

THE USABILITY OF THE ABBEY SCALE IN CAREGIVERS' PAIN ASSESSMENT
OF HOSPICE PATIENTS WITHOUT ABILITY TO SELF- REPORT

by

Camelia Martin

Copyright © Camelia Martin 2019

A DNP Project Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF NURSING PRACTICE

In the Graduate College

THE UNIVERSITY OF ARIZONA

2019

THE UNIVERSITY OF ARIZONA
GRADUATE COLLEGE

As members of the DNP Project Committee, we certify that we have read the DNP project prepared by Camelia Martin, titled The Usability of the Abbey Scale in Caregivers' Pain Assessment of Hospice Patients without Ability to Self-Report and recommend that it be accepted as fulfilling the DNP project requirement for the Degree of Doctor of Nursing Practice.

Allen Prettyman Date: Nov 20, 2019
Allen Prettyman, PhD, FNP-BC, FAANP

Heather L. Carlisle Date: Nov 21, 2019
Heather L. Carlisle, PhD, DNP, RN, FNP, AGACNP, CHNP

Jennifer Ruel DNP, FNP-BC, ENP-BC Date: Nov 21, 2019
Jennifer Ruel, DNP, RN, FNP-BC, ENP-BC

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

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

Allen Prettyman Date: Nov 20, 2019
Allen Prettyman, PhD, FNP-BC, FAANP
DNP Project Committee Chair
College of Nursing

ARIZONA

ACKNOWLEDGMENTS

I would like to first of all thank Dr. Allen Prettyman, who has served as Committee Chair for this project and who has patiently guided and encouraged me throughout the journey this project has been. I am grateful for his availability to discuss my many questions and concerns and for the invaluable advice. I am quite sure he has answered some of my emails in his time off and I am profoundly thankful for all the help he has offered. I am also grateful for the support of the Committee members, Dr. Heather Carlisle and Dr. Jennifer Ruel. Both of them have seen this project develop from its infancy and they have provided priceless advice and recommendations. I am thankful for their amazing support and their encouragement along the way.

Secondly, I would like to thank the Aviant Hospice team for their partnership and support, and, in particular, Executive Director, Leslie Cooper, and Director of Clinical Services, LaDawn Griffith, who have been so helpful and supportive of this project. Their amazing nurses, Raina, Heidi, Karen, and Deb, are absolute angels and they have been very kind to allow me to join them in home visit during the implementation of this project. Thank you for all you do!

DEDICATION

This project is dedicated first and foremost to my husband, Andrei and my son, Andrei Jr. Honey, you are my rock, my biggest form of support. Thank you for taking over just about each one of my tasks so I can focus on this study and the entire program. Throughout this program, you have cleaned, cooked, fixed my car, made me coffee for the day, stayed by me in the hospital when I was sick, talked me off virtual ledges, and took over much of the parenting role for our son. I will never forget your arms around me when times were tough and your whispers telling me it will all be okay. Thank you for sacrificing your dreams and supporting me as I followed mine. I only hope I can one day return the support you have given me.

My son, for as long as you can remember me, I have dedicated much of my time to furthering my studies. I hope you see in me an example of never giving up, of working hard and dedicating time and effort for whatever it is you believe in. I hope you see that juggling the time with you and your dad and the endless nights and days studying and writing was worthwhile. And I hope you follow your dreams as I have, whatever they may be.

To my parents, thank you for your support in prayer and for your encouragements. I know you have been many miles away from me as I went through this journey, but you have always been close to my heart in your spirit. To the rest of my family and friends, thank you for pitching in where needed and for your patience with my status of “missing in action.” I promise we will catch up.

More importantly, I am grateful for God’s grace and for His love for me despite me failing Him daily. I do not always understand how He works, but I have seen what He has done in my life.

