

2020

The Caregiver Advise Record and Enable (CARE) Act and Compassion Fatigue in the United States

Karen Marie Johnson
Walden University

Follow this and additional works at: <https://scholarworks.waldenu.edu/dissertations>



Part of the [Epidemiology Commons](#), and the [Public Health Education and Promotion Commons](#)

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact ScholarWorks@waldenu.edu.

Walden University

College of Health Sciences

This is to certify that the doctoral dissertation by

Karen Johnson

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee

Dr. Eboni Green, Committee Chairperson, Public Health Faculty
Dr. Michael Brunet, Committee Member, Public Health Faculty
Dr. Muazzam Nasrullah, University Reviewer, Public Health Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
2020

Abstract

The Caregiver Advise Record and Enable (CARE) Act and Compassion Fatigue in the
United States

by

Karen Johnson

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Health – Epidemiology

Walden University

February 2020

Abstract

The transition from hospital to home can be complicated, leaving family caregivers in stressful situations that they may not know how to handle. The burden that is placed on these individuals has led researchers to focus on the public health implications of caregiving in hopes of identifying at-risk caregivers. This quantitative analysis identified what relationships exist between caregiver compassion fatigue among family caregivers and training or education received per the Caregiver Advise Record and Enable (CARE) Act and if education influences readmission rates. A purposive sample of 385 family caregivers participated in this study. The Care Transitions Measure (CTM-15), the Caregiver Reaction Scale (CRS), and the LACE (length of stay, acuity of admission, comorbidities, and emergency department visits) index were used to explore the relationship between caregiver education received, caregiver compassion fatigue, and rates of readmission. The results of this study did not support a significant relationship between the education that caregivers receive according to the CARE Act and readmission rates of the care receiver when utilizing the CTM-15 and the LACE index but it did support a relationship between the caregiver's compassion fatigue and the amount of training the caregivers receive from the CARE Act in some areas of the CRS. While research continues to identify flaws in the caregiver transition, the CRS and CTM-15 show a significant relationship in some areas of the CRS, identifying some caregivers are better educated prior to leaving the hospital and with a potential reduction in compassion fatigue.

The Caregiver Advise Record and Enable (CARE) Act and Compassion Fatigue in the
United States

by

Karen Johnson

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Health – Epidemiology

Walden University

February 2020

Dedication

I would like to dedicate this paper to the Labor and Delivery Floor at Willis-Knighton Bossier in Bossier City, Louisiana. They will never know how thankful I am for the care they provided us with during my pregnancy/renal failure extended stay at their lovely facility. The late-night scares and early morning Dr. Stat visits made it for an interesting stay. They made my husband feel at home and involved him in daily coffee making activities. Without their support and allowing me to keep my baby in labor in delivery for our extended stay, I would be in jail at present for escaping the hospital with a dialysis machine attached just to be with my baby.

I also want to thank the Willis-Knighton dialysis team for answering all of my questions, helping me hold back the tears and just for being there for me during every 4-hour treatment. All the support I received gave me the drive to see if others like us need the great support we received.

Acknowledgments

I want to acknowledge my husband; without him, I would not be where I am today. His love for me and our boys means more to me than he will ever know.

Table of Contents

List of Tables	iv
Chapter 1: Introduction to the Study.....	1
Background	2
Problem Statement	3
Purpose of the Study	7
Research Questions and Hypotheses	9
Theoretical and/or Conceptual Framework for the Study.....	9
Nature of the Study	10
Definitions.....	11
Assumptions.....	12
Scope and Delimitations	12
Limitations	14
Significance.....	14
Summary	16
Chapter 2: Literature Review	17
Introduction.....	17
Literature Search Strategy.....	18
Theoretical Foundation	18
Literature Review.....	19
Summary	20
Chapter 3: Research Method.....	22

Introduction.....	22
Research Design and Rationale	23
Methodology.....	24
Population	24
Procedures For Recruitment, Participation, and Data Collection	24
Threats to Validity	42
Ethical Procedures	25
Summary.....	26
Chapter 4: Results.....	27
Introduction.....	27
Data Collection	27
Results.....	28
Descriptive Statistics.....	30
Binary Logistic Regression.....	31
Linear Regression Analysis	32
Summary.....	38
Chapter 5: Discussion, Conclusions, and Recommendations.....	40
Introduction.....	40
Interpretation of the Findings.....	40
Limitations of the Study.....	41
Recommendations.....	42
Conclusion	44

References.....44

List of Tables

Table 1. Baseline Descriptive and Demographic Characteristics.....	29
Table 2. Summary Statistics Table for Interval and Ratio Variables	31
Table 3. Logistic Regression Results with Caregiver Education Received Predicting LACE Readmission Binned.....	32
Table 4. Results for Linear Regression with Caregiver Education Received predicting Role Captivity.....	33
Table 5. Results for Linear Regression with Caregiver Education Received predicting Overload.....	34
Table 6. Results for Linear Regression with Caregiver Education Received predicting Relational Deprivation	34
Table 7. Results for Linear Regression with Caregiver Education Received predicting Caregiving Competence.....	35
Table 8. Results for Linear Regression with Caregiver Education Received predicting Personal Gain	36
Table 9. Results for Linear Regression with Caregiver Education Received predicting Family Beliefs.....	37
Table 10. Results for Linear Regression with Caregiver Education Received predicting Family Actions.....	37
Table 11. Results for Linear Regression with Caregiver Education Received predicting Employment.....	38

Chapter 1: Introduction to the Study

Improvements in medical technology have increased the average life expectancy, which has increased the need for family caregivers as well increased the public health concerns for these family members who inadvertently become lifelong caregivers (Talley & Crews, 2007). Decades of caregiving research have focused on activities of daily living (ADL) the caregivers perform but have not highlighted the complicated medical tasks they are expected to do (Reinhard & Ryan, 2017). The lack of focus on these complicated tasks is the continuing public health concern for caregivers.

This research includes an analysis of the relationship between the education that caregivers receive prior to discharge of their loved ones and compassion fatigue in order to determine whether caregiver education at the time of discharge influences readmission rates. Coleman, Roman, Hall and Min (2015) stated that current caregiver research has analyzed caregiver burden and caregiver satisfaction but has not identified goals to improve outcome. Focusing on the negative aspect of their burden leaves a gap in research on the entire caregiver experience and this gap includes a lack of quantitative assessment of the full caregiver experience (O'Malley & Qualls, 2017).

This study needs to be conducted because, as highlighted by Reinhard, Capezuti, Bricoli, and Choula (2017) value-based care is causing earlier discharges, leaving the family caregivers overwhelmed and without appropriate support from health care professionals. The potential positive social implication of this study is that, if the education caregivers received prior to discharge of their loved ones is effective in reducing their compassion fatigue and potential readmissions, then healthcare providers

can use that information to argue for funding for such programs, thereby improving the overall health of patients and their caregivers.

Background

Coleman (2016) stated that the Caregiver Advise Record and Enable (CARE) Act was created because key elements were not included in current translational care. Coleman also questioned why it took a legislative action to include caregivers in the hospital discharge process. The John A. Hartford Foundation funded Home Alone: Family Caregivers Providing Complex Chronic Care, a nationwide survey that identified gaps in what caregivers are expected to do and the guidance they received to do these things (Reinhold & Ryan, 2017). The CARE Act was created to close the gap and hospitals are now required to provide caregivers with a better transition from hospital to home by making sure they receive the information and instructions they need (Reinhold & Ryan, 2017).

Jencks, Williams, and Coleman, (2009) analyzed rehospitalizations of Medicare beneficiaries and found that further research needs to be done to identify why the discharge process and outpatient and community care was so inadequate that it seemed to be causing an increase in readmission rates within 30 days after discharge. Hubbard and McNeil (2012) highlighted that numerous hospitals are now moving to find ways to improve both their quality of care during the discharge process and the patient's transition from hospital to community, hoping to reduce further avoidable readmissions.

Alyahya et al. (2016) argued that hospital readmissions should be viewed as a public health endemic; caregivers are receiving unclear instructions during the discharge process and this is found to contribute to readmission rates.

The AARP Foundation (n.d.) supports the CARE Act that assists family caregivers and their care recipient during their transition home. Caregivers provide such a supportive role and most with no medical training. The CARE Act seeks to provide additional education for the caregivers and has been signed into law in 36 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. The Act requires hospitals to record the name of the family caregiver in the recipient's medical records, inform caregivers when the care recipient is discharged and provide caregivers with education and instruction.

Problem Statement

The transition from hospital to home can be very complicated, leaving family caregivers in stressful situations that they may not know how to handle. In fact, the National Academies of Sciences, Engineering, and Medicine (2016) stated that most studies have focused on the negative aspect of caregiving. Focusing on the positive or negative aspects leaves out the entire caregiver experience (O'Malley & Qualls, 2017). This problem represents a significant public health concern because of the small pool of individuals that are left to care for their loved ones when leaving the hospital. The burden that is placed on these individuals has led researchers to focus on the public health implications of caregiving in hopes of identifying at-risk caregivers.

