients are over the age of 65 (Hall, Levant, & DeFrances, 2012). Stroke patients and their caregivers must make multiple transitions, including navigating from a medical care model to a community-based model (Winstein et al., 2016). Accordingly, their perceptions are essential in tailoring a stroke-specific TC model.

Purpose and Significance of Study

The purpose of this study is to engage the primary stakeholders – individuals and caregivers affected by stroke – in the refinement and tailoring of a stroke-specific TC model corresponding to essential TC components (Naylor et al., 2017): patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. This study will provide important preliminary data that will underpin a future community – hospital partnership and community-based TC intervention for persons affected by stroke. The research question and aims guiding this study are shown.
Research Question

What do the primary stakeholders identify as stroke-specific characteristics corresponding to each of Naylor’s (2017) essential TC components (patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability)?

Aim 1

Engage stakeholders, individuals and caregivers affected by stroke, to refine a stroke model of care that addresses each of Naylor’s (2017) essential TC components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability.

Aim 2


Conceptual Framework Underpinning Study

Scientific inquiry and nursing research are foundational components underpinning the nursing profession, resulting in development of knowledge guiding nursing practice, shaping healthcare policy, promoting health and wellness, and managing or eliminating symptoms of illness, chronic conditions, and palliation. Domains of nursing research include clinical research, health systems research, and nursing education (American Association of Colleges of Nursing, 2006; National Institute of Nursing Research, n.d.; Reed & Shearer, 2011; Rolfe, 2011). Central to each is the use of theories, models, and conceptual framework; their reflexive function
informing both the science and practice of nursing. Theories, models, and conceptual framework underpin the process of generating knowledge or discovering gaps in knowledge, as is the case for the TC needs for persons affected by stroke.

Broadly guiding this study and its conceptualization, as pertains to the state of the science and directions for future study, is Meleis’ transition theory, a middle-range nursing theory (Meleis, 2010). Meleis’ transition theory posits that individuals experience healthy transitions or unhealthy transitions. In studies examining unhealthy transitions, Meleis (2011) noted the relationship between unhealthy or ineffective transitions and role insufficiency, defined as a cognitive or performance difficulty in attaining a goal or role, as perceived by the person or significant others (Im, 2011; Meleis, 2011). By contrast, a healthy transition is defined as a non-problematic process by which a person masters the behaviors, cues, and symbols associated with a new role or identity (Meleis, 1975; Meleis, 2011). Individuals affected by stroke and their caregivers frequently experience unhealthy transitions, largely attributable to lacking hospital-centric or community-based TC services. These incomplete or unhealthy transitions can manifest into stroke recurrence, medication errors, suboptimal medication adherence, increased depression incidence, diminished quality of life, and increased healthcare utilization and costs (Bettger et al., 2012; Prvu Bettger et al., 2015; Puhr & Thompson, 2015; Rennke et al., 2013). Transitional care approaches are underpinned by several models guiding healthy transitions. A discussion of these models, interventions, and supporting evidence base follows in Chapter 2.

Specifically guiding the conceptualization and methods of this study is the TC Core Components framework (Naylor et al., 2017), identifying the following essential TC components, as shown in Figure 1: patient engagement, caregiver engagement, complexity
management, patient education, caregiver education, well-being, care continuity, and accountability. Naylor et al.’s (2017) framework is the product of a patient-centered outcomes research institute funded national study, the aim for which was to identify and define comprehensive and effective TC components that yield desired patient and caregiver outcomes (Naylor et al., 2017). Naylor et al., (2017) define TC core components as “a critical element of traditional medical care, community-based services, and non-traditional services provided by the healthcare team that patients and caregivers should receive to promote positive health outcomes throughout periods of acute illnesses extending from hospital to home” (Naylor et al., 2017, p. 2). While these authors identify each core component singularly, they also view all core components in totality, comprising a holistic care process. However, the degree of application for each component will vary depending upon the specific needs of patients and caregivers in any given population and setting. Naylor et al. (2017), assert that all core components are to be addressed – in varying degrees - in care delivery, to optimize TC outcomes.
Summary

This chapter built the foundation for engagement with primary stakeholders – individuals and caregivers affected by stroke- to refine and tailor a stroke-specific, community-based TC model corresponding to the Naylor (2017) essential TC components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. Stroke is the leading cause of preventable disability, and is projected to increase by 20.5% by 2030. The fiscal burden for adult stroke disability accounts 1.7% of national health expenditures. Stroke lifetime care is among the top 10 most expensive Medicare diagnoses. However, current clinical management of postacute stroke care lacks healthcare policy to guide and resources to develop and maintain community-based TC models as called for by the current AHAASA guidelines. This study will provide important
preliminary data that will underpin a future community-hospital partnership and TC intervention for persons affected by stroke.
CHAPTER 2: REVIEW OF LITERATURE

This chapter discusses the complexity of stroke consequences for individuals and caregivers affected by stroke, and the interprofessional teams that manage and deliver this care. A literature review of TC characteristics, and evidence for TC in general, TC specific to stroke populations, and Bridge model are also discussed.

Methods for Literature Review

The primary investigator (PI) conducted a computerized search of the literature using PubMed Central and MeSH database, Cumulative Index to Nursing and Health Literature (CINAHL), Ovid Medline, Cochrane, ProQuest, Web of Science, PsychInfo, Embase, and Joanna Briggs Institute databases. Multiple text combinations used in the search included the following key words: stroke, patient, survivor, caregiver, TC, transitions of care, care continuity, hospital to home, bridge, bridging intervention, nurse community health, and nurse community health planning. Initial searches returned 15,802 results (Figure 2). The filters applied to these articles were articles within five years and written in English, resulting in 1,293 articles. The PI then reviewed the titles of each of these articles for TC relevance, eliminated 855 non-relevant articles, yielding 438 relevant articles. Inclusion criteria included TC approaches, postacute stroke care, and discharging to home or community setting. The PI reviewed the abstracts for each of the 438 articles, eliminated 393 not-specifically-relevant articles, yielding 45 highly relevant articles. Each of the 45 articles were read. Predecessor and antecedent searches were completed in PubMed, from which eight seminal studies published from 1994 – 2009 were included. After combining articles published within five years with the eight seminal studies, a total of 53 articles are referenced in this literature review. The PI grouped these articles across
four domains: characteristics of frequently used TC models (Table 1), representative TC studies in general (Table 2), TC models and interventions specifically examining the stroke population (Table 3), and a summary of bridging interventions and bridging model (a sub-type of TC that specifically connects health services to community services, resources, and supports; discussed in detail below) studies (Table 4).

**FIGURE 2.** Literature review search strategy.
<table>
<thead>
<tr>
<th>Program, Primary Investigator, Study Design</th>
<th>Duration of Intervention</th>
<th>Early Admission Assessment</th>
<th>Medication Reconciliation</th>
<th>Patient Education</th>
<th>Post-Discharge Phone Follow-up</th>
<th>Home Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Better Outcomes for Older Adults Through Safe Transitions (BOOST) (Hansen et al., 2013)</strong></td>
<td>Varies; hospital discharge planning through 72 hours discharge</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>One call within 72 hours</td>
</tr>
<tr>
<td>Non-experimental comparison group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Care Transitions Intervention (CTI)</strong></td>
<td>30-days post hospital discharge</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Three weekly calls</td>
</tr>
<tr>
<td>Seminal work: (Coleman et al., 2001, 2004, 2006) RCTs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 visit</td>
</tr>
<tr>
<td><strong>Healthways Care Transitions Solution (CTS)</strong></td>
<td>4 weeks</td>
<td>x</td>
<td>X</td>
<td>X</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Hamar et al., 2016</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quasi-experimental</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Re-engineered Discharge (Project RED) (Jack et al., 2009)</strong></td>
<td>2-3 days post-discharge</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>One call</td>
</tr>
<tr>
<td>RCT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Transitional Care Model (TCM)</strong></td>
<td>90-days post hospital discharge</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Eight weekly calls</td>
</tr>
<tr>
<td>RCTs</td>
<td>APRN phone support 7 days per week</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>APRN accompanies patient to first provider visit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
TABLE 1 – Continued

<table>
<thead>
<tr>
<th>Program, Primary Investigator, Study Design</th>
<th>Duration of Intervention</th>
<th>Early Admission Assessment</th>
<th>Medication Reconciliation</th>
<th>Patient Education</th>
<th>Post-Discharge Phone Follow-up</th>
<th>Home Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bridge Model - Enhanced Discharge Planning Program (EDPP)</td>
<td>Varies (5.5-day average); follow up survey call completed 30-60 days post-discharge</td>
<td>X</td>
<td>Limited to confirming discharge meds were obtained</td>
<td>x</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Altfeld et al., 2013

RCT

---

TABLE 2. Representative transitional care efficacy studies (excluding stroke studies), quality improvement projects, and systematic reviews.

<table>
<thead>
<tr>
<th>Model</th>
<th>Study Authors</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Transitions Solution</td>
<td>Hamar et al., 2016</td>
<td>Retrospective quasi-experimental</td>
<td>14 acute care hospitals in Texas</td>
<td>Not reported</td>
<td>N=560; 3,340 from which matching occurred on 8 coarsened demographic, diagnosis, and severity variables</td>
<td>Inclusion criteria for CMS readmission-penalty diagnoses: HF, AMI, COPD, pneumonia (no stroke). 1- Treatment group risk of readmission was 22% lower overall (incidence rate ratio [IRR], 0.78; p &lt; .01) and 30-day readmission risk was 25% lower (IRR, 0.75; P = .01) relative to the comparison group. 2- Odds of any or 30-day readmission were 0.47 (95% CI, 0.35-0.65) and 0.56 (95% CI, 0.41-0.77), respectively, for treatment relative to comparison.</td>
</tr>
<tr>
<td>Model</td>
<td>Study Authors</td>
<td>Design</td>
<td>Setting</td>
<td>Percent of Eligible Participants Enrolled</td>
<td>Sample Size: Intervention; Control</td>
<td>Key Findings</td>
</tr>
<tr>
<td>---------------------</td>
<td>--------------------</td>
<td>---------</td>
<td>--------------------------------------</td>
<td>------------------------------------------</td>
<td>-----------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Project Boost       | Hansen et al., 2013| Semi-controlled pre/post | Volunteer sample of 11 hospitals with varying demographics | 36.7% of eligible hospitals | 11 hospitals enrolled; 19 did not participate in analysis. Participating hospitals significantly larger, more likely to be in urban area, academic medical centers | 1 - Reduced rehospitalization at 12 months (12.7% vs. 14.7%, p=.01)  
2 - Mean absolute reduction in readmissions in intervention vs. control 2% (p=.054)  
3 - Length of stay decreased an average of 0.5 days (intervention) vs. 0.3 days (control)  
4 - No difference in length of stay (p=0.966) |
| TCM Efficacy study  | Naylor et al., 1994| RCT     | University hospital                  | Not reported                             | 276 patients aged > 75 years in selected medical or surgical diagnostic-related groups, 125 caregivers randomly assigned and matched in health status and socioeconomic variables - to study and control groups | 1 - Reduced rehospitalizations (10% vs. 23%, p=.04)  
2 - Cost of Rehospitalization: Total days were less for study group at 2 weeks (p=.002), and between 2-6 weeks (p=.01) but were similar 6-12 weeks after discharge  
3 - Mean post discharge costs were less for study group ($1,237) than control group ($3,613) (p=.06)  
4 - Cumulative data for health care charges at 6 weeks for study group were $295,598 less than control group (p=.02). Mean charges for study group at week 6 were $2,454 compared to control group ($6,746) (p=.01). Charges were similar for both groups between weeks 6-12.  
5 - Charge for Nurse Specialist’s Services: Mean charge of $93.30 per patient/caregiver |
<table>
<thead>
<tr>
<th>Model</th>
<th>Study Authors</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>TCM</td>
<td>Naylor et al., 2004</td>
<td>RCT</td>
<td>Six academic and community hospitals</td>
<td>Not reported</td>
<td>118: 121</td>
<td>TC increased time between hospital discharge and readmission or death (log rank $x^2 = 5.0$, $p = .026$), reduced total hospital readmissions (104 vs. 162, $p = .047$), decreased healthcare costs ($7,636 vs $12,481, $p = .002$)</td>
</tr>
<tr>
<td>TCM</td>
<td>Naylor et al., 1999</td>
<td>RCT</td>
<td>Two academic hospitals</td>
<td>39.7%</td>
<td>177: 186</td>
<td>Control group more likely than intervention group to be readmitted (37.1% vs 20.3%, $p &lt; .001$), intervention group had fewer multiple readmissions (6.2% vs. 14.5%, $p = .01$), intervention group fewer hospital days (1.53 vs. 4.09 days; $p &lt; .001$). Time to first readmission increased in intervention group ($p &lt; .001$). 24 weeks’ post-discharge, total Medicare reimbursements about half in intervention group ($1.2 million vs $0.6 million; $P &lt; .001$)</td>
</tr>
<tr>
<td>Model</td>
<td>Study Authors</td>
<td>Design</td>
<td>Setting</td>
<td>Percent of Eligible Participants Enrolled</td>
<td>Sample Size: (Intervention; Control)</td>
<td>Key Findings</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------------</td>
<td>----------------------------</td>
<td>----------------------------------------------</td>
<td>-------------------------------------------</td>
<td>--------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| TCM                           | Naylor et al., 2014 | Comparative effectiveness study | Three hospitals within an academic health system | 40%                                       | Augmented Standard Care group n = 65, Resource Nurse Care group n = 71, TCM group n = 66 | TCM lower mean rehospitalizations compared to RNC (p < 0.001) and ASC groups (p = 0.06) at 30 days  
TCM lower mean rehospitalizations compared to ASC group (p = 0.02) at 90 days  
No significant group differences in functional status |
| TCM                           | Naylor et al., 2013 | Quasi-experimental          | Aetna Medicare Advantage members in mid-Atlantic region | 56.3%                                     | TCM intervention group n = 155; matched control group n = 155 | Significant decrease in number of rehospitalizations (45 vs. 60, p < 0.041) and total hospital days (252 vs. 351, p < 0.032) at 3 months.  
TCM associated with short-term decrease of $439 per member per month in total healthcare costs at 3 months; cumulative per member savings of $2,170 at one year (p < 0.037) |
<table>
<thead>
<tr>
<th>Model</th>
<th>Study Authors</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
</table>
| CTI Efficacy study (RN as transition coach) | Parry et al., 2009 | RCT    | Hospital contracted with Integrated Delivery System | 52.4%                                    | 49; 49                               | 1. Rehospitalizations decreased at 30, 60, and 90 days (p = .15, .01, .08, respectively)  
2. Rehospitalized for same diagnosis at 30, 60, and 90 days (p = .20, .03, and .008, respectively) |
<p>| CTI Efficacy study (APN as transition coach) | Coleman et al., 2006 | RCT    | Hospital contracted with Integrated Delivery System | 76%                                      | 379; 371                             | Intervention patients had lower readmissions at 30 days (8.3 vs. 11.9; p = .048) and 90 days (16.7 vs 22.5; p = .04) than control patients as well as readmission for precipitating condition at 90 days (5.3 vs 9.8; p = .04) and 180 days (8.6 vs 13.9; p = .046). Mean hospital costs lower for intervention patients than control ($2,058 vs $2,546) at 180 days (log-transformed P = .049) |
| CTI Efficacy study | Coleman et al., 2004 | Quasi-experimental | One hospital contracted with not-for-profit group model managed care delivery system | 75%                                      | 158; 1,235                           | Adjusted OR comparing rehospitalization of intervention vs. control group 0.52 (95% CI = 0.28–0.96) at 30 days, 0.43 (95% CI = 0.25–0.72) at 90 days, and 0.57 (95% CI = 0.36–0.92) at 180 days |</p>
<table>
<thead>
<tr>
<th>Model</th>
<th>Study Authors</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interprofessional Collaboration Practice Model (NP, Geriatrician, PharmD) Efficacy study</td>
<td>Reidt et al., 2016</td>
<td>Quasi-experimental</td>
<td>County Medical Center and SNF</td>
<td>Not reported</td>
<td>87189</td>
<td>Adding a pharmacist to the existing model of NP and geriatrician collaborative care resulted in lower risk of ED visits (OR = 0.47, 95% CI = 0.21-1.08)</td>
</tr>
</tbody>
</table>
| Re-engineered discharge (Project RED)                                | Adams et al., 2014      | Quality Improvement Pilot Project | Southwestern Pennsylvania 30-bed medical-surgical unit | Not reported                             | 336 admissions, discharges over a 4-month period | 1. Reduction of readmissions by 32%  
2. Overall monthly reduction from baseline 27%  
3. Reduction from baseline during preview 6 months  
4. Positive patient and family perception of discharge process. |
| TC comprised of 3 elements: Nurse case manager phone follow-up, medication reconciliation, physician follow-up | Hitch et al., 2016      | Retrospective study comparing readmission rates before vs. after TC implementation | Large mountain area academic family medicine practice | Not reported                             | Usual care group of 100 patient records, TC group 164 patient records | With ~90% of patients receiving all three components of intervention:  
1. Reduced 30-day rehospitalization rate (14.2% vs. 5.3%, p = .011) |
<table>
<thead>
<tr>
<th>Model</th>
<th>Study Authors</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model</td>
<td>Study Authors</td>
<td>Design</td>
<td>Setting</td>
<td>Percent of Eligible Participants Enrolled</td>
<td>Sample Size: (Intervention; Control)</td>
<td>Key Findings</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------------------------------</td>
<td>--------------------</td>
<td>---------</td>
<td>------------------------------------------</td>
<td>--------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Transitional Care for Patients with Congestive Heart Failure</td>
<td>Vedel &amp; Khanassov, 2015</td>
<td>Systematic Review</td>
<td>41</td>
<td>n/a</td>
<td>n/a</td>
<td>TC interventions (TCI) resulted in: 1. 8% reduction of readmission (RR = .92; 95% CI, .87 - .98; p=.006) 2. 29% reduction ED visits (RR = .71; 95% CI, .51 - .98; p=.04)  3. High intensity TCIs reduced readmission risk independent of TCI duration 4. Moderate intensity TCIs efficacious if implemented &gt; 6 months. 5. Low intensity TCI were not efficacious.</td>
</tr>
<tr>
<td>Transitional Care Interventions to Prevent Readmissions for Persons with Heart Failure (HF)</td>
<td>Feltner et al., 2014</td>
<td>Systematic Review</td>
<td>47</td>
<td>n/a</td>
<td>n/a</td>
<td>1. At 30-days, high-intensity home-visit program reduced all-cause readmissions, low strength of evidence (SOE)). 2. At 3-6 months, home-visiting programs and multidisciplinary clinic interventions reduced all-cause readmissions (high SOE). 3. Home-visiting programs reduced HF-specific readmissions (moderate SOE). 4. Structured telephone support reduced HF-specific readmission (high SOE), but not all-cause readmissions (moderate SOE). 5. Neither telemonitoring nor primarily educational interventions reduced readmission or mortality rates.</td>
</tr>
</tbody>
</table>
### TABLE 2 – Continued

<table>
<thead>
<tr>
<th>Model</th>
<th>Study Authors</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic Review of Planned Care Transitions for Persons with Dementia (PWD)</td>
<td>Ray et al., 2015</td>
<td>38 studies</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>Components of a good care transition process specifically for PWD involve three elements: 1. support adaptation or maintenance of social environments. 2. steps to improve caregiver involvement in care planning and pragmatic support for caregivers through transition period. 3. Support for management of challenging behaviors. Majority of studies from hospital to home or institution.</td>
</tr>
<tr>
<td>Review of Systematic Reviews of Care Transitions Literature</td>
<td>Kansagara et al., 2016</td>
<td>Literature review</td>
<td>17 recent and broadly scoped systematic reviews; 10 intervention-based, 7 population-based</td>
<td>n/a</td>
<td>n/a</td>
<td>Found no evidence directly examining whether intervention effectiveness depends upon factors such as: 1. shared EHR 2. access to community resources 3. integration of hospital and primary care 4. presences of a medical home Common themes of successful interventions addressed: 1. more aspects of the care transition 2. included means to assess and respond to individual peridischarge needs 3. components span care settings 4. interventions often tailored to the needs of individual patients with use of needs assessment and patient-centered personalized health records Likelihood that TC gaps not the same in all settings or for all populations</td>
</tr>
</tbody>
</table>
TABLE 2 – Continued