TABLE OF CONTENTS

ABSTRACT.....	7
INTRODUCTION.....	9
Background Knowledge	9
Local Problem	12
Purpose	13
Rationale	13
Stakeholders	14
Significance to Practice	14
Study Question	15
Theoretical Framework	15
Other Key Concepts	17
Holism	17
Family as a Unit of Care	17
Synthesis of Evidence	18
Pain Assessment Concerns in Family Caregivers	18
Strategies to Alleviate Concerns	19
Pain Assessment in Patients with Communication Limitations	20
Strengths and Weaknesses of the Evidence	20
Summary and Gaps in Literature	21
METHODS	22
Study Design	22
Setting	23
Participants	23
Intervention	24
Data Collection	24
Survey Design	25
Content Delivery	25
Data Analysis	26

TABLE OF CONTENTS – *Continued*

Ethical Considerations	27
Respect for Persons	27
Beneficence	28
Justice	28
RESULTS	29
Findings	29
DISCUSSION	31
Interpretation	31
Limitations	34
Doctor of Nursing Practice Essentials	35
Dissemination	36
Conclusion	36
APPENDIX A: SITE AUTHORIZATION LETTER	37
APPENDIX B: STUDY INFORMATION LETTER	39
APPENDIX C: ABBEY PAIN ASSESSMENT TOOL USE QUESTIONNAIRE.....	41
APPENDIX D: ABBEY PAIN SCORE AND INTERVENTION RECORD	45
APPENDIX E: HOW TO USE THE ABBEY PAIN SCALE.....	47
APPENDIX F: THE ABBEY PAIN SCALE	49
APPENDIX G: TABLE OF APPRAISED ARTICLES.....	51
APPENDIX H: THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD DETERMINATION LETTER.....	58
APPENDIX I: GRAPH REPRESENTATION OF DEMOGRAPHICS	60
APPENDIX J: GRAPH REPRESENTATION OF ABBEY SCALE USE	62
APPENDIX K: GRAPH REPRESENTATION OF ANSWERS TO LIKERT-STYLE QUESTIONS	64
REFERENCES	66

ABSTRACT

Background: Evidence has shown that one of the main concerns of family caregivers of hospice patients with limitations in verbalization was with their own ability to recognize whether their loved one was in pain and how severe was their pain.

Purpose: The purpose of the project was to evaluate the usefulness of the Abbey pain scale in the assessment of pain in adult patients who cannot express or describe pain by family caregivers.

Methods: This project followed a descriptive study design. The participants were family caregivers of patients who received services from a hospice agency in Phoenix, Arizona, and who had limitations in verbalization. The intervention was delivered in the family home. After the participants who agreed to be trained in the use of the Abbey scale had the opportunity to be familiarized with the scale for two weeks they were asked to complete a paper-format 16-item survey composed of demographic, Likert-style, and open-ended questions regarding their experience with the scale. They were also asked to turn in the record sheets they had used to enter the pain assessment scores obtained and the interventions provided to patients as a result. Due to the small number of participants, data analysis focused on describing and comparing answers between the completed surveys. The answers to the open-ended question were subjected to theme extraction. The score and intervention records were analyzed for trends in Abbey scale use.

Results: Out of the three participants who agreed to be trained in the use of the Abbey scale, only two (67%) returned the completed questionnaires and score and intervention records. One of the participants agreed that the Abbey scale was useful in helping recognize pain in their loved

one, while the other disagreed. However, both participants agreed that the scale helped them determine the severity of the pain. Trends in the use of the scale revealed that participants provided interventions for every score higher than '0' on the Abbey scale. Analysis of short answers showed that personal health factors may play a role in caregivers' interactions with the Abbey scale.

Implications: Although the results showed promising value of the Abbey scale in helping family caregivers determine the severity of pain in their loved ones, limitations in number of participants in this study invite further investigation into this issue on a larger scale. Further study of ways to counteract personal health challenges in caregivers related to pain assessment may also be beneficial.