In January 2018 the President of the United States of America Donald Trump, signed the recognize, assist, include, support, and engage (RAISE) Family Caregivers Act into law (AARP Foundation, 2018). The AARP Foundation (2018) stated that:

The RAISE Family Caregivers Act (S. 1028/H.R. 3759) requires the Secretary of Health and Human Services to develop, maintain and update a strategy to recognize and support family caregivers. The law brings representatives from the private and public sectors, such as family caregivers; older adults and persons with disabilities; veterans; providers of health care and long-term services and supports (LTSS); employers; state and local officials; and others together to advise and make recommendations regarding this new strategy. The advisory council meetings will be open to the public, and there will be opportunities for public input. The strategy will identify recommended actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers, including with respect to:

- promoting greater adoption of person- and family-centered care in all health and LTSS settings, with the person and the family caregiver (as appropriate) at the center of care teams
- assessment and service planning (including care transitions and coordination) involving care recipients and family caregivers
- information, education, training supports, referral, and care coordination
- respite options
- financial security and workplace issues.

The president signing into law an act that will identify the gaps in our caregiver support shows how current researchers continue to identify problems but we still have not developed an all-encompassing plan to support family caregivers. In this study, I analyzed the relationship between the current education that caregivers receive prior to discharge of their loved ones and caregiver compassion fatigue and care recipient readmission rates during 2017 to 2018.

While looking at readmission rates among the 11,855,702 Medicare beneficiaries, one fifth of all patients (19.6%) were rehospitalized within 30 days of discharge from the hospital (Jencks, Williams & Coleman, 2009). MedPac (2007) estimated potentially preventable 30-day rehospitalizations are costing Medicare \$12 billion every year. According to Reinhard et al. (2017) researchers have shown the hospital experience has become more focused on more family responsibility to align with lower costs by encouraging earlier discharges, leaving the family caregiver alone to accomplish complex medical tasks. The National Academies of Sciences, Engineering, and Medicine (2016) further stated that family caregivers are overburdened with complicated chronic care and financial issues leading to burnout, stress, feelings of inadequacy and depression; all of which are directly related to increased hospital readmission and return emergency room visits.

The Readmission Reduction Program was started to help address these readmission problems by enforcing penalizing payments for hospitals with higher readmission rates (Hubbard & McNeil, 2012). After identifying many of the causes of readmissions as avoidable, Hubbard and McNeil (2012) found that hospitals that

improved their discharge process started to reduce their readmissions. Sadak et al. (2017) found that valid clinical assessments for caregiver stress and burden are not built into clinical practice and because family caregivers are not considered patients and their warning signs are often missed. Public policies, such as the Partnership for Patients, focus on improving care transitions (CMS.gov, 2017a) and have identified that the discharge and transition to home process is lacking. Unfortunately, because the discharge process needs improvement, the preventable readmission rates continue to increase. Medicare now offers billing codes to incentivize clinical teams in the identification, education and referral for caregiver potential needs; however, these procedures have yet to be incorporated into routine care (Sadak et al., 2017).

Giosa, Stolee, Dupuis, Mock, and Santi (2014) described the caregiver transition from hospital to home as stressful and further found that many caregivers feel unprepared. This lack of preparation among family caregivers often leads to errors in care at home, a practice that frequently results in hospital readmissions. Coleman et al. (2015) also found that the family members themselves feel unprepared to perform medical caregiving tasks, needing their own type of support for their caregiving and most feel they have not received appropriate training.

The CARE Act was implemented to address the challenges that family caregivers face and now requires hospitals to identify and educate the family caregiver about the medical tasks they will need to perform after discharging the patient (Coleman, 2016). The gap in research is that no programs have facilitated effective ways to assess these discharge processes. The purpose of this study was to analyze the education that

caregivers receive prior to discharge of their loved ones and to determine if compassion fatigue or caregiver education at the time of discharge influenced readmission rates.

Purpose of the Study

Alyahya et al. (2016) identified avoidable readmission rates as a public health problem that should be considered a primary health issue that needs to be further analyzed for specific risk factors. A retrospective cohort of internal medicine patients indicated that clear discharge instructions could reduce the readmission rate by 37% and save the government hundreds of thousands of dollars in medical costs (Alyahya et al., 2016).

Although this public health concern remains underexamined, recent literature continues to suggest that vulnerabilities during the transition from hospital to home are leaving the patient and caregiver assuming roles they feel inadequate and unprepared to fill (Coleman, Rosenbek, & Roman, 2013). Pitsikali, Galanakis, Varvogli and Darviri, (2015) stated that these family caregivers are left responsible for daily care of their relatives to include challenging tasks that are stressful, emotionally intense and often physically exhausting. Tan et al. (2017) studied the psychosocial, behavioral and environmental factors behind frequent hospital admissions only to discover that the lack of caregiver support led to caregiver stress, social isolation and poor communication during the transition home were key to frequent readmissions.

Some barriers that may cause this perceived lack of attention to caregivers are that health professionals not having adequate time to provide the lengthy discharge process needed, uncertainty of how to prepare these caregivers and the lack of continued

feedback after the discharge process compounds the issue (Coleman, 2016). Researchers continue to highlight the lack of translation from hospital to home for the caregiver but our knowledge gap is what programs or interventions are the most effective in preparing caregivers for their assumed roles. The purpose of this study was to quantitatively analyze the relationship between the education that caregivers receive prior to discharge of their loved ones and to determine if compassion fatigue or caregiver education at the time of discharge influenced readmission rates during 2017 to 2018. The effectiveness of the CARE Act was also explored.

The Care Transitions Measure (CTM-15) was created by Coleman, Mahoney and Parry (2005) in hopes of finding a valid and reliable tool that would measure patient transition health care settings. The CTM-15 proved reliable and a validated method to measure the patient's perspective of their transition of care. The CTM-15 (2005) was used in this study to measure the patient's perspective of their transition of care from hospital to home to measure the education received by the CARE Act. O'Malley and Qualls (2017) validated the Caregiver Reaction Scale as a tool to assess the positive aspects of caregiving but also highlight the stress and burden the caregivers endured. The LACE index (length of stay, acuity of admission, comorbidities, and emergency department visits) was used to quantify the risk of unplanned readmissions for the care recipients since their discharge from hospital to home (van Walraven, et al., 2010). The intent of this study was to quantify the data from these three scales in hopes to explore the relationship between caregiver education received, caregiver stress and rates of readmission during 2017 to 2018.

Research Questions and Hypotheses

1. RQ1-Does a relationship exist between the education that caregivers receive according to the CARE Act and readmission rates of the care receiver?

2. RQ2-Is there a relationship between the caregiver's compassion fatigue and the amount of training the caregivers receive from the CARE Act?

The hypothesis was that the caregiver population is not prepared or educated enough prior to the transition from hospital to home potentially leading to an increase in stress and burden. The alternative hypothesis was the CARE Act had provided enough education to prepare caregivers for the transition home with little or no stress and burden.

I looked at the response variables to see if there were any relationships, themes, or patterns regarding the difficulties the caregivers face. The three variables in this study were (a) education that caregivers received prior to discharge of the care recipient (the independent variable), (b) compassion fatigue (dependent variable) and (c) readmission rates (the covariate). Additional covariate variables analyzed were demographic characteristics (caregiver's age, sex, education level, employment status and years as a caregiver) to look for further relationships or patterns.

Theoretical and/or Conceptual Framework for the Study

The theoretical concept of this study is the subjective burden or compassion fatigue of family caregivers as Graessel, Berth, Lichte, and Grau (2014) stated this concept has demonstrated predictive powers on the effect of our caregiver's health. Graessel et al. stated this theory of subjective burden is itself subjective of many facets; therefore, multiple scales were utilized to capture the caregivers self-assessed burden.

Day, Anderson, and Davis (2014) stated the background of compassion fatigue and the caregiver have always been focused on the nurse, social worker or psychologist and have since adopted this type of behavior into other caregiver type settings. Subsequent research utilizing this theory offers insight to the challenge of caregiver compassion fatigue. Sadak et al. (2017) agreed the best way to reduce the burden for our caregivers is by identifying these subjective stressors. Sadak et al. discussed the multiple avenues to measure and assess caregiver burden and compassion fatigue but noted that there is a lack of translation of these burdens into our health care settings. The framework of this study utilized validated surveys to assess the relationship between the caregiver's compassion fatigue and the quality of training the caregivers received from the CARE Act and if this additional education affected readmission rates.