<table>
<thead>
<tr>
<th>Model</th>
<th>Study Authors</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
</table>
| Review of experimental transitional care studies examining readmissions in older adults | Kim & Thyer, 2015 | Literature review | Nine articles reviewed | n/a | n/a | 1. Seven of nine studies detected varying degrees of TC impact upon readmission over time.  
2. TC effectiveness vary per components or intensity of intervention  
3. Well-developed service systems and well-trained providers may be instrumental in effective TC provision  
4. To fully understand TC effectiveness on rehospitalization, the nature of intervention, intensity, and process phases should be considered together.  
5. Three of four studies noted lower health care costs in those receiving TC  
6. Functional status was not related to TC in three studies.  
7. One study indicated a positive association between TC and patient quality of life satisfaction |
<table>
<thead>
<tr>
<th>Model</th>
<th>Primary Investigator</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Treatment; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>TCM NP-led Transitional Stroke Clinic</td>
<td>Condon et al. (2016)</td>
<td>Single center observational pre/post QI study</td>
<td>Joint Commission certified comprehensive stroke center</td>
<td>35.9%</td>
<td>N = 510</td>
<td>48% reduction in 30-day hospital readmission rates (OR .518, 95% CI .272 - .986)</td>
</tr>
<tr>
<td>Allen’s APN Model</td>
<td>Allen et al., (2002)</td>
<td>RCT</td>
<td>Community teaching hospital in Ohio</td>
<td>23%</td>
<td>47:46</td>
<td>Improved profile of health and prevention (p &lt; .0001) at 3-months post-discharge</td>
</tr>
<tr>
<td>Allen’s APN Model</td>
<td>Allen et al., (2009)</td>
<td>RCT</td>
<td>Community teaching hospital in Akron, OH</td>
<td>67.8%</td>
<td>165:154</td>
<td>Stroke knowledge and lifestyle modification (p = .0003) indicate postdischarge stroke education shows potential to enhance stroke outcomes.</td>
</tr>
<tr>
<td>Coleman’s CTI</td>
<td>Feldman et al., (2015)</td>
<td>Study protocol of ongoing three-arm RCT</td>
<td>Post-acute care division of large urban non-profit Medicare-certified home health organization</td>
<td>Not available, ongoing clinical trial</td>
<td>Target of 495 black and Hispanic adults; 165 randomized to each group: Usual home care (UHC), UHC + NP, UHC + NP + Health coach</td>
<td>Not available, ongoing clinical trial</td>
</tr>
<tr>
<td>Model</td>
<td>Primary Investigator</td>
<td>Design</td>
<td>Setting</td>
<td>Percent of Eligible Participants Enrolled</td>
<td>Sample Size: (Treatment; Control)</td>
<td>Key Findings</td>
</tr>
<tr>
<td>-----------</td>
<td>---------------------------</td>
<td>-------------------</td>
<td>----------------------------------------------</td>
<td>------------------------------------------</td>
<td>-----------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Not described | Haynes et al., (2015) | Descriptive | Get with the Guidelines 8Ur-Stroke affiliated urban stroke center | n/a                                      | N = 276                            | Elements affecting transitions of care in the stroke population:  
  ▪ Length of hospital stay, age  
  ▪ Insurance status  
  ▪ Discharge disposition  
  ▪ Comorbidities, emotional health  
  ▪ Concerns related to ‘next steps’  
  ▪ Perceived importance of need for ongoing care or follow-up  
  ▪ Designated liaison post-discharge  
  Elements not examined in this study:  
  ▪ Stroke severity, health literacy  
  ▪ Cognitive capacity, depression  
  ▪ Living status  
  Recommendations:  
  ▪ TC include in-hospital and post-hospital components |
| Not described | Prvn Bettger et al., (2015) | Retrospective analysis | Get With The Guidelines (GWTG)-stroke Hospitals | n/a                                      | Final study 849,780 stroke admissions from 1,687 GWTG-stroke hospitals | Four in 10 stroke patients discharged home without services. Persons under 65 years discharged to home without services 60.4% of the time as compared to 37.5% for persons over 65 years.  
  Two strongest clinical predictors of postacute care service utilization:  
  ▪ Patient not ambulating on second day of hospital stay (OR 3.30; 95% CI 2.86 – 3.23)  
  ▪ Patient failing dysphagia screen or has order restricting oral intake (OR 2.48; 95% CI, 2.37 – 2.59) |
<table>
<thead>
<tr>
<th>Model</th>
<th>Primary Investigator</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Treatment; Control) Control = usual care</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic Review of various TC models in stroke &amp; ACS studies</td>
<td>Bettger et al., (2012)</td>
<td>Systematic review</td>
<td>44 total studies (MI, stroke). 27 stroke studies, N=4,307</td>
<td>n/a</td>
<td>n/a</td>
<td>Clinical: No significant differences in ADLs. Caregiver effects (strain, QoL) inconsistent. Utilization not reported. Marked study design heterogeneity precludes comparison of effects across 20 community-based interventions Need for consensus in TC taxonomy and components, clearly defined control groups, measures of intervention fidelity, clearly defined usual care, and validated outcome measures.</td>
</tr>
<tr>
<td>Systematic review of TC models in patients with stroke</td>
<td>Pulir &amp; Thompson, (2015)</td>
<td>Systematic review</td>
<td>11 studies (only 3 of which were in US) examining stroke patient transitions from hospital to inpatient rehabilitation or to home.</td>
<td>n/a</td>
<td>n/a</td>
<td>1. Paucity of TC studies in stroke, due to comprehensive stroke unit care, lack of standardized for TC components, lack of consensus on outcome measures. 2. Healthcare utilization rates and associated costs need to be measured in every study examining TCMs. The use of a TCM may depend upon its cost effectiveness. 3. Fewer than half of studies reported significantly improved results on selected outcomes; usual care components not defined. 4. Across all studies, TC did not result in decreased readmissions or emergency room visits. 5. Substantial heterogeneity in intervention providers, types of TC intervention, and outcome measures. 6. Six of thirteen studies report successful interventions.</td>
</tr>
<tr>
<td>Model</td>
<td>Primary Investigator</td>
<td>Design</td>
<td>Setting</td>
<td>Percent of Eligible Participants Enrolled</td>
<td>Sample Size: (Treatment; Control)</td>
<td>Key Findings</td>
</tr>
<tr>
<td>-------</td>
<td>----------------------</td>
<td>--------</td>
<td>---------</td>
<td>------------------------------------------</td>
<td>----------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Omaha System framework: 4-week TC Program for Hong Kong stroke survivors</td>
<td>Wong &amp; Yeung, 2015</td>
<td>RCT</td>
<td>Hong Kong TC study of stroke patients discharged from hospital to home</td>
<td>88.5%</td>
<td>54:54</td>
<td>1. Quality of Life improved in physical domain ($F(1, 104) = 10.15, p = .002$) and mental domain ($F(1, 104) = 8.41, p = .005$); physical domain achieved significant time x intervention interaction effect ($F(1, 103) = 7.73, p = .006$). 2. Intervention group experienced improved satisfaction and Modified Barthel Index scores; lower depression scores. 3. Intervention group had lower readmission rate 4. Decreased emergency room utilization (1.9% vs. 10.0%, $x^2 = 4.86, df = 1, p = .027$)</td>
</tr>
<tr>
<td>Nurse navigator TC</td>
<td>Poston et al., (2014) Quality Improvement Project</td>
<td>700-bed US academic medical center</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Comparative analysis demonstrates: 1. Reduced 30-day readmissions from 9.39% to 3.24% 2. Reduced emergency room visits from 17.36% to 12.08%</td>
<td></td>
</tr>
<tr>
<td>Model</td>
<td>Primary Investigator</td>
<td>Design</td>
<td>Setting</td>
<td>Percent of Eligible Participants Enrolled</td>
<td>Sample Size: (Treatment; Control)</td>
<td>Key Findings</td>
</tr>
<tr>
<td>-------</td>
<td>----------------------</td>
<td>--------</td>
<td>---------</td>
<td>-----------------------------------------</td>
<td>---------------------------------</td>
<td>--------------</td>
</tr>
</tbody>
</table>
| Developing stroke rehabilitation and community services | Reed et al., (2012) | Meta-synthesis of qualitative literature | United Kingdom meta-synthesis of 18 articles | n/a | n/a | 1. Impact of stroke influenced by: person, close social relationships, social environment (home and outside the home), and interactions between all three.  
2. Stroke support most effective when delivered in social world context  
3. Key factors to consider in supporting stroke survivors:  
a. identify personal patient and caregiver goals  
b. Provision of adaptations and supports to facilitate residing in home  
c. Guidance in how to overcome barriers (physical, economic, psychological) in outside world  
d. Augment confidence by supporting positive social interaction  
4. A positive post-stroke outcome can be viewed as one who is comfortable within their social world independent of lingering stroke effect(s) |
<table>
<thead>
<tr>
<th>Model</th>
<th>Primary Investigator</th>
<th>Design</th>
<th>Setting</th>
<th>Percent of Eligible Participants Enrolled</th>
<th>Sample Size: (Treatment; Control)</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>What type of TC effectively reduced mortality and improved ADL of stroke patients? A meta-analysis</td>
<td>Wang et al., (2017)</td>
<td>Meta-analysis of 31 RCTs reporting mortality and activities of daily living</td>
<td>Articles included from seven non-US countries (United Kingdom, Norway, Sweden, Spain, China, Thailand, Denmark)</td>
<td>n/a</td>
<td>n/a</td>
<td>1. Home visiting TC programs could decrease mortality rates (RR=0.34; 95% CI: 0.17-0.81); the best intervention was led by a multidisciplinary team &lt; 3 month (RR = 0.19; 95% CI 0.05 – 0.71). 2. Home visiting TC programs improved activities of daily living (RR = 0.56; 95% CI 0.31 – 0.81). 3. Patient independence improved with TC as compared to usual care (RR = 1.12; 95% CI: 1.02 – 1.23)</td>
</tr>
<tr>
<td>Social worker or Online Informational Website</td>
<td>Michigan State University (2017)</td>
<td>RCT study protocol; results not published as of 8/7/18</td>
<td>Academic medical setting</td>
<td>n/a</td>
<td>n/a</td>
<td>Primary outcome measures: global quality of life, and caregiving life changes. Secondary and other outcome measures: survivor self-efficacy, survivor and caregiver depressive symptoms, survivor anxiety, and hospital readmissions, among others</td>
</tr>
<tr>
<td>Community Participation Transition After Stroke</td>
<td>Washington University School of Medicine (2015)</td>
<td>Feasibility RCT study protocol; results not published as of 8/7/18</td>
<td>Academic medical setting</td>
<td>n/a</td>
<td>n/a</td>
<td>Primary outcome measure: patient safety (e.g. rate and severity of patient falls). Secondary and other outcome measures: measuring the intervention dose over two months, measuring intervention adherence over six months, and measuring healthcare utilization over twelve months.</td>
</tr>
<tr>
<td>Model or Intervention</td>
<td>Study Authors</td>
<td>Study Design</td>
<td>Setting</td>
<td>Sample Size: Intervention; Control</td>
<td>Nature of Bridging Intervention; Key Findings</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------</td>
<td>-------------------------------</td>
<td>-----------------------</td>
<td>---------------------------------------</td>
<td>-----------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
</tbody>
</table>
| Effects of an enhanced discharge planning intervention for hospitalized older adults: A randomized trial | Altfeld et al., (2013)        | RCT block design      | Chicago university medical center      | Block size of six allocated patients (high-risk older adults) to intervention and usual care groups N= 360 intervention, N= 360 control | Nature of bridging intervention: Social-work based telephone intervention identifying unmet psychosocial and health issues, connecting to community resources.  
Key Findings:  
1 – 83.3% of intervention group experienced significant barriers to care  
2 – Of the above 83.3%, 73.3% of this group’s barriers did not emerge until after discharge  
3- Intervention patients more likely to have scheduled (OR 2.7; 95% CI 1.54 – 4.45) and completed physician visits (OR 2.09; 95% CI 1.51 – 2.89) by 30 days  
4 – No differences between groups on patient or caregiver stress, hospital readmission |
| Innovative approach to patient-centered care coordination in primary care practices | Clarke et al., (2015)         | Program Evaluation:  
Matched case-control differences-in-differences  
Non-licensed comprehensive care coordinators (patient navigator) addressing unmet medical and social needs | UCLA health network          | 14 of 28 patient-centered medical homes embedded with CCC; all adult patients eligible, focus on patients recently in ED or acute care, high-risk patients, and those referred directly from primary care provider | Nature of bridging intervention: over 1-year period, interventions included:  
1 – execution of care (38%)  
2 – coordination of transitions (32%)  
3 – self-management support, link to community resources (15%)  
4- monitor and follow-up (10%)  
5 – patient assessment (1%)  
Key Findings:  
1-Reduced ED visits by 20% (negative binomial regression coefficient -0.22; p < .0001)  
2-Estimated fiscal impact: estimated payor cost of $2,000 per ED visit  $1.4 million. Cost of personnel, including salary and benefits for 14 CCCs and 2 clinical advisors over 12 months $950,000; annual net savings $450,000 |
<table>
<thead>
<tr>
<th>Model or Intervention</th>
<th>Study Authors</th>
<th>Study Design</th>
<th>Setting</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Nature of Bridging Intervention; Key Findings</th>
</tr>
</thead>
</table>
| Comprehensive geriatric assessment and TC in acutely hospitalized patients: The TC bridge randomized clinical trial | Buurman et al., (2016)             | RCT: double-blind, multicenter | 3 Netherlands hospitals affiliated with home care organizations         | N=674 of older adults with acute medical diagnoses | Nature of bridging intervention: TC bridge program initiated during hospitalization by Community Care RN, continuing after discharge with home visits at 2 days, and at 2, 6, 12, and 24 weeks.  
Key findings:  
Primary outcome: Intent-to-treat analysis found no differences in ADLs at 6 months.  
Secondary outcomes: Lower risk on time to death within 6 months of hospital admission (25.2% vs. 30.9%) |
| Effects of a psychosocial transitional care model on hospitalizations and cost of care for high utilizers | (Weerahandi et al., 2015)           | Retrospective cohort matched pair study | East Harlem, NY medical center                                         | N= 579 intervention and N= 579 matched control patients; adults with one admission in 30 days, or two hospitalizations in six months | Nature of bridging intervention: 35 days post-discharge community-based follow-up care coordination. Tailored to each patient, in collaboration with family via phone, home visit, and while accompanying patients to appointments. SW scheduled primary care appointment within 10 days of discharge. Duration: 35 days post-discharge. Average cost of intervention $819/patient  
Key Findings:  
1. Reduced 30-day readmissions by 34% (p<.001)  
2. Reduced 60-day readmission rate by22% (p=.004)  
3. Reduced 90-day readmissions by 19% (p=.006).  
4. No impact on 180-day readmission rates  
5. At 30-days post discharge, intervention group inpatient costs $2.7 million compared to $3.6 million for controls |
<table>
<thead>
<tr>
<th>Model or Intervention</th>
<th>Study Authors</th>
<th>Study Design</th>
<th>Setting</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Nature of Bridging Intervention; Key Findings</th>
</tr>
</thead>
</table>
| The social work role in reducing 30-day readmissions: The effectiveness of the Bridge Model of TC | Alvarez, Ginsburg, Grabowski, Post, & Rosenberg, (2016) | State of Science: Medicare demonstration projects and replication program sites | University medical center, community care | n/a | Nature of intervention: Medicare demonstration project – Community-based care transitions at Rush University Medical Center. Key findings: Adjusted Bridge Model for high-cost, high-needs patients (Medicare beneficiaries with 5+ hospitalizations in prior year, n=456). Comparing patient utilization at 6 months prior to intervention as compared to 6 months after intervention (raw, unadjusted Medicare claim data, program ongoing)  
  - 30-day readmissions reduced by 61.1%  
  - Hospital admissions reduced by 50.3%  
  - ED utilization reduced by 36.4%  
  - Out-patient no-show reduction of 19.8% |
| Social work-based model of TC to reduce hospital readmissions | Boutwell, Johnson, & Watkins, (2016) | Secondary analysis of preliminary data | Rush University Medical | N=3,123; 3,701 | Nature of Intervention: Social Worker-led 30-day individualized interventions include: care coordination, caregiver engagement, interprofessional collaboration, arranging for community services  
Key findings: Analyses demonstrate: 20% relative reduction in readmissions, with or without home care (a 4.5% absolute rate reduction) |
<table>
<thead>
<tr>
<th>Model of Intervention</th>
<th>Study Authors</th>
<th>Study Design</th>
<th>Setting</th>
<th>Sample Size: (Intervention; Control)</th>
<th>Nature of Bridging Intervention; Key Findings</th>
</tr>
</thead>
</table>
Key findings:  
1- 51.6% reduction in hospital readmissions at 3 months  
2- 52.8% reduction in hospital readmissions at 6 months  
3- 47.1% reduction in emergency room visits at 3 months  
4- 48.2% reduction in emergency room visits at 6 months |
| The care transitions innovation (C-TraIn) for socioeconomically disadvantaged adults | Englander, Michaels, Chan, & Kansagara, (2014) | Cluster RCT       | Oregon single site urban academic medical center | Total of 224 clusters ranging from 42-67 participants; N=293 | Nature of intervention: beginning at hospitalization, through 30-days post discharge, delivery of: transitional nurse coaching and education (telephone and home visit for highest-risk patients), pharmacy care with provision of 30-day supply of medication and medication reconciliation, post-hospital primary care linkages, system integration through monthly quality improvement meetings.  
Key findings:  
1 - No significant difference in 30-day readmissions, ED visits.  
2 - Intervention associated with improved TC quality; 47.3% in intervention group reporting high quality transition compared to 30.3% in control group (OR 2.18, 95% CI 1.30-3.64)  
3 – Fewer mortalities within 30 days post discharge (intervention:0, control: 5, p = 0.02) |
<table>
<thead>
<tr>
<th>Model or Intervention</th>
<th>Study Authors</th>
<th>Study Design</th>
<th>Setting</th>
<th>Sample Size (Intervention; Control)</th>
<th>Nature of Bridging Intervention; Key Findings</th>
</tr>
</thead>
</table>
| A multidisciplinary intervention for reducing readmissions among older adults in a patient-centered medical home | Stranges et al., (2015)                | Retrospective cohort study           | Academic, community-based patient-centered medical home                 | N = 572,572                         | **Nature of Intervention:** Pharmacist-initiated phone call 2-4 days after discharge of high-risk older adult, social worker assessment within one week of discharge and assistance with accessing community resources, medical provider appointment and alignment of medical and social health determinants, and coordination of referrals and follow-up appointments  
**Key findings:**  
1. Reduced readmission rates (11.7% vs. 17.3%, p < .001)  
2. Decreased time to readmission (18 +/- 9 days vs. 12 +/- days; p = .015) |
| Systematic review of hospital-initiated TC interventions (using bridging strategy)  | Rennke et al., (2013)                   | Systematic review                   | n/a                                                                     | 47 eligible studies; 28 RCTs, 10 controlled clinical trials            | **Nature of Studies:** 30 studies (21 RCTs) used a bridging strategy, providing both pre- and postdischarge intervention components, 20 of bridging studies had designated transition provider with patient contact for inpatient and outpatient care.  
**Key findings:**  
1. Bridging intervention incorporating dedicated transition provider contacting patients before and after discharge reduced ED visits and readmissions in 10 fair-quality studies |

Abbreviations: RCT; randomized controlled trial
Challenges for Individuals and Caregivers Affected by Stroke

Individuals affected by stroke and their caregivers experience tremendous disruption to a life once known, requiring considerable engagement in adapting and rebuilding a new life and post-stroke identity; which is frequently unstable and temperamental (Lou, Carstensen, Jørgensen, & Nielsen, 2017). More than 50% of persons at risk for a major stroke perceive it as ‘worse than death’ (Duncan et al., 1997; Hong, Ko, Lee, Yu, & Rha, 2015; Hong & Saver, 2009). In a qualitative descriptive study, Danzl et al., (2013) interviewed 13 individuals and 12 caregivers, affected by stroke, in rural Kentucky. Study participants described the stroke experience as occurring within the following structure: (a) stroke onset, (b) transition through the healthcare continuum, and (c) community reintegration. Danzl et al’s (2017) findings reflect similar conceptual stroke care pathway elements reported by Clarke and Foster (2015).

Challenges specific to community dwelling individuals were identified in a meta-ethnographic review by Woodman, Riazi, Pereira, and Jones (2014) and include change and disruption, perceived magnitude of individual barriers, perusing personal choice, building individual confidence, and evaluating personal meaning. Pertaining to an individual’s community reintegration in the first year following a stroke, Walsh et al. (2015) examined 18 qualitative studies in a meta-synthesis. Here, the authors also identify primary effects of the stroke and personal factors, as well as social factors and relationships with professionals. For individuals seeking to return to work, the complex process is similarly facilitated or impeded by personal, social, and organizational factors, in addition accessibility of appropriate health and community services (Brannigan et al., 2017).
Individuals who experienced a stroke are frequently fraught with anxiety, fatigue, depression, and diminished quality of life (Bennett, 2012; Creutzfeldt, Holloway, & Walker, 2012; Duncan, Wu, & Mead, 2012; Lerdal & Gay, 2017; van Mierlo et al., 2014). Post-stroke depression, for example, affects nearly 1:3 persons affected by stroke (Volz, Mobus, Letsch, & Werheid, 2016). Accordingly, persons who experienced a stroke reluctantly experience a deeply changed and slowed life (Simeone, Savini, Cohen, Alvaro, & Vellone, 2015), perceive themselves as being a burden to their spouse, caregiver, or family (Simeone et al., 2015; Taha & Kazan, 2015), miss social support and functions, struggle with new routines, and have difficulty reconciling a new, and uninvited, lifestyle (Lou et al., 2017). Simply put, individuals who experienced a stroke are ‘striving for a life worth living’ (Taule, Strand, Skouen, & Raheim, 2015).

The caregiver is also profoundly affected by stroke consequences, which often disrupt their physical, mental, and emotional health (Rigby, Gubitz, & Phillips, 2009; Salter, Zettler, Foley, & Teasell, 2010). In a meta-synthesis of 12 qualitative research studies examining spousal experiences of coping and adapting to caregiving, Quinn, Murray, and Malone (2014) identified the following caregiver themes: searching for their own space and well-being, suffering in silence, putting one’s own needs aside, adapting to a changed role, social support, hope and optimism, and instilling a positive focus. Caregivers report difficulty with adjustment, coping, general stress and/or stress to the marital (or partner) relationship, lack of communication, altered roles, daily burdens, and interacting with multiple care providers and settings (Buschenfeld, Morris, & Lockwood, 2009; Godwin, Swank, Vaeth, & Ostwald, 2013; Kitzmuller, Asplund, & Haggstrom, 2012; Saban & Hogan, 2012). In other words, caregivers
must adapt from ‘a life that once was’ (Buschenfeld et al., 2009) to their uninvited new life. Caregivers must also transition through a continuum of recovery and care environments: acute care admission, medical stabilization, preparing for home discharge, early months at home, and long-term adjustment to community living (Cameron & Gignac, 2008; Cameron et al., 2015). Stroke caregiver improvements are needed (Lutz et al., 2017), in the following critical areas: performing a patient and caregiver risk assessment, identifying gaps in patient needs and caregiver’s capacity and commitment to meeting those needs, and developing a caregiver readiness plan.

Both individuals and caregivers experience challenges in the transition from a pre-stroke life to a post-stroke life. Engaging the primary stakeholders – individuals and caregivers affected by stroke- in the refinement and tailoring of a stroke-specific TC model corresponding to essential TC components (Naylor et al., 2017), as this study proposes, is in alignment with the AHAASA guidelines (Winstein et al., 2016) calling for stroke to be managed as a chronic condition underpinned by community-based care models.

Social Determinants of Health

The AHAASA calls for a shift in post-acute stroke care away from a temporary, transient acute condition underpinned by the medical model towards care management guided by community-based care models. Further, the AHAASA reports several unmet needs in post-acute stroke care management: social reintegration, restoration or maintenance of activity levels, self-efficacy, and health-related quality of life (Winstein et al., 2016). The medical model, focused on biology and physiology, does not address these unmet needs. A community-based care model viewing stroke as a chronic condition must, therefore, consider social determinants of health;
defined as neighborhood and built environment, health and healthcare, social and community context, education, and economic stability (Booske, Athens, Kindig, Park, & Remington, 2010; CDC, 2016b; Heiman & Artiga, 2015; Office of Disease Prevention and Health Promotion, 2016; Robert Wood Johnson Foundation, 2014). The inclusion of social health determinates is supported by the Affordable Care Act, containing provisions for better alignment between healthcare system services and community health resources and services. Projects examining the connection between health outcomes and social determinants of health are ongoing; such as CMS studies underpinned by the Accountable Health Communities model, and by various Medicaid programs (CMS, 2016a; Heiman & Artiga, 2015; "Patient Protection and Affordable Care Act," 2012).

**Healthcare Policy**

The Institute for Healthcare Improvement (n.d.) developed a widely-used *triple aim* framework for optimizing healthcare system performance. The triple aim calls for healthcare systems, programs, and professionals to align in accepting responsibility for improving the health of populations, improving the patient care experience, and reducing the per capita cost of care. As pertains to TC, Section 3026 of the Affordable Care Act provides CMS funding for a Community-based care transitions program, seeking to reduce hospital readmissions (CMS, 2016b). The 48 studies participating in this CMS program demonstrated mixed results in efficacy; many investigators citing problematic process indicator metrics as detracting from intervention delivery and diluting focus on patient health and healthcare utilization outcomes (Hancock, 2015). One of the participating studies occurred in the Phoenix, Arizona area (Logue & Drago, 2013), where investigators reported that a modified community-based care transitional
program for Medicare beneficiaries was associated with high levels of patient satisfaction, self-care confidence, and a 73% reduction in readmissions. After accounting for program expenses, this nine-month trial saved the two participating hospitals a total of $214,192.

Another policy initiative, the Hospital Readmissions Reduction Program (HRRP), set forth in Section 3025 of the Affordable Care Act (ACA), requires CMS to decrease reimbursements to the Inpatient Prospective Payment System for hospitals with excessive readmissions for the following diagnoses: acute myocardial infarction, heart failure, pneumonia, chronic obstructive pulmonary disease, hip or knee arthroplasty, and coronary artery bypass graft surgery (CMS, n.d.-b). While stroke was initially recommended to be a qualifying diagnosis for CMS hospital readmission penalties, it was opposed by the AHAASA due to an instrument development oversight in not considering stroke severity as a factor influencing hospital readmission. By not accounting for stroke severity, the guidelines, therefore, do not adequately account for stroke risk, resulting in a flawed measure. The AHAASA (2014b) contends that the National Institute of Health Stroke Scale is the best determinant of 30-day stroke outcomes. This position was endorsed by the National Quality Forum Neurology Steering Committee, resulting in CMS withdrawing stroke as a penalized diagnosis. Currently, the AHAASA is working with CMS to develop stroke readmission measures that are adjusted for stroke severity using the National Institute of Health Stroke Scale, but it is not clear when a resolution will be available (AHAASA, 2014b). Currently, CMS updating the risk adjustment methodology used in the stroke 30-day mortality measure to include NIH stroke scale severity codes (CMS, 2017b). Hospitals, therefore, are not yet penalized if a stroke patient experiences a readmission within 30
days. Lacking this fiscal incentive, hospital-based stroke TC programs are rare, in general, and do not exist in Southern Arizona.

The Affordable Care Act includes other mandates to better align, or bridge, healthcare and community health. A number of federal (CMS), state (Medicaid), and local entities are analyzing and performing community needs screening and assessments to better integrate social determinants of health in supporting both individual and community health (Heiman & Artiga, 2015). One such framework is the CMS Accountable Health Communities model. Some 32 sites received CMS funding in 2017 to examine the utility of a Bridge organization in linking clinical and community services. The 32 Bridge organizations are diverse in composition (e.g., county government, hospital, universities, health departments), size, location and population demographics (CMS, 2017a); none of which directly examine stroke populations. Accordingly, this study aligns with the triple aim, Affordable Care Act, CMS programs, and AHAASA guidelines in transitioning hospital-centric post-acute stroke care from a medical model towards community-based stroke TC model of care.

Clinical Management of Stroke

Health care in the United States is traditionally underpinned by the biomedical model, commonly referred to as the medical model, which presupposes the existence of a health alteration. The medical model emphasizes a medical diagnosis, resulting in clinical interventions (Shi & Singh, 2017; Wolinsky, 1988). The medical model takes a reductionist stance in seeking to identify a somatic disease etiology and apply a pharmaceutical or invasive procedure to improve a patient’s outcome or prognosis. This approach has been successful in certain health alterations such as infectious disease, consequences of major trauma, or conditions requiring
surgical intervention (Abelson, Rupel, & Pincus, 2008). However, the medical model is limited in other applications, such as cardiovascular disease-related chronic conditions. These limitations led to the development of a biopsychosocial model which posits that disease etiology is multifactorial across biological, psychological, and social domains (Engel, 1989). Given the US aging population and chronic conditions contributing to most morbidities and mortalities, there is an even greater need to move away from a biomedical model toward a biopsychosocial model (Wade & Halligan, 2017). Applying the biopsychosocial model to stroke care demonstrates significant improvement in stroke outcomes (Claiborne, 2006; Mayo et al., 2015).

Stroke care, whether underpinned by the biomedical or biopsychosocial model, occurs over a trajectory involving various healthcare settings and interprofessional teams. The stroke care pathway (Clarke & Forster, 2015) involves five distinct care phases at each of the following stroke stages: (1) the TIA or stroke, (2) emergency room assessment, diagnosis, and treatment, (3) inpatient stroke unit care, (4) care and rehabilitation in community settings, and (5) longer term support in the community setting. The clinical management of stroke, as pertains to post-acute stroke care pathway stages, are discussed separately below.

**Stroke Care Pathway Stage 4: Care and Rehabilitation in Community Settings**

Once a stroke patient is ready for hospital discharge, there are three widely used disposition settings: in-patient rehabilitation, skilled nursing facility, or patient’s home in the community. The patient’s preference is to be discharged to home (Gregory et al., 2010), but discharge disposition has little to do with patient preference. Rather, discharge disposition is driven by availability of services, age, and insurance status (Buntin et al., 2005; Prvu Bettger et al., 2015).
In a study pertaining to discharge disposition by age, the following discharge dispositions occurred: in-patient rehabilitation (22.6% under age 65; 25.3% over age 65), skilled nursing facility (8.2% under age 65; 28.0% over age 65), home health program (8.7% under age 65; 12.1% over age 65), and home without services (60.4% under age 65; 37.5% over age 65) (Prvu Bettger et al., 2015). Further, approximately 42% of stroke patients were not supported by post-acute or community-based stroke care programs (Winstein et al., 2016), while 11.7% of those classified with a severe stroke were discharged to home without services or supports (Prvu Bettger et al., 2015).

In the AHAASA (2016) guidelines for adult stroke rehabilitation and recovery (Winstein et al., 2016), the authors acknowledged that stroke health care is primarily focused on stabilizing the patient; delivering acute stroke interventions and initiating preventative or prophylactic therapies. Winstein et al., (2016) asserted that rehabilitation, generally not a top priority, should commence as soon as the patient can tolerate it. As the median stroke hospital stay is four days (Winstein et al., 2016), it is imperative that rehabilitation assessment occur within this time. The AHAASA rehabilitation and recovery guidelines further recommend the following levels of care (Winstein et al., 2016): (a) individuals needing post-acute rehabilitation are to receive organized, coordinated interprofessional care, (b) discharge disposition should be to an in-patient rehabilitation facility over a skilled nursing facility, (c) community-based and coordinated interprofessional rehabilitation care is recommended in both outpatient and in-home circumstances, and (d) early supported discharge services should be considered for those with mild to moderate disability. Given the relatively recent release of the AHAASA rehabilitation and recovery guidelines, healthcare systems, interprofessional teams, and community services
and supports are poorly, if at all, integrated; posing significant risks to patient and caregiver health outcomes while contributing to increased healthcare utilization and costs.

**Stroke Care Pathway Stage 5: Longer Term Support in the Community Setting**

Prior to the 2016 release of the AHAASA rehabilitation and recovery guidelines, stroke was viewed as an acute care episode (Winstein et al., 2016). Accordingly, few stroke TC models and interventions exist, and there are no community-based TC models supporting persons affected by stroke when discharged to home (Bettger et al., 2012; Kansagara et al., 2016; Puhr & Thompson, 2015; Rennke et al., 2013). Lacking stroke TC models likely contributed to nearly 200,000 (30%) of stroke patients who have a second stroke within 90 days of the initial stroke (Bretz et al., 2014; Bushnell & Reynolds, 2011; Fonarow et al., 2011) or were a factor for the 25% chance of recurrence thereafter (Mozaffarian et al., 2015), highlighting the importance of community-based transitional stroke care models and interventions.

The AHAASA recommends that hospital and rehabilitation facilities maintain current inventories of community-based resources. These resources should be provided to individuals affected by stroke, caregivers, and their families, and be offered through formal or informal referral. The AHAASA guidelines (Winstein et al., 2016) also recommend care models including social supports and caregiver supports, while integrating the caregiver as a key member of the rehabilitation and decision-making team. Additional recommended caregiver supports include education, training, counseling, support structure development, and financial assistance. Lastly, the AHAASA recommends that individuals affected by stroke, their caregivers, and family are to receive follow-up support to ensure the necessary community resources were actually received (Winstein et al., 2016). In light of the recent publication of AHAASA recommendations for these
important community-based services and support, there is currently a gap in the clinical
management of stroke care. While great strides have been made in clinically managing the acute
phases of stroke, hospitals are unsupported by healthcare policy (e.g., Hospital Readmissions
Reduction Program) in providing TC to non-qualifying diagnoses, such as stroke. There is a gap
between the science of post-acute stroke care, the clinical management of stroke, and healthcare
policy. This study seeks to, in part, address this gap by obtaining stakeholder input - from
individuals and caregivers affected by stroke – in tailoring Naylor’s (2017) essential TC
components to inform a future TC model for this population.

**Transitional Care Models, Programs and Interventions**

Transitional care is defined as a set of actions designed to ensure the coordination and
continuity of health as patients between different locations or different levels of care (Coleman,
2003), bridging the gap between and among a diverse range of providers, services and settings
(Naylor, 2006; Parry, Mahoney, Chalmers, & Coleman, 2008). Specifically, TC complements
other care models (e.g., primary care, discharge planning, care coordination, and case
management) by delivering time-limited services, including patient and caregiver education, with
emphasis on identifying and addressing root-cause factors contributing to poor health outcomes
and hospital readmissions (Naylor et al., 2011).

A major challenge in evaluating TC literature, identified in several systematic reviews
(Bettger et al., 2012; Kansagara et al., 2016; Kim & Thyer, 2015; Olson et al., 2011; Puhr &
Thompson, 2015), is heterogeneity in TC models and interventions, patient populations, settings,
implementation strategies, and intervention fidelity; all of which contribute to a low strength
evidence rating. Lacking a set of standard set of definitions, methodology, and rigorous
identification of ‘usual care’ components, the evidence base as a whole doesn’t reflect the same significant findings as demonstrated in the large-scale TC randomized controlled trials (RCTs) (Altfeld et al., 2013; Buurman et al., 2016; Coleman et al., 2006; Englander, Michaels, Chan, & kansagara, 2014; Naylor et al., 1994; Naylor et al., 1999; Naylor et al., 2004; Parry, Min, Chugh, Chalmers, & Coleman, 2009). Further, as TC is a multidisciplinary endeavor with multiple care components, and not every TC investigator examines every TC component, contributing to methodological and outcome inconsistencies within the evidence base (Olson et al., 2011). Also lacking is sufficient evidence demonstrating whether TC affects various patient populations differently (Kansagara et al., 2016).

Of particular relevance to the proposed study is that no evidence exists directly examining access to community resources or other social determinants of health (Kansagara et al., 2016). The evidence base consists of hospital-initiated TC services; no studies examined a community-based TC model ‘reaching in’ to the hospital (Kansagara et al., 2016). Nor do the components of the most widely-used and evidence supported TC models include a specific component for community-based care (National Transitions of Care Coalition, n.d.; Naylor et al., 2017; Tingley, Dolansky, & Walsh, 2015), highlighting the importance of developing a community-based stroke TC care model and intervention that is consistent with current AHAASA guidelines (Winstein et al., 2016).