INTRODUCTION

“Of pain you could wish only one thing: that it should stop. Nothing in the world was so bad as physical pain. In the face of pain there are no heroes” (George Orwell, 1949/2003). These words have a very real meaning for many people confronted with terminal illness and approaching the end of their lives. An approximate 90 % of dying cancer patients are estimated to experience pain and many other terminal illnesses have an associated component of pain (Whitecar, Jonas, & Clasen, 2000). For patients who also do not have the ability to express their needs, pain is silent and can go unrecognized and, subsequently, inadequately treated. This thus becomes a valid concern for families involved in the care of their dying loved ones at home and is a source of caregiver distress and discomfort. Hospice services are aimed at supporting terminally ill patients in their journey towards a comfortable and peaceful death and providing their families with resources, reassurance, emotional support, and education (National Hospice and Palliative Care Organization, 2018). Advanced practice nurses have an important role in coordinating the efforts of the hospice interdisciplinary teams to help support the family as a unit. Despite the hospice teams’ efforts, many families remain concerned with their own ability to recognize the presence and severity of pain in order to report it to clinicians or administer readily available medication.

Background Knowledge

The large majority of hospice patients are cared for in the place they call home, often by caregivers who do not have formal training (NHPCO, 2018; NHHCS, 2004). According to the National Home and Hospice Care Survey (2004), hospice patients’ caregivers are more likely to be spouses and/or adult children, but assisted living facility-employed caregivers rank high on

the list as well. Family caregivers are not likely to have any formal healthcare training. They are not likely to have been instructed in assessment and other aspects of end-of-life care and, furthermore, their requests for more information regarding pain management are often sub-optimally addressed (Han et al., 2018).

Lack of familiarity with aspects of end-of-life care is a contributing factor to caregiver anxiety and concerns, particularly when it comes to the pain management of patients without the ability to self-report (Chi, Demiris, Pike, Washington, & Oliver, 2018; Oliver et al., 2013). Although extensive research has not been done on this particular topic, limited qualitative data shows that family caregivers are not comfortable with their ability to recognize and assess pain in their loved ones who are terminally-ill (Oliver et al., 2013). This is important because pain is one of the common experiences to many terminal illnesses, and it is believed that more than half of the terminally-ill experiencing pain as they approach the end of life (Weiss, Emanuel, Fairclough, & Emanuel, 2001). A Centers for Medicare and Medicaid Services hospice quality of care study looking at data reported on seven quality measures recently found that the only exception in the list of highly-scored quality measures was pain assessment, with a less-than-stellar average national score of 78.2% (Zheng et al., 2018). In other words, too many patients have the potential of being left with untreated or inadequately treated pain and, subsequently with a poor quality of life.

Pain at the end of life takes different forms: somatic, visceral, and neuropathic. These types of pain manifest themselves in different ways and they may coexist. Pain in the dying adult is often exacerbated by social isolation or tension, stress, and spiritual distress (Whitecar, Jonas, & Clasen). When patients are able to express their pain and its severity—as well as any other

needs that may complicate it—clinicians and families may find it easier to address it. When this ability is lost, families can struggle with uncertainty in the absence of hospice clinicians (Oliver et al., 2013). This will, over time, create a state of social tension and stress in the family, perpetuating a vicious cycle of discomfort.

Additionally, caregivers' own perceptions of insufficient knowledge regarding care and inadequate support and resources were some of the highest predictors of burnout among caregivers of hospice patients in a study by Townsend et al. (2010). Caregiver burnout may result in strained relationships between caregiver and care receiver, as well as inadequate response to the needs of the patient, impacting the quality of life of both sides (Litzelman et al., 2015; Cheung & Chow, 2011). Providing a tool with potential to support caregivers can benefit the relationship between the patient and the family caregiver and can help the family reach balance.