Nature of the Study

The nature of this study was quantitative. This quantitative analysis helped identify the relationship between caregiver compassion fatigue among family caregivers and training or education received per the CARE Act and if education influenced readmission rates. The separation of quantitative and qualitative assessment of caregiver compassion fatigue has created gaps in assessing the full experience in caregivers (O'Malley & Qualls, 2017). It is hopeful that this study in some way contributed by analyzing the compassion fatigue of caregivers but also incorporating the training received by the CARE Act to determine the direct relationship. This study also assessed the effectiveness of the CARE Act and if it related to the reduction in readmission rates by surveying a large representative group of caregivers provided through the nonprofit

organization research registry at Family Caregiver Alliance-National Center on Caregiving (2017). The nature of the study explored and determined the relationship between caregiver compassion fatigue among family caregivers and training or education received per the CARE Act and if the additional education influenced readmission rates. El Morr, Ginsburg, Nam, and Woollard (2017) stated including socioeconomic factors could identify confounding factors related to readmission rates. Basic demographic questions were included with the surveys.

Definitions

Some of the terms used that may have had multiple meanings are defined here:

Family caregiver and informal caregiver: Family member, friend or neighbor that is not paid but provides care to an individual to include tasks such as bathing, dressing, medications, feeding and ventilator care (Reinhard, Given, Petlick & Bemis, 2008).

Compassion fatigue: Day and Anderson (2011) stated the most common definition of compassion fatigue involves adverse consequences from caring for individuals and often results in anger, depression or apathy for the caregiver.

Caregiving: O'Malley and Qualls (2017) defined caregiving as a normal family experience experienced in different ways with different risks and benefits.

Readmission rate: El Morr, Ginsburg, Nam, and Woollard (2017) defined readmission rate as the total urgent readmissions within the 30 days following an admission divided by the total elective and urgent admissions.

Evidence based medicine: "Evidence-based medicine de-emphasizes intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for

clinical decision making and stresses the examination of evidence from clinical research. Evidence-based medicine requires new skills of the physician, including efficient literature searching and the application of formal rules of evidence evaluating the clinical literature” (Evidence-Based Medicine Working Group, 1992).

Evidence based public health: “The process of integrating science-based interventions with community preferences to improve the health of populations” (Evidence-Based Medicine Working Group, 1992).

Assumptions

The CARE Act has been signed into law in 36 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. Aspects of the study that were believed but cannot be demonstrated are the states the CARE Act have been made into law, an assumption is the CARE Act has been implemented if the care recipients were discharged from a hospital in one of these 36 states. Assumptions are necessary in the aspect of this study because surveying the caregiver about their knowledge of the CARE Act may not be accurate. Caregivers may have received the additional education but may not be familiar with the name of the implemented Act.

Scope and Delimitations

Alyahya et al. (2016) identified avoidable readmission rates a public health concern. Coleman, Rosenbek, and Roman (2013) suggested caregivers are assuming roles they are unprepared for and Pitsikali, Galanakis, Varvogli and Darviri, (2015) stated these roles they fill are leading to emotionally stressful situations. Tan et al. (2017) suggested the lack of caregiver support and poor transitions from hospital to home lead to

frequent readmissions. Tan et al. quantified relationships between caregiver burden, potential readmission rates, and the relationship to the education received during the discharge process in hopes to increase internal validity.

The study participants were recruited from the Family Caregiver Alliance (FCA)-National Center on Caregiving (2017) research registry. This research registry has a forum for current research projects being done where caregivers can gain access if they would like to participate. A Survey Monkey link was posted which included the Caregiver Reaction Scale, CTM-15, LACE index and demographic characteristics (caregiver's age, sex, Education Level, employment status and years as a caregiver). I received the responses, analyzed after data collection was complete and all data will be kept electronically for six years after study closure.

The Family Caregiver Alliance (FCA)-National Center on Caregiving (2017) is a nonprofit organization that provides support services for caregivers, showing this population of caregivers is reaching out for assistance and is willing to accept support. Recruiting participants from the research registry listed on this organization's website may be considered a potential boundary as these caregivers know they need some type of support and are willing to accept the assistance. This study population may have excluded those caregivers that are unaware of the burden they carry. This study may have also excluded the caregiver population that needs the most help. The intent of this study was to look at relationship between caregiver compassion fatigue, training or education received per the CARE Act and if the additional education influenced readmission rates.

Results of this study may not be generalizable to the general population but may give researchers a future focus.

Limitations

Possible limitations of this study include the condition of the family member and their daily routine. If the family member had a full-time job and their family to consider, they may be more burdened than when considering a caregiver that is retired with ample free time. These differences could cause potential transfer from hospital to home issues but this quantitative study looked to identify similarities and common factors of the caregiver's daily routine and their difficulties. By analyzing the caregiver experiences including retired caregivers and caregivers with full time jobs, the potential need for future research could be determined.

The interviewer has a personal interest in caregiver support and could be looked at as a bias when interpreting the results. To address this bias, the Care Transitions Measure (CTM-15), a validated caregiver burden scale was used to assess the overall quality of the transition. Caregiver Reaction Scale was used to assess caregiver burden and positive aspects of caregiving. The LACE index was used to identify the risk of unplanned readmissions for the care recipients. These three validated tools along with basic demographics identify the caregiver experience from their perspective addressing the potential bias and limitations.

Significance

Since the introduction of evidence-based medicine by Professor Guyatt at the Evidence-Based Medicine Working Group (1992), clinicians have followed a universal

practice across all specialties by adopting the best evidence based medicine (Fallah, 2015). With health funding decreasing, diseases increasing, and the demand for validated public health strategies, Jacobs, Jones, Gabella, Spring, and Brownson, (2012) stated that public health practitioners need to ensure they implement evidence-based public health practices for the best results.

In January 2018, the President signed the RAISE Family Caregivers Act into law (AARP Foundation, 2018). The AARP Foundation (2018) stated this law requires the Secretary of Health and Human Services to develop a plan to better support family caregivers. The potential contributions of this study could contribute to this law and evidence-based public health practices as this brings representatives from the private and public sectors looking for current relevant research on policies that may or may not be improving our family caregiver support. The president recently signed the RAISE Family Caregivers Act into law and demanded better policies be implemented. This demonstrates family caregiver support is a public health issue that requires attention. In this research I attempt to fill a gap in understanding if the current CARE Act has made an impact on the relationship between education received by the CARE Act by addressing if education influenced caregiver compassion fatigue and reduced readmission rates.

The results of this study advance our knowledge in this discipline and show the relationship between the CARE Act, caregiver compassion fatigue and readmission rates. Ample research has been conducted to identify the difficulties caregivers face, but the public health concern is the lack of assessing the public policies in place to better assess the transition from hospital to home for the caregivers.

The significance of this study identifies how the CARE Act, compassion fatigue and readmission rates are related. It also identified if this act is helping reduce the burden on our caregivers. The potential implications for positive social change in this research are that the results identified if the CARE Act is helping our current family caregivers with a reduction in caregiver stress and burden. Potential implications for positive change at the community level include a reduction in readmission rates and potential implications for positive social change at the society level includes the assessment of current policies available for caregivers.

Summary

The transition from hospital to home can be difficult for caregivers with little or no training. While research continues to identify flaws in the caregiver transition, public health reach lacks an effective assessment of current policies on caregiving and care recipient readmission rates.

The study quantitatively analyzed the relationship between the education that caregivers received prior to discharge of their loved ones and determined if compassion fatigue or caregiver education at the time of discharge influenced readmission rates. Chapter 2 discusses the current literature related to the problem and purpose of this study, the literature search strategy, information about the theoretical foundation and current gaps in literature.

Chapter 2: Literature Review

Introduction

The caregiver transition from hospital to home can be very complicated, leaving caregivers in stressful situations they may not know how to handle. The research problem is that current studies focus on the negative aspect of caregiving rather than the entire experience, which often includes the positives. In this study I analyzed the relationship between the education that caregivers received prior to discharge of the care recipient and to determine if compassion fatigue or caregiver education at the time of discharge influenced readmission rates. This problem is relevant and a significant public health concern because in January 2018 the U.S. president signed the RAISE Family Caregivers Act into law (AARP Foundation, 2018) requiring the Secretary of Health and Human Services to create a better method of support for the family caregivers.

The Care Transitions Measure (CTM-15), validated by Coleman, Mahoney, and Parry (2005), was used to measure the patient's perspective of their transition of care from hospital to home in order to assess the education received under the CARE Act. The Caregiver Reaction Scale, validated by O'Malley and Qualls (2017), was used to assess the positive aspects of caregiving but also highlighted the stress and burden the caregivers endured. The LACE index was used to quantify the risk of unplanned readmissions for the care recipients since their discharge from hospital to home. The intent of this study was to quantify the data from these three surveys in order to explore the relationship between caregiver education received, caregiver compassion fatigue, and rates of readmission.

This chapter includes a discussion of the current literature related to the problem and purpose of this study. The first section will consist of the literature search strategy. The second section provides information about the theoretical foundation, and the fourth section focuses on current gaps in literature.