**Characteristics of Transitional Care Models and Interventions**

Without exception, the two most widely used TC model and intervention, supported by numerous RCTs are Naylor’s Transitional Care Model (TCM) and Coleman’s Care Transitions (CTI) Intervention (Pitzul et al., 2015); each of which have also been the subject of comparative
effectiveness studies (Naylor et al., 2014, 2016; Voss et al., 2011). Other evidence-based TC models and interventions, supported by RCTs, are Re-engineered Discharge (Project RED) (Jack et al., 2009) and a Bridge model Enhanced Discharge Planning Program (EDPP) (Altfeld et al., 2013). Weaker study designs support the Better Outcomes for Older Adults through Safe Transitions (BOOST) (Hansen et al., 2013), Healthways Care Transitions Solution (CTS) (Hamar et al., 2016); for which few (if any) comparative effectiveness studies exist (Kansagara et al., 2016). TC studies demonstrated lower hospital readmissions (Coleman et al., 2006), fewer days in hospital and longer time between discharge and readmission (Misky, Wald, & Coleman, 2010; Naylor et al., 1999), and reduced healthcare costs (Naylor et al., 1999; Naylor et al., 2004).

Table 1 describes the characteristics of the various studies informing TC models and interventions. Except for the social worker led EDPP, all models address early admission assessment, medication reconciliation, and patient education. All TC models are multidisciplinary and include some form of post-discharge telephone follow-up.

Differences between the models include intervention duration: less than one-week from discharge (e.g., EDPP, Project RED, BOOST), between one and four weeks (e.g., CTI, CTS), and up to 12-weeks (TCM). There are variations in the number and frequency of telephone follow-up, ranging from one single call up to eight weekly calls and seven-day per week APRN telephone support. Only two TC models or interventions consider home visits; Coleman’s CTI provides one home visit, while Naylor’s TCM model provides 2-8 home visits.

Lacking from the above TC evidence base is the inclusion of social risks and health determinants, aligning health and community services, and chronic disease management. Accordingly, the TC essential components (Naylor et al., 2017), discussed above, align with and
support managing stroke as a chronic condition while developing a community-based TC model, pursuant to the current AHAASA guidelines (Winstein et al., 2016).

**Transitional Care Evidence Base**

Transitional care, in general, is well-established in terms of efficacy, effectiveness, and pragmatic applications, the evidence base for which is summarized in Table 2. Transitional care for the stroke population is not well-studied, and is informed by an outdated evidence base (Bettger et al., 2012; Puhr & Thompson, 2015). The following sections discuss the state of science pertaining to TC, in general, and then stroke TC while highlighting the gaps in science and clinical practice with respect to community-based stroke TC viewing stroke as a chronic condition.

**General Transitional Care Models and Interventions**

Transitional care models and interventions are widely used and include the TCM and CTI, supported by the most robust evidence base and implementation across various settings and populations. The TCM interprofessional approach centers on a focused hospital discharge-to-home planning, led by a master’s prepared APRN. The TCM incorporates patient and caregiver goals while planning and implementing the TC plan across various settings, and providers; including additional acute care needs that may arise. The TCM is supported by three RCTs examining older adults with complex health conditions and heart failure populations (Naylor et al., 1994; Naylor et al., 1999; Naylor et al., 2004), establishing efficacy in reducing hospital readmissions, healthcare utilization, and net healthcare cost savings (Kim & Thyer, 2015).

In examining community-based, cognitively impaired older adults, Naylor et al., (2014), conducted a comparative effectiveness study demonstrating TCM effectiveness in significantly
reducing all-cause hospital readmissions within 60-days of discharge. A TCM adaption pilot study (Hirschman et al., 2015) extended the TCM into community-based patient-centered medical homes for older adults with chronic conditions. Here, the addition of the TCM resulted in lower mortality rates and longer time to first hospital readmission. The TCM has been translated into practice in an academic-healthcare insurance partnership, examining real-world context and application (Naylor et al., 2013), demonstrating significant reductions in readmissions, total hospital days, and reduced net health care costs.

Where Naylor’s TCM is an APRN-led and interprofessional approach to care, Coleman’s CTI features a ‘transition coach’ who may be an APRN, RN, social worker, or trained volunteer who follows the patient over four weeks focusing on pillars of care: medication self-management, patient-centered health record, follow-up, and red flags (and strategies to overcome challenges) (Parry, Coleman, Smith, Frank, & Kramer, 2003). The CTI is supported by RCTs (Coleman et al., 2006; Coleman et al., 2004; Parry et al., 2009) demonstrating efficacy in decreasing all-cause readmissions, decreasing same-diagnosis readmissions, and reducing net health care expenses in several healthcare financing approaches (e.g., managed care, capitated healthcare delivery, and Medicare fee-for-service) (Rennke et al., 2013). Both Coleman’s CTI and Naylor’s TCM framework demonstrated a 30-50% reduction in hospital readmissions (Coleman et al., 2006; Naylor et al., 1994; Naylor et al., 2004), and have been implemented, in whole or part, in a myriad of healthcare settings, financing systems, and patient populations (Coleman, n.d.; University of Colorado School of Medicine & Coleman, n.d.; University of Pennsylvania & Naylor, n.d.).
In another TC approach, the Care Transitions Solution (CTS) (Hamar et al., 2016) investigators examined patients in accordance with the CMS Inpatient Prospective Payment System which mandates penalties for hospitals with excessive 30-day readmissions for included diagnoses (e.g., heart failure, acute myocardial infarction, chronic obstructive pulmonary disorder, and pneumonia). As stroke is not a qualifying diagnosis, it was excluded from the study criteria. In this retrospective, quasi-experimental study, outcomes for these patient populations demonstrated a 22% lower risk of readmission. Similarly, Hansen et al., (2013) examined 11 hospitals using Project BOOST in their units, finding that this TC model also significantly reduced rehospitalizations at 12 months. Investigators examining Project RED TC model in a quality improvement pilot project had similar findings; hospital readmissions were reduced by 32% with an improved patient-family perception of care (Adams, Stephens, Whiteman, Kersteens, & Katruska, 2014). Also, demonstrating significantly reduced 30-day hospital readmissions is a TC intervention comprised of RN case manager phone follow-up, medication reconciliation, and physician follow-up (Hitch et al., 2016). Lastly, Reidt et al., (2016) examined the effect of adding a pharmacist to an NP-geriatrician TC model, which resulted in a lower risk of post-discharge emergency room visits. Despite demonstrated efficacy and effectiveness of TC models, in general, further studies are needed to identify which TC models or components are best suited to support specific patient populations, care settings, and contextual factors (Hansen, Young, Hinami, Leung, & Williams, 2011; Kansagara et al., 2016; Pitzul et al., 2015). Naylor et al.’s (2017), recent publication of core components for comprehensive and effective TC is a pivotal first step toward this end.
In systematic reviews considering non-stroke diagnoses (evidence for stroke TC is discussed below), investigators examined TC themes and components, and intensity of TC intervention pertaining to readmission and emergency room visits. Common themes in effective TC align closely with Naylor’s (2017) components described above, and include: discharge planning, interprofessional communication and coordination, clear and timely organized information, medication reconciliation and adherence, engagement in social and community support groups, risk management, and outpatient follow-up (Albert, 2016). Concepts not considered in Naylor’s (2017) components were advance care planning, palliation, and end-of-life care. Considering persons with dementia, Ray et al., (2015) asserted that TC should include support and adaptation in social environments, pragmatic caregiver support, and strategies for managing challenging behaviors (depending upon stroke location in the brain, dementia or challenging behaviors may also manifest in a stroke patient). In addition to the above identified TC components and themes (Naylor et. al, 2017; Albert, 2016), Kansagara et al., (2016) asserted that no evidence directly examines access to community resources as it relates to TC outcomes. Further, little comparative effectiveness evidence exists; presenting a challenge in further identifying specific TC intervention components pertaining to specific patient populations, care settings, and contextual factors.

Pertaining to hospital readmission outcomes, the impact of TC varies over time. The nature, intensity, and phases of TC interventions are inconsistently examined (Kim & Thyer, 2015). In a systematic review and meta-analysis of heart failure patients (Feltner et al., 2014; Vedel & Khanassov, 2015), the investigators found intensity of TC intervention affected hospital readmissions over time. High-intensity interventions (home visits plus phone follow-up, clinical
visits or telecare combined with prearranged direct contact with patients) reduced readmission rates independent of TC duration. TC moderate-intensity interventions (home visit only or combination of telephone follow-up with periodic clinic follow-up or telecare) demonstrated efficacy if implemented over six months. Low-intensity TC interventions (phone call only or outpatient clinic follow-up) were efficacious for heart-failure readmissions, but not efficacious for all-cause readmissions. The TC evidence base suggests that improving service systems, designing community-based TC models, performing needs assessment, and accessing community resources warrant further investigation (Kansagara et al., 2016; Kim & Thyer, 2015).

**Transitional Care Models and Interventions Evaluated in Stroke Populations**

Due to lacking CMS penalties for stroke hospital readmissions, there is no fiscal incentive for hospitals to develop and sustain stroke TC programs. Accordingly, stroke TC studies should include healthcare utilization rates and TC program costs, as the use of a TC model or intervention may be dependent upon cost effectiveness; however, these factors have not been examined (Bettger et al., 2012; Puhr & Thompson, 2015). As such, the evidence base for TC models evaluated in the stroke population is scant, with very few of published studies occurring in the US, likely attributable to the following lacking or sub-optimal factors: standardized TC taxonomy, consistent TC components, consensus for validated TC outcome measures, marked study design heterogeneity, defined control group characteristics, measures of intervention fidelity, and clearly defined usual-care (Bettger et al., 2012; Puhr & Thompson, 2015). As with TC models in general, systematic reviews examining stroke TC report mixed results due to an inconsistent and methodologically diverse evidence base. Approximately 50% of studies report significant findings on select outcomes, despite RCTs demonstrating TC
efficacy on select measures. An overview of the stroke TC evidence base is outlined in Table 3 and discussed below.

Seminal APRN-led TC stroke RCT studies were conducted in Ohio community teaching hospitals (Allen et al., 2009; Allen et al., 2002). The investigators reported improved health profile and stroke prevention, improved stroke knowledge, and lifestyle modification; demonstrating TC potential in enhancing stroke outcomes. In a quality improvement project using a nurse navigator to direct a TC intervention, Poston, Dumas, and Edlund’s (2014) comparative analysis reported the 30-day readmissions were reduced by 6.15%, and emergency room visits were reduced by 5.28%.

Guided by the Omaha System Framework, Hong Kong TC investigators Wong and Yeung (2015) conducted a four-week TC RCT of adult stroke patients. Investigators reported improved quality of life (physical and mental domains), improved patient satisfaction with healthcare services, improved modified Barthel index scores assessing post-stroke self-care ability (Rehabilitation Measures Database, 2010), reduced depression scores, decreased readmissions, and significantly reduced emergency room visits.

In a joint commission certified comprehensive stroke center, investigators (Condon, Lycan, Duncan, & Bushnell, 2016) conducted a quality improvement study an using APRN-led Transitional Stroke Clinic, which resulted in a 48% reduction in 30-day readmission rates, but did not impact 90-day readmissions. Currently, several ongoing clinical trials (Feldman et al., 2015; Karolinska Institutet, 2016; Michigan State University, 2017; Sunnybrook Health Sciences Centre, 2017; University of Pennsylvania, 2016; Washington University School of Medicine,
2015) are examining various TC aspects in stroke populations, the summaries for which are outlined in Table 3.

Overall, the stroke transitional care evidence base is limited. In the two systematic reviews examining the outdated evidence base, the most recent study was published in 2008 (Bettger et al., 2012; Puhr & Thompson, 2015). Further, in the Bettger et al., (2012) review, only seven of the 27 studies were conducted in the US. Similarly, in Puhr and Thompson’s (2015) review, only three of the 11 studies were conducted in the US. The remaining published studies include one Hong Kong-based RCT (Wong & Yeung, 2015), a US academic medical center quality improvement project (Poston et al., 2014), a retrospective Get with the Guidelines® - Stroke analysis (Prvu Bettger et al., 2015), and a descriptive study by Haynes, Gallek, Sheppard, Drake, and Ritter (2015) identifying elements affecting TC in the stroke population. These studies, in addition to the US-based RCT protocols described above, are situated in academic hospitals and are primarily grant supported; calling into question the sustainability and generalizability of the resulting program and study findings. To meet the guidelines set forth by the AHAASA calling for community-based TC models addressing stroke as a chronic condition (Winstein et al., 2016), sustainable, innovative, evidence-and-community-based care TC models are required.

**Stroke TC Factors**

Approximately 40% individuals who experienced a stroke are discharged to home without any services or supports (Prvu Bettger et al., 2015), signifying the need for community-based stroke TC models. The impact of stroke is influenced by the individual, close relationships – including caregivers, and social environment within and outside the home (Reed, Wood,
Harrington, & Paterson, 2012). Consistent with the TC model proposed in this study, Reed, Wood, Harrington, & Patterson (2012) asserted that stroke support is most effective when delivered in the individual’s and caregiver’s social context, in alignment with their goals, while providing supports and adaptations to facilitate home living. Additional factors influencing stroke TC identified by Haynes, Gallek, Sheppard, Drake, and Ritter (2015) were age, length of hospitalization, insurance status, discharge disposition, comorbidities, emotional health, concerns regarding ‘next steps,’ perceived importance for ongoing care, and follow-up. The authors recommended stroke TC programs include in-hospital and post-hospital components, with future TC studies needed to examine stroke severity, health literacy, cognitive capacity, living status, and depression.

The evidence base, while limited, does align with AHAASA guidelines (Winstein et al., 2016) calling for transitions in care, community rehabilitation, social and family caregiver support, referral to community resources, and rehabilitation into the community setting. However, the community-specific factors are not addressed by existing TC models and interventions, with the exception of Bridge Models and Bridging Interventions; a sub-type of TC which does include connecting health services to community services, resources, and supports.

**The Bridge Model and Bridge Organizations**

The Bridge Model represents a subset of TC models guided by a community-centric focus. The Bridge Model principles include hospital-community collaboration, community-specific focus, and social determinants of health. Table 4 summarizes the Bridge Model evidence base efficacy in identifying post-discharge barriers to care, completed follow-up physician appointments (Altfeld et al., 2013), reduced emergency room visits and healthcare utilization
costs (Alvarez, Ginsburg, Grabowski, Post, & Rosenberg, 2016; Clarke et al., 2015), reduced hospital readmissions at 30-, 60-, and 90-days (Boutwell, Johnson, & Watkins, 2016; Low et al., 2015; Weerahandi et al., 2015), improved TC quality (Englander et al., 2014). No studies have been conducted that examine the efficacy of the Bridge Model in the stroke population.

The CMS (2016a, 2016c) is actively examining the use of the Bridge Model in 32 demonstration projects. Central to these projects are use of a Bridge organization, which serves as a community ‘hub’ to address and align health and health-related social needs while developing more robust clinical-community partnerships. A Bridge organization, as defined by CMS, is any organization (e.g., hospital, healthcare, community based, health system, higher education institution, and for-profit and not-for-profit local and national entities) with capacity to develop and maintain relationships with clinical and community service providers (CMS 2106d). Should ongoing demonstration projects prove successful, integrating a Bridge organization into a community-based stroke TC model may serve as an innovative strategy.

Despite the promise of Bridge organization-led TC, the findings from the 32 demonstration projects are not yet available. Accordingly, the APRN-led TCM best aligns with the unique needs of the post-acute stroke population by providing a 90-day duration, APRN telephone support seven-days-per-week, eight scheduled weekly telephone calls, and 2-8 scheduled home visits. The TCM is selected to frame this dissertation study.

Summary

The efficacy, effectiveness, and translation of TC models is well studied in acute myocardial infarction, chronic obstructive pulmonary disease, heart failure, coronary artery bypass grafts, and hip/knee arthroplasty patient populations. Only 10 of 38 stroke TC studies
included in systematic reviews were conducted in the US. The only recent stroke TC RCT, conducted in Hong Kong, reported improved quality of life, decreased depression scores, and reduced healthcare utilization. The stroke TC evidence base is outdated and primarily reliant upon grant funding to academic institutions, placing the few stroke TC programs at risk for sustainability. As such, US stroke-specific TC studies are needed to begin the process of complying with the AHAASA guidelines (Winstein et al., 2016) in moving post-acute stroke care toward a community-based model, aligning healthcare services with community resources and supports. In consideration of the TC evidence base, healthcare policy, and clinical management of stroke, it is imperative to elicit individuals affected by stroke and their caregiver’s perspectives and needs to tailor a stroke-specific TC model.
CHAPTER 3: METHODOLOGY

Informed by the literature review and the AHAASA stroke rehabilitation guidelines (Winstein et al., 2016) calling for a community-based TC models, a qualitative descriptive design has potential to reduce the TC service gaps pertaining to stroke-specific, community-based TC. Further, a qualitative descriptive design aligns with this study’s purpose of engaging the primary stakeholders – individuals and caregivers affected by stroke – in the refinement and tailoring of a stroke-specific TC model corresponding to essential TC components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. This study will provide important preliminary data that will underpin a future community – hospital partnership and community-based TC intervention for persons affected by stroke.

**Research Question and Aims**

The research question and aims guiding this study are:

**Research Question**

What do the primary stakeholders identify as stroke-specific characteristics corresponding to each of Naylor’s (2017) essential TC components (patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability)?

**Aim 1.** Engage stakeholders, individuals and caregivers affected by stroke, to refine a stroke model of care that addresses each of Naylor’s (2017) essential TC components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability.

Design

The design chosen for this study is qualitative descriptive. A qualitative descriptive approach solicits stakeholder descriptions of factors useful in developing a program or intervention (Sullivan-Bolyai, Bova, & Harper, 2005), while being grounded in cultural and environmental contexts (Sandelowski, 2000; 2010).

A qualitative descriptive design is minimally constrained by pre-existing philosophical and theoretical commitments. One of the objectives of qualitative descriptive design is to collect data that provides a straightforward, pragmatic description of participant experiences. As compared to other qualitative designs, such as grounded theory or phenomenology, qualitative descriptive studies are more descriptive than interpretive. As such, the investigator stays ‘closer to the data’ (Sandelowski, 2000; 2010).

Setting and Sample

Setting

The setting of this study was Tucson, AZ. The primary investigator (PI) used a purposive sampling method with a snowball sampling technique. Purposive sampling is frequently employed for qualitative descriptive designs (Sandelowski, 2000; 2010), because this method deliberately reduces sample variability to focus on a particular population or phenomenon of interest (Creswell, 2013) – such as individuals who experienced a stroke and their caregivers. Snowball sampling complements purposive sampling. Snowball sampling draws upon recruiting
participants from a known network (e.g., stroke support group) who then tell other potential participants about the study. Snowball sampling is useful to identify participants that would otherwise be difficult to locate (Dattalo, 2008).

**Sample**

Adequacy of qualitative descriptive sample size, according to Sandelowski (1995), is a matter of judgment. Sandelowski (1995) suggested that a sample size of 10 could be adequate for a purposive, homogenous sampling technique, while Sullivan-Bolyai (2005) identified several qualitative descriptive health disparity studies with sample sizes ranging from nine participants to 52 participants. Specific to a homogeneous sampling technique, Guest, Bunce, and Johnson (2006) indicated that a sample size as small as six may be sufficient, subject to attaining data saturation criteria and answering study research question(s).

Data saturation is a concept introduced by Glaser and Strauss (1967) pertaining to the state where further data collection does not yield additional information; a gold standard principle used by qualitative researchers (Walker, 2012). Data saturation is a helpful concept, yet little pragmatic support is available for estimating adequate sample sizes that will result from saturation (Guest et al., 2006); particularly for a PhD dissertation study (Mason, 2010). However, the sample size determining data saturation becomes less relevant in a qualitative descriptive approach, as it is influenced by the interaction between interviewer and participant who mutually determine the quality of data being obtained (Guest et al., 2006; Morse, 2008). Hence, while there is not a ‘one size fits all’ approach to reaching data saturation, it typically occurs when: (a) there is enough information for study replication, or (b) when no new information is being obtained, or (c) when additional coding is no longer feasible, and (d) when the research
question(s) have been answered (Fusch & Ness, 2015; Guest et al., 2006). Guest, Bunce, and Johnson (2006) further asserted that by using homogeneous sampling techniques, data saturation is generally attained with 6-12 interviews. These 6-12 interviews provide approximately 94-97% of study codes. With focus group interviews, data saturation generally is reached within 3-5 meetings (Morgan, 1998).

Therefore, in consideration of the above, a total of five focus groups were scheduled. Participants self-selected into one or more the following focus groups: Focus Group 1 (individual survivors only), Focus Group 2 (caregivers only), and Focus Groups 3-5 (all-comers). The all-comers groups consisted of individuals, caregivers, and individual-caregiver dyads.

Rationale for the three-focus group structure is: (a) data are analyzed by group, and not individual, (b) not all participants, but some, are associated with a specific individual-caregiver grouping, and (c) not every individual will speak freely if their caregiver is present, and vice-versa. So, the option of a second individual-only or participant-only focus group facilitated openness and richer data than would have otherwise been obtained.

**Individuals Affected by Stroke - Inclusion Criteria**

1. Self-report of stroke or cerebral vascular accident (CVA), of any etiology, at any time, which may have occurred in conjunction with a transient ischemic attack (TIA).
2. Demonstrated acceptable cognitive ability by scoring 19 or greater on the Telephone-Montreal Cognitive Assessment (T-MoCA).
3. Adult age 18 years or older.
4. Discharged from hospital, in-survivor rehabilitation facility, or skilled nursing facility to home.
5. Speaks and reads in English.
6. Able to independently respond to semi-structured interview questions.
7. Had access and ability to talk on a functioning telephone.

**Individuals Affected by Stroke - Exclusion Criteria**

1. Discharged to home with hospice care.
2. To prevent potential study participant fatigue, participant was not actively engaged in another investigator’s study.
3. Not able to sign informed consent form.
4. Self-report of a TIA without corresponding stroke or CVA.

**Rationale for Individual Affected by Stroke Inclusion and Exclusion Criteria**

Given the study aims, it is appropriate to consider all stroke etiologies (e.g., ischemic, hemorrhagic), and all genders, races, and ethnicities. Temporal inclusion criteria vary in the literature. Pertaining to time since stroke onset, investigators included participants ranging from all-comers (e.g., any time after stroke onset) (Bastawrous, Gignac, Kapral, & Cameron, 2015; Danzl et al., 2013; Danzl et al., 2016; Sadler et al., 2017), one-month to one-year after stroke onset (Cameron, Naglie, Silver, & Gignac, 2013), four-weeks post-discharge (Chen, Xiao, & De Bellis, 2016), within the past year (Harrison, Ryan, Gardiner, & Jones, 2017). The all-comers recruitment strategy encompassed primary stakeholder perspectives independent of time and aligned with this study’s purpose.

To answer focus group questions, minimal post-stroke cognitive impairment is required. The Telephone Montreal Cognitive Assessment (T-MoCA) is a valid, reliable, and clinically feasible measure in differentiating persons with or without cognitive impairment (Burton &
Tyson, 2015; Pendlebury et al., 2013). The T-MoCA is an abbreviated version of the in-person MoCA. The T-MoCA eliminates pencil and paper visuospatial/executive and naming domains (Pendlebury et al., 2013). A T-MoCA score of 19 or greater demonstrates optimal sensitivity and specificity to detect multidomain mild cognitive injury and clinical dementia in the post-stroke population (Pendlebury, Cuthbertson, Welch, Mehta, & Rothwell, 2010; Pendlebury et al., 2013; Wong et al., 2015; Zietemann, Kopczak, Müller, Wollenweber, & Dichgans, 2017). The PI completed the 60-minute T-MoCA training and certification. When used for educational purposes, the T-MoCA may be used, reproduced, and distributed without permission (Nasreddine, n.d.)

English-speaking participants are required to support the interviewer-participant relationship (Fusch & Ness, 2015; Råheim et al., 2016). Because individuals affected by stroke also discharged on hospice care have different needs than non-hospice individuals, the former individuals are excluded from the study. The ability to communicate using a functioning telephone is essential to screen potential applicants and schedule focus group meeting(s). A TIA is a temporary interruption of blood flow to the brain that does not damage brain cells or result in permanent disability, which often precedes stroke (AHAASA, n.d.). Individuals who experienced a TIA, followed by a stroke are eligible to participate in the study. Individuals who experienced a TIA only did not have a stroke and, therefore, cannot describe post-stroke TC and are not eligible for this study.
Caregiver Inclusion Criteria

1. Self-identifies as a caregiver of an individual affected by stroke.
2. Demonstrated acceptable cognitive ability by scoring 19 or greater on the Telephone-Montreal Cognitive Assessment (T-MoCA).
3. Adult over the age of 18 years.
4. Speaks and reads in English.
5. Able to independently respond to semi-structured interview questions.
6. Had access and ability to talk on a functioning telephone.

Caregiver Exclusion Criteria

1. Individual who experienced the stroke, and for whom caregiving is identified, is discharged to home with hospice care.
2. To prevent potential study participant fatigue, participant was not actively engaged in another investigator’s study.
3. Not able to sign the informed consent form

Rationale for Caregiver Inclusion and Exclusion Criteria

The rationale for the following inclusion and exclusion criteria is the same as for the individuals affected by stroke. Self-identification as a caregiver is determined as meeting Hileman, Lackey, and Hassanein’s (1992) definition of a caregiver as someone who lives with the affected individual, is most closely involved in taking care of that person, or an unpaid person helping with the physical care or coping of the disease (Anderson, Linto, & Stewart-Wynne, 1995); in this case a post-acute stroke status.
Participant Recruitment and Enrollment

After obtaining approval from the University of Arizona Institutional Review Board, the PI recruited study participants from Tucson stroke support groups: Stroke Resource Center of Southern Arizona, Tucson Medical Center Stroke Support Group, HealthSouth Rehabilitation Hospital of Tucson, and HealthSouth Rehabilitation of Southern Arizona. The PI distributed a recruitment flyer (Appendix A) electronically and in paper format to the above stroke support groups. Interested prospective participants then contacted the PI.

Telephone Recruitment

During the initial phone contact with prospective participants, the PI asked eligibility questions (Appendix B) and noted prospective participant responses in the enrollment form (Appendix C). If the prospective participant did not meet eligibility requirements, they were thanked for their time. The PI informed the prospective participant that any information provided will be destroyed and terminated the call. If the prospective participant met eligibility requirements, the T-MoCA (Appendix D) screening occurred. If the prospective participant’s T-MoCA score was less than 19, the PI informed them that they were not eligible for the study and that the information provided will be destroyed. If the prospective participant’s T-MoCA score was 19 or greater, the PI informed them that they were eligible to participate in the study. The PI asked the prospective participant if they would like to participate in the study. If the prospective participant elected not to participate in the study, the PI thanked them for their time, and informed them that the information provided will be destroyed and terminated the call. If the prospective participant stated they would participate in the study, the PI described the focus group format and disclosed that discussions would be audio recorded. The PI reminded
prospective participants that their participation is completely voluntary, and that they may choose not to participate at any time. The prospective participants were enrolled into the study.

The PI scheduled participant into their choice of focus group(s). PI sent participants an information packet by email or US postal service. The information packet contained the following documents: informed consent form (Appendix H), demographic questionnaire (Appendix E), directions to focus group setting with parking instructions, and a pre-paid US postal service return envelope. The PI directed participants to complete, sign, and return the forms via US postal service, or bring them to the focus group. The PI asked the participant if they had questions and answered accordingly. The PI provided her contact information, thanked the participant for their time, and terminated the call.

FIGURE 3. Telephone recruitment flow chart.
Email Recruitment

To recruit prospective participants by email, the PI emailed prospective participants pursuant to the verbiage on the email recruitment script (Appendix B). This verbiage introduced the PI, described the study, outlined eligibility requirements, described focus group format, and disclosed that the discussion would be audio recorded. Lastly, the prospective participant was informed that their participation was voluntary, and they could choose not to participate in the study. Prospective participants were asked to contact the PI to schedule a telephone eligibility screening. PI schedules a telephone appointment and uses the above telephone recruitment script (Appendix B) during the call. Qualifying prospective participants were enrolled in the study.