Although the literature highlights the concerns expressed by families of hospice patients regarding their pain assessment abilities, minimal interventions aimed at reducing these concerns are documented (Cagle et al., 2015; Parker Oliver et al., 2010). The idea of teaching caregivers without healthcare training how to use pain assessment scales with the goal of improving the recognition of pain in patients and communication with medical teams is not new in research. Ammaturo, Hadjistavropolous, and Williams tested such intervention and arrived at the conclusion that proper instruction in using pain assessment tools leads to adequate accuracy of pain recognition (2017). Although not included in the study, teaching the Abbey scale has the potential for similar or better results for family caregivers of hospice patients, due to its general ease of use and short time involved in its utilization (Lukas, Barber, Johnson, & Gibson, 2013).

The Abbey Pain Assessment Tool—or Abbey Pain Scale—was initially developed and validated with patients with moderate- and end-stage dementia (Abbey et al., 2004) and was later applied to other groups of adults with communication limitations and/or cognitive impairments (Okimasa et al., 2016; Sheu, Versloot, Nader, Kerr, & Craig, 2011). The scale was determined to be accurate and take under 1 minute on average to complete (Abbey et al., 2004; Lukas, Barber, Johnson, & Gibson, 2013). The scale was chosen for the purpose of this project due to the above-mentioned characteristics, as well as its ease of use.

Local Problem

In 2016 alone, 1.43 million Medicare beneficiaries had received hospice care, based on the latest report from the National Hospice and Palliative Care Organization (2018). In Arizona, in the same year, local hospice agencies were offering services to just under 32, 000 patients (CMS, 2016). The literature shows that caregivers of hospice patients are concerned about controlling loved ones' pain correctly and are not confident in their ability to recognize pain and assess its levels (Chi et al., 2018). Although comprehensive pain management intervention models created to address these concerns exist (Cagle et al., 2015), they often entail significant training and resources and, in some cases, may take significant time to complete (Cagle et al., 2015; Parker Oliver et al., 2010). This may not be feasible in some of the many Arizona hospice agencies managing lower patient censuses, as smaller hospice agencies tended to have higher costs and smaller margins of profit in a Hospice Association of America fact analysis (2010). These agencies have limited staff and financial resources and may benefit from deploying alternatives that are simpler and more time- and cost-effective.

Purpose

The purpose of the project was to evaluate the usefulness of a readily validated scale—the Abbey Pain Assessment Scale—in the assessment of pain in adult patients who cannot express or describe pain by family caregivers.

Rationale

This was a quality improvement project designed to alleviate caregivers' concerns regarding pain assessment and management in a small-scale hospice agency. Literature exploring the experiences of terminally ill patients and their caregivers with pain has shown that caregivers desperately need information and clearer instructions on how to recognize and assess the severity of pain (Meeker, Finnell, & Othman, 2011). Because large-scale education initiatives such as EMPOWER (Cagle et al., 2015) may not be affordable for smaller hospice agencies, the focus was shifted towards a more feasible alternative.

Pain assessment scales vary in terms of required training time and ease of use. A more recent study showed that with adequate training, caregivers who had no prior healthcare training were just as accurate in using more complex scales, such as PAINSLAC and PAINAD, as formally trained nurses (Ammaturo, Hadjistavropoulos, & Williams, 2017). The Abbey scale was chosen for this project, as it has no specific training requirements and it is considered easy to use (Lichtner et al., 2014). The goal is to improve caregivers' confidence in their ability to recognize and determine the intensity of pain in their loved ones after being instructed in the use of the Abbey pain scale.

Stakeholders

In planning this project, it was vital to recognize stakeholders who are preoccupied with and invested in the needs of hospice patients. The determined stakeholders are families of adult hospice patients, hospice nursing staff, hospice physicians, advanced practice nurses, physician's assistants, and hospice administration. When providing direct care, families are directly impacted by the intervention. Healthcare providers in the hospice agency are responsible for formulating pain treatment plans and protocols that lean heavily on patient and caregiver reports of pain. Hospice nursing staff is deeply involved in the coordination of care as well as education and support for the caregiver. Hospice agency administration must ensure that their agency meets the goals set for the quality of care measures, to include pain assessment and management. By addressing an important aspect of pain management in the terminally-ill patient, this project seeks to positively impact all stakeholders.