Literature Search Strategy

The databases accessed included Google Scholar, Medline, ProQuest Central, PubMed, Sage Premier, and Science Direct. The search keywords were *family caregivers, compassion fatigue, caregiver burden, CARE Act, Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, readmission reduction, and transitional care*. The scope of the literature review was focused on research from 2013 to 2018, but older pertinent articles were included where relevant.

Theoretical Foundation

The theoretical concept of this study was the subjective burden of family caregivers. This concept has demonstrated the effect of our caregiver's health (Graessel, Berth, Lichte, & Grau, 2014). This theory of subjective burden is itself subjective in many facets (Graessel et al., 2014); therefore, multiple scales are utilized to capture the caregivers self-assessed burden. Day, Anderson, and Davis (2014) observed that the discussions of compassion fatigue and the caregiver have always been focused on the nurse, social worker, or psychologist who have since adopted this type of behavior into other caregiver type settings. Subsequent research utilizing this theory offers insight into the challenge of caregiver compassion fatigue. Sadak et al. (2017) agreed that the best way to reduce the burden for caregivers is to identify these subjective stressors. Sadak et

al. discussed the multiple avenues to measure and assess caregiver burden and compassion fatigue but noted that there is a lack of translation of these burdens into health care settings. The framework of this study consisted of validated surveys to assess the relationship between the caregiver's compassion fatigue and the quality of training the caregivers received from the CARE Act and if this additional education affected readmission rates.

Literature Review

While caregiving is becoming the norm in many families, current research has focused on burden and lacks a measure of the full caregiver experience (O'Malley & Qualls, 2017). Many validated tools have been created for caregivers, but none were designed for clinical experience (Sadak et al., 2017). O'Malley and Qualls (2017) created the Caregiver Reaction Scale (CRS) to include the entire caregiver experience; it includes family components and has been validated across a variety of illnesses and with diverse types of caregivers (e.g., spouse, child, or other relative). The CARE Act was created because of challenges caregivers and health care providers were facing (Coleman, 2016), therefore, I will use the CRS to measure the effectiveness of the CARE Act.

From a public health perspective, Alyahya et al. (2016) argued that, preventing and reducing avoidable readmission rates is a public health issue and needs to be further studied. Although evidence-based medicine has been the gold standard, it has been focused on clinical treatment. Alyahya et al. suggested combining evidence-based medicine with evidence-based public health as an innovative way to reduce readmission rates. Van Walraven et al. (2010) had similar intentions to quantify and reduce unplanned

readmissions after discharge from hospital to home and therefore created the LACE index, which has been validated to be accurate in predicting unplanned readmissions. Ritt and Taylor (2016) studied the readmission experience and found that the focus on the patient, caregiver, and health care team communication improved the entire discharge process and reduced readmission rates. Damery and Combes (2017) found the LACE index effective in predicting readmission rates, but they also found sociodemographic variables to be a factor in readmissions, and such variables are often left out of the research. To help fill this gap, demographic factors were included, such as age, gender, education level (less than high school, high school, some college, college degree), income level, marital status, occupation, and admission location, as well as a rating of the care recipient's health during the last 12 months (fair, poor, good, very good, excellent) as study variables.

Summary

Although current research has focused on caregiver support, the gap in research is the lack of assessment of current policies. Also lacking is an assessment of the CARE Act and whether the associated increase in education has a relationship to readmission and caregiver burden. This study analyzed the relationship between the education that caregivers received prior to discharge of the care recipient and whether the relationship with compassion fatigue or caregiver education at the time of discharge influenced readmission rates.

Chapter 3 includes the research design and methods for this study, exploring the relationship between caregiver education received, caregiver stress, and rates of

readmission. I also identify the research design and rationale, including the variables and how the design related to the research questions. Chapter 3 also provides the methodology, including the populations, sampling procedures, and data collection.

Chapter 3: Research Method

Introduction

The caregiver transition from hospital to home can be very complicated, leaving caregivers in stressful situations with potentially little knowledge. The research problem addressed in this study is that the bulk of research on caregiving focused on the negative aspects of caregiving, leaving out the entire experience, which often included positive elements as well. The purpose of this study was to analyze the relationship between the education that caregivers received prior to discharge of the care recipient, and to determine if compassion fatigue or caregiver education at the time of discharge influenced readmission rates. This problem is relevant and a significant public health concern reaching the highest levels of policy. For example, in January 2018, the U.S. president, Donald Trump, signed the RAISE Family Caregivers Act into law (AARP Foundation, 2018) requiring the Secretary of Health and Human Services to investigate a better method of support for the family caregivers.

The CTM-15, validated by Coleman, Mahoney and Parry (2005), was used to measure the patient's perspective of their transition of care from hospital to home to measure the education received by the CARE Act. The Caregiver Reaction Scale, validated by O'Malley and Qualls (2017), was used to assess the positive aspects of caregiving, but also highlighted the stress and burden the caregivers endured. The LACE index was used to quantify the risk of unplanned readmissions for the care recipients after their initial discharge from hospital to home.

This chapter details the research design and methods for this study which quantified the data from these three scales and explored the relationship between caregiver education received, caregiver stress and rates of readmission. In the first section, I identify the research design and rationale to include variables, design and how it related to the research questions. In the second section, I identify the methodology to include the populations, sampling procedures, and data collection.

Research Design and Rationale

The three variables in this study are (a) education that caregivers received prior to discharge of the care recipient (the independent variable), (b) compassion fatigue (dependent variable) and (c) readmission rates (the covariate). Additional covariate variables analyzed were demographic characteristics (caregiver's age, sex, education level, employment status and years as a caregiver) to look for further relationships or patterns. This prospective quantitative analysis identifies the relationship between caregiver compassion fatigue among family caregivers and training or education received per the CARE Act, and if education influenced readmission rates. The cross-sectional analysis will be conducted using Version 25 of SPSS software. The data analysis will allow me to identify factors associated with compassion fatigue. Principles of epidemiology in public health practice (2012) stated cross-sectional is a type of observational study where the study population can be exposed to certain variables and be simultaneously measured while also analyzing the health outcomes.

Methodology

Population

The target population was a group of caregivers provided through the nonprofit organization research registry at Family Caregiver Alliance-National Center on Caregiving. Purposive sampling was used as this is a specific population being studied. The target population is caregivers providing care to their family members. According to U.S. Population (2018) the current U.S. population is 327,923,308 as of December 29, 2018. An appropriate sample size with a 95% confidence level and a margin of error of 5%, a sample size of at least 385 people would be necessary. I compile 385 completed survey responses. This is an appropriate sample size in order to receive multiple responses throughout the United States where the Care Act has been implemented.

Procedures For Recruitment, Participation, and Data Collection

Recruiting procedures were conducted through a public accessible registry. The available research registry at Family Caregiver Alliance-National Center on Caregiving allows recruitment for graduate study research projects. This allowed family caregivers who may be seeking for support, to access the survey regarding their recent care and admission related to their role as a family caregiver. The Walden Participation Pool was also used to post the invitation and survey to reach Caregivers within the Walden community.

The first page of the survey contained the entire informed consent process to the participants with all required elements. Once the participant read and accepted the consent script to continue, this signified their willingness to participant. The scales were

distributed via SurveyMonkey where only deidentified results were collected for analysis. The participants were informed that they were able to exit the study at any time. Those participants that wished to complete the scales were thanked for their participation at the end of the survey. No results were shared with participants and no follow up procedures will be completed. Once participant completed the scales, results are obtained from Survey Monkey for analysis. Deidentified results were saved on my personal computer where they were analyzed and Version 25 of SPSS was used to complete logistic regression and linear regression for analysis with a statistical significance level $P < 0.05$. McFadden's R-squared was also used to examine the fit of the model, where values higher than .2 indicate great fit models (Louviere, Hensher, & Swait, 2000).

Ethical Procedures

Agreements to gain access to participants' data, institutional permissions, including Walden IRB approval number 04-19-19-0318920 was obtained prior to collecting any data. Data received was anonymous and no way to contact the participants. Deidentified data is currently stored on a password protected hard drive where only I have access. It will be destroyed six years after closure of the study.

To ensure ethical concerns related to data collection, participants were recruited from nonprofit organizations where caregivers chose to reach out for support and guidance. The participants had chosen to access the research registry where available graduate projects are posted and looking for participants. Participants were thoroughly informed of all potential risks, and how their data will be protected and remain

anonymous. Participants were also informed that they could exit the survey at any time to eliminate any type of coercion.

The IRB approved consent process fully informed the participants of the voluntary nature of the study, how the data was to be recorded, analyzed and IRB/HRPP contact information was provided. Confidentiality was maintained as the participants survey results were anonymous and waiver of documentation of consent was approved from the IRB to protect the link to the subjects.

Summary

The results of these surveys were quantitatively analyzed and identified any patterns or relationships between the education received from the CARE Act, compassion fatigue and readmission rates. The nature of the anonymized survey ensured less than minimal risk to study participants.