Enrollment

Prospective participants were enrolled in the study when PI was in receipt of their signed informed consent form (Appendix H). All participants received a copy of the signed consent form, either in person, by email, or by US mail.

Data Collection Procedures

Focus Groups

Focus group data collection involves a planned series of semi-structured interview questions designed to elicit perceptions pertaining to phenomena of interest, in a non-threatening and supportive environment (Krueger & Casey, 2000; Morgan, 1998). Focus group methods are particularly well-suited for the qualitative exploration of complex clinical health issues (Carey, 1994). Interaction of focus group participants supports self-disclosure among participants (Côté-Arsenault & Morrison-Beedy, 2005), which facilitates exploration of a topic that would be less readily accessible in an individual interview (Kitzinger, 1995; Sim, 1998; Stewart &
Shamdasani, 2014). Focus group methodology is frequently used in qualitative stroke studies as well as transitional care and effectiveness research studies (Boger, Demain, & Latter, 2015; Cameron et al., 2013; Coleman, Mahoney, & Parry, 2005; Jones, 2016; Levine et al., 2006; Xian et al., 2015). Accordingly, the assumption for this study is that focus groups comprised of individuals and caregivers will provide descriptive data pertaining to stroke-specific characteristics of Naylor’s (2017) core transitional care components.

**Demographic Data Collection Tool**

Demographical information was collected and then analyzed by descriptive statistical methods to describe the characteristics of a group or population (Trochim, Donnelly, & Arora, 2015). The demographic data tool (Appendix E) was used to collect participant characteristics such as age, gender, race or ethnicity, employment status, date of stroke, length of hospitalization, discharge disposition, home health and social service status, and primary and secondary language(s) spoken at home.

**Focus Group Procedure**

The PI used the focus group method described by Krueger and Case (2015). In this procedure, two facilitators are required: the PI who facilitated the discussion and the research assistant (RA) who facilitated the focus group process (e.g., audio recording, document seating arrangement, field notes). The procedures that guided Focus Groups 1, 2, and 3 are outlined in the focus group procedure and interview guide (Appendix F), the interview question development table (Appendix G).

Key principles to consider in planning focus group data collection (Kidd & Parshall, 2000) include: (a) the number of questions to be asked, (b) time allotted for each discussion
question and total session length, and (c) format of the group. The nature of and number of questions to be asked in this study are framed by the operational definitions of Naylor’s (2017) essential TC components, and interview question development table (Appendix G). The focus group procedure and interview guide (Appendix F) aligns with Kidd and Parshall (2000) criteria. There were eight topic interview questions and 22 probing interview questions. If participants answered the probing questions as a by-product of the topic interview question discussion, then the PI did not ask the corresponding probing interview question(s). Time allotted for each of the 30 interview questions was six minutes, resulting in a session time of approximately 180 minutes. After approximately 90 minutes elapsed, the PI paused the discussion for a 15-minute break. During the break, participants were offered refreshments.

Focus group discussions took place at the College of Nursing, University of Arizona. One focus group took place at a community rehabilitation setting. The PI, at her own cost, provided nutritious beverages and snacks. Study participants were offered a $20 gift card at the completion of each focus. Gift cards were purchased using the PI’s personal funds.

**Data Management and Analysis**

**Data Management**

Qualitative descriptive data for this study was collected using focus group interviews, field notes, observations, and memos. Field notes were used to record the observed behaviors, activities, and events during the focus group discussion (Schwandt, 2015). Field notes were taken by a trained and CITI-certified RA during and immediately following the focus group discussion (e.g., seating arrangement, non-verbal communications, procedures, and observations) and by the
PI after the last informant left each focus group session. The field note template is embedded in the discussion group procedure and interview guide (Appendix F).

Memoing is a technique used to record reflective thoughts during data collection and analysis (Miles & Huberman, 1994). The memoing technique supports the trustworthiness and credibility of a qualitative study (Groenewald, 2008). The PI maintained an ongoing memo in the form of a Word document to record procedural and analytical decisions (Birks, Chapman, & Francis, 2008), and decisions pertaining to the coding and categorization of data (Creswell, 2014; Hesse-Biber & Leavy, 2011).

After each focus group, digital audio recordings were securely downloaded from the recording device to Box@UA and transcribed by a CITI-certified transcriptionist. The PI verified the transcript against the audio recording for accuracy and consistency. Any personal information artifacts in the transcript were removed to maintain participant confidentiality. The PI reviewed the transcript in parallel with field notes to capture non-verbal nuances and context. The PI uploaded the transcript into Atlas.ti version 8.1 qualitative software management program. Atlas.ti is widely used to support data storage, organization, and management. Through software applications, data was formatted in rich text format, from which defined codes and categories were generated for subsequent automatic or manual coding, described in detail below.

Transcripts were reviewed weekly by PI and Dr. Lois Loescher (dissertation chair), who has experience in analysis of qualitative data, to identify emerging themes and data saturation status. Weekly Skype consultations with Dr. Loescher also ensured the maintenance of an audit trail, monitored potential research bias, and promoted trustworthiness of data. Dr. Marylyn McEwen, an expert in qualitative methods, provided ongoing consultation for data analysis
decisions. The PI uploaded audio recordings and electronic documents to the University of Arizona’s Box@UA, a secure cloud-based storage system. Drs. Loescher and McEwen were added to Box@UA with editor status. Paper documents were stored in PI’s home office safe. After publication of results, the transcripts will be destroyed. Upon completion of the study and approval of the final dissertation, the recordings, and paper documents were destroyed. The analyzed data will remain in Box@UA for a total of seven years, and then will be deleted.

Data Analysis

In qualitative descriptive studies, content analysis is the recommended strategy for data analysis (Sandelowski, 2000). Data collection and data analysis mutually inform one another, meaning that codes are systematically applied, but are also generated from the data. Investigators may establish a priori coding systems, which may be modified or discarded, to ensure the best alignment between the data and coding system (Sandelowski, 2000).

For this study, both inductive and deductive data analysis approaches (Fereday & Muir-Cochrane, 2006) were used. For the deductive approach, a priori codes corresponded with each of Naylor’s (2017) essential transitional care components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. For the inductive approach, the PI used open coding to capture content that did not reflect the a priori codes. Figure 4 depicts the inductive and deductive analytic processes, represented by the following phases: preparation (e.g., selecting unit of analysis, making sense of the data), organizing (e.g., inductive approach using open coding process and deductive approach using a priori coding categories), and reporting (e.g., reporting analytical process and results) (Elo & Kyngäs, 2008).
In this study, the unit of analysis is meaningful segments, derived from the transcript. Meaningful segments may include manifest content (e.g., a phrase, sentence, or quote) and/or latent content (e.g., paralanguage cues) (Morse, 1994; Robson, 1993). Sense-making of data involves obtaining a sense of the whole while simultaneously learning ‘what is going on’ with the data (Morse, 1995). The PI immersed herself in the data, asking the following sense-making
questions (Dey, 1993): (a) who is telling? (b) where did this happen? (c) when did it happen? (d) what is happening?

Deductive content analysis was completed by using a structured categorization matrix informed by Naylor’s (2017) essential transitional care components. The PI reviewed data for content and code for correspondence to the matrix categories. When using a structured categorization matrix, only aspects that fit within the matrix are chosen from the data (Sandelowski, 1993, 1995). When data did not fit into the categorization matrix, the PI analyzed it according to inductive content analysis principles.

Inductive content analysis was done by open coding, creating categories, and abstraction (Elo & Kyngäs, 2008). To open code, the PI made notes and headings in the transcript. The PI re-read the transcript and headings and added notes and additional headings as warranted. The PI then transferred the headings noted within the transcript to a coding sheet. The PI generated categories using an inductive decision-making process (Dey, 1993). Lastly, the PI used an abstraction process to classify codes as representing a main category, generic category or sub-category (Dey, 1993; Elo & Kyngäs, 2008; Robson, 1993).

The PI’s iterative inductive and deductive analyses, codes, and categories were reviewed on a weekly basis by Dr. Loescher, who confirmed accurate data extraction and analysis. The PI reconciled the data analysis findings with the study’s aims. The data corresponded to study aims, from which the PI developed stroke-specific exemplars of and refinements to each of Naylor’s (2017) essential components.
Rigor and Trustworthiness

In qualitative research, scientific rigor is a means by which confidence or trust in a study’s findings are established. Lincoln and Guba (1985) provided a model of trustworthiness consisting of four components: (a) credibility – referring to the ‘truth’ of the findings and confidence thereof, (b) transferability – the demonstration that study findings are applicable in other contexts, (c) dependability – indicating the study findings are consistent and could likely be repeated, and (d) confirmability – pertaining to objectivity of the findings; the extent to which findings are shaped by the participant as opposed to investigator bias, motivations, or perspectives.

Establishing Credibility

Techniques used to meet Lincoln and Guba’s (1985) credibility criteria relevant to this QD study during data analysis were peer debriefing and member checking (Creswell, 2014). Peer debriefing is a process involving the PI and peers to identify and analyze any emerging PI biases, perspectives, or assumptions. Consistent with established peer debriefing processes (Lincoln & Guba, 1985), the PI met via Skype with Dr. Lois Loescher weekly to review data collection and analysis procedures, observe for evidence of PI bias, errors, or omissions. Member checking was performed after the initial data analysis. The PI randomly selected two participants to verify the initial analysis of participant findings, which was recorded in the field notes and memos. Lastly, the PI iteratively monitored for the emergence of potential biases and assumptions explicated in the reflexivity statement (Appendix K) to ensure that they did not interfere with this dissertation study.
Establishing Transferability

Thick description is the approach used in achieving transferability and involves sufficiently explaining a phenomenon (Lincoln & Guba, 1985); in this study, the stroke-specific characteristics corresponding to Naylor’s (2017) essential transitional care components. Techniques to establish thick description and transferability of findings include data saturation (discussed above), member checking (discussed above), peer debriefing (discussed above), and thorough analysis of memos.

Establishing Dependability

To demonstrate that the findings of this study are consistent and replicable, the PI maintained an audit trail. The audit trail provides information required for an independent auditor to evaluate the process and products of the study (Creswell, 2014; Miles & Huberman, 1994). The PI maintained the following records comprising the audit trail (Lincoln & Guba, 1985): raw data, data reduction and analysis files, field notes, reflexive journal, and process notes and memos. Her dissertation chair reviewed the audit trail and determined that the conclusions set forth by the PI are, indeed, supported by the data.

Establishing Confirmability

Techniques to be used in establishing confirmability are the validation of the audit trail (discussed above) and completing a reflexivity journal prior to study commencement (Appendix I). Reflexivity refers to the degree of influence an investigator may intentionally or unintentionally imparts upon the research process or findings (Jootun, Marland, & McGhee, 2009). To mitigate potential researcher bias, Lincoln and Guba (1985) recommend using a
reflexive journal as one strategy to establish confirmability. The PI completed a reflexive journal.

**Procedures to Protect Human Subjects**

The PI received approval from the University of Arizona’s Institutional Review Board (IRB) (Appendix J). To safeguard the human rights of research participants, the ethical principles of beneficence, autonomy, and justice (Dunn & Chadwick, 1999) are incorporated into this study.

**Beneficence**

The PI is obligated to prevent harm and ensure participants are not subjected to harm or discomfort; neither of which are expected to occur during focus group interviews. The benefits and potential risks are described in the informed consent (Appendix H) document. The participant’s right to be protected from exploitation was verbalized, as described in the interview guide (Appendix F). While the PI is a registered nurse, the PI’s professional role is that of a university educator. As such, there is limited risk to participant resulting from confusion between nurse-participant or PI-participant relationships.

**Respect for Human Dignity**

Respect for human dignity includes the right to autonomy, self-determination, and the right to full disclosure. Self-determination rights include the prospective participant’s right to voluntarily opt-out of the study without fear of prejudicial treatment. Participants opting to participate in the study will self-determine to do so, free of coercion, and were able to withdraw any time. Full disclosure involves the right to make informed and voluntary decisions about participating in a study. The study did not involve concealment or deception techniques.
Informed consent was obtained (Appendix H) and included: participant status, study goals, type of data collected, procedures, nature of commitment, sponsorship, participant selection, potential risks, potential benefits, compensation, confidentiality pledge, voluntary consent, right to withdraw and withhold information, and contact information.

The participants in this study received a $20 gift card at the end of each focus group completed, as an incentive. The funding for this gift card came from the PI’s personal funds. To ensure there was no coercion in recruitment or enrollment, the compensation amount was not included in recruitment flyers, referrals, or invitations (Dunn & Chadwick, 1999).

**Justice**

Justice pertains to a participant’s right to fair treatment and privacy. Study participant selection was based upon the study requirements of engaging individuals affected by stroke and caregivers; and not any particular group’s vulnerability. Participants were not expected to directly benefit from the proposed study. All prospective participants and actual participants were treated fairly and in a nonprejudicial manner. Further, all data and reports generated from the proposed study were de-identified. Any documents containing the participant’s name or other personal health information was securely stored in accordance with IRB and HIPAA requirements.
CHAPTER 4: RESULTS

Chapter 4 presents the qualitative content data analysis findings elicited from focus group participants. This chapter describes the sample and discusses a priori and emerging categories resulting from the qualitative content analysis method. The following research question guided the study: What do the primary stakeholders identify as stroke-specific characteristics corresponding to each of Naylor’s (2017) essential TC components (patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability)?

Sample Characteristics

The participants were individuals or caregivers affected by stroke, living in or near Tucson, Arizona. Recruitment from March 28 to May 22, 2018. There were 27 prospective participants who contacted or were referred to PI, with permission, from stroke support group leaders. Eight prospective participants did not participate in the study for the following reasons: not eligible (n=1), did not return PI’s phone call and/or email (n=1), scheduling conflict or inconvenient venue (n=4), and health challenges secondary to stroke (n=2). The remaining 19 persons participated in the study. Table 5 lists the numbers and gender of participants for each group.
TABLE 5. Focus group characteristics.

<table>
<thead>
<tr>
<th>Focus Group Description</th>
<th>Number of Male Survivors</th>
<th>Number of Female Survivors</th>
<th>Number of Male Caregivers</th>
<th>Number of Female Caregivers</th>
<th>Number of Participants in Focus Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Individuals Only</td>
<td>2*</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>#2 Individuals Only</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>#3 All-comers</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>#4 All-comers</td>
<td>1*</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>#5 All-comers</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Totals</td>
<td>6</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>20</td>
</tr>
</tbody>
</table>

*One male survivor attended Focus Group #1 and Focus Group #4. Demographic information for this participant is reported once, described in Table 6 and below.

Demographic and disease characteristics of the sample are in Table 6. Participants had a mean age of 67 years. The majority of the sample reported non-Hispanic white ethnicity and White/Caucasian race; ten (53%) participants were female and nine (47%) were male.

The average number of months since stroke onset was 26.2 (SD 18.2); one participant reported numerous strokes and transient ischemic attacks over a five-year period. The majority of participants (53%) reported the individual who experienced the stroke was discharged to home.

Three participants (16%) reported current use of in-home health services (e.g., physical therapy, speech therapy, occupational therapy, caregiving services).

TABLE 6. Sample characteristics.

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N= 19</th>
<th>Individual = 10</th>
<th>Caregiver = 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range, years of age</td>
<td>48-87</td>
<td>53-78</td>
<td>48-87</td>
</tr>
<tr>
<td>Mean, years of age (standard deviation) SD:</td>
<td>67.4 (SD 11.3)</td>
<td>67.5 (SD 8.0)</td>
<td>67.3 (SD 14.7)</td>
</tr>
<tr>
<td>Race or Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Native American or American Indian</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>15 (79%)</td>
<td>8 (90%)</td>
<td>6 (67%)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>4 (21%)</td>
<td>1 (10%)</td>
<td>3 (33%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10 (53%)</td>
<td>5 (50%)</td>
<td>5 (56%)</td>
</tr>
<tr>
<td>Male</td>
<td>9 (47%)</td>
<td>5 (50%)</td>
<td>4 (44%)</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed, full-time</td>
<td>4 (21%)</td>
<td>0 (0%)</td>
<td>4 (44%)</td>
</tr>
<tr>
<td>Retired</td>
<td>14 (74%)</td>
<td>9 (90%)</td>
<td>5 (56%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (5%)</td>
<td>1 (10%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>
Deductive Content Analysis: Naylor et al. (2017) Essential TC Components

The PI, in collaboration with her dissertation chair, used qualitative content analysis to analyze the focus group data. Naylor’s essential TC components (patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability) served as a guide for deductive analysis. Naylor’s operational definitions for the TC components are in Figures 5-12.

Category 1: Patient Engagement

Optimizing the central role of engaging individuals through deliberate and consistent efforts of healthcare professionals and systems to identify what outcomes of their care is most important; assess their perspectives, needs, and capabilities; foster shared decision-making regarding plans of care; promote shared accountability for actions related to these care plans; and ensure trusting, reciprocal, and respectful relationships (Naylor et al., 2017, p. 3).

FIGURE 5. Operational definition of patient engagement.
and communication from healthcare professionals. “We need to know [from providers] what the goals are,” “. . . a neurologist who would have given us a plan. . .we just didn’t have a plan,” and we need “knowledge, information, and communication” with “one point of contact,” “an advocate,” “a caseworker,” or “a person to coordinate it.” The patient engagement process was a “dark black hole” with “nobody to talk to.” Participants recommended “patience, understanding, and a positive attitude,” encouragement, emotional support, a list of stroke doctors and resources, support groups, and stroke camps to improve patient engagement.

One participant described a strategy to support trusting and respectful relationships: “. . . be supportive, but not letting that come out or showing up as [survivor] pity.”

**Category 2: Caregiver Engagement**

Optimizing the central role of engaging caregivers through deliberate and consistent efforts of healthcare professionals and systems to identify what outcomes of care are most important to caregivers related to their role in caring for patients; assess their perspectives, needs, and capabilities; foster shared decision-making related to patients’ plans of care; promote shared accountability for actions related to these care plans; and ensure reciprocal and respectful relationships (Naylor et. al, 2017, p. 3).

*FIGURE 6. Operational definition of caregiver engagement.*

**Outcomes of care most important to caregivers related to caregiving role.**

Participants described the importance of family and social support in optimizing their care role, which was frequently lacking: “. . . just knowing that I wasn’t alone,” “we have no family here,” “we’re surrounded by family, but we didn’t really get support from them,” and “an occasional thanks from her [survivor’s] family would be nice, but I’m not counting on it.”

Participants described lacking caregiver assessment: “. . . they [healthcare professionals] never interviewed me [the caregiver, about] how my lifestyle was at home, so how could they tell me what to expect?” “They [healthcare professionals] didn't know us from Adam.” and “. . .
certain people are not good at caretaking.” They also described lack of caregiving preparedness “[I wasn’t ready for] the stress. . . and the emotions. How do we deal with that?” “[He] had a very limited skill set for dealing with [caregiving],” and “just didn't have the tools.” There were issues relating to caregiver burn-out: “[my caregiver] was getting burned out,” and “the big challenge . . . is not getting burned out.” Communication and information between caregivers and healthcare professionals was suboptimal: “what is a care plan?” “I’ve never seen a care plan,” “give me a recipe,” [we need] “information and . . . goals,” and “an advocate . . . to weed through the information.”

**Caregiver engagement facilitators.** Participants described *facilitators* of caregiving engagement: “[we need] a support system set up right away” because “there is no support, nowhere,” “[we] keep ourselves busy doing things,” and to “go out of the house once a day . . . because I don’t want us to be stuck in the house.” Common facilitators of caregiver engagement were emotional support, patience, and communication: “. . . patience,” “. . . a lot of patience,” “she [caregiver] needs emotional support,” “she [caregiver] needs me to be more emotionally responsive,” “emotionally involved with . . . where we’re at,” “understand what she’s [caregiver] going through,” and “for me to be supportive instead of just not having my needs met.”

Caregiver respite care was described as a needed caregiver engagement facilitator, “she wants to take a break away from everything . . .” and “she needs a break.”

**Caregiver engagement barriers.** Participants described *barriers* of caregiver engagement, such as caregiver employment and financial challenges which created competing demands and work-life imbalances: “she’s gone [at work] 10-12 hours a day,” “a tremendous amount of juggling and responsibility and doing it alone,” “it’s just one more thing to do, one
more task,” and “[we need] financial support,” …. he [survivor] made 3.5 times as much as me … I have the stress of working two jobs, 60 hours a week …”

Participants described an overall lack of time as “time management.” Another participant said, “It's a lack of time. It's a concentric circle. It's not only lack of time of the person, the stroke victim, but lack of time for the caregiver to do what needs to be done.” Another participant described, “I [caregiver] need time for myself.” Other barriers were physical demands, role shifts, and caregivers’ own health status: “Sometimes they gotta move you around . . . put me in the wheelchair . . . the car . . . it’s really hard on them,” “. . . things like [changing oil in the care, household repairs, yard work] . . . things he would normally do, now fall on me,” and “my biggest interference [in caregiving] has been my own health . . . and emotional needs.”

Category 3: Complexity Management

Person-centered care that is holistic, consistent with patient goals and characterized by anticipation, prevention, or early identification of problems (including health problems that develop during the acute hospitalization) that represent the most common clinical reasons for poor outcomes among the target population. This high-risk, chronically ill population presents clinicians and caregivers with challenging care issues associated with managing complex physical, emotional, and social needs. One critical dimension of complexity management is medications. Medication management is person-centered care characterized by an organized effort to ensure optimum therapeutic outcomes through greater accuracy in medication use and reduction of adverse events. Efforts to promote adherence are integrated within a comprehensive care plan (Naylor et. al, 2017, p. 3).

FIGURE 7. Operational definition for complexity management.

Anticipating problems and holistic person-centered care. Participants described anticipating multiple problems associated with stroke consequences and other comorbidities: “. . . the needs [after stroke] are a lot,” “. . . a lot of stroke victims are older – and their caregivers as well – and they have other [health] issues,” “you may be having to deal with [comorbidities] while you’re trying to deal with the issues of stroke,” and “. . . you have other physical problems that are . . . not related to the stroke, but they’re there.” Participants also described seeking
integrative approaches to meet their holistic care needs, such as medical marijuana and acupuncture: “We’re looking for different solutions. Medical marijuana might be one of them,” “we’re looking into a service dog” and “acupuncture . . . my neurologist has suggested . . . that I go . . . .”

**Managing complex physical needs.** Participants described challenges in gait, balance, and walking: “[my challenges are] mobility [points to electronic wheelchair with hand controls] and my speech,” “. . . physical challenges like walking. . . especially downstairs or up the stairs because of my left leg and foot,” “the biggest physical challenge is coordination, especially your gait. . . ,” “. . . she couldn't navigate stairs....” “. . . when I get tired, my right leg drags,” and “yeah, I fell.”

Other challenging physical care issues were described as limiting activities of daily living: “My husband couldn't be left alone. He couldn't bathe himself . . . somebody, me, still had to be in the shower with him. . . . He wasn't cooking for himself . . . personal needs and care he still was not able to do for himself;” “. . . when I came home I couldn't walk. I couldn't dress myself. I couldn't bathe myself. I fed myself sloppily. I had a lot and I still have physical challenges. . . ,” “. . . she can't open a bottle. She can't open a can, like the flip up can....” “I had to cut his food, help him get dressed,” and “. . . my biggest challenge was trying to tie my shoes. . . with one hand.”

Fatigue was described as a challenging physical care issue interfering with patient goals: “I fatigue,” “. . . “when she gets very tired, she gets hyper [hand gestures above head, then quickly down to table],” and “. . . you can now do for a bit what you used to be able to do all day.”
Managing complex emotional needs. Participants described a range of challenging issues associated with managing complex emotional needs; from no emotional challenges, to not discussing emotions, to feeling they would be better dead: “We don't talk about emotions,” “I just have not had any emotional challenges. It is what it is . . . but mine [stroke] wasn't a serious event either,” “. . . my emotional ups and downs . . . it's been hard on me,” “she [survivor] was more easily hurt and also out of the blue. . . .”, “I have my really low days,” “. . . this little thing would make her cry,” and “[NAME has] a lot of feelings. Why I'm here for, why didn't I die, why should I burden my kids, and burden to you? I need help for everything. I should be better dead than . . . [this].”

Anger, fear manifesting as insecurity, and depression were also described as challenging emotions associated with complexity management: “I get mad . . . ,” “She did get angry . . . when the doctor. . . took away her [driver’s] license,” “she [my wife] did become kind of . . . like what you said [insecure],” “[NAME] has had very severe depression, extreme depression, with all kinds of ways that he's been trying to deal with it,” “the injury [stroke], it brings on depression . . . you start thinking ugly . . . ,” and “depression . . . that’s a big thing, a big challenge.”

Managing complex social needs. Participants described the physical manifestations of fatigue, aphasia, and hearing alterations as adversely affecting social needs: “She would like to do more [socially],” “We stayed there for about an hour . . . she told me . . . I am so exhausted. I wanted to stay longer, but I can't, I'm so exhausted.” “The primary [social] problem that I have is with aphasia. . . aphasia is loss of words, not intellect,” “[regarding aphasia] I will also point out that it is just the speech. The cognitive ability is fine,” “. . . because of the tinnitus, the hearing, the aphasia. Social events are very difficult. . . ,” “[socially, it’s] not only the hearing but it's the
dealing with so much going on . . . overstimulation. . .,” and “it overwhelms her [socially] that there's so much noise. It's too loud. You can hear more, [but] it's too much going on for one person.”

Participants with facial droop, contractures, and hemiparesis described physical limitations and appearances as affecting social needs: “. . . I remember that in the first year of the stroke and it was very, very hard. He just didn't want people to see him. He was very self-conscious about his appearance and what people would think,” “. . . for the first year [NAME] didn't want to go out at all. He just stayed home,” “It was very, very sad because he just couldn't bring himself to go [out] . . . ,” “. . . she [survivor] can tell when somebody’s averting their eyes. They don’t wanna look at a woman in a wheelchair,” and “sometimes I feel left out of things that I can't go to, all the things I used to. I was at a big social event this weekend and people are all up here [gestures to a height above her wheelchair] and they're talking and having a good time, and I'm like this [gestures to wheelchair and contracted hand], you know?”

Lacking social systems, financial insecurity, and caregiver abuse were also described as challenging social issues: “. . . if you don't have a social network or family to step in, what then?” “. . . having our financial needs met . . . being able to have a roof over our head, have food in the refrigerator . . . ,” and “I think he [extended family caregiver] was being abusive . . . So, yeah, I had a stroke . . . but I’m not braindead . . . I recognized he was being abusive and it's easy to be abusive to somebody that's disabled in a wheelchair or whatever . . . ”

**Managing medications.** Medication management includes greater accuracy in medication use, reduction of adverse events, and adherence. Participants described medication management, overall, as complex, expensive, and annoying: “I remember, [it was] a little scary
and overwhelming … because now it was gonna be my job to make sure he took his medications at certain times. . .,” “. . . at first, you know, I could tell by the pills, the color and the shape, and then all the sudden two of them changed. Different shape and different color. So, we talked to the pharmacist and then his answer was that, ‘oh it's because another maker is making that one so now they're a different color, different shape.’ But I mean, you could get easily confused, take more of one or the other.” “. . . some of the prescriptions . . . they're just ghastly expensive,” and “. . . prescription management . . . somebody [caregiver] has to get the prescription refilled. Then it has to be picked up and to me [caregiver] it's just a huge annoyance.”

One participant described a medication management strategy: “[my caregiver] got all of the pill bottles and some cards and scotch tape. . . what the name is and here's the card for the [morning and the] evening. That is just incredibly helpful.”