Significance to Practice

Advanced practice nurses (APRNs) working in the field of palliative and hospice care are invested in providing optimal support to patients and families confronted with terminal illness. In this realm of nursing, the APRN must address more than just the needs of the patient, but consider the whole family as the recipient of nursing care (Pace & Lundsford, 2011). When caring for a loved one suffering from terminal illness, families need additional resources, emotional support, affirmation of their care efforts, and learning activities that empower them to continue their journey. The APRN must adopt these aspects as part of the nursing role and find ways to help families identify their needs and develop strategies to meet them. When teaching families to identify pain in their loved one who cannot communicate its presence, the APRN

aims to accomplish not only relieving the patient's pain, but also easing family caregivers' anxiety, reassuring them that their efforts are worthwhile, and helping the family unit reach balance.

Study Question

For family caregivers, is the Abbey scale useful in the pain assessment of adult hospice patients without the ability to self-report?

Theoretical Framework

The framework to guide this Doctor of Nursing Practice (DNP) project was identified in Katherine Kolcaba's Theory of Comfort (2003). This theory proposes that comfort is a desirable outcome of holistic care aimed at meeting physical, psychospiritual, environmental, and sociocultural needs (Kolcaba & Kolcaba, 1991). This particular theory is relevant for this project because it expands its focus to not only patients but also to their families and even their communities, aligning with the general hospice philosophy of patient and family support. Pain management is a major aspect of comfort care for dying adults and is at the forefront of all hospice interdisciplinary teams' care efforts. Lack of knowledge about the assessment and management of pain is a predominant source of anxiety in families of hospice patients, further causing discomfort in the family unit.

The Theory of Comfort came to be as the author found the concept of *comfort* often used by Florence Nightingale was often oversimplified and took a back seat to other nursing priorities (Kolcaba, 2001). The first application of this theory was in the care of Alzheimer's disease and dementia patients (Kolcaba, 2001), but its content became relevant and used in practice in the pediatric nursing practice (Kolcaba & Dimarco, 2005), the perianesthesia setting (Wilson &

Kolcaba, 2004), the care of cardiac patients (Krinski, Murillo, & Johnson, 2014), and even labor and delivery (Koehna, 2000).

The theory classifies the concept of comfort in three categories of forms: *relief*, *ease*, and *transcendence* (Kolcaba & Kolcaba, 1991). *Relief* is achieved when immediate physical needs are met (Kolcaba & Kolcaba, 1991). Looking through the lens of Kolcaba's theory, adequate pain management would achieve the comfort of the patient in the form of *relief*. *Ease* is achieved when particular situations causing anxiety or spiritual distress are resolved or clarified (Kolcaba & Kolcaba, 1991). In addressing the needs of the family unit, *ease* may be reached by improving the knowledge and confidence of family caregivers regarding the pain assessment and management of their dying loved one. Finally, *transcendence* is met when the family learns to cope with their challenges and difficulties and rise above them (Kolcaba & Kolcaba, 1991). Specific to the problem addressed by this project, this form of comfort is achieved when the family unit finds solace in its ability to care for a loved one while maximizing the quality of their time left together.

This DNP project sought to offer a validated tool that families can use to recognize and assess the severity of pain in their loved one who cannot tell them he or she is in pain. The hope was that using the Abbey Pain Scale tool may help recognize and treat the pain more adequately and relieve some of the anxiety and tension caused by uncertainty in the family. The project was thus aimed at achieving the *relief* and *ease* dimensions of comfort, setting patients and families on a path to *transcendence*. Kolcaba's theory portrays comfort as a highly individualized concept (2003). Comfort is defined by the individual and usually not quantifiable. This project focused on gathering and analyzing quantitative and qualitative data in order to capture family

caregiver's individual perceptions of ease and confidence assessing pain before the tool was introduced and after it has been used, as well as their perceived patient level of comfort.