Chapter 4: Results

Introduction

The purpose of this study was to quantitatively analyze the relationship between the education that caregivers received prior to discharge of the care recipient and to determine if compassion fatigue or caregiver education at the time of discharge influenced readmission rates. The CTM-15, validated by Coleman, Mahoney and Parry (2005), was used to measure the patient's perspective of their transition of care from hospital to home. This represented the education received by the CARE Act. The Caregiver Reaction Scale, validated by O'Malley and Qualls (2017), was used to assess the positive aspects of caregiving, but also highlighted the stress and burden the caregivers endured. The LACE index was used to quantify the risk of unplanned readmissions for the care recipients after their initial discharge from hospital to home.

This chapter details the data collection and results for this study which quantified the data from these three scales and explored the relationship between caregiver education received, caregiver stress and rates of readmission. In the first section, I identify the data collection and the timeframe. In the second section, I identify the results and how it related to the research questions.

Data Collection

Data was collected from surveys that were completed between April 24, 2019 and June 23, 2019. Recruiting procedures were conducted via a Survey Monkey link that included the Caregiver Reaction Scale, CTM-15, LACE index and demographic characteristics (caregiver's age, sex, education level, employment status and years as a

caregiver). Caregivers were recruited from the Family Caregiver Alliance-National Center on Caregiving and the Walden Participation Pool.

Results

Table 1 displays the sample's descriptive and demographic baseline features. The sample is representative of the population in the United States and representative of a diverse range of caregivers. Frequencies and percentages for age of caregiver, education level, sex, employment status, caregiver status, and hours caregiving were calculated. The majority of the caregiver participants were males (n = 233, 61%) and between the age of 25 and 34 (n = 233, 61%). The most common education level of the caregivers was a graduate degree (n = 177, 46%). A majority of the caregivers worked outside the home (n = 354, 92%), and many were full time employees (n = 250, 65%). The most commonly observed category for hours of caregiving was 10 to -20 hours per week (n = 141, 37%).

Table 1

Baseline Descriptive and Demographic Characteristics

Variable	<i>n</i>	%
Age of Caregiver		
18-24	50	13.02
25-34	233	60.68
35-44	58	15.10
45-54	22	5.73
55-64	10	2.60
65 or older	8	2.08
Missing	3	0.78
Education Level		
Did not complete high school	1	0.26
High School	24	6.25
Some college	62	16.15
Undergraduate degree	119	30.99
Graduate degree	177	46.09
Missing	1	0.26
Sex		
Female	149	38.80
Male	233	60.68
Missing	2	0.52
Employment Status		
Retired	25	6.51
Works outside of home	354	92.19
Missing	5	1.30
Caregiver Status		
Full time	250	65.10
Part time	121	31.51
Long distance caregiver	9	2.34
Missing	4	1.04
Hours Caregiving		
10 or fewer hours per week	68	17.71
10-20 hours per week	141	36.72
20-40 hours per week	103	26.82
More than 40 hours per week	71	18.49
Missing	1	0.26

Note. Due to rounding errors, percentages may not equal 100%.

Descriptive Statistics

Role Captivity, Overload, Relational Deprivation, Caregiving Competence, Personal Gain, Family Beliefs, Family Actions, Employment, LACE Readmission, and Caregiver Education Received summary statistics were calculated. The CTM-15 (2005) was used in this study to measure the patient's perspective of their transition of care from hospital to home to measure the education received by the CARE Act. The CTM-15 Likert scale was Strongly Disagree =1; Disagree =2; Agree =3; Strongly Agree =4 with a higher score representing a better transition. The overall findings received for Caregiver Education based on the CTM-15 were 3.23 (SD = 0.44, Min = 1.00, Max = 4.00) on average.

The subscales of the CRS were used to measure the effectiveness of the CARE Act. The CRS subscale responses are measured using a Likert scale from 1 (not at all) to 4 (completely) indicating how much the caregiver felt it applied to their family. Relational Deprivation and Caregiving Competence subscales reflect positive reactions, so higher scores indicate self-reported benefit or resilience (O'Malley & Qualls, 2017). Higher marks on the Role Captivity, Overload, Personal Gain, Family Beliefs, and Employment subscales indicate more distress while Management of Meaning/ Distress and Expenses are to be reviewed for clinical purposes therefore were not included in the results.

The LACE index was used to quantify the risk of unplanned readmissions for the care recipients since their discharge from hospital to home with any score greater than or

equal to 10 indicating high risk of readmission (van Walraven, et al., 2010). The LACE Readmission results were 10.96 on average (SD = 4.32, Min = 1.00, Max = 28.00). The summary statistics are in Table 2.

Table 2

Summary Statistics Table for Interval and Ratio Variables

Variable	<i>M</i>	<i>SD</i>	<i>n</i>	Min	Max
Caregiver Education Received	3.23	0.44	251	1.00	4.00
Caregiving Competence	2.79	0.83	384	0.00	4.50
Employment	2.38	0.84	384	0.00	4.40
Family Actions	2.31	0.88	384	0.00	4.00
Family Beliefs	2.43	0.89	384	0.00	4.00
LACE Readmission	10.96	4.32	360	1.00	28.00
Overload	2.34	0.78	384	0.00	3.75
Personal Gain	2.77	0.85	384	0.00	5.25
Relational Deprivation	2.48	0.86	384	0.00	4.57
Role Captivity	2.45	0.91	384	0.00	4.25

Binary Logistic Regression

A binary logistic regression was performed to examine whether the amount of caregiver education received corresponded with the odds of participants being in the LACE Readmission score's high-risk category. The reference category for LACE Readmission was the low-risk category; this allows outcomes to all described in terms of the odds of being in the high-risk category as compared to (i.e., in reference to) the low-risk category. The regression coefficient was not significant based on an alpha of 0.05, $\chi^2(1) = 2.86, p = .091, OR = 1.68, 95\% CI = [-0.08, 1.12]$, suggesting that Caregiver Education Received did not have a significant impact on the odds of observing the high-

risk category of LACE Readmission. McFadden's R -squared has been calculated to examine the fit of the model, where values higher than .2 indicate great fit models (Louviere, Hensher, & Swait, 2000). The calculated McFadden R -squared value was 0.01 for this model, which corroborated the nonsignificant results. Since the overall model was not significant, there was no further examination of the individual predictors. The results of this regression show the caregiver education received or quality of the care transition measured by the CTM-15 was not significantly related to the risk of hospital readmission as measured by the LACE index. Table 3 summarizes the results of the regression model.

Table 3

Logistic Regression Results with Caregiver Education Received Predicting LACE Readmission Binned

Variable	B	SE	95.0% CI	χ^2	p	OR
(Intercept)	-0.94	0.99	[-2.88, 1.01]	0.89	.344	
Caregiver Education Received	0.52	0.31	[-0.08, 1.12]	2.86	.091	1.68

Note. $\chi^2(1) = 2.88, p = .089, \text{McFadden } R^2 = 0.01.$

Linear Regression Analysis

A linear regression analysis was performed to evaluate whether the continuous role captivity score was substantially predicted by the amount of education caregivers received. The findings of the linear regression were significant, $F(1,249) = 6.77, p = .010, R^2 = 0.03$, indicating that Caregiver Education Received explains roughly 3% of the variance in role captivity. In testing the model further through a t test, Caregiver Education Received was confirmed to significantly predict Role Captivity, $B = 0.29$,

$t(249) = 2.60, p = .010$. The beta value identified at this step showed that a one-unit rise in received Caregiver Education will boost the value of Role Captivity by 0.29 units on average. The results of this regression show the CRS subscale Role Capacity is significantly related to the education received as measured by the CTM-15. Table 4 summarizes the results of the regression model.

Table 4

Results for Linear Regression with Caregiver Education Received predicting Role Captivity

Variable	<i>B</i>	<i>SE</i>	CI	β	<i>t</i>	<i>p</i>
(Intercept)	1.66	0.37	[0.93, 2.39]	0.00	4.50	< .001
Caregiver Education Received	0.29	0.11	[0.07, 0.52]	0.16	2.60	.010

Note. CI is at the 95% confidence level. Results: $F(1,249) = 6.77, p = .010, R^2 = 0.03$
Unstandardized Regression Equation: Role Captivity = 1.66 + 0.29*Caregiver Education Received

A linear regression analysis was carried out to evaluate whether the continuous measure of overload was significantly predicted by the amount of education caregivers received. The findings of the linear regression model were not significant, $F(1,249) = 2.18, p = .141, R^2 = 0.01$, suggesting that a significant percentage of variation in overload was not explained by Caregiver Education Received. The results of this regression show the CRS subscale Overload is not significantly related to the education received as measured by the CTM-15. Since the overall model was not significant, the individual predictors were not examined further. Table 5 summarizes the results of the regression model.