Corresponding to greater accuracy in medication use, reduction of adverse events, and adherence, participants described challenges with pill to milligram conversions, drug compatibilities, and the need for reminders: “. . . they'll tell you take two or three pills of this, but the challenge was the milligrams. The doctor will say take 10 mg. That could be two pills . . . but how many milligrams? Milligrams to pills, you gotta figure it out,” “compatibility … I use the pharmacist. I take in my phone. It has all my drugs on it and if I have something that I need, I have them check with compatibility. [Managing medications across multiple providers] . . . greatly needs improving.” “I've never been a pill taker all my life, so now for me to do pills on a regular basis every morning and then every night . . .,” and “she needs a lot of reminders.”
Category 4: Patient Education

Continuous interactive teaching and learning processes involving the healthcare team and patient. Participation should be based upon an assessment of patient goals and designed to enable patients to assume increased responsibility for their own health; use strategies that encourage patients to make healthier lifestyle decisions; avoid or reduce adverse events related to condition or treatments; ensure continuity of care; and promote independence in activities of daily living (Naylor et. al, 2017, p. 3).

FIGURE 8. Operational definition for patient education.

Continuous interactive teaching and learning. Participants described lacking continuous interactive teaching and learning processes involving the healthcare team and patient:

(in response to reading the lay-person patient education definition - Appendices F & G) “I would say you’ve got to be kidding,” “the only person that gave us any help was the speech therapist. We really had no education at all [another participant replies ‘none,’ followed by another participant reply of ‘none of those things happened’],” “[We need] the advocate, instructional support,” and “we finally got some reading material from our speech therapist . . . the stroke support group was very helpful. But [survivor] has aphasia. He has trouble reading.”

Education delivery and participation. Participants described facilitators to patient education delivery and participation being based upon an assessment of patient goals, designed to enable patients to assume increased responsibility for their own health. Facilitators were scaffolding, visual images, review of diagnostic findings, and informational booklets: “. . . build on what she [survivor] knows best, whatever that is. If it's her organization skills, if it's some technical, you know, something with her hands. Get them going on something that they are best at so they can gain confidence and build it up,” “. . . he shows me the photograph of what it was. He shows me the photograph of what it is now,” “it was comforting for me for all of them to go down the list [of diagnostic findings] . . . because they're drawing blood and they're giving me all
these tests and stuff like that, and they'd show me. Okay, you're good. You're getting better,” and “I was given a booklet about stroke that answered a lot of questions. Different definitions, the type of stroke, what studies have found. It was really a helpful book.”

**Promote independence in activities of daily living.** Participants described successful learning strategies on certain ADLs: “. . . playing cards before [meals], or we'd sit in the waiting room and play cards or whatever. So, it was encouraging me to remember how to play,” “. . . training like maybe doing your wash, cooking a little bit, washing dishes because at first, I had a really hard time . . .”, and “. . . go to a driving school to learn how to drive with the left hand.” Participants described needing patient education in “how to get a bra on,” and “oh, yeah, or socks.” One participant described the need for “vocational rehabilitation” to promote independence.

**Category 5: Caregiver Education**

| Deliberate and consistent efforts to involve caregivers with decision-making regarding patient care. Prepare with the skills needed to care for patient when transitioning to home, including skills in early identification and management of worsening symptoms. Caregivers are provided with access to community resources and supports and develop competencies and confidence that can help provide for patients’ needs and address their own needs (Naylor et. al, 2017, pgs. 3-4). |

**FIGURE 9.** Operational definition for caregiver education.

**Efforts to involve caregivers with patient care decision-making.** Participants described flaws in healthcare team assumptions regarding caregivers. For example, having someone at home does not necessarily translate into that person being capable of caregiving and patient decision-making: “. . . Someone home, yes, well that's [a caregiver] ‘taken care of’ [gestures air quotes]. No, not necessarily ‘taken care of’ [gestures air quotes], that just means there's someone home. So, how about they be very careful of the assumptions they make. . . ,”
and “. . . we can't assume that education and support for the supposed caregiver will be sufficient. It could be that no amount of help will be sufficient.” Participants described needing caregiver assessments prior to involving them with patient care decision-making: “do an assessment to see if the supposed caregiver in place is adequate to the task and if they're not, they have to have a resource that is.” Caregivers were described as not always being available, willing, or capable: “he was a deer in the headlights. He wasn't able to deal with the situation, period” and “not to expect much from friends and family because. . . they don't have the time themselves. . . they don't want to deal with it.”

Prior to involving caregivers with patient care decision-making, participants described needing more information regarding stroke in general: “. . . there is no such thing as [caregiver education] that I know of. . . it's not there. . . so we're learning a lot of stuff [on our own],” “we didn't know what it [stroke] looked like, what to expect, or anything. . . this is foreign to us,” and “we're not the experts. . . we had no experience with stroke.”

When actively involving caregivers with decision-making, participants described being overwhelmed, and the importance of repeating information: “. . . at the very beginning when something like that has happened to your family member, it was just too much. . .,” “. . . they handed me materials. . . I couldn't even look at the materials. I was in such shock. . . I didn’t look at the materials for some time,” “I'm not sure if I heard everything that was told. In fact, I know I wasn't. I was so overwhelmed with the whole thing and, my god he's in ICU. . .,” and “. . . number one is just explaining what has happened to the patient and the family and keep explaining it. Don't stop at [one time]. This is what happened and that's it. You need to explain it again and maybe again.”
Caregiver skill preparation and managing worsening symptoms. Another aspect of caregiver education is preparing caregiver with skills needed to care for patient when transitioning home, including skills in early identification and management of worsening symptoms. Participants described the need to tailor the care plan, and to educate caregivers in knowing what to expect: “. . . this mythical care team needs to . . . tailor whatever is needed . . . for [caregiver] and for the person who has had the stroke. . . one size doesn't fit all,” and “. . . be educated on what do I do next [after leaving healthcare facility], because their natural response will be to . . . take me to the hospital . . . .”

Specifically pertaining to preparing the caregiver with skills needed to care for the patient when transitioning to home, participants described needing to be educated in basic caregiving and ADL skills, such as patience, wheelchair mechanics, patient transfers, bathing, toileting, and clothing suitability: “Patience . . . is a skill . . .,” “some real basic skills. . . move from the car to get in a wheelchair and moving into a chair or bed. . . learn how to use body mechanics to move up and down, how to move safely for both caretaker and survivor,” “getting in and out of the shower,” “how are you going to bathe them?” “Going to the toilet, putting your clothes,” and “don't use this type of clothes, use the other ones, they're easier [gestures to contracted hand].”

Regarding identification and management of worsening symptoms, participants described the need for a feedback loop and someone to call for critical and unexpected situations such as patient falls, sleep apnea, mood swings, depression, and personality changes (e.g., ‘act crazy’): “when you get home, you're gonna run into situations that you did not anticipate nor did they [healthcare team] anticipate when they discharged the person. So, you need to have a feedback loop,” “phone number . . . someone to call” in “critical situations,” “. . . know what kind of
issues might arise. . . be aware that you need to call for help.” Participants described “preparing for falls,” “having sleep apnea,” “. . . dealing with . . . the mood swings . . . the depression,” “this person might act crazy [personality change] at some point . . . you're gonna have to cope with it and maybe discount it, walk out, do whatever. Never did they ever talk about that, never,” and “this person's going to be different . . . they may cry more easily . . . get angry or impatient.”

Community resources and caregiver competencies. Caregivers, pursuant to the operational definition, should be provided with access to community resources and supports to develop competencies and confidence in providing for both patient and caregiver needs. Participants described needing support groups, retreats, therapists, counselors, a public health nurse, and a hotline, resources for grieving and loss, and non-health related resources: “. . . a list of support groups . . . or even therapists that have experience working with . . . [stroke],” “I attended a retreat . . . I really liked how they separated the caregivers from the survivors because then you can be candid . . . You can speak about things that you don't want to say in front of your survivor,” . . . ‘A counselor . . . that has experience with stroke,” “. . . a hotline or some resource that I could have at my fingertips and say . . . this is what I'm experiencing . . . how I'm feeling . . . ,” “. . . resource person . . . a public health nurse,” “[resources for] grieving and loss,” and “. . . information . . . that doesn't have anything directly to do with the stroke. Like, where can you get your car modified? Some sort of referral to services that have to do with your life . . .” Provision of resources was also described as being overwhelming at times: “She [social worker] was making sure that I had information on how to . . . get the supplies and the modifications done to my house . . . I remember how she gave me lists and there was like all these names and I said to
her, ‘this is overwhelming me. Can you narrow this down for me? Can you give me a recommendation?’”

Respite care and caregiving support was described as essential, because “the caregiver has to be helped to understand that they have to schedule breaks whether or not they recognize the need because they're probably the least likely to recognize when it's [most] necessary.” Participants described the need for respite care resources, and concern for the cost of same: “[Caregivers] need to have two or three backups “and “resources where you can get temporary respite care.” “You have to pay out of pocket [for respite care] and that's a big problem.”

Participants described difficulty in locating caregiving services and the consequences of lacking caregiver education and preparedness: “how would you go about finding a caregiver if you needed one?” and “[we need] . . . a pool of caregivers under one umbrella.” Even if caregiving classes are offered, not every caregiver is open to the resource: “[NAME] tried to get him some caregiver classes and he refused . . . [later, participant added] he reached his limit . . . he felt so trapped . . .,” “The fallout . . . these people [healthcare professionals] could prepare us better for that . . . because they didn't do nothing in [our case],” and “we’re just dropped back into the community, trying to survive.”

Participants described the need for community resources to support social determinants of health (e.g., housing, economic stability): “[we need] financial resources . . . you lose your apartment because you can't pay the rent, and you have to go out in the community and try to find a place to live because when he comes out of the hospital, he can't just be homeless, so you have to find another place to live? Then try to get social security. That is a crazy process that everybody calls a game now, and you get denied no matter what,” and “we're at the point of
trying to get our disability or social security or something. That's gonna take 16 to 18 months.

So, we're in the process of that right now with a lawyer.”

**Category 6: Patient and Caregiver Well-Being**

<table>
<thead>
<tr>
<th>Recognition of patients’ and caregivers’ emotional reactions to stressful experiences and deliberate efforts of healthcare team members to acknowledge such reactions, foster coping skills, enable care recipients to be respected and treated as whole human beings, and support decisions that contribute to patients’ and caregivers’ quality of life (Naylor et. al, 2017, p. 4).</th>
</tr>
</thead>
</table>

**FIGURE 10.** Operational definition for patient and caregiver well-being.

**Emotional reactions to stressful experiences.** Participants described emotional reactions and stressful experiences being centered on communication, honesty, trust, and financial security: “I found very, very, very often that communications are the weakest points we have. We never talk about stuff. We never acknowledge certain things,” “. . . I can say anything, we can discuss . . . frustrations and joys . . .,” “. . . you need to be honest with each other . . .,” “being able to talk about it and express what I'm feeling . . . just to say what I need to say without judgment . . .,” “I just want that sense of peace . . . trusting and knowing that everything is going to be okay,” and “It’s stressful . . . not having . . . financial security.” One participant described not dealing with stress or emotions: “I'm very good at managing stress. I don't deal with it . . . but I really don't know what stress is and I really don't know emotions . . .”

**Coping skills.** Participants described the importance of communication and a social network: “[we need] someone to talk to . . .,” “we communicate between us . . . [but] . . . and we don't always do that,” “I wanted my extended family to be around. I needed that lift. I needed to laugh. I needed to feel some sense of my old life . . .,” “[Being around friends and family] . . . felt normal, what was . . . my life before the stroke. Just interacting with people again and not about the stroke,” and “I’d like . . . a list available . . . to come to a [support group] meeting.”
Participants described needed coping skills pertaining to independence, guidance, and life balance: “to be more independent,” “[I] . . . need guidance sometimes,” “balance . . . if I could just have all the things that matter to me balanced and kind of working in a balanced fashion . . .,” “I feel guilty about this but I [caregiver who works 60 hours per week] just lay in my room, put my earbuds in, and listen to music or watch movies and just lay there with the lights off and the curtains drawn, and just lay there and just close my eyes. Sometimes I feel guilty because I don't have that much time off where I can do stuff with [survivor] and I feel . . . selfish . . . doing that, but I have to do that sometimes. I have to completely shut down or it's too stressful.”

**Quality of life.** Participants described decisions to live life fully, be healthy, religious practices, and enjoying leisure activities within limits: “living each day to the fullest,” “peaceful moments, and fun moments,” “we love God . . . we’re doing our own bible study. . . .” Having “time to do my own things or relax” with “adequate rest . . . not having too much overstimulation,” but “don't push yourself to the limit so you cannot handle it.” Participants described the importance of a healthy diet and regular exercise, which is not always possible with comorbidities: “I need time for myself. I need to have a good diet for myself, I need my exercise time . . . every day,” “[I need] alone time and rest,” “staying healthy,” and “sometimes what's important for you is impossible. For me, the exercise is vital . . . I have a hip [needing replacement], and it aggravates the hell out of me, all day long.”

Participants described economic status as relates to quality of life: “I [need to] get back to doing something [employment] four or five hours a day . . . to be [financially] supportive,” “money [is important],” “. . . you don't necessarily need money to go out and have fun. Go to the
park, have a picnic . . . go to the movies, whatever,” and “. . . we're very, very comfortable
economic wise. That's my quality of life.”

**Category 7: Care Continuity**

| Comprehensive implementation of individualized care plans, including ensuring timely access to appropriate, high-value health and community-based services (management continuity), timely exchange of information between and among all team members (informational continuity), and access to continuous sources of care to foster trust with patients and caregivers (relational continuity) (Naylor et. al, 2017, p. 4). |

**FIGURE 11.** Operational definition of care continuity.

**Management continuity.** Participants described challenges in timely access to care: "We didn't see the neurologist until six months later,” “no one was giving me clear answers . . . the
neurologist was the least informative, and I waited almost six months to get in,” and “they're so
overwhelmed also in their fields that they don't have time to . . . put emphasis on that part of the
patient's life [outside the healthcare system].” Pertaining to accessing appropriate, high-value
health and community-based services, participants described: “it's a black hole,” “just failure
after failure,” and “we were just cut loose [hospital discharge]. Did not have one piece of paper,
not one bit of information of diet, exercise, any therapies, and we just went home.”

Lacking plans and resources were problematic: “[we needed] a plan . . . we didn’t have a
plan,” “a schedule . . . to follow every day,” “[they need to] meet with you in your home at least
once [second participant adds] . . . someone coming to your home where you can have a
conversation face-to-face is far better than a list or a phone number . . .,” and “guidance and
counseling,” “periodic case review,” and “check with us, please. Please, check on us.” One
participant compared stroke TC to hospice care: “I think hospice services do[es] better work with
the dead people than with us. They [hospice] check on people, how they're doing after somebody
dies. They check on the family ‘Do you think that you need another visit to your house? A social
work[er] can go and visit you. The chaplain can go and visit you and help.’ Stroke patients, they
don't have none of that.”

**Informational continuity.** Participants described the exchange of information as
fragmented, lacking an access point, and needing a patient advocate: “I was given the
runaround,” “we needed . . . but . . . didn't get . . . information and somebody, a resource,”
[second participant adds] . . . “the advocate,” . . . [third participant states] “. . . there has to be a
team leader so that rather than having seven phone calls, seven phone numbers . . . you don’t
need the confusion of trying to be part of the healthcare system yourself,” “. . . information, yes,
but there's no access point. If there's an access point, I can go there and I can get information . . .
but if there's not access point, you don't know where to go. The information is great, but what's
the number you call? Where's the location? Where's the email address? Where's anything?” And
“. . . rather than getting lost in the myriad of never ending bureaucracy, could there be one
contact person?” [second participant responds] “that would have helped tremendously. [third
participant adds] and the advocate, instructional support.”

Participants described the need for timely information transfer regarding support groups:
“I wish that we would have gotten involved in the support groups sooner, because we didn't
[know about them] . . . until . . . seven or eight months after he got out of the hospital,” and “. . .
that's a catch 22 too, is when you need it when she first comes home and you don't have time to
go to a support group because you're providing the care, you know? You can't be in . . . [second
participant adds] . . . two places at once.”
Relational continuity. Participants described needing “... help ... [second participant adds, nodding head affirmatively] help,” with support groups and retreats as needed sources of care: “... what's been ... helpful for me is support groups ... they can relate to you what you're going through,” and “that [stroke retreat] was really good ...”

One participant verbalized an overview of relational continuity issues: “The healthcare system itself is a barrier of getting any kind of trusting relationship with healthcare professionals, that's number one. Number two, the insurance company in between you and the doctor. Number three, the just overwhelming mass of people. Number four, the requirement that once you get to see the doctor, it's not so bad, but getting through that mass of barriers is the problem. Finally, you gotta have an advocate. You can't just say, okay, you got an appointment in July [three months away], yeah okay, I'll take it. Bullshit, okay? You have to be an advocate otherwise you get steamrolled by the system,” to which another participant added “... if you don’t advocate for the patient yourself, they could die.”

Barriers to fostering trust were described as lacking professional competence, the 15-minute appointment time, and a problematic healthcare system: “professional competence would be nice.” “I remember the neurologist, I will never forget this, coming in and pulling me aside and saying, ‘your husband will never be the same,’ and I thought ... what does that mean?” “I trusted those professionals because they knew ... but they didn't know anything about coming out in the real world outside of the [healthcare system],” “they have 15 minutes per patient. [second respondent adds] ... it's the system. They are so hurried ...” and “the system is the problem. How do you develop trust with a system that is the problem?”
Category 8: Accountability

Assuming responsibility for ensuring high-quality implementation of TC services customized to meet individualized needs of patients and caregivers. Clinician accountability refers to partnerships between healthcare professionals and patients in designing plans of care and ensuring effective implementation of these plans. Team accountability refers to the responsibility of each healthcare professional to contribute expertise and actively collaborate with all team members to ensure that patients and caregivers achieve their health goals. Organizational accountability refers to the system's responsibility to ensure an environment and services conducive to optimizing the TC experiences of patients and caregivers. (Naylor et. al, 2017, p. 5).

FIGURE 12. Operational definition of accountability.

Accountability involves assuming responsibility for ensuring high-quality implementation of TC services customized to meet individualized needs of patients and caregivers. One participant described a positive TC experience: “they had a list . . . in so many weeks you need to schedule an appointment with your primary, and then in so many days you need to schedule an appointment with neurologist, and in so many days you need to schedule an appointment with the cardiologist, all of these appointments. They gave me names, they gave me phone numbers, they told me when and how much time I would need to do that. That was very, very helpful.” Other participants described lacking customized TC service implementations: “A psychologist. That was not on the list. A counselor or anything of that matter. It was not on the list,” “she was processed and released [from the hospital] . . . with nothing. Not a prescription, not a referral, not even the name of a neurologist to get the [anti-platelet] medication,” “. . . the medical establishment makes sense to itself . . . It's a baffling bureaucracy beyond measure for people who are not part of it. So, they [healthcare professionals] have to realize that the people who are not part of it, it's a strange foreign animal to them,” and “the term healthcare team does not exist. It's not just stroke. There is no healthcare team. Both terms are . . . oxymorons - healthcare and team.”
Clinical accountability. Participants described positive experiences with home health nurses and therapists: “the nurse was there to help us [at home], but it was nothing in depth,” and “. . . the individual [physical, speech] therapists . . . they were amazing.” Participants described negative experiences with physicians: “I just feel like they [doctors] don’t understand what I'm going through and where I'm trying to get,” “. . . there is no support that I call support from the hospital or the doctors,” “I don't trust the doctors,” and “. . . it's such a mystery, to even the doctors, how to treat us . . . [second participant adds] I haven’t had a good experience with these doctors . . . .” One participant described needing a partnership with stroke-specific physicians: “Is there any group of physicians that deal just with stroke victims? Are they in existence?”

Participants described the need for on-going assessments, in-home follow-up appointments, and mentorship: “having an evaluation of this is where they're at, this is what they need, and direction [course of action],” “[we need] a follow-up. Someone coming into the home a couple weeks after. That would be very helpful, because then at that point in time, you have a better idea of what the needs are and then get help that way,” and “having the mentor come out a couple weeks after [returning home] and maybe a month after, a month after that. Maybe on a monthly basis for the first six months or something or maybe longer.”

Organizational accountability. Some participants describe positive TC services: “They do . . . an interview to see how your house is set up, and then when we started with the home physical therapy, they walked around and did . . . so, I think that was important,” and “I went to see a psychologist for about six visits, and it was really good. Then Medicare decided to cancel this [service] . . . .” Other participants described system issues related to health insurance and medical bills: “You know what the insurance says? They don't wanna cover everything. I know
that they're the ones that control [healthcare services], the insurance companies. We're at their mercy.” “Then you have the whole issue of dealing with the medical [insurance and bills] . . . [second participant adds] . . . let's not go there . . .,” “it was a rat race and I really had a difficult time connecting with resources and with help,” and “I really don't have much good to say about the healthcare system. I'd rather clean the oven.”

**Inductive Content Analysis and Emerging Categories**

Some categories emerged from the data that could not be explained in the context of Naylor’s model: Psychological stuff, I don’t want it to be my new normal, Fearful and absolutely overwhelmed, Determination, What’s Next, Transportation Challenges, and Information seeking.

**Psychological Stuff**

Participants described mood, behavioral, and personality changes in the survivor that persist for years after the initial stroke, or indefinitely: “. . . the psychological deals that occur . . . they [survivor] do change, really . . .,” “all the psychological stuff started to happen, and there was no preparation for that whatsoever,” “she was more argumentative . . . more bossy,” and “it seems like it’s still changing.”

Participants described challenges with survivor impulsivity: “I can't control that impulsivity,” “. . . being impulsive, not thinking before you speak. . .,” “sometimes he says inappropriate things. . .,” “sometimes I could get in trouble,” and “I didn’t want to be that way because it was just creating problems.”

**I Don’t Want it to be My New Normal**

Participants described challenges adjusting to a post-stroke life. Challenges in adjusting to a new normal occurred in family dynamics, unemployment, and denial and acceptance of
stroke consequences. Family dynamic challenges were described as “. . . there are definitely parts of the new [NAME] that are very difficult . . .,” “. . . is it's almost like living with an infant that wants instant gratification . . . If you don't give it to him right then and there, it's like the end of the world . . . and I don’t want it to be my new normal.” “When I went back to [full-time] work, I felt guilty that I could no longer give him nearly 100% of my time, but I was juggling . . . my schedule . . . to get him to appointments . . . I wiped out all of my leave, all of my sick, all of my vacation. I had absolutely nothing,” “. . . everybody . . . expects me to be the strong one . . . I'm not.” “I [survivor] just want to take care of my wife . . .” “I find that my boy's condescending. Even my caregiver is condescending at times . . .” “What's not normal is that you're not normal. We have to live a different life.” “You just came home and we continued to live, with a lot of bitching.” “For them [school-age children] . . . my son especially, did not want his dad at his school. He didn't want people to see his dad. He didn't want people to ask him about his dad . . . ‘let's keep it quiet, keep it private,’ and I was desperate for help.” “We just wanna be a happily married couple,” “[I am] missing my husband that I knew and also . . . I became a caregiver and no longer the wife . . . who do I talk to about that?” “. . . [family] denial that there was any impact by the stroke . . . they saw him and he looked fine. He was speaking fine; he was mobile . . . they would literally tell him . . . ‘You're okay, you're good,’ [caregiver response] ‘oh my god, come live in my house. This is like a Martian. This is not my husband.’ “I would put myself somewhere else . . . even if I could just get away, just escape everything . . . just to feel somewhat normal again . . .,” and “I'm just sick of it. I just want it to go away and I want things to be regular. . . .”
Participants described employment challenges pertaining to a new, unwanted normal: “What is not normal is that I'm not allowed to work.” “I ran my own business in California so it's really frustrating that I can't do these things that I'm used to doing.” “I've never been dependent on anybody. So, this is a big step for me to depend on somebody. . .,” and “we're just barely making our ends meet right now, so it's another frustration.”

In transitioning to a new normal, participants described denial and acceptance of stroke consequences: “I have been an articulate person most of my life. I'm a singer, an actor, a preacher, and those things have gone from me [due to aphasia]. I can't act anymore. I directed a choir and I can't do that anymore. I can't preach because I can't put words together. [Caregiver adds] We had both been extremely social [dabs eyes with tissue].” “It adds stress to the fact that your quality of life is challenged.” “[Being] accepting, being realistic,” “. . . this is pretty much how I'll be and it's very different than what I imagined for myself.” “[I am] self-conscious. I don't people to know. I don't ever tell nobody what happened to me because I don't want them to know, and I don't wanna revisit that,” “. . . too much of life is gone . . .,” “. . . two years later . . . one of my main goals is to live with where I am and say, okay, this is the way it's gonna be . . . it would have been helpful had we defined that process sooner,” and “I know I'm on a journey and I'm learning every day every time . . . .”

Fearful and Absolutely Overwhelmed

Participants described being fearful and overwhelmed during and after the transition process. Challenges described by participants included being fearful when formal healthcare services were discontinued, being fearful about stroke recurrence and falls, and with changes in caregivers: “It's different when you come home. Things change when you come home,” “I was
just overwhelmed, absolutely overwhelmed,” “. . . when he was released from . . . intensive care, I felt absolutely overwhelmed.” “I didn't know what to do. I didn't have a concept of what the general plan would be. I dreaded them coming to say that we're having your discharge conference and discharge. What am I going to do? I had no idea. I was cut loose and I just felt awful,” and “I'm an RN, I knew that I needed some sort of continuation of care . . . I was scared to death. I didn't know what to do.”

Participants described ADL-related concerns and fears about stroke recurrences, being left alone, falls, and changes in caregiver: “I remember being very fearful of him trying to use the stove . . . and leave the stove [turned] on,’ “. . . taking a shower by myself because . . . it's slippery and [if] you fall, then you go back to the hospital.” “I have this fear about getting a second stroke because people have gotten second and third strokes . . . .” “He was very fearful . . . that he was gonna be alone . . . that I would leave him, that his children would leave him.” “. . . one of my greatest fears, and it still is, to take a fall and end up back in the hospital,” and “she says, you don't fall . . . don't anything that you're not supposed to do because it could be deadly to you.” Lastly, “[Current caregiver] is gonna leave and she's been a great help for me . . . what am I gonna do here?”

**Determination**

Participants described being determined during and after the transition from the healthcare facility to home: “My wife was very determined,” “. . . strong-headed,” “. . . determined to fight,” and “when she makes up her mind she's gonna do something, she does it.” [I was] “. . . just willing myself,” “. . . to try to get better.” “I needed to be independent, so I tried to do a lot of things by myself;” “I'd have to work through that pain to be where I'm at right now.
I had to be mentally strong.” “She was very, very, very optimistic, very participating in whatever they said, going beyond what they said because . . . she was gonna beat this.” [So I] “. . . keep on doing the exercise, otherwise, you're gonna walk backwards . . .,” and “[I] challenge myself and just do it.”

What’s Next?

Participants described uncertainty with respect to next steps, and difficulty identifying resources to support them in next steps: “They [healthcare professionals] basically done their job and put me back in the community, and now it's up to me to figure out what's next,” “. . . right now it's maintaining, so what's next?” “. . . I can't do the stuff I was used to doing, what's next? What do I now?” “I wanna be financially supportive, physically, mentally, spiritually. I don't even know how to, what to do next.” “What's the next thing we can do? What's the next program we can get involved with?” And “once this [meeting] is over with, what's next? What's the next thing we can do?”

Transportation Challenges

Participants described transportation challenges, including asking for or providing rides, and learning how to drive post-stroke. Many participants described being unable to drive: “the doctor at [LOCATION] took away her license . . . for medical reasons,” “my wife, she brings me everywhere,” “we're trying to find a way around while she's at work,” “I [caregiver] provided all of the transportation for him,” and “one of the hardest things for me [survivor] is to ask people to give me a ride . . . .”

Participants described challenges in using alternate forms of transportation: “I know nothing about busses . . .,” and “I only got on the bus one time.” “I've got Uber on my phone and
I'm set up . . . [but] there's no phone number for me to call them . . .,” and “I went and got a bike so that I can get around, but I don't really . . . I can't really trust myself because my left side.”

Some participants described sneaking out and teaching themselves how to drive again, while others took classes and were re-licensed to drive: “You know what . . . helped me a lot? To get back on the road. I had to learn how to drive on my own, sneak out on the streets and stuff, and it's still not all there because the brain . . .,” “it's so important to be able to drive because that improves your quality of life through getting out of the house, going places, running errands, going to the store and getting groceries . . .” “If they could have somebody to train [you to drive] at first. Nobody trained me,” “go to a driving school to learn how to drive with the left hand.” “I completed my course and had my car modified just this week.” And “so, I did start driving a little bit.” “[She] had to fight . . . to get her license back.”

**Information Seeking**

Participants describe seeking information “online . . . [by] Googling a lot.” “I didn't even know what a stroke was. We looked it up on . . . his phone . . .,” “most of the information comes from Mr. iPhone, looking things up and finding the answers or possible things you could do, but it still doesn't give you a human being out there . . .” “So you can go and research and do what’s available. She [caregiver] did that,” “[caregiver] has gone through her cell phone to the internet,” and “I signed up for a lot of the stroke support online . . . I get emails . . . and a lot of helpful information from stroke.org and things like that.”

Participants described seeking medical and pharmaceutical information online: “I had [prescription medication] . . . I don’t wanna take it because I read the research on the side effects and I don’t want that,” “. . . the biggest thing for me is the meds, and they’re the worse. I don’t
care what anybody says. They are bad. I did some research on all the meds, and they all got bad side effects,” and “[survivor] likes to go online and do his own research . . . but then I think sometimes it can be a negative, too, because he might be looking at the wrong information . . . .”

Summary

This chapter presented a comprehensive data analysis overview from demographic data and qualitative data obtained from focus group discussions. Deductive content analysis of the data reflected Naylor’s essential TC components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. Seven inductive categories emerged from the data: Psychological stuff, I don’t want it to be my new normal, Fearful and absolutely overwhelmed, Determination, What’s Next, Transportation Challenges, and Information seeking.
CHAPTER 5: DISCUSSION

This chapter discusses key findings of the study that address the study aims, presents strengths and limitations regarding application of Naylor’s TC model (Naylor et al., 2017) for the stroke population. Also discussed are stroke-specific essential TC components which inform an expanded stroke-specific TC model. The chapter concludes with discussion regarding implications for research, and nursing practice and political advocacy, along with outlining the strengths and limitations of this dissertation study.

Refinement of Naylor’s Essential TC Components and Stroke-Specific Exemplars

Aim 1 was to engage stakeholders, individuals and caregivers affected by stroke to refine a stroke model of care that addresses each of Naylor et al. (2017) essential TC components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. Aim 2 was to develop stroke-specific exemplars for each of those components. Naylor et al., (2017) described the TC core components as “a critical element of traditional medical care, community-based services, and non-traditional services provided by the healthcare team that patients and caregivers should receive to promote positive health outcomes throughout periods of acute illnesses extending from hospital to home” (Naylor et al., 2017, p. 2). What follows is a discussion of key findings relative to each core component and stroke-specific exemplars to each corresponding operational definition.

Complexity Management

Complexity management is a broad category encompassing several aspects (e.g. physical, emotional, social) of the AHAASA guideline (Winstein et al., 2016), along with problem
identification, and medication management. The majority of stroke patients are over age 65 years (Hall et al., 2012; Mozaffarian et al., 2016), aligning with the mean survivor age of 67.5 years in this dissertation study. For older stroke survivors multimorbidity and polypharmacy (discussed below) are considerably more common than for older adults unaffected by stroke (Gallacher et al., 2014). In this study, participants described needing support with multimorbidity management for both survivor and caregiver, mirroring other investigator’s findings (Byun, Riegel, Sommers, Tkacs, & Evans, 2016; Haynes et al., 2015; Winstein et al., 2016).

Participants in this study described encountering multiple problems during and after the transition to home, a finding reflected in a RCT by Altfeld et al.’s (2013b) reporting that 83% older adults with polypharmacy experience significant post-discharge barriers; 73% of which do not emerge until after patient resumes living at home. Participants also described needing integrative management strategies such as medical marijuana, acupuncture, and pet therapy. These integrative strategies are not specifically addressed in Naylor’s (2017) TC model but are similar to needs reported previously in the literature (Briscoe & Casarett, 2018; Creagan, Bauer, Thomley, & Borg, 2015; Fang et al., 2016).

Similar to other studies, participants described needing support in managing physical consequences of stroke: gait, coordination, balance, ADLs, and fatigue (Wang et al., 2017; Winstein et al., 2016), as well as the need for behavioral and emotional support (Harrison et al., 2017; Wong & Yeung, 2015), including post-stroke depression, emotional “ups and downs,” and anger management. Participants described needing assistance in transcending social isolation secondary to stroke consequences, lacking family or social support, and financial insecurity; reflecting similar findings in the literature (Reed et al., 2012; Winstein et al., 2016).
Effective medication management is essential for stroke survivors, many of whom are elderly with polypharmacy (Gallacher et al., 2014; Mozaffarian et al., 2016a). The Naylor et. al, (2017) TC model highlights the importance of medication management throughout the transition period. The AHAASA guideline (Winstein et al., 2016) only addresses medication management through early supported discharge, highlighting the importance of stroke-specific TC. Participants described needing regular and frequent medication self-management support, consistent with other findings in the literature (Chapman & Bogle, 2014; Puhr & Thompson, 2015), highlighting needed strategies to obtain medications at lowest out-of-pocket cost; and drug compatibilities, and dose-unit conversion training. Stroke-specific exemplars for complexity management, generated in this study, are underlined in Figure 13.

**FIGURE 13.** Operational definition for complexity management with stroke-specific exemplars added.

**Accountability**

Participants’ descriptions of the accountability of the healthcare clinician, team, and organization varied from being provided a comprehensive list of community providers, to being discharged without any instructions or referrals. These descriptions are consistent with findings
in a systematic review and meta-ethnography study (Pindus et al., 2018) that reported passivity of postacute stroke services. Passivity is described as a passive postacute healthcare system mobius loop: survivors and caregivers feel helpless, unsupported, and misdirected by the passive provision of healthcare services. Pindus et al. (2018) describe a lack of continuity of care, no active follow-up, limited and delayed access to community services, and inadequate information regarding stroke, recovery, and healthcare services. Similarly, participants in this dissertation study also described lacking postacute healthcare services, being “cut loose” and “on our own,” while experiencing the healthcare system as a “baffling bureaucracy.”

Pindus et al. (2018) reported that survivors and caregivers need health literacy support in the following areas: stroke information in general, secondary prevention of stroke, locating reputable sources of information, and managing conflicting information across multiple providers. Participants in this dissertation study described similar unmet health literacy needs. For example, they described healthcare interprofessional role and setting confusion; expecting a neurologist to provide the comprehensive care plan through the rehabilitation and chronic phases of stroke. Participants in this dissertation study also frequently described setting confusion, referring to any in-patient care facility (e.g., rehabilitation or skilled nursing facilities) as a hospital; echoing Pindus et al.’s (2018) call for improved stroke health literacy education and management.

Participants described other accountability factors, such as the need for on-going health and safety assessment, in-home follow-up appointments, mentorship for at least six months after returning home, psychological services beyond Medicare’s limit of six sessions, and assistance with reconciling insurance billing and claims. These stroke-specific accountability factors are not
encompassed by Naylor’s TC model but are supported by other studies (Haynes et al., 2015; Reed et al., 2012; Wang et al., 2017). The AHAASA guideline (Winstein et al., 2016) calls for frequent and on-going assessment across domains: physical, rehabilitative, psychological, emotional, and behavioral states, risk of falling, and pain, among others. Participants in this study stated these assessments were nonexistent. The stroke-specific operational definition for accountability generated in this study is presented in Figure 14.

Assuming responsibility for ensuring high-quality implementation of TC services customized to meet individualized needs of patients and caregivers. Clinician accountability refers to defining the roles and responsibilities of identified healthcare team members, partnerships between healthcare professionals and patients and caregivers in designing tailored plans of care commensurate to health literacy attainment and ensuring effective delivery and implementation of these plans. Team accountability refers to the responsibility of each healthcare professional to contribute expertise and actively collaborate with all team members, including patient and caregiver, to ensure that patients and caregivers achieve their health and care plan goals. Organizational accountability refers to the system's responsibility to ensure an environment and services for a minimum of six months after returning home (e.g. on-going in-home assessments, psychological services, a patient or insurance advocate) conducive to optimizing the TC experiences of patients and caregivers.

**FIGURE 14.** Operational definition for accountability with stroke-specific exemplars added.

**Patient Education**

Participants in this study described an overall lack of patient education, which conflicts with Naylor et al.’s (2017) TC model and extant literature. In seminal stroke TC RCTs, Allen et al. (2002; 2009) incorporated APRN-led patient/caregiver education as part of an in-home visit within one week of hospital discharge. Findings of these trials demonstrated improved health, stroke knowledge, stroke prevention, and lifestyle modifications. Building upon the efficacy of an in-home education intervention, the current AHAASA guideline (Winstein et al., 2016) includes alternative educational delivery methods such as telephone consultations, telehealth services, and availing web-based resources. Naylor et al., (2017) recommend identifying and addressing health literacy as one strategy by which to operationalize this patient education TC
component, but a similar strategy is not included for caregiver education. While Naylor’s (2017) TC patient education component calls for continuous and iterative teaching and learning processes, it does not specify delivery methods.

Consistent with the literature (Reed et al., 2012), participants described the need to integrate patient goals and benchmarking progress, along with providing educational materials for persons with aphasia (Shrubsole, Worrall, Power, & O’Connor, 2017). Aligning with AHAASA guidelines and a scoping review by Wang et al., (2017), participants described a need for education supporting ADL independence, driving, and vocational rehabilitation. Suggestions of other education strategies, including playing cards, board games, and video games are supported by the findings of a survey study (Hung, Huang, Chen, & Chu, 2016) and systematic review and meta-analysis (Lohse, Hilderman, Cheung, Tatla, & Van der Loos, 2014). The stroke-specific operational definition for patient education generated in this study is presented in Figure 15.

| Continuous interactive teaching and learning processes (e.g. continual access to web-based multimodal and aphasia-targeted content) involving the healthcare team and patient. Participation should be based upon an assessment of patient goals and designed to enable patients to assume increased responsibility for their own health (e.g. use of scaffolding techniques, visual images, games, integrating patient goals with benchmarking progress reports); use strategies that encourage patients to make healthier lifestyle decisions; avoid or reduce adverse events related to condition or treatments (e.g. periodic case review); ensure continuity of care; and promote independence in activities of daily living (e.g. skills training in grooming, dressing, household tasks, and vocational rehabilitation). |

*FIGURE 15. Operational definition for patient education with stroke-specific exemplars added.*

**Caregiver Education**

Naylor’s (2017) TC caregiver education component aligns with the AHAASA guideline (Winstein et al., 2016) in that effective caregiver education involves caregivers in planning, values their contributions, avails appropriate information and training, and refers caregivers to
community-based resources. Participants in this dissertation study described a general lack of caregiver education: “we’re just dropped back into the community, trying to survive.” While the AHAASA guideline calls for a detailed caregiver assessment during the survivor’s inpatient stay (Winstein et al., 2016), Naylor’s (2017) TC components do not fully address the scope of needed caregiver assessment. This study’s participants describe a faulty assumption on behalf of in-patient healthcare teams, who frequently assume that having someone reside in the home with a survivor translates into a willing, capable, or available caregiver.

Consistent with the findings of Lutz and Camicia (2016), participants described the need for caregiving capacity and availability assessment. They also voiced a need to know what to anticipate after the patient returns home (Haynes et al., 2015; Reed et al., 2012). Aligning with findings reported by Pindus et al. (2018), participants in this dissertation study desired increased provision of timely information in an incremental, iterative manner; including an identified feedback loop for contact information when unanticipated challenges arise. Participants in this study also described needing support in differentiating normal consequences of stroke from a worsening symptom from stroke risk factors; supported by Benjamin et al. (2017). The AHAASA guideline recommends strategies for patient ADL support, but does not specifically include caregiver education regarding how to support the patient with ADLs. Participants described needing basic caregiving education (e.g., wheelchair mechanics, patient transfers, bathing, toileting, and clothing suitability), a finding that mirrors the AHAASA guideline regarding the need for a local web-based repository of educational and community resources to support caregiver. Participants described needing educational support in respite care, support groups, counselors, public health nurses, paid caregivers, a hotline, grieving and loss, and social
determinants of health. The stroke-specific operational definition for caregiver education generated in this study is presented in Figure 16.

Conduct a caregiver assessment, identify caregiver needs and goals, and provide a tailored patient care plan. Deliberate and consistent efforts to involve caregivers with decision-making regarding patient care. Prepare caregiver (by using incremental, iterative education strategies, including an identified feedback loop and contact person) with the skills needed to care for patient when transitioning to home, including skills in differentiating between normal consequences of stroke and early identification and management of worsening symptoms. Caregivers are provided with a local, web-based repository for access to community resources and supports (e.g. ADL training, respite care, support groups, stroke counselors and public health nurses, a hotline, grieving and loss services, and resources to support social determinants of health) to develop competencies and confidence that can help provide for patients’ needs and address their own needs.

FIGURE 16. Operational definition for caregiver education with stroke-specific exemplars added.

Care Continuity

Participants described the care continuity process as “a black hole,” “just failure after failure,” contrary to care continuity as defined by Naylor et al., (2017) and recommended by the AHAASA guideline (Winstein et al., 2016). However, participant descriptions of care continuity aligned with Pindus et al.’s (2018) study reporting that stroke survivors and caregivers feel abandoned and marginalized by the healthcare system, and lack knowledge or skills to re-engage with providers and services. An effective interprofessional team is essential for ensuring care continuity, but this collaboration frequently ends once the patient has met system-based rehabilitation goals, after which the care plan may be assumed by community-based teams (Clarke & Forster, 2015). This study’s participants described a lacking or incomplete transfer of care plans to survivor, caregiver, and community providers; in other words, “the system is the problem.”

Consistent with the findings of Haynes et al. (2015), participants described needing a case manager, public health nurse, or advocate, because without one “you get steamrolled by the
participants described needing in-home follow-up, periodic case review; in addition to the immediate provision of a tailored care plan and community referrals (e.g., stroke support groups). These needs align with the AHAASA guideline (Winstein et al., 2016). The stroke-specific operational definition for care continuity generated in this study is presented in Figure 17.

![FIGURE 17. Operational definition for care continuity with stroke-specific exemplars added.](image)

**Patient and Caregiver Well-Being**

Participants described a range of well-being factors, ranging from denial of emotions to the importance of communication, honesty, trust, and financial security. Participants did not directly describe deliberate efforts of healthcare teams to acknowledge emotional reactions to stress, as Naylor et al. (2017) indicated in this essential TC component (Naylor et al., 2017). Consistent with the literature, participants described needing support in coping skill development (Visser et al., 2015; Winstein et al., 2016) in the following areas: support groups, social network (Reed et al., 2012), developing skills to optimize survivor independence (Wang et al., 2017), counseling (Reed et al., 2012; Winstein et al., 2016), and strategies to improve overall life balance (Hayes et al., 2015).
The AHAASA guidelines discuss the importance of addressing financial security (Winstein et al., 2016), which participants described as affecting quality of life. Financial security is frequently threatened due to healthcare and caregiving direct or indirect costs. The survivor needs, on average, 22 hours per week of family caregiving (Skolarus, 2016). Unpaid caregiving support, as described by this study’s participants, is frequently provided by a spouse who may also need to re-enter or expand their role in the workplace. The costs associated with family caregiving, approximately $11,300 per annum (Skolarus, Freedman, Feng, Wing, & Burke, 2016), were described by participants as negatively impacting their financial security and well-being.

Other well-being and quality of life factors are robustly reported in the literature (Bettger et al., 2012; Winstein et al., 2016; Wong & Yeung, 2015) and were similarly described by participants in this dissertation study as: living life fully, health lifestyle (e.g., proper diet, exercise, time for self), religious or spiritual practices (Skolarus et al., 2012), and enjoying leisure activities (Winstein et al., 2016). The stroke-specific operational definition for patient and caregiver well-being generated in this study is presented in Figure 18.

Recognition of patients’ and caregivers’ emotional reactions to stressful experiences and deliberate efforts of healthcare team members to acknowledge such reactions (e.g., denial of emotional reactions, communication, honesty, trust, financial security concerns), foster coping skills (e.g., support groups, counseling, strategies to optimize survivor independence and caregiver overall life balance), enable care recipients to be respected and treated as whole human beings, and support decisions that contribute to patients’ and caregivers’ quality of life (e.g., healthy diet, exercise, time for self, spiritual or religious practices, leisure activities, and financial stability).

FIGURE 18. Operational definition for patient and caregiver well-being with stroke-specific exemplars added.
Caregiver Engagement

Caregivers of stroke survivors experience physical, emotional, and mental stress (Camak, 2015), requiring support in the form of caregiver assessment and preparedness (Lutz et al., 2016), and a care plan (Naylor et al., 2017) to mitigate caregiver burnout (Oliva-Moreno et al., 2018). Participant descriptions of the tendency for caregivers to put their needs aside reflect those of Oliva-Moreno et al., (2018). Participants described caregiver engagement facilitators mirroring those of Reed et al., (2012): immediately establish a support system, emotional support, strategies for developing patience and effective communication, and respite care resources. Participants described barriers of caregiver engagement, all of which increase the risk of caregiver burden and burn-out (Oliva-Moreno et al., 2018) and align with other investigators’ findings (Bettger et al., 2012; Skolarus, 2016; Winstein et al., 2016): employment and financial challenges, work-life imbalances, ineffective time management skills, physical demands of caregiving, roles shifts (e.g., from homemaker to primary financial provider), and caregiver health status. The stroke-specific operational definition for caregiver engagement generated in this study is presented in Figure 19.

Optimizing the central role of engaging caregivers by performing a caregiver assessment and providing caregiver preparedness resources through deliberate and consistent efforts of healthcare professionals and systems to identify what outcomes of care are most important to caregivers related to their role in caring for patients (e.g. establishing a support system, emotional support resources, patience and communication skill building, respite care resources); assess their perspectives, needs, and capabilities beyond the caregiver assessment (e.g. employment and financial challenges, work-life imbalances, time management skills, capacity to perform physical tasks, support in role shifts, and caregiver health support); foster shared decision-making related to patients’ plans of care; promote shared accountability for actions related to these care plans; and ensure reciprocal and respectful relationships.

**Patient Engagement**

Participants encountered difficulty discussing patient engagement as they did not directly experience their needs, perspectives, capabilities, or care outcomes as being considered by healthcare professionals (Naylor et al., 2017). Also, participants in this dissertation study described a general lack of system passivity, as reported by Pindus et al. (2018). These investigators posited that system passivity contains a relational aspect, specifically for healthcare professionals. Activating support from healthcare professionals during the first post-stroke year would likely increase the survivor’s capacity to engage and self-manage the stroke as a chronic condition. Consistent with Pindus et al. (2018), this study’s participants described not having a plan, and needing information and communication.

Participants’ descriptions paralleled the findings of Haynes et al.’s (2015) findings and the AHAASA recommendations (Winstein et al., 2016), which are not directly reflected in Naylor’s TC components (2017); that having a designated community liaison, advocate, nurse, or caseworker, is an important factor affecting stroke TC, community rehabilitation, and patient engagement. Naylor’s TC components (2017) do not reflect these findings. Similar to other studies, participants voiced a need to support the patient engagement process. Inherent to this process are qualities such as patience, understanding, encouragement, a positive attitude, and support but not pity, and stroke resources such as a list of community-based stroke health and social professionals, support groups, and stroke camps (Bettger et al., 2012; Puhr & Thompson, 2015; Reed et al., 2012; Winstein et al., 2016). The stroke-specific operational definition for patient engagement generated in this study is presented in Figure 20.
Optimizing the central role of engaging individuals through deliberate and consistent efforts of patients, caregivers, healthcare professionals and systems to identify what outcomes of their care is most important and provide patient with a tailored care plan; assess their perspectives, needs, and capabilities (e.g., provide support and encouragement); foster shared decision making regarding plans of care; promote shared accountability for actions related to these care plans (e.g., provide a list of community-based stroke healthcare professionals, stroke resources, support groups, and stroke camps); and ensure trusting, reciprocal, and respectful relationships.


Summary of Key Findings: Naylor’s TC Model

Naylor et al.’s (2017) essential TC components provide an adequate, but not complete, framework for guiding stroke TC specific to patients who have experienced a stroke and their caregivers. The findings of this dissertation study inform stroke-specific operational definitions for each essential TC component; each of which required tailoring with stroke-specific exemplars, as described above. Further, there is a need to include additional inductively derived stroke-specific TC components (discussed below): self-determination and efficacy, neuropsychiatric changes, and transportation and driving.

Complexity management deficits in managing survivor and caregiver morbidity and polypharmacy exist. Many barriers, including social isolation secondary to stroke consequences, emerge after home life is restored. Patient and caregiver education components lack essential health literacy assessment and stroke-specific educational delivery methods. Stroke education content is best delivered using incremental, iterative, multi-modal, and aphasia-friendly methods. Caregivers require an initial assessment to establish the capacity, willingness, and availability to care give. Once established, caregivers need an identified feedback loop to incrementally confirm and expand knowledge of stroke and their caregiver role. Patient and caregiver well-being are strikingly affected by various threats to financial security, such as increased health and
caregiving costs, diminished income from a stroke survivor who can no longer work, or a caregiver who must enter the workforce or work two jobs to meet basic living needs.

Care continuity and accountability components of the TC model were generally described as being unmet. Participants described being abandoned and marginalized by healthcare teams and systems, and repeatedly identified the need for one community-based point of access, contact person, and feedback loop. There is considerable system passivity in delivering post-acute care services, manifesting as subpar or lacking care continuity, limited or absent follow-up, and lacking or delayed access to community resources and supports. Ongoing health and safety assessments are needed, along with consistent and long-term delivery of psychological, emotional, social, vocational, and behavioral services.

**Key Inductive Analysis Findings**

Key findings emerged from the data that could not be explained in the context of Naylor et al.’s (2017) essential TC components. These findings bring a novel perspective as to the additional components needed to specifically address stroke TC needs. The following categories emerged and are discussed in detail below: Psychological stuff, I don’t want it to be my new normal, Fearful and absolutely overwhelmed, Determination, What’s next, Transportation challenges, and Information seeking.

Three categories warrant inclusion as stroke-specific essential TC components: neuropsychiatric management, self-determination and self-efficacy, and transportation and driving. Each of these stroke specific components are unique in that they are the first to address consequences unique to the stroke survivor and caregiver. For example, as written, Naylor’s (2017) essential TC components do not specifically address: (a) neuropsychiatric changes
resulting from stroke, (b) the importance of self-determination and self-efficacy in motivating stroke survivors and caregivers to overcome the numerous barriers encountered throughout the stroke recovery trajectory, and (c) health and safety issues for a survivor who resumes driving without an assessment for their fitness to do so; or a survivor who cannot drive and is unable to fully reintegrate into the community due to the inability to access or use alternate forms of transportation.

The remaining categories (I don’t want it to be my new normal, Fearful and absolutely overwhelmed, What’s next, and Information seeking) are categories for which issues would be resolved if TC was guided by implementing the stroke-specific exemplars described below and delivered by active postacute stroke care delivery described by Pindus et al. (2018).

**Psychological Stuff**

Stroke consequences may present unique neuropsychiatric changes, described by one participant as “psychological stuff,” beyond the depression discussed above. Neuropsychiatric changes include, but are not limited to depression, anxiety, impulsivity (Byars & Jorge, 2015), personality changes (Hackett, Köhler, T O'Brien, & Mead, 2014), post-traumatic stress disorder, and aggressive or apathetic personality change (Ferro, Caeiro, & Figueira, 2016). Survivors may never recover to pre-stroke status. This study’s participants, similarly, described impulsive behavior, altered personality traits, and inappropriate behavior that proved challenging for intimate partner relations, communication, and social interactions. These descriptions aligned with systematic review findings (Ferro et al., 2016) reporting similar neuropsychiatric post stroke sequelae, which often adversely affect stroke recovery, diminish quality of life, and lead to caregiver exhaustion.
I Don’t Want it to be My New Normal

Participant descriptions of change and disruption mirrored other findings regarding the difficulty in reconciling the life that once was to a new lifestyle that feels like living with a ball and chain (Buschenfeld et al., 2009; Danzl et al., 2013; Danzl et al., 2016; Lou et al., 2017; Woodman et al., 2014). One of this study’s participants described a deeply changed life as “I just want it to go away . . . and things to be regular . . . .” This description reflects the theme in a phenomenology study conducted by Simeone et al. (2015) that described post stroke experiences when returning home. As long as two years after stroke onset, this study’s participants described difficulty in making personal, professional, and social adjustments after the stroke – resisting the new normal against hope of an improved new normal. Participants recommended that this recovery process be defined and addressed earlier. These descriptions align with studies examining recovery, adjustment, hope, and resilience among stroke survivors (Lou et al., 2017; Sarre et al., 2014).

For survivors needing to return to work, a complex process fraught with barriers (e.g., personal, social, and organizational factors; lacking health and community services) awaits them (Brannigan et al., 2017). Approximately 1:3 stroke survivors are of working age, but access to vocational support is limited, despite its effectiveness (Dworzynski, Ritchie, & Playford, 2015). With the annual cost for stroke care being $11,450 (Benjamin et al., 2017), participants described the inability to work and provide for one’s family was described by this study’s participants as a “really frustrating” experience resulting significantly diminished family income that barely meets essential living needs.
Fearful and Absolutely Overwhelmed

The sudden change and disruption brought on by stroke can amplify the perceived magnitude of individual barriers for survivors (Woodman et al., 2014). Caregivers often experience fear, anger, loneliness, financial pressures, and lack of social support (Camak, 2015). This results in feeling “absolutely overwhelmed,” described by this study’s participants and by other investigators (Danzl et al., 2016; Lutz & Camicia, 2016). Consistent with the literature, participants described being fearful of survivor falls (Fang et al., 2016), stroke recurrence (Bretz et al., 2014; Mozaffarian et al., 2016), and survivor safety when independently performing ADLs (Wang et al., 2017).

Determination

Determination is reported to mediate a survivor’s control of capability (Morris, Oliver, Kroll, Joice, & Williams, 2015), influence self-efficacy, and contribute to improved outcomes for independence in ADLs (Frost, Weingarden, Zeilig, Nota, & Rand, 2015). This study’s participants described determination as simply willing themselves to get better; an essential strategy in becoming more independent. These descriptions align with other studies reporting that determination and confidence influence survivor’s motivation to be active (Morris et al., 2015) and resolved in overcoming the consequences of stroke (Morris, Oliver, Kroll, Joice, & Williams, 2017).

What’s Next?

One factor affecting stroke TC is the concern related to next steps (Haynes et al., 2015), particularly uncertainty regarding survival and ADLs (Wong & Yeung, 2015), described by this study’s participants as “what’s next.” Caregivers experience persistently high levels of
uncertainty, particularly during the first six weeks after onset. A key factor to include in TC is guidance in how to overcome barriers in the outside world (e.g., physical, economic, psychological) (Reed et al., 2012). This study’s participants described being abandoned by healthcare teams and systems: “they basically [done] their job and put me back in the community and now it’s up to me to figure out what’s next.” Participant descriptions echo the findings of Pindus et al. (2018) regarding poststroke healthcare service passivity. A properly implemented stroke-specific TC model may prove a pivotal step in addressing “what’s next” by providing essential information, tools, and resources; thereby transitioning from healthcare service passivity to service activity and self-management (Pindus et al., 2018).

**Transportation Challenges**

The Centers for Medicare and Medicaid Services classifies transportation as a health-related social need (CMS, n.d.), frequently associated with hospital readmissions (Adler et al., 2016). Reliable transportation supports survivor in recovery, safety, and community reintegration (Ing, Vento, Nakagawa, & Linton, 2014) and independence in ADLs (Winstein et al., 2016). Between 33-66% of survivor’s resume driving within the first year post-stroke; very few of whom are formally assessed (Winstein et al., 2016), posing a health and safety risk. Of this study’s participants, a few resumed driving after being assessed and re-licensed to do so. One participant “snuck out” to learn how to drive independently, acknowledging that “it’s not all there . . .the brain”; echoing Winstein et al.’s (2016) findings. Driving is, as described by participants, an essential factor positively affecting quality of life, social activities, and independence.
Information Seeking

Participants described “Googling” health information, along with 82% of US adults who use the internet (Sharma, Tridimas, & Fitzsimmons, 2014); many of whom lack appropriate health literacy to fully comprehend the stroke information provided. There are no studies directly examining the readability of US online stroke information, however, a study in the United Kingdom (Sharma et al., 2014) reports a Google search for stroke returned 228 million web pages. Of the 100 highest Google ranked, layperson stroke web pages assessed by Sharma et al., (2014), none of them met acceptable levels of readability. Participants in this study described lacking care plans, supports or a “point of access” from which reliable and appropriate health literate information should be availed, in direct conflict with recommendations put forth by the AHAASA guideline (Winstein et al., 2016). Aspects of health literacy are associated with health status and behavior in stroke populations (Aaby, Friis, Christensen, Rowlands, & Maindal, 2017). However, participants described concerns with “Googling” information, given the nature of brain injury in stroke and determining if the information obtained is valid and reliable.