Table 5

Results for Linear Regression with Caregiver Education Received predicting Overload

Variable	B	SE	CI	β	t	p
(Intercept)	2.06	0.30	[1.47, 2.65]	0.00	6.87	< .001
Caregiver Education Received	0.14	0.09	[-0.05, 0.32]	0.09	1.48	.141

Note. CI is at the 95% confidence level. Results: $F(1,249) = 2.18, p = .141, R^2 = 0.01$
 Unstandardized Regression Equation: Overload = $2.06 + 0.14 * \text{Caregiver Education Received}$

A linear regression analysis was carried out to evaluate whether Relational Deprivation was significantly predicted by the amount of education caregivers received. The linear regression model findings were significant, $F(1,249) = 4.23, p = .041, R^2 = 0.02$, indicating that the amount of education caregivers received explained roughly 2% of the variance in Relational Deprivation. Caregiver Education Relational deprivation was a significant predictor, as measured by *t* test, $B = 0.21, t(249) = 2.06, p = .041$. This suggests that, based on the sample, a one-unit rise in Caregiver Education Received corresponds with an average increase of 0.21 in Relational Deprivation scores. The results of this regression show the CRS subscale Relational Deprivation is significantly related to the education received as measured by the CTM-15. Table 6 summarizes the regression model's outcomes.

Table 6

Results for Linear Regression with Caregiver Education Received predicting Relational Deprivation

Variable	B	SE	CI	β	t	p
(Intercept)	2.00	0.33	[1.35, 2.65]	0.00	6.02	< .001
Caregiver Education Received	0.21	0.10	[0.01, 0.41]	0.13	2.06	.041

Note. CI is at the 95% confidence level. Results: $F(1,249) = 4.23, p = .041, R^2 = 0.02$
 Unstandardized Regression Equation: Relational Deprivation = $2.00 + 0.21 * \text{Caregiver Education Received}$

A linear regression analysis was conducted to assess whether Caregiver Education Received significantly predicted Caregiving Competence. The results of the linear regression model were significant, $F(1,249) = 80.61, p < .001, R^2 = 0.24$, indicating that approximately 24% of the variance in Caregiving Competence is explainable by Caregiver Education Received. Further testing confirmed that Caregiver Education Received significantly predicted Caregiving Competence with a beta of .68, $t(249) = 8.98, p < .001$. This indicates that on average, a one-unit increase of Caregiver Education Received will increase the value of Caregiving Competence by 0.68 units. The results of this regression show the CRS subscale Caregiving Competence is significantly related to the education received as measured by the CTM-15. Table 7 summarizes the results of the regression model.

Table 7

Results for Linear Regression with Caregiver Education Received predicting Caregiving Competence

Variable	<i>B</i>	<i>SE</i>	CI	β	<i>t</i>	<i>p</i>
(Intercept)	0.77	0.25	[0.28, 1.26]	0.00	3.12	.002
Caregiver Education Received	0.68	0.08	[0.53, 0.83]	0.49	8.98	< .001

Note. CI is at the 95% confidence level. Results: $F(1,249) = 80.61, p < .001, R^2 = 0.24$
Unstandardized Regression Equation: Caregiving Competence = 0.77 + 0.68*Caregiver Education Received

A linear regression analysis was conducted to assess whether the amount of education caregivers received significantly predicted Personal Gain. The results of the linear regression model were significant, $F(1,249) = 63.09, p < .001, R^2 = 0.20$, indicating that approximately 20% of the variance in Personal Gain is explainable by Caregiver Education Received. Based on further testing within the model, Caregiver Education

Received was confirmed to significantly predict Personal Gain, $B = 0.62$, $t(249) = 7.94$, $p < .001$. The beta value from this stage of testing indicates that on average, a one-unit increase of Caregiver Education Received will increase the value of Personal Gain by 0.62 units. The results of this regression show the CRS subscale Personal Gain is significantly related to the education received as measured by the CTM-15. Table 8 summarizes the results of the regression model.

Table 8

Results for Linear Regression with Caregiver Education Received predicting Personal Gain

Variable	<i>B</i>	<i>SE</i>	CI	β	<i>t</i>	<i>p</i>
(Intercept)	0.97	0.25	[0.47, 1.47]	0.00	3.82	< .001
Caregiver Education Received	0.62	0.08	[0.47, 0.77]	0.45	7.94	< .001

Note. CI is at the 95% confidence level. Results: $F(1,249) = 63.09$, $p < .001$, $R^2 = 0.20$
Unstandardized Regression Equation: Personal Gain = $0.97 + 0.62 * \text{Caregiver Education Received}$

A linear regression analysis was conducted to assess whether the amount of education caregivers received significantly predicted Family Beliefs. The results of the linear regression model were significant, $F(1,249) = 13.05$, $p < .001$, $R^2 = 0.05$, indicating that approximately 5% of the variance in Family Beliefs is explainable by Caregiver Education Received. Further testing confirmed that Caregiver Education Received significantly predicted Family Beliefs, $B = 0.37$, $t(249) = 3.61$, $p < .001$. This indicates that on average, a one-unit increase of Caregiver Education Received will increase the value of Family Beliefs by 0.37 units. The results of this regression show the CRS subscale Family Beliefs is significantly related to the education received as measured by the CTM-15. Table 9 summarizes the results of the regression model.

Table 9

Results for Linear Regression with Caregiver Education Received predicting Family Beliefs

Variable	<i>B</i>	<i>SE</i>	CI	β	<i>t</i>	<i>p</i>
(Intercept)	1.46	0.33	[0.81, 2.11]	0.00	4.42	< .001
Caregiver Education Received	0.37	0.10	[0.17, 0.56]	0.22	3.61	< .001

Note. CI is at the 95% confidence level. Results: $F(1,249) = 13.05, p < .001, R^2 = 0.05$
 Unstandardized Regression Equation: Family Beliefs = 1.46 + 0.37*Caregiver Education Received

A linear regression analysis was conducted to assess whether the amount of education caregivers received significantly predicted Family Actions. The results of the linear regression model were not significant, $F(1,249) = 1.92, p = .168, R^2 = 0.01$, indicating Caregiver Education Received did not explain a significant proportion of variation in Family Actions. The results of this regression show the CRS subscale Family Actions is not significantly related to the education received as measured by the CTM-15. Since the overall model was not significant, the individual predictors were not examined further. Table 10 summarizes the results of the regression model.

Table 10

Results for Linear Regression with Caregiver Education Received predicting Family Actions

Variable	<i>B</i>	<i>SE</i>	CI	β	<i>t</i>	<i>p</i>
(Intercept)	1.99	0.36	[1.28, 2.70]	0.00	5.54	< .001
Caregiver Education Received	0.15	0.11	[-0.06, 0.37]	0.09	1.38	.168

Note. CI is at the 95% confidence level. Results: $F(1,249) = 1.92, p = .168, R^2 = 0.01$
 Unstandardized Regression Equation: Family Actions = 1.99 + 0.15*Caregiver Education Received

A linear regression analysis was conducted to assess whether the amount of education caregivers received significantly predicted Employment. The results of the

linear regression model were not significant, $F(1,249) = 2.16, p = .143, R^2 = 0.01$, indicating Caregiver Education Received did not explain a significant proportion of variation in Employment. The results of this regression show the CRS subscale Employment is not significantly related to the education received as measured by the CTM-15. Since the overall model was not significant, the individual predictors were not examined further. Table 11 summarizes the results of the regression model.

Table 11

Results for Linear Regression with Caregiver Education Received predicting Employment

Variable	<i>B</i>	<i>SE</i>	CI	β	<i>t</i>	<i>p</i>
(Intercept)	2.04	0.34	[1.37, 2.70]	0.00	6.04	< .001
Caregiver Education Received	0.15	0.10	[-0.05, 0.36]	0.09	1.47	.143

Note. CI is at the 95% confidence level. Results: $F(1,249) = 2.16, p = .143, R^2 = 0.01$
 Unstandardized Regression Equation: $\text{Employment} = 2.04 + 0.15 * \text{Caregiver Education Received}$

Summary

Chapter 4 displayed the results of data analysis and verified there is a not a significant relationship between the education that caregivers received according to the CARE Act and readmission rates of the care receiver. However, the data did verify a relationship between several subscales of the caregiver's compassion fatigue and the amount of education the caregivers receive from the CARE Act. The CRS subscales that showed a significant relationship were the Family Beliefs, Personal Gain, Caregiver Compassion, Rational Deprivation and Role Capacity. This shows that the CARE Act has provided education to prepare caregivers for the transition home with possible reduced compassion fatigue in terms of these five subscales. Chapter 5 will include the

discussion, conclusion and recommendations for this study which will discuss the results of the relationship between caregiver education received, compassion fatigue and rates of readmission.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to quantitatively analyze the relationship between the education that caregivers received prior to discharge of the care recipient and to determine if compassion fatigue or caregiver education at the time of discharge influenced readmission rates. This chapter discussion, conclusion and recommendations for this study which will discuss the relationship between caregiver education received, caregiver stress and rates of readmission. In the first section, I will identify the interpretation of the findings. In the second section, I will identify the recommendations in relation to the research questions.

Interpretation of the Findings

Sadak et al. (2017) agreed that the best way to reduce the burden for caregivers is to identify their stressors in order to translate these into the multiple avenues to measure and assess caregiver burden and compassion. The hypothesis was that the caregiver population is not prepared or educated enough prior to the transition from hospital to home potentially leading to an increase in stress and burden. The alternative hypothesis was that the CARE Act had provided enough education to prepare caregivers for the transition home with little or no stress and burden.

Question number 1 asked if a relationship existed between the education that caregivers receive according to the CARE Act and readmission rates of the care receiver. The Care Transitions Measure (CTM-15) was used to measure the patient's perspective of their transition of care from hospital to home in order to assess the education received

under the CARE Act. The LACE index was used to quantify the risk of unplanned readmissions for the care recipients since their discharge from hospital to home. Damery and Combes (2017) may have found the LACE index effective in predicting readmission rates but the results of this study did not find a relationship between the education that caregivers receive according to the CARE Act and readmission rates of the care receiver.

Question 2 asked if there was a relationship between the caregiver's compassion fatigue and the amount of training the caregivers receive from the CARE Act. The CRS was used to assess the positive aspects of caregiving but also highlight the stress and burden the caregivers endured. The CTM-15 was used to measure the patient's perspective of their transition of care from hospital to home in order to assess the education received under the CARE Act. The CRS and CTM-15 showed a significant relationship between caregiver's compassion fatigue and the amount of education the caregivers receive from the CARE Act. The CRS subscales that showed a significant relationship were the Family Beliefs, Personal Gain, Caregiving Competence, Rational Deprivation and Role Capacity.

Limitations of the Study

The CRS sections F, Management of Meaning/Distress, and J, Expenses, were not included in this analysis since they are to be reviewed for clinical purposes as they apply to an individual's coping mechanism (O'Malley & Qualls, 2017). This could be a limiting factor and important details not included in the analysis.

The demographics of the family member and their daily routine was included to identify possible limitations. The age group completing over 60% of the surveys was 25

to 34. This could be considered a limitation if the older population of caregivers was not properly represented in the results. The survey was only solicited online and may have not been accessible to some populations with little or no access to computers. Another possible limitation is the state participants lived was not included in the survey, without having location of respondents it may be difficult to predict if the results reflected the United States all over and not consolidated to a few states.

Threats to Validity

The population of this study was recruited from organizations where caregivers are reaching out for help or guidance. This represents a potential bias to validity, as this population may already be educated on caregiver burden which in turn could impact the results. I mitigated this potential bias to validity by quantifying the relationships between caregiver burden, potential readmission rates and the relationship to the education received during the discharge process to increase the internal validity. Comparing populations that were in the states where the CARE Act has been implemented and some that have not will additionally address the internal validity.

Implications and Social Impact

The results of this study suggest the CARE Act has potential impact of positive social change. Specifically, the implications for social change relates to the significant relationship between caregiver's compassion fatigue and the amount of education the caregivers receive from the CARE Act that was part of the study results. The results of this study also show a positive change for the caregiving community as caregivers who are better prepared through access to education about the care for their family members

potentially experiencing less stress. An additional potential impact of positive social change can be experienced by professionals focusing resources on supporting caregivers via education providing a benefit for the health and well-being of caregivers.

Additionally, recruiting the study population from the Family Caregiver Alliance-National Center on Caregiving show the implications for positive social change while providing education programs and resources to caregivers.

Recommendations for Future Research

Future research should be done to further analyze each section of the CRS that was significantly related to education received to look for other commonalities and those that were not related. Additional research should also look for common demographic variables in areas where education is lacking, compassion fatigue is increased, or focusing on the older population of caregivers since the group that completed over 60% of the surveys was 25 to 34. Another recommendation for future research would be not recruiting participants through an organization like the Family Caregiver Alliance-National Center on Caregiving, which is a digital platform of education and services for caregivers. The data from these different groups may be drastically different.

The results of the relationship between caregiver stress and education received under the CARE Act should be provided to hospital staff to display the positive results of the caregiver education they provide. This could be a positive social change for health care workers to see their efforts may have a relationship in reducing caregiver stress.

Conclusion

In conclusion the relationship between the education that caregivers receive according to the CARE Act and readmission rates of the care receiver was not significant when utilizing the CTM-15 and the LACE index. The relationship between the caregiver's compassion fatigue and the amount of training the caregivers receive from the CARE Act was significant in some areas of the CRS. While research continues to identify flaws in the caregiver transition, the CRS and CTM-15 show a significant relationship identifying some caregivers are better educated prior to leaving the hospital and with a potential reduction in compassion fatigue. If a few minutes of dedicated Caregiver education from the CARE Act can provide such a positive impact with caregivers, imagine what a little more time and focus could do for the caregiver community.

References

- AARP Foundation. (2017). Long-Term Services and Supports State Scorecard. Retrieved December 12, 2017 from <http://www.longtermscorecard.org/about-us/about-the-scorecard>
- AARP Foundation. (2018). RAISE Family Caregivers Act Now Law. Retrieved from <https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2015/raise-family-caregivers-act.html>
- AARP Foundation. (n.d.). New State Law to Help Family Caregivers – AARP. Retrieved from https://www.google.com/search?source=hp&ei=mBzzWrWDOKnH_QbsiliYCA&q=caregiver+advise+record+and+enable+act&oq=he+caregiver+advise+record+and+en&gs_l=psy-ab.3.0.0i22i30k113.22320.27766.0.28820.34.16.0.0.0.0.407.2240.2-3j2j2.7.0....0...1.1.64.psy-ab..27.6.2005...0i13k1j0i13i30k1.0.AUKB-Eb8NNI
- Al-Rawashdeh, S., Lennie, T. A., & Chung, M. L. (2016). Psychometrics of the zarit burden interview in caregivers of patients with heart failure. *Journal of Cardiovascular Nursing, 31*(6), E21-E28.
- Alyahya, M. S., Hijazi, H. H., Alshraideh, H., A., Alsharman, M., A., Abdi, R., A., Harvey, H. L. (2016). Integrating the principles of evidence based medicine and evidence based public health: Impact on the quality of patient care and hospital readmission rates in Jordan. *International Journal of Integrated Care, 16*(3), 12. <http://doi.org/10.5334/ijic.2436>

- Centers for Medicare and Medicaid Services. (2017a). Partnership for Patients.
<https://innovation.cms.gov/initiatives/Partnership-for-Patients/>
- Centers for Medicare and Medicaid Services. (2017b). Standard Analytical Files (Medicare Claims) – LDS. <https://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/LimitedDataSets/StandardAnalyticalFiles.html>
- Coleman, E. A. (2016). Family caregivers as partners in care transitions: The caregiver advise record and enable act. *Journal of Hospital Medicine, 11*(12), 883-885.
doi:10.1002/jhm.2637
- Coleman, E. A., Mahoney, E., & Parry, C. (2005). Assessing the Quality of Preparation for Posthospital Care from the Patient's Perspective: The Care Transitions Measure. *Med Care. 2005;43*(3):246–255.
- Coleman, E. A., Rosenbek, S. A., & Roman, S. P. (2013). Disseminating Evidence-Based Care into Practice. *Population Health Management, 16*(4), 227-234.
doi:10.1089/pop.2012.0069
- Coleman, E. A., Roman, S. P., Hall, K. A., & Min, S. (2015). Enhancing the Care Transitions Intervention Protocol to Better Address the Needs of Family Caregivers. *Journal for Healthcare Quality, 37*(1), 2-11.
doi:10.1097/01.jhq.0000460118.60567.fe
- Damery S, & Combes G. (2017). Evaluating the predictive strength of the LACE index in identifying patients at high risk of hospital readmission following an inpatient episode: a retrospective cohort study. *BMJ Open 2017;7*:e016921. doi: 10.1136/bmjopen-2017-016921