Summary of Inductive Findings

Stroke survivors and their caregivers have unique physical, emotional, social, psychological, and lifestyle needs that are not directly captured by Naylor’s (2017) TC essential components. The components do not address neuropsychiatric manifestations, integrate self-determination and self-efficacy, or consider transportation challenges; each of which warrant further study in the context of stroke TC.

Adjusting to a new normal, feeling fearful and overwhelmed, wondering what’s next, and seeking information are, directly or indirectly, resultant from lacking stroke TC in general, and
the healthcare system’s current inability to actively deliver needed postacute health and social services. Without active follow-up, information, or when faced with delayed responses, etc., stroke survivors and caregivers feel marginalized; needing to “fight through the system” in an attempt to get their needs met. Assuming survivor and caregiver successfully “fight through the system,” they are once again met with passive delivery of healthcare services.

The findings of Pindus et al. (2018) accurately reflect the findings in this dissertation study regarding system issues and the overall abandonment of the stroke population when transitioning to home and community-based care. Further, Pindus et al. (2018), posited that by actively providing post-acute stroke healthcare services, including active follow-up, information support, and timely responses, that improved stroke self-management would result. In other words, patients and caregivers would be equipped with the tools required to manage stroke consequences as a chronic condition; in alignment with the AHAASA guideline for stroke rehabilitation and recovery (Winstein et al., 2016). Accordingly, subsequent healthcare system encounters would be targeted and effective in addressing lingering problems. The deductive and inductive findings of this dissertation study, along with the general evidence base findings discussed herein, are used to propose stroke-specific TC components and corresponding model.

**Application of Naylor’s TC Model in Stroke Population**

Of the TC models described in Table 1, Naylor’s TC model is the most comprehensive and best suited for the stroke population. Fully implemented, Naylor’s 90-day duration with 2-8 home visits, eight weekly calls, and seven-days/week APRN telephone support meets several stroke TC needs identified by the participants in this study. When Naylor’s team developed TC
components and operational definitions, patient and caregiver input was integrated to reflect their perspectives (Naylor et al., 2017).

While there is mention of patient and caregiver throughout the operational definitions, the application is more proscriptive; reflecting the traditional hospital-centric, systems-based application of this model. Of note, Naylor’s (2017) essential TC components were developed and tested largely in hospital settings. As such, the essential TC components are proscriptive, hospital-centric, and systems-based. For a community-based stroke TC model, aligning with the AHAASA guidelines (Winstein et al., 2016), the stroke-specific TC components need to be developed and tested in a community setting, scaffolding from survivor and caregiver’s collective efficacy; tailored to the survivor’s unique stroke outcomes and caregiver needs. Further, the stroke-specific TC components and corresponding TC model should be applied from a community perspective, rather than a healthcare perspective, aligning with survivor’s care plan and identified survivor-caregiver personal goals and capacities.

The findings of this dissertation study demonstrate that the healthcare system is not sufficiently engaged with stroke TC. Healthcare professionals may be experts in the area of clinical stroke management, but the patient and caregivers are the experts of their daily living. These important factors should be reflected in a stroke TC model.

Naylor’s TC model is useful in organizing how an investigator approaches and thinks about stroke TC, as was the case in this dissertation study, but may not solely be sufficient to guide the application of stroke TC. Participants described needing caregiver assessments in addition to service and supports long after the 90-day duration of Naylor’s TC model. Participants also described needing assistance with various health-related social needs, which are
beyond the scope of Naylor’s TC model. Self-determination and self-efficacy, reported to improve stroke self-management behaviors, health-related quality of life, and social outcomes (Lo, Chang, & Chau, 2018) warrant inclusion in a stroke TC model.

**Future Directions for a Stroke-Specific TC model**

The findings from this study demonstrate an immediate need for a community-based, stroke-specific TC model from which interventions can be developed and tested. The findings from this study explicate the specific needs of this population in navigating the transition from healthcare facility to home and community reintegration, which align with the findings of Winstein et al.’s (2016) transitions in care and community rehabilitation guidelines.

Figure 5 depicts a stroke-specific TC model, informed by the findings of this study and expanding upon Naylor et al.’s (2017) essential TC components. Survivors and caregivers in this study described the unique and complex post-stroke sequelae, requiring considerable self-determination and efficacy to manage and transcend. Actively delivering stroke TC in a patient-centered approach includes factoring of the survivors’ and caregivers’ determination and self-efficacy. This PI posits that leveraging and scaffolding upon these abilities throughout the chronic phase of stroke will improve survivor and caregiver TC experiences and outcomes.

Neuropsychiatric management, for survivor and caregiver, is another stroke-specific TC component added to this refined stroke TC model as informed by this study’s findings. Depending upon the location and severity of stroke, the survivor could have minimal to severe neuropsychiatric consequences, for which mental and behavioral health services are currently limited, if offered at all, and virtually no support for the caregiver exists.
The findings of this study indicate transportation as another stroke-specific TC component warranting addition to these components. The inability to drive or manage public transportation after a stroke is problematic for both survivor and caregiver, adversely affecting quality of life and community reintegration. The majority of survivors’ resume driving without being assessed for their ability to do so, posing a health and safety risk for the survivor and the general public.

While each of the components are described and depicted (Figure 21) individually, all model components are to be viewed as holistically and iteratively applied in an active, comprehensive care process.

**Research Implications**

The National Institute of Neurological Disorders and Stroke received a $337 million cut to their 2018 budget (U.S. Department of Health and Human Services Administration, 2018), affecting stroke research funding across the care continuum. Combined with healthcare policy challenges described above, it may prove challenging for an investigator to secure funding for community-based stroke TC research. The PI recommends that future investigators examine (a) a community-based stroke-specific TC model that “reaches in” to a hospital (Kansagara et al., 2016), (b) a central bridge organization connecting health and community services (Centers for Medicare & Medicaid Services (CMS), n.d.-a), and (c) incorporate some or all of the refined stroke-specific components informed by this study, and (d) further develop and test the inductively derived TC components described above.

Without healthcare policy and fiscal resources to support and fund stroke TC, a self-sustaining financial model is required. Strategies to consider include: building capacity within local stroke communities, perhaps using a trained volunteer as a transition mentor (Daaleman & Fisher, 2015), and considering a modified concierge financing model (Dalen & Alpert, 2017), funded by nominal membership fees and/or volunteer service contributions in kind.

**Implications for Nursing Practice**

Nursing is the most trusted profession, encompassing a very broad scope of practice; from hyperacute care through community reintegration (American Nurses Association, n.d.). As such, nurses are uniquely positioned to lead interprofessional stroke TC studies and translate findings into practice. However, lack of policy and funding preclude provision of nurse-led stroke TC. Currently, the healthcare facility’s policy and patient’s insurance plan drive what little
care or service is offered at discharge. For rural and non-stroke accredited hospitals, there may be a discharge protocol, but no nurse stroke coordinators. Primary stroke center hospitals require defined leadership and roles, but a nurse stroke coordinator or TC coordinator is not required. Comprehensive stroke center hospitals, generally situated in large urban and academic settings may employ a nurse stroke coordinator; whose role centers on reperfusion therapies and other hospital-centric care outcomes (AHAASA, 2017; 2017a).

Regardless of hospital accreditation status, stroke TC is not delivered, and considerable heterogeneity exists regarding discharge planning, continuity of care, and referral to health and community services. Nurses represent the only interprofessional team member whose scope of practice encompasses the survivor and caregiver transitions from hyperacute stroke care through home recovery and community reintegration. As such, nurses and nurse scholars are uniquely positioned to develop and test a stroke-specific TC model of care, from which interventions can be tested, and community-based stroke management guidelines can be further refined and translated into practice.

Further, the findings of this study demonstrate the need for a new professional role for a community stroke nurse; one who is the point of access, providing consistent communication with an identified feedback loop. The community stroke nurse would support the survivor and the caregiver in navigating community health and social services, while providing need referrals to community resources and disseminating information regarding stroke support groups and stroke community events. The community stroke nurse has potential to serve as a facilitator in building stroke community capacity.
The findings of this study identify current healthcare policies as a barrier to the provision of stroke TC, calling importance to the nurses’ role in political and policy advocacy. The nursing professional is uniquely positioned to advocate for health equity and social justice while being involved with healthcare policy development (Eaton, Sanford, Lee, Trull, & Smith, 2017). It is imperative that the modifiable factors impeding nurses from taking an active role be addressed (Woodward, Smart, & Benavides-Vaello, 2016), including: (a) including healthcare policy education in nursing curricula, (b) facilitate nurses’ active interest and civic engagement with healthcare politics and policy development and implementation, and (c) leveraging the value of collective influence in nurse-specific organizations, such as the American Association of Nurses (and the state equivalent thereof), and the American Association of Colleges of Nursing.

**Strengths and Limitations of Study**

The use of qualitative description methodology resulted in rich data, in breadth and depth, describing participant transition experience from healthcare facility to home. The first strength of this study is that it is the first of its kind to examine stakeholder descriptions pertaining to stroke-specific essential TC components informing a community-based stroke TC model from which interventions may be developed and tested. Participants self-selected into their preferred focus group composition (e.g., survivors only, caregivers only, or all-comers). Four participants chose to attend a focus group without their corresponding survivor or caregiver and described so doing because they could ‘speak freely’; contributing to the richness of data. With the research process comes inherent bias from both participant (discussed below) and researcher. The PI used a reflexive journaling process to minimize PI-participant bias to enhance confirmability and dependability of the study.
The PI and RA took field notes during and after each focus group, recording reflective thought, rich quotes, and non-verbal communication thereby establishing credibility and dependability. The PI took a methodical approach to reflective thought and data analysis as described by Nowell, Norris and White (2017) including collaborating with her dissertation chair about coding judgments, decontextualizing and recontextualizing the data, and maintaining a reflexivity journal. The PI and her dissertation chair independently coded data, met weekly to debrief and discuss data analysis, identify emerging themes, and assess data saturation progress. Data saturation, which establishes transferability, was attained by the end of the third focus group for most categories, with the remaining categories saturating after the fourth focus group. The PI and her dissertation chair consulted with qualitative methods expert Dr. Marylyn McEwen, contributing to study trustworthiness. The PI conducted member checks during the focus group discussions and after transcription to establish credibility.

There are several limitations with the study. To satisfy the research question, a homogenous sample was required, thereby limiting the transferability of the study findings. Data were self-reported, which may be subject to social desirability responses and recall bias. One focus group conducted at an off-site rehabilitation facility posed logistical challenges that occasionally interfered with the discussion. A limitation in the data collection tool (Appendix E) regarding the number of days hospitalized emerged during focus group discussions; participants referred to any in-patient care facility (e.g., inpatient rehabilitation, skilled nursing facility) as a ‘hospital.’ The PI may have veered slightly off course when translating a couple of the operational definitions into lay-person definitions (Appendix G). Naylor et al.’s (2017) essential TC component operational definitions each contain several sentences and are written from a
systems perspective. In the first focus group, participants expressed difficulty understanding the system-centric verbiage. As a result, and after conferring with her dissertation chair, the PI re-translated a few aspects of the lay-person definitions, which may have affected if a participant responded from a personal or systems perspective. The focus groups met in the Tucson, AZ area, which may limit the transferability of the findings; highlighting the importance of thick description so persons seeking to transfer these findings to other populations and settings can determine suitability to do so (Nowell et al., 2017). Despite these limitations, this study is the first to engage primary stakeholders in developing stroke-specific refinement to and exemplars for each of Naylor et al.’s (2017) TC model core components, the findings from which may be used to guide stroke TC models, interventions, and care plans.

Summary

This chapter discussed qualitative descriptive findings in the context of Naylor’s TC model, the current evidence base, and healthcare policy. Existing healthcare policies do not support stroke TC funding or delivery. No community-based, stroke-specific TC models exist. The AHAASA guidelines and recommendations for the chronic phase of stroke are largely unmet. Of available TC models, Naylor’s TC model is the best fit; meeting several stroke TC needs but falling short in others. Naylor’s TC model is not solely sufficient to guide community-based stroke TC that meets the AHAASA guidelines. Integrating Naylor’s TC model and corresponding stroke-specific exemplars with a community-based bridge organization, using an independent funding approach, may be the best strategy in meeting the TC needs of this population.
Conclusion

This study aimed to engage primary stakeholders in developing stroke-specific refinements to and exemplars of Naylor’s essential TC components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability. The research question was examined using a qualitative descriptive approach using focus group discussions of semi-structured interview questions.

The findings of this study demonstrate considerable healthcare system passivity in delivering postacute stroke care, leaving survivors and caregivers feeling abandoned and marginalized. There is a need for multimorbidity and polypharmacy management, integrative therapies, health literacy assessments, and caregiver capacity and burden assessments. Educational content should be delivered using incremental, iterative, multi-modal, and aphasia accessible methods. Of particular importance is the need for one community point of access and a community stroke nurse serving as the linchpin for the identified feedback loop, source of active follow-up, and resource for community supports and services. Survivors and caregivers require support groups, a robust social network, counseling services, and vocational rehabilitation. Caregivers need strategies to support work-life-caregiving balance to mitigate caregiver burnout. Inductively derived findings suggest the need for additional stroke-specific TC components: self-determination and self-efficacy, neuropsychiatric management, and transportation challenges.

This study is the first of its kind to examine stakeholder descriptions to partially inform stroke-specific TC components. The findings of this study contribute novel and innovative
stroke-specific TC components may inform a future community-centric stroke TC model and testing of subsequent interventions derived therefrom. The findings of this study are unique in proposing a community-centric, stroke nurse-led model of care and recommending future use of alternate funding strategies to support sustainability while building local stroke community capacity. Findings from this study may also be useful in guiding future community-based stroke TC studies “reaching back” to the hospital while aligning with the 2016 AHAASA guidelines for adult stroke rehabilitation and recovery.
APPENDIX A:

RECRUITMENT FLYER
Stroke Individuals and Stroke Caregivers Research Study

Be part of an important stroke research study

- Are you an adult who has experienced a stroke?
- Are you a caregiver to an adult who experienced a stroke?

If you answered YES to either of these questions, you may be eligible to participate in a stroke research study.

The purpose of this research study is to engage individuals and/or caregivers affected by stroke in tailoring a stroke-specific transitional care model. Transitional care is often provided during hospital discharge and continues through home rehabilitation. Focus groups will meet once or twice, for 2-3 hours, to discuss transitional stroke care after leaving the hospital.

Adults over the age of 18 who experienced a stroke and/or a caregiver to an adult who experienced a stroke may be eligible to participate in this study.

This study is being conducted by the University of Arizona, College of Nursing.

For more information, please contact Lorre Laws:

Phone: [redacted]
Email: [redacted]
APPENDIX B:

RECRUITMENT SCRIPT: TELEPHONE AND EMAIL
Telephone Recruitment Script

Hello. My name is Lorre Laws and I am a doctoral student from the College of Nursing at the University of Arizona. I obtained your contact information from (if applicable, describe source). I’m contacting you to talk about participating in my research study. Do you have time to talk with me now about the study? It will take about 10 minutes.

Yes: proceed
No: Ok, when would be a good time for me to call you back?

The aim of my research study is to develop a stroke-specific transitional care model. Transitional care is often provided during hospital discharge and continues through home rehabilitation. I am inviting individuals affected by stroke and stroke caregivers to describe your transitional care experience. Your descriptions will help me to develop this stroke-specific transitional care model.

Would you be interested in learning if you are eligible for this study?

No: Ok, thank you for taking the time to talk with me today!
Yes: Thanks for your interest! Now I need to determine if you are eligible to participate. If you are on a phone speaker, please take yourself off of the speaker, if you are able. Now, please answer yes or no to the following questions:

<table>
<thead>
<tr>
<th>Q1 (individual). Have you experienced a stroke, a TIA (transient ischemic attack), or both?</th>
<th>Q1 (caregiver). Did the person for whom you are a caregiver experience a stroke, a TIA (transient ischemic attack), or both?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, to stroke or stroke + TIA (proceed to Q2)</td>
<td>Yes, to TIA only No (That means you are not eligible for the study. Thank you for your interest and time).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q2. Are you an adult, over the age of 18?</th>
<th>Q3. Are you living in your home?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes (proceed to Q3)</td>
<td>Yes (proceed to Q4)</td>
</tr>
<tr>
<td>No (That means you are not eligible for the study. Thank you for your interest and time).</td>
<td>No (That means you are not eligible for the study. Thank you for your interest and time).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q4: Do you speak and read in English?</th>
<th>Q5: Can you complete a five-minute telephone screening to establish your ability to respond to focus group interview questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes (proceed to Q5)</td>
<td>Yes (proceed to T-MoCA)</td>
</tr>
<tr>
<td>No (That means you are not eligible for the study. Thank you for your interest and time).</td>
<td>No (That means you are not eligible for the study. Thank you for your interest and time).</td>
</tr>
</tbody>
</table>
Now, I am going to ask you twenty questions that will help me determine your ability to participate in the focus group (Read questions from T-MoCA screening, Appendix D).

If T-MoCA score < 19: I am sorry, but you are not eligible for the study. I thank you for your time on the phone today. I will not be keeping any of the answers to the questions I asked you today.

If T-MoCA score is >19: Thanks for answering those questions. You are now eligible to participate in the study. Do you still want to participate?

If no: thank you for your time and interest. I will not be keeping any of the answers to the questions that I asked you today.

If yes: I will be asking you to be a part of one or two focus groups that will meet for about 2-3 hours, each. In the focus group, we will discuss several questions about stroke care based on your experience after you left the hospital. The focus group discussion will be audio recorded. The information will help me to develop a stroke-specific transitional care model. There will be one break in the group for refreshments. You will also receive free parking and a gift card at the end of the focus group.

Thank you for your interest in participating. Your participation is completely voluntary and you can change your mind at any time. I would like to send you by email or by US mail a consent form to read and sign, along with a short demographic questionnaire to complete. You may send those back to me by email or in a pre-paid US mail envelope, or bring them with you when you come to your first focus group.

Your focus group is scheduled on ----------. Will you be able to make it then?

(if applicable) You may participate in a second focus group, scheduled for -----------------. Will you be able to make it then?

I will include directions to the location in the packet, along with your consent form and questionnaire.

If you have more questions about this process, or if you need to contact me about participation, I may be reached at (provide phone number and email address).

Thank you so much.
Email Recruitment Script

For all participants

Dear (insert name),

Hello. My name is Lorre Laws and I am a doctoral student from the College of Nursing at the University of Arizona. I obtained your contact information from (if applicable, describe source). I’m contacting you to talk about participating in my research study.

The aim of my research study is to develop a stroke-specific transitional care model. Transitional care is often provided during hospital discharge and continues through home rehabilitation. I am inviting individuals affected by stroke and stroke caregivers to describe your transitional care experience. Your descriptions will help me to develop this stroke-specific transitional care model.

If you have experienced a stroke or are a stroke caregiver for an adult, you may be eligible to participate in the study if you are: over the age of 18, are living at your home, are English speaking, have access to and can talk on a telephone, and complete a ten-minute telephone screening to establish your ability to respond to focus group interview questions.

If you decide to participate in the study, you will attend 1-2 focus groups, that will meet for 2-3 hours, each. In the focus group, we will discuss several questions about stroke care based on your experience after you left the hospital. The focus group discussion will be audio recorded. The information will help me to develop a stroke-specific transitional care model. There will be one break in the group for refreshments. You will also receive free parking and a gift card at the end of the focus group.

Your participation in the study is completely voluntary. You may choose to participate in the study. Or, you may choose not to participate in the study. If you’d like to participate, I can schedule a short telephone appointment to review the eligibility requirements, complete the 10-minute screening, obtain background information, and schedule you for one or two focus groups.

Do you have any questions for me?

For the subsequent telephone appointment

Thank you again for your interest in participating in this study. At this time, we will review the study eligibility requirements. Next, I will perform a 10-minute screening to establish your ability to respond to focus group interview questions.

Move to telephone script.
APPENDIX C:

ENROLLMENT FORM
Study Identification Number: ____________________________
Participant Name: ________________________________
Participant Identifier: __________________________
Participant is an _____ individual affected by stroke _____ caregiver

**Individual eligibility criteria checklist – participant will qualify for study if all the following are met:**

- Self-report of a stroke or cerebral vascular accident (CVA), of any etiology, at any time
- Adult aged 18 years or older
- Discharged from hospital, in-survivor rehabilitation facility, or skilled nursing facility to home
- Reads and speaks English
- Ability to independently respond to semi-structured interview questions
- Have access and ability to talk on a functioning telephone.
- T-MoCA screening score at 19 or above

**Individual eligibility criteria checklist – participant will be excluded from study if any of the following are checked:**

- Discharged to home with hospice care
- Currently enrolled in an open research study
- Not able to sign informed consent form
- Experienced a transient ischemic attack (TIA) without a stroke

**Caregiver eligibility criteria checklist – participant will qualify for study if all the following are met:**

- Self-identifies as a caregiver of an adult stroke survivor discharged to a home setting
- Adult over the age of 18 years
- Reads and speaks English
- Ability to independently respond to semi-structured interview questions
- Have access and ability to talk on a functioning telephone.
- T-MoCA screening score at 19 or above

**Caregiver eligibility criteria checklist – participant will be excluded from study if any of the following are checked:**

- Individual who experienced the stroke, and for whom caregiving is identified, is discharged to home with hospice care
- To prevent potential study participant fatigue, participant is not actively engaged in another investigator’s study
- Not able to sign the informed consent form
Prospective participant meets all inclusion criteria and no exclusion criteria is identified. Enroll participant into the study. Schedule participant for Focus Group 1, Focus Group 2, Focus Group 3.

Prospective participant does not meet inclusion criteria, or exclusion criteria is identified. They are disqualified from the study. Thank them for their time and interest in this study.
APPENDIX D:

T-MOCA SCREENING
Note: The T-MoCA is an abbreviated form of the traditional MoCA screening. For the T-MoCA, the following domains are not screened and, therefore, are omitted from the traditional MoCA instrument: visuospatial/executive and naming.

Telephone Montreal Cognitive Assessment (T-MoCA)
Version 8.1 English

Name:

Date:

<table>
<thead>
<tr>
<th>MEMORY</th>
<th>FACE</th>
<th>VELVET</th>
<th>CHURCH</th>
<th>DAISY</th>
<th>RED</th>
<th>NO POINTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.</td>
<td>1st TRIAL</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd TRIAL</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATTENTION</td>
<td>Subject has to repeat them in the forward order.</td>
<td>[ ] 2 1 8 5 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read list of digits (1 digit/sec.).</td>
<td>Subject has to repeat them in the backward order.</td>
<td>[ ] 7 4 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read list of letters. The subject must tap with his hand at each letter A. No points if = 2 errors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serial 7 subtraction starting at 100.</td>
<td>[ ] 93</td>
<td>[ ] 86</td>
<td>[ ] 79</td>
<td>[ ] 72</td>
<td>[ ] 65</td>
<td></td>
</tr>
<tr>
<td>4 of 5 correct subtractions: 3 pts., 2 or 3 correct: 2 pts., 1 correct: 1 pt., 0 correct: 0 pt</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LANGUAGE</td>
<td>Repeat: I only know that John is the one to help today.</td>
<td>[ ]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The cat always hid under the couch when dogs were in the room.</td>
<td>[ ]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fluency / Name maximum number of words in one minute that begin with the letter F.</td>
<td>[ ]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(N = 11 words)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABSTRACTION</td>
<td>Similarity between e.g. banana - orange = fruit</td>
<td>[ ]</td>
<td>[ ]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] train - bicycle</td>
<td>[ ] watch - ruler</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DELAYED RECALL</td>
<td>Memory Index Score (MIS)</td>
<td>[X] Face</td>
<td>[X] Velvet</td>
<td>[X] Church</td>
<td>[X] Daisy</td>
<td>[X] RED</td>
</tr>
<tr>
<td>MIS = _____/15</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ORIENTATION</td>
<td>[ ] Date</td>
<td>[ ] Month</td>
<td>[ ] Year</td>
<td>[ ] Day</td>
<td>[ ] Place</td>
<td>[ ] City</td>
</tr>
<tr>
<td>Add 1 point if = 12 yr edu</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>© Z. Nasreddine MD</td>
<td><a href="http://www.mocatest.org">www.mocatest.org</a></td>
<td>TRAINING AND CERTIFICATION ARE REQUIRED TO ENSURE ACCURACY</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administered by: ____________________</td>
<td>TOTAL</td>
<td>___/30</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

To score:

Add the points in each domain. Total score will be # of points/30

Interpretation of results:

A score of 19 or better meets inclusion criteria for this study. A score less than 19 does not meet inclusion criteria for this study.
APPENDIX E:

DEMOGRAPHIC DATA TOOL
Q1 What is your age?

- write your age here: __________ (1)

Q2 Which of the following best describes your race or ethnicity?

- Hispanic or Latino (1)
- Black or African American (2)
- Native American or American Indian (3)
- Asian or Pacific Islander (4)
- White or Caucasian (5)

Q3 What is your gender?

- Female (1)
- Male (2)
- Transgender (3)
- Other: _________________ (please specify) (4)
- Prefer not to say (5)
Q4 What is your employment status?

- Employed, full-time (1)
- Employed, part-time (2)
- Retired (3)
- Student (4)
- Unemployed (5)

Q5 When did the stroke occur?

- Insert date here: __________ (1)

Q6 Was the person who experienced a stroke hospitalized at the time of the stroke?

- Yes. Please specify number of days in the hospital: __________ (1)
- No (2)

Q7 If the person who experienced a stroke was hospitalized, to which location did they go after being discharged from the hospital?

- Home (1)
- In-patient rehabilitation facility (2)
- Skilled nursing facility (3)
Q8 Is the person who experienced a stroke currently receiving home health or social services, such as in-home nursing care, physical therapy, occupational therapy, speech and language therapy, social worker consultations, etc.

(1) Describe in-home service #1, if applicable: ________________________________

(2) Describe in-home service #2, if applicable: ________________________________

(3) Describe in-home service #3, if applicable: ________________________________

(4) Describe in-home service #4, if applicable: ________________________________

Q9 In what language do you speak most often?

(1) Arabic

(2) Chinese

(3) English

(4) French

(5) German

(6) Japanese

(7) Korean

(8) Persian

(9) Russian

(10) Spanish

(11) Tagalog

(12) Other: please specify: __________
Q10 Other languages spoken (please select all that apply)

- Arabic (1)
- Chinese (2)
- English (3)
- French (4)
- German (5)
- Japanese (6)
- Korean (7)
- Persian (8)
- Russian (9)
- Spanish (10)
- Tagalog (11)

Other: please specify: __________ (12)
APPENDIX F:

FOCUS GROUP PROCEDURE AND INTERVIEW GUIDE

**Moderator (PI) Role:** greet participants, introduce study, answer questions, facilitate discussion, conclude discussion, dismiss participants, write field notes.

**Assistant Moderator (RA) Role:** Assist with room and refreshment logistics, greet participants upon arrival, distribute and collect documents, sit outside the conversation circle, diagram the seating chart, take notes throughout discussion (template below), audio record but do not participate in discussion, give incentive at completion, thank each person for participating, debrief with moderator, give feedback on analysis and reports upon request.

**Welcome participants:**
Good evening and welcome. Thank you for taking time to join us to talk about transitional care for individuals and caregivers affected by stroke. My name is Lorre Laws. I am a doctoral candidate at University of Arizona – College of Nursing. With me is my assistant, Katie DiBene. She’s also affiliated with the University of Arizona. I will be moderating our focus group discussion. Katie will assist me today by audio recording our discussion, and taking notes on her computer.

**Overview of Study Topic:**
I am conducting a study to engage individuals and caregivers affected by stroke in the development of a future community-based stroke transitional care intervention. Today, we will be talking about essential transitional care components. Your description of your transitional care experience after the stroke will be used to develop a future stroke-specific transitional care intervention. You were selected to participate in this study because you are an adult who experienced a stroke, or are a caregiver to an adult who experienced a stroke and was discharged from a healthcare facility to home, are English-speaking, and demonstrated acceptable cognitive ability to respond to interview questions.

**Ground Rules**
Katie will be audio recording our discussion [point to table microphone]. We’re recording this session so we don’t miss any of your comments. People talk faster than we can write everything down. Because we are recording, we can only have one person speaking at a time. We are on a first-name basis today, and please identify yourself by name when speaking. I won’t use any names in my reports. I ask that you not talk about the people in the group or the group discussion to anyone outside of the group. There are no right or wrong answers for this discussion. Please feel free to describe your experience, even if it differs from what others have experienced.

I have about 30 questions to ask, but my job is really to listen. It will be more interesting for everyone if we treat our focus group discussion as a conversation. If someone says something, you are free to discuss it further, or offer a different perspective. You may converse with one another. You don’t need to address all your comments to me. However, only one person may talk at a time and please no side conversations because we are recording the session.
If you have a cell phone, please place it in silent mode. Should you need to take a telephone call, please step out and then return as quickly as possible.

**Informed Consent**
Before we begin, I need to obtain your consent to participate in the study. If you brought your signed Informed Consent form, Katie will collect that now. If you do not have an Informed Consent form, raise your hand and Katie will bring one to you. Please take a moment to read and sign the Informed Consent form [provide whatever time is required for each participant to read and sign the form]. Your participation in this study is completely voluntary, and you may stop participating in the study at any time. To protect the privacy of all focus group members, only the transcriptionist and I will have access to the audio recording, which will be securely stored at all times. The transcriptionist will type the audio recordings word for word, but your real name will not be used in the transcript. [Obtain participants signature on Informed Consent form. Provide participant a copy of the Informed Consent form, have them sign and retain for their records. Katie to collect completed forms]. I will also ask you to complete the Demographic Data Questionnaire, if you have not already done so. This is a short questionnaire that asks about some of your personal characteristics.

We will take a 5-minute break, and then begin the focus group discussion. The focus group discussion will last 2-3 hours, with one 15-minute break. Do you have any questions before we take our first break? [describe restroom location] [While participants are on break, PI and RA reconcile signed Informed Consent forms, to verify each participant is properly consented] [PI and RA check Demographic Data Questionnaire for completeness].

**Describe Question Format**
Let’s all take our seats, and we’ll get started. You’ll see on the projector slide that I will first show and read aloud a general description of one aspect of care that occurs during the transition from hospital through rehabilitation in the home. Then I will advance to the next slide, which shows the discussion question. You will discuss the question. When you are finished discussing a question, I will then advance to the next slide which will contain another question, a different definition, and so forth. Do you have any questions before we start the discussion? [Format of power point interview questions: define transitional care component, advance slide, topic question, advance slide, probing question(s), advance slide. Repeat process until interview is complete].

**First Question**
Let’s begin. We’ve placed your first names on the cards in front of you to help up remember each other’s names. Let’s introduce ourselves to the group, specify if you are an individual who experienced a stroke or a caregiver, and tell us about your experience in transitioning from the healthcare facility to home.

**Definitions, Topic and Probing Questions:** [Interview question development table is in Appendix G].
Define patient engagement in lay-person terms:
- How involved the individual is with their care plan and goals.
- The individual’s perspectives, needs, capabilities, and goals are included in the care plan.
- The individual and healthcare professionals have respectful and trusting relationships.
- The individual and healthcare professionals share responsibility for meeting care plan goals.

Topic question 1a: What do you need to feel more engaged with your care goals and decision making?
   Probing question 1b: What is important to you when making decisions about your care?
   Probing question 1c: Describe some of your challenges with meeting care plan goals.

Define caregiver engagement in lay-person terms:
- How involved the caregiver is with their caregiving role.
- The caregiver’s perspectives, needs, capabilities, and goals are included in the care plan.
- The caregiver is included in the decision-making for care plan goals and activities.
- The caregiver and healthcare professionals share responsibility for meeting care plan goals.

Topic question 2a: What do you, as a caregiver, need to feel more engaged in your caregiving role?
   Probing question 2b: What’s important to you when making decisions about your loved one’s care?
   Probing question 2c: Describe some of the challenges for staying engaged in the caregiver role.

Define complexity management in lay-person terms:
- Healthcare services are focused on the individual and aligns with personal goals.
- Individuals, caregivers, and healthcare professionals anticipate and prevent health problems.
- The individual and caregiver’s physical, emotional, and social needs are managed effectively.
- Individuals and caregivers know how to manage medications to make sure they are taken in the right amount, at the right time.

Topic question 3a: What would a program look like that had a plan to meet the complex needs of individuals and caregivers?
   Probing question 3b: Describe some of the difficult physical challenges you have experienced.
   Probing question 3c: Describe some of the difficult emotional challenges you have experienced.
   Probing question 3d: Describe some of the difficult social challenges you have experienced.
   Probing question 3e: What do you need help with in managing medications?
Define patient education in lay-person terms:
- Individuals and healthcare professions work together in learning activities.
- Healthcare professionals help individuals learn how to reach their goals and independence.
- Healthcare professionals help individuals learn how to take responsibility for their stroke, including healthy lifestyle choices.
- Healthcare professionals help individuals to learn how to manage treatments and medications.

Topic question 4a: What would a program look like that had a plan to meet the individual’s learning needs?

Probing question 4b: What learning activities are helpful to the person who experienced a stroke?
Probing question 4c: Describe how healthcare professionals can help you learn how to reach goals?
Probing question 4d: What learning activities would be helpful in managing treatments and medications?

Define caregiver education in lay-person terms:
- Caregivers are included in care plan decision-making.
- Caregivers learn how to care for themselves and their loved one when they come home.
- Caregivers learn how to recognize and manage worsening symptoms.
- Caregivers learn what community resources are available to help them take care of themselves and their loved one.

Topic question 5a: What would a program look like that had a plan to meet the caregiver’s learning needs?

Probing question 5b: What learning activities are helpful to the caregiver?
Probing question 5c: Describe how healthcare professionals can help you learn how to care for yourself and your loved one?
Probing question 5d: What learning activities would be helpful in managing worsening symptoms?
Probing question 5e: What community resources would help you to take care of yourself and your loved one?

Define patient and caregiver well-being in lay-person terms:
- Individuals, caregivers, and healthcare professionals all acknowledge stressful emotional reactions.
- Healthcare professionals provide individuals and caregivers with coping skill support.
- Individuals, caregivers, and healthcare professionals all work together to achieve well-being and high quality of life.
**Topic question 6a:** What would a program look like that had a plan to manage your well-being?

**Probing question 6b:** What is important to you in managing stress and emotions?

**Probing question 6c:** What is important to you in achieving well-being and high quality of life?

**Define care continuity in lay-person terms:**
- Care plans are carried out in a timely manner.
- Timely, continual access to health and community services.
- Developing trusting relationships between healthcare professionals, individuals, and caregivers.

**Topic question 7a:** What would a program look like that had a plan to coordinate your care after returning to home?

**Probing question 7b:** What health and community services would be helpful to use when returning home?

**Probing question 7c:** How is information best shared between individuals, caregivers, and healthcare professionals?

**Probing question 7d:** What are some of the barriers to developing trusting relationships with healthcare professionals?

**Define accountability in lay-person terms:**
- Accountability between individuals, caregivers, and healthcare professionals in meeting care plan goals.
- Accountability between healthcare professionals to collaborate effectively.
- Healthcare system accountability to provide services supporting the transition from hospital to home.

**Topic question 8a:** What would a program look like that had accountability in meeting your needs when transitioning from hospital to home?

**Probing question 1:** What do you need to stay on track with care plan goals?

**Probing question 2:** What challenges did you experience with the healthcare system while making the transition from hospital to home?

**Ending Question**
Is there anything else that you would like me to know about experience of going from hospital to home and your needs after being home that we have not discussed so far?

**Adjourn Meeting**
Thank participants, offer incentive. Complete field notes. Securely store digital and paper documents.
Field Note-Taking Summary Template (enlarge as necessary)

<table>
<thead>
<tr>
<th>Date of Focus Group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Location of Focus Group</td>
<td></td>
</tr>
<tr>
<td>Number of Participants</td>
<td></td>
</tr>
</tbody>
</table>
| Describe make-up for the focus group  
(Provide information that describes the focus group participants. Be as descriptive as possible without identifying individual) |  |
| Moderator (PI) Name |  |
| Asst. Moderator (RA) Name |  |
| Describe any distractions that occurred during interview |  |
| Describe any technical difficulties |  |
| Asst. Moderator (RA) reflection notes |  |

Moderator (PI) reflection notes

Notes:

<table>
<thead>
<tr>
<th>Question #</th>
<th>Notes 2</th>
<th>Note Taker/Facilitator Comments 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3a</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Add/Subtract question numbers as needed
2 Please provide raw notes, quotes (not attributed to specific people) and information gathered. Please do not summarize or make inferences based on statements by focus group participants.
3 If applicable, facilitators and note takers are able to provide additional context to provide additional clarification/information to those conducting analysis of the information provided. Examples of comments may include the following:
   • One or two participants dominated the discussion related to this question
   • There was consensus of all focus group participants related to this area of focus
### Systematic Analysis Process

1. **Start while still in the group**
   - Listen for inconsistent comments and probe for understanding
   - Listen for vague or cryptic comments and probe for understanding

2. **Immediately after the focus group**
   - Draw a diagram of seating arrangement (RA)
   - Spot check recording to ensure proper operation (RA)
   - PI and RA debrief to identify and make note of potential PI biases and assumptions. PI and RA note evidence of errors or omissions.
   - Note themes, hunches, interpretations, and ideas (PI)
   - Compare and contrast this focus group to other groups (PI)
   - Label and file field notes, recordings and other materials (RA)

3. **Soon after the focus group--within hours begin analysis for individual focus group.**
   - Send digital file to transcriptionist for computer entry with deadline date (PI)
   - PI listens to tape, reviews field notes and reads transcript
• PI prepares report of the individual focus group in a question-by-question format with amplifying quotes
4. Later--within days analyze the series of focus groups
  • Compare and contrast results by categories of individual focus groups
  • Look for emerging themes by question and then overall
  • Construct typologies or diagram the analysis
  • Describe findings and use quotes to illustrate
APPENDIX G:

INTERVIEW QUESTION DEVELOPMENT TABLE
**A note about terminology:** The operational definitions for each TC component include use of the word ‘patient’. This study engages community-dwelling participants who may no longer view themselves as a ‘patient’, but as a ‘survivor’, or simply an ‘individual’ who experienced a stroke. For consistent terminology use and to mitigate participant objectification, this study uses ‘individual affected by stroke’ or ‘individual’ synonymously with Naylor et al.’s (2017) use of ‘patient’.

<table>
<thead>
<tr>
<th>Transitional Care Component</th>
<th>Operational Definition of Transitional Care Component (Naylor et al., 2017)</th>
<th>Translation of operational definition into lay-person terms (to be read to participants prior to interview question)</th>
<th>Topic Interview Question</th>
<th>Probing Interview Question(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient engagement:</td>
<td>Optimizing the central role of engaging individuals through deliberate and consistent efforts of healthcare professionals and systems to identify what outcomes of their care is most important; assess their perspectives, needs, and capabilities; foster shared decision-making regarding plans of care; promote shared accountability for actions related to these care plans; and ensure trusting, reciprocal, and respectful relationships (Naylor et al., 2017, p. 3).</td>
<td>How involved the individual is with their care plan and goals. The individual’s perspectives, needs, capabilities, and goals are included in the care plan. The individual and healthcare professionals have respectful and trusting relationships. The individual and healthcare professionals share responsibility for meeting care plan goals.</td>
<td>What do you need to feel more engaged with your care goals and decision making?</td>
<td>What’s important to you when making decisions about your care? Describe some of your challenges with meeting care plan goals.</td>
</tr>
<tr>
<td>Caregiver engagement</td>
<td>Optimizing the central role of engaging caregivers through deliberate and consistent efforts of healthcare professionals and systems to identify what outcomes of care are most important to caregivers related to their role</td>
<td>How involved the caregiver is with their caregiving role. The caregiver’s perspectives, needs, capabilities, and goals are included in the care plan. The caregiver is included in the decision-making for care</td>
<td>What do you, as a caregiver, need to feel more engaged in your caregiving role?</td>
<td>What’s important to you when making decisions about your loved one’s care? Describe some of the challenges for staying engaged in the caregiver role.</td>
</tr>
<tr>
<td>Transitional Care Component</td>
<td>Operational Definition of Transitional Care Component (Naylor et al., 2017)</td>
<td>Translation of operational definition into lay-person terms (to be read to participants prior to interview question)</td>
<td>Topic Interview Question</td>
<td>Probing Interview Question(s)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Complexity management:</td>
<td>Person-centered care that is holistic, consistent with patient goals and characterized by anticipation, prevention, or early identification of problems (including health problems that develop during the acute hospitalization) that represent the most common clinical reasons for poor outcomes among the target population. This high-risk, chronically ill population presents clinicians and caregivers with challenging care issues associated with managing complex physical, emotional, and social needs. One critical dimension of complexity management is medications.</td>
<td>Healthcare services are focused on the individual and aligns with personal goals. Individuals, caregivers, and healthcare professionals anticipate and prevent health problems. The individual and caregiver’s physical, emotional, and social needs are managed effectively. Individuals and caregivers know how to manage medications to make sure they are taken in the right amount, at the right time.</td>
<td>What would a program look like that had a plan to meet the complex needs of individuals and caregivers?</td>
<td>Describe some of the difficult physical challenges you have experienced. Describe some of the difficult emotional challenges you have experienced. Describe some of the difficult social challenges you have experienced. What do you need help with in managing medications?</td>
</tr>
<tr>
<td>Transitional Care Component</td>
<td>Operational Definition of Transitional Care Component (Naylor et al., 2017)</td>
<td>Translation of operational definition into lay-person terms (to be read to participants prior to interview question)</td>
<td>Topic Interview Question</td>
<td>Probing Interview Question(s)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------</td>
<td>------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Medication management</td>
<td>Medication management is person-centered care characterized by an organized effort to ensure optimum therapeutic outcomes through greater accuracy in medication use and reduction of adverse events. Efforts to promote adherence are integrated within a comprehensive care plan (Naylor et. al. 2017, p. 3).</td>
<td>Individuals and healthcare professions work together in learning activities. Healthcare professionals help individuals learn how reach their goals and independence. Healthcare professionals help individuals learn how to take responsibility for their stroke, including healthy lifestyle choices. Healthcare professionals help individuals to learn how to manage treatments and medications.</td>
<td>What would a program look like that had a plan to meet the individual’s learning needs?</td>
<td>What learning activities are helpful to the person who experienced a stroke? Describe how healthcare professionals can help you learn how to reach goals? What learning activities would be helpful in managing treatments and medications?</td>
</tr>
<tr>
<td>Transitional Care Component</td>
<td>Operational Definition of Transitional Care Component (Naylor et al., 2017)</td>
<td>Translation of operational definition into lay-person terms (to be read to participants prior to interview question)</td>
<td>Topic Interview Question</td>
<td>Probing Interview Question(s)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>--------------------------------</td>
</tr>
<tr>
<td>Caregiver Education</td>
<td>Deliberate and consistent efforts to involve caregivers with decision-making regarding patient care. Prepare with the skills needed to care for patient when transitioning to home, including skills in early identification and management of worsening symptoms. Caregivers are provided with access to community resources and supports and develop competencies and confidence that can help provide for patients’ needs and address their own needs (Naylor et al., 2017, pgs. 3-4).</td>
<td>Caregivers are included in care plan decision-making. Caregivers learn how to care for themselves and their loved one when they come home. Caregivers learn how to recognize and manage worsening symptoms. Caregivers learn what community resources are available to help them take care of themselves and their loved one.</td>
<td>What would a program look like that had a plan to meet the caregiver’s learning needs?</td>
<td>What learning activities are helpful to the caregiver? Describe how healthcare professionals can help you learn how to care for yourself and your loved one? What learning activities would be helpful in managing worsening symptoms? What community resources would help you to take care of yourself and your loved one?</td>
</tr>
<tr>
<td>Patient and Caregiver Well-being</td>
<td>Recognition of patients’ and caregivers’ emotional reactions to stressful experiences and deliberate efforts of healthcare team members to acknowledge such reactions, foster coping skills, enable care recipients to be respected and treated as whole human beings, and support decisions that contribute to patients’ and caregivers’ quality of life</td>
<td>Individuals, caregivers, and healthcare professionals all acknowledge stressful emotional reactions. Healthcare professionals provide individuals and caregivers with coping skill support. Individuals, caregivers, and healthcare professionals all work together to achieve</td>
<td>What would a program look like that had a plan to manage your well-being?</td>
<td>What is important to you in managing stress and emotions? What is important to you in achieving well-being and high quality of life?</td>
</tr>
<tr>
<td>Transitional Care Component</td>
<td>Operational Definition of Transitional Care Component (Naylor et al., 2017)</td>
<td>Translation of operational definition into lay-person terms (to be read to participants prior to interview question)</td>
<td>Topic Interview Question</td>
<td>Probing Interview Question(s)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Care Continuity</td>
<td>Comprehensive implementation of individualized care plans, including ensuring timely access to appropriate, high-value health and community-based services (management continuity), timely exchange of information between and among all team members (informational continuity), and access to continuous sources of care to foster trust with patients and caregivers (relational continuity) (Naylor et. al, 2017, p. 4).</td>
<td>well-being and high quality of life.</td>
<td>What would a program look like that had a plan to coordinate your care after returning to home?</td>
<td>What health and community services would be helpful to use when returning home? How is information best shared between individuals, caregivers, and healthcare professionals? What are some of the barriers to developing trusting relationships with healthcare professionals?</td>
</tr>
<tr>
<td>Accountability (clinician, team, organizational)</td>
<td>Assuming responsibility for ensuring high-quality implementation of TC services customized to meet individualized needs of patients and caregivers. <strong>Clinician accountability</strong> refers to partnerships between healthcare professionals and patients in designing plans of care and ensuring effective implementation of these plans. <strong>Team accountability</strong></td>
<td>Accountability between individuals, caregivers, and healthcare professionals in meeting care plan goals. Accountability between healthcare professionals to collaborate effectively. Healthcare system accountability to provide services supporting the transition from hospital to home.</td>
<td>What would a program look like that had accountability in meeting your needs when transitioning from hospital to home?</td>
<td>What do you need to stay on track with care plan goals? What challenges did you experience with the healthcare system while making the transition from hospital to home?</td>
</tr>
<tr>
<td>Transitional Care Component</td>
<td>Operational Definition of Transitional Care Component (Naylor et al., 2017)</td>
<td>Translation of operational definition into lay-person terms (to be read to participants prior to interview question)</td>
<td>Topic Interview Question</td>
<td>Probing Interview Question(s)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td></td>
<td>refers to the responsibility of each healthcare professional to contribute expertise and actively collaborate with all team members to ensure that patients and caregivers achieve their health goals. Organizational accountability refers to the system's responsibility to ensure an environment and services conducive to optimizing the TC experiences of patients and caregivers. (Naylor et al., 2017, p. 5).</td>
<td>home.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX H:

INFORMED CONSENT
University of Arizona
Consent to Participate in Research

Study Title: Engagement of primary stakeholders in the development of a future community-based stroke transitional care intervention

Principal Investigator: Lorre Laws

You are being asked to participate in a research study. Your participation in this research study is voluntary and you do not have to participate. This document contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate.

Purpose of Study and Expected Duration
The purpose of this study is to engage the primary stakeholders – individuals and caregivers affected by stroke – in the refinement and tailoring of a stroke-specific TC model corresponding to essential TC components: patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability.

This study will provide important preliminary data that will underpin a future community – hospital partnership and community-based TC intervention for persons affected by stroke.

The expected length of this study is estimated to be from March 1, 2018 – August 20, 2018.

Requirements of the Study
By participating in a focus group discussion, individuals and caregivers affected by stroke will discuss what is needed to develop stroke-specific transitional care components. The components that will be discussed are patient engagement, caregiver engagement, complexity management, patient education, caregiver education, well-being, care continuity, and accountability.

Summary of the Risks and/or Benefits
There are no expected risks to you as a result of participating in this study. You will not benefit directly from participating in this study.

Time Commitment:
Participants in this study will attend 1-2 focus group discussions which will last approximately 2-3 hours, each.

Incentive to Participants:
At the conclusion of each focus group, participants will be offered a $20 gift card.

Confidentiality of Information:
All information collected from the participants is confidential. During the focus group
discussion, a first-name only format will be used. Data collected during the focus group discussion will be de-identified. Your name will not be used in any report. Identifiable research data will be encrypted and password protected.

Participant names will be de-identified by using a participant identifier instead of a name. De-identified data will then be analyzed and reported. During the study, the primary investigator may contact you to obtain clarification or to verify the initial analysis findings. Information collected about you will not be shared with other researchers or used for future research.

Your responses will be assigned a code number. The list connecting your name to this code will be kept in an encrypted and password protected file. Only the research team will have access to the file. When the study is completed and the data have been analyzed, the list will be destroyed.

With your permission, I would like to audiotape this interview so that I can make an accurate transcript. Once I have made the transcript, I will erase the recordings. Your name will not be in the transcript or my notes.

You will not be identified in any report or publication of this study. Even though we will tell all participants in the study that the comments made during the focus group should be kept confidential, it is possible that participants may repeat comments outside the group.

The audio recordings, transcripts, data, and data analysis documents will be securely and electronically stored at University of Arizona’s Box@UA, a secure cloud-based storage system. Electronic documents stored at Box@UA are securely stored for seven years, after which time they are destroyed. Paper documents will be stored in a locked cabinet or safe at the University of Arizona – College of Nursing departmental or home office. Paper documents will be destroyed on or before August 20, 2018.

The information that you provide in the study will be handled confidentially. However, there may be circumstances where this information must be released or shared as required by law. The University of Arizona Institutional Review Board may review the research records for monitoring purposes.

Who to Call for Questions
For questions, concerns, or complaints about the study you may contact Lorre Laws (email: lorre.lawes@u.arizona.edu).

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at (520) 621-6246 or online at http://rgw.arizona.edu/compliance/human-subjects-protection-program.
**Signing the consent form**

I have read (or someone has read to me) this form, and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

<table>
<thead>
<tr>
<th>Printed name of subject</th>
<th>Signature of subject</th>
<th>Date</th>
</tr>
</thead>
</table>
APPENDIX I:

REFLEXIVITY JOURNAL
To facilitate PI bias awareness, Hesse-Biber and Leavy (2011) recommend including the following questions in a reflexive journal:

1. What specific biases, if any, do I bring to or impose upon this study?
2. How do my theoretical perspectives, values, and attitudes influence my research style?
3. Do I ask questions solely from my own perspective?
4. How does my personal or professional agenda influence my questions and findings?

How does my position on these issues impact how I gather, analyze, and interpret the data?
APPENDIX J:

THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD APPROVAL LETTER
Date: March 22, 2018
Principal Investigator: Lorre Ann Laws
Protocol Number: 1803352708
Protocol Title: Engagement of primary stakeholders to tailor a comprehensive transitional care model for persons who have experienced a stroke and their caregivers
Determination: Approved
Expiration Date: March 21, 2023

Documents Reviewed Concurrently:
- Data Collection Tool: Appendix Ev2_Demographic_Data_Tool.docx
- Data Collection Tool: Appendix Ev2_Focus Group Procedure and Interview Guide EDIT1.docx
- Data Collection Tool: Appendix Gv2_Interest Question Development.docx
- HSPP Forms/Correspondence: Advisor Signature.pdf
- HSPP Forms/Correspondence: Laws_IRB_030418_LAL.pdf
- HSPP Forms/Correspondence: Scientific Review and Department Signature.pdf
- Other: Lic Baldry response 031618.docx
- Participant Material: Focus group power point.pptx
- Recruitment Material: Appendix A_Recruitment_flyer 05Mar2018.docx
- Recruitment Material: Appendix Ev2_Recruitment script.docx
- Recruitment Material: Appendix C_Screening Enrollment form.docx
- Recruitment Material: Appendix Dv2_T-MoCA.docx

Regulatory Determinations/Comments:
- The project is not federally funded or supported and has been deemed to be no more than minimal risk.
- The project listed is required to update the HSPP on the status of the research in 5 years. A reminder notice will be sent 60 days prior to the expiration noted to submit a 'Project Update' form.

This project has been reviewed and approved by an IRB Chair or designee.
- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted according to the approved protocol and the policies and guidance of the IRB.
- The Principal Investigator should notify the IRB immediately of any proposed changes that affect the protocol and report any unanticipated problems involving risks to participants or
APPENDIX K:

REFLEXIVITY STATEMENTS
1. **What specific biases, if any, do I bring to or impose upon this study?** I, like many people, have received terrific care and health outcomes as a result of the fragmented US healthcare system. I also, have almost been killed by fragmented healthcare delivery. I have been misdiagnosed a number of times. Similarly, I have observed stroke patients experience positive and negative outcomes are a result of stroke care delivery and follow-up. As a professional, I respond to any actual or perceived healthcare delivery shortcoming with integrity, while bracketing any bias I may have from research study.

2. **How do my theoretical perspectives, values, and attitudes influence my research style?** I draw upon Meleis’ Transitions Theory (Meleis, 2010), caring science and mindful practice (Sitzman & Watson, 2018), Munhall’s unknowing perspective (Munhall, 1992), and appreciative inquiry (Watkins, Mohr, & Kelly, 2011). I general, I approach life and my activities, including research and education, from a positive framework. We only know what we know. We aren’t aware of what we don’t yet know. Therefore, it is important to hold receptive space for the unknown within for the process of discovery.

3. **Do I ask questions solely from my own perspective?** I am 100% confident that my questions emerged from theoretical underpinnings and a comprehensive synthesis of the evidence base. For example, the focus group discussion questions were derived from Naylor et al’s (2017) operational definitions for each essential TC component, which also serve as the *a priori* deductive categories for the content analysis process. Any data not captured by these categories will analyzed using an inductive process, with published literature – not my personal biases and assumptions – as supporting evidence.

4. **How does my personal or professional agenda influence my questions and findings?** This is my final career chapter. As such, my focus is to make a difference and I am open as to how this manifests through me. By virtue of doing this work, I am contributing to science. The outcomes, whether anticipated or unanticipated, are equally important. I am not personally or professionally invested in a particular outcome or finding. As a mindfulness practitioner for over thirty years, I have considerable experience in detaching from my biases and assumptions in favor of observing from a neutral and theoretically unencumbered perspective.

5. **How does my position on these issues impact how I gather, analyze, and interpret the data?** My experience with the stroke population, while important, does not influence my process as a scientist. I am well-trained and experience with detaching from my perspective, freeing me to collect and analyze data from a neutral perspective. I am mindful of conducting a dissertation study aligning with the trustworthiness criteria set forth by Lincoln and Guba (1985). Throughout this study and subsequent publication processes, I will iteratively assess myself for the emergence of biases or assumptions and discuss same with my dissertation chair immediately.
REFERENCES


Englander, H., & Kansagara, D. (2012). Planning and designing the care transitions innovation (C-Train) for uninsured and Medicaid patients. *Journal of Hospital Medicine, 7*(7), 524-529. doi:10.1002/jhm.1926

Englander, H., Michaels, L., Chan, B., & Kansagara, D. (2014). The care transitions innovation (C-Train) for socioeconomically disadvantaged adults: Results of a cluster randomized controlled trial. *Journal of General Internal Medicine, 29*(11), 1460-1467. doi:10.1007/s11606-014-2903-0


Mason, M. (2010). *Sample size and saturation in PhD studies using qualitative interviews* (Vol. 11).


McHugh, M. D. & Ma, C. (2013). Hospital nursing and 30-day readmissions among Medicare patients with heart failure, acute myocardial infarction, and pneumonia. Medical Care, 51(1), 52.


Saban, K. L. & Hogan, N. S. (2012). Female caregivers of stroke survivors: Coping and adapting to a life that once was. *Journal of Neuroscience Nursing, 44*(1), 2-14. doi:10.1097/JNN.0b013e31823ae4f9