- Day, J. R., Anderson, R. A., & Davis, L. L. (2014). Compassion Fatigue in Adult Daughter Caregivers of a Parent with Dementia. *Issues In Mental Health Nursing*, 35(10), 796-804 9p. doi:10.3109/01612840.2014.917133
- El Morr, C., Ginsburg, L., Nam, S., & Woollard, S. (2017). Assessing the Performance of a Modified LACE Index (LACE-rt) to Predict Unplanned Readmission After Discharge in a Community Teaching Hospital. *Interactive Journal of Medical Research*, 6(1), e2. <http://doi.org/10.2196/ijmr.7183>
- Evidence-Based Medicine Working Group. (1992). A new approach to teaching the practice of medicine. *Journal of the American Medical Association*, 268(17), 2420–2425.
- Fallah A. (2015). Moving beyond evidence-based medicine: incorporating patient values and preferences. *Epilepsy & Behavior*. 2015;53:209–210. doi: 10.1016/j.yebeh.2015.10.006.
- Family Caregiver Alliance-National Center on Caregiving. (2017). Research Registry. Retrieved from <https://www.caregiver.org/research-registry>
- Forster, A. J., Murff, H. J., Peterson, J. F., Gandhi, T. K., & Bates, D. W. (2003). The Incidence and Severity of Adverse Events Affecting Patients after Discharge from the Hospital. *Annals of Internal Medicine*, 138(3), 161-174. doi:10.7326/0003-4819-138-3-200302040-00007
- Giosa, J. L., Stolee, P., Dupuis, S. L., Mock, S. E., & Santi, S. M. (2014). An Examination of Family Caregiver Experiences during Care Transitions of Older Adults. *Canadian Journal on Aging / La Revue canadienne du vieillissement*,

33(02), 137-153. doi:10.1017/s0714980814000026

- Glenny, C., Stolee, P., Sheiban, L., & Jaglal, S. (2013). Communicating during care transitions for older hip fracture patients: family caregiver and health care providers perspectives. *International Journal of Integrated Care*, 13(4), 1-13. doi:10.5334/ijic.1076
- Graessel, E., Berth, H., Lichte, T., & Grau, H. (2014). Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatrics*, 14, 23. <http://doi.org/10.1186/1471-2318-14-23>
- Greysen, S. R., Schiliro, D., Horwitz, L. I., Curry, L., & Bradley, E. H. (2012). "Out of sight, out of mind": Housestaff perceptions of quality-limiting factors in discharge care at teaching hospitals. *Journal of Hospital Medicine*, 7(5), 376-381. doi:10.1002/jhm.1928
- Hubbard, T. & McNeil, N. (2012). Thinking outside the pillbox: Improving medication adherence and reducing readmissions. *Nehi*, (October), 1-12.
- Jacobs, J. A., Jones, E., Gabella, B. A., Spring, B. & Brownson, R. C. (2012). Tools for Implementing an Evidence-Based Approach in Public Health Practice. *Prev Chronic Dis* 2012;9:110324. DOI: <http://dx.doi.org/10.5888/pcd9.110324>
- Jencks, S. F., Williams, M. V., & Coleman, E. A. (2009). Rehospitalizations among patients in the medicare fee-for-service program. *N Engl J Med*, 360(14), 1418-1428. doi:10.1056/NEJMsa0803563 References
- Kuller, L. (2007). Is phenomenology the best approach to health research? *American Journal of Epidemiology*, 166(10), 1109-1115.

doi:<http://dx.doi.org/10.1093/aje/kwm258>

Lin, C., Wang, J., Pai, M., & Ku, L. E. (2017). Measuring burden in dementia caregivers: Confirmatory factor analysis for short forms of the zarit burden interview. *Archives of Gerontology and Geriatrics*, 68, 8-13.

doi:10.1016/j.archger.2016.08.005

Louviere, J. J., Hensher, D. A., & Swait, J. D. (2000). *Stated choice methods: Analysis and Applications*. Cambridge, UK: Cambridge University Press.

MedPac. (2007). *Payment Policy for Inpatient Readmissions. Promoting Greater Efficiency in Medicare*. Washington, DC, 2007. Available at http://67.59.137.244/chapters/Jun07_Ch05.pdf Accessed March 7, 2017.

El Morr, C., Ginsburg, L., Nam, S., & Woollard, S. (2017). Assessing the Performance of a Modified LACE Index (LACE-rt) to Predict Unplanned Readmission After Discharge in a Community Teaching Hospital. *Interactive Journal of Medical Research*, 6(1), e2. <http://doi.org/10.2196/ijmr.7183>

National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. Washington, DC: The National Academies Press.

O'Malley, K. & Qualls, S. (2017). Preliminary Evidence for the Validity and Reliability of the Caregiver Reaction Scale, *Clinical Gerontologist*, 40:4, 281-294, DOI: 10.1080/07313115.2016.1198858

Parry C, Mahoney E, Chalmers SA, et al. Assessing the quality of transitional care: further applications of the care transitions measure. *Med Care* 2008;46:317-22

Pitsikali, A., Galanakis, M., Varvogli, L., & Darviri, C. (2015). Kingston Caregiver

Stress Scale (KCSS). Greek Validation on Dementia Caregiver Sample.

Psychology, 6, 1180-1186. <http://dx.doi.org/10.4236/psych.2015.69116>

Principles of epidemiology in public health practice: An introduction to applied epidemiology and biostatistics. (2012). Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), Office of Workforce and Career Development.

Reinhard, S. C., Capezuti, E., Bricoli, B., & Choula, R. B. (2017). Feasibility of a family-centered hospital intervention. *Journal of Gerontological Nursing*, 43(6), 9-16.

<http://dx.doi.org.contentproxy.phoenix.edu/10.3928/00989134-20160516-01>

Reinhard, S. C., Given B., Petlick N. H., & Bemis, A. (2008). Supporting Family Caregivers in Providing Care. In: Hughes RG, editor. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr. Chapter 14. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK2665/>

Reinhard, S., & Ryan, E. (2016). Stepping Up to Support Family Caregivers. Retrieved from <https://blog.aarp.org/2016/06/07/stepping-up-to-support-family-caregivers/>

Ritt, E., and Taylor, N. P. 2016. "The identification of post-acute patients at risk for hospital readmission: Clinical implications of the LACE index," *Clinical Nursing Studies* (4:3).

Robinson, R., & Hudali, T. (2017). The HOSPITAL score and LACE index as predictors of 30 day readmission in a retrospective study at a university-affiliated community hospital. *PeerJ*, 5, e3137. <http://doi.org/10.7717/peerj.3137>

- Rodakowski, J., Rocco, P. B., Ortiz, M., Folb, B., Schulz, R., Morton, S. C., Leathers, S. C., Hu, L. and James, A. E. (2017), Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis. *Journal of the American Geriatrics Society*, 65: 1748–1755. doi: 10.1111/jgs.14873
- Sadak, T., Korpak, A., Wright, J. D., Lee, M. K., Noel, M., Buckwalter, K., & Borson, S. (2017). Psychometric Evaluation of Kingston Caregiver Stress Scale. *Clinical Gerontologist*, 40(4), 268-280. doi:10.1080/07317115.2017.1313349
- Salehi-Tali, S., Ahmadi, F., Zarea, K., & Fereidooni-Moghadam, M. (2017). Commitment to care: The most important coping strategies among family caregivers of patients undergoing haemodialysis. *Scandinavian Journal of Caring Sciences*, doi:10.1111/scs.12432
- Schnipper, J. L., Kirwin, J. L., Cotugno, M. C., Wahlstrom, S. A., Brown, B. A., Tarvin, E., . . . Bates, D. W. (2006). Role of Pharmacist Counseling in Preventing Adverse Drug Events After Hospitalization. *Archives of Internal Medicine*, 166(5), 565-571. doi:10.1001/archinte.166.5.565
- Seng, B. K., Luo, N., Ng, W. Y., Lim, J., Chionh, H. L., Goh, J., & Yap, P. (Oct 2010). Validity and reliability of the zarit burden interview in assessing caregiving burden. *Ann Acad Med Singapore.*, 39(10), 758-763.
- Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *Am J Public Health*, 97(2), 224-228. doi:10.2105/AJPH.2004.059337
- Tan, S et al (2017). Understanding the psychosocial, behavioral and environmental factors behind frequent hospital admissions. *International Journal of Integrated*

Care, 17(5): A194, pp. 1-8, DOI: [dx.doi.org/10.5334/ijic.3502](https://doi.org/10.5334/ijic.3502)

Tay, K. C. P., Seow, C. C. D., Xiao, C., Lee, H. M. J., Chiu, H. F. K., & Chan, S. W. (2016). Structured interviews examining the burden, coping, self-efficacy, and quality of life among family caregivers of persons with dementia in singapore. *Dementia*, 15(2), 204-220. doi:10.1177/1471301214522047

U.S. Population. (2018). Retrieved December 29, 2018, from <http://www.worldometers.info/world-population/us-population/>

van Walraven, C., Dhalla, I.R., Bell, C., et al. (2010). Derivation and validation of an index to predict early death or unplanned readmission after discharge from hospital to the community. *Canadian Medical Association Journal*. 2010; 182(6): 551-557. <http://dx.doi.org/10.1503/cmaj.091117>

Research Resources: Walden University Participant Pool. (2018). Retrieved February 21, 2019, from

<https://academicguides.waldenu.edu/researchcenter/resources/participantpool> Yu,

H., Wang, X., He, R., Liang, R., & Zhou, L. (2015). Measuring the caregiver burden of caring for community-residing people with alzheimer's disease. *Plos One*, 10(7), e0132168-e0132168. doi:10.1371/journal.pone.0132168