Other Key Concepts

Aside from the concept of comfort and its different forms and implications, hospice nursing frequently utilizes two other concepts when addressing pain management: holism and family as a unit of care.

Holism

This is a widely encountered aspect in nursing care and has been defined as “viewing the patient as a whole person” (Baldwin & Greenwood, 2011). This view assumes that the person is composed of physical, psychological, social, cultural, spiritual, and emotional dimensions, along with interrelationships among them, functioning as a unique, integrated whole (Baldwin & Greenwood, 2011; Macleod, 1997). This concept is relevant to hospice nursing because the presence of terminal illness dramatically impacts every aspect of the patient as a whole, and each affected dimension has the potential to disturb the homeostasis of the whole.

Family as a Unit of Care

While patient-centered care is always at the forefront of nursing practice in general, the presence of terminal illness affects not just the patient suffering from it, but also the other family members who are now confronted with significant changes in roles and everyday activities. Hospice nursing, thus, must address the entire family as the recipient of care, while maintaining its patient-centered focus (Nebel, 2011).

Synthesis of Evidence

To better understand family caregivers' perception of their experiences with the pain management of hospice patients as well as attempts to alleviate their concerns, an extensive literature search was performed using the PubMed, CINAHL, and Embase databases. Key terms used were *Abbey*, *Abbey scale*, *hospice*, *hospice care*, *pain management*, *pain assessment*, *pain assessment tool*, *cognitive impairment*, *cognitively impaired*, *dementia*, *family caregivers*, *informal caregivers*. The search was limited to full-text articles published in English during the past five years and yielded only 275 results in total. After excluding duplicates, reviews, case studies, articles relevant to pediatric patients, and studies with no reference to pain assessment or management, only four articles were retained as relevant to this project. Extending the publication year limit to the last 10 years yielded 559 total results and, after excluding duplicates and articles irrelevant to the project's focus as described above, only 10 articles were retained as relevant and further evaluated. The detailed appraisal of the articles found relevant to this project is discussed in Appendix G.

Pain Assessment Concerns in Family Caregivers

Half of the studies retained explored the experiences and challenges of informal caregivers in assessing and managing the pain of hospice patients (Kelley, Demiris, Nguyen, Parker Oliver, Wittenberg-Lyles, 2013; Tarter, Demiris, Pike, Washington & Parker Oliver, 2016; Parker Oliver, Wittenberg-Lyles, & Washington, 2013; McPherson, Hadjistavropoulos, Lobchuk, & Kilgour, 2013; Mehta, Chan, & Cohen, 2013). Out of these five articles, one included the perspectives of patients along with those of caregivers (McPherson, Hadjistavropoulos, Lobchuk & Kilgour, 2013) and another particularly focused on the

experiences of those caring for hospice dementia patients. Across all studies emerged the common themes of inadequate end-of-life symptom knowledge, inadequate medication knowledge, issues in communication with the hospice interdisciplinary team, and emotional distress related to overwhelming responsibility or watching their loved one suffer. Particular to the Tarter et al. (2016) study was the issue of difficulties in communication, one source of caregiver distress being the patient's inability to express their needs or presence of pain. In a qualitative study by Han et al. (2018) the discussion focused mostly on the communication between family caregivers and nurses and the ways caregivers' concerns were addressed. Although the major themes were organized in terms of nurses' responses, the subthemes repeated throughout the report further revealed caregivers concerns in patterns similar to the five studies discussed above.

Strategies to Alleviate Concerns

Two of the studies proposed solutions to alleviate these concerns. Cagle et al. (2015) studied an extensive intervention called Effective Management of Pain: Overcoming Worries to Enable Relief (EMPOWER). The plan involved training hospice staff in assessing barriers and concerns regarding pain and assessment and management upon admission to hospice services and educating families and patients on effective ways to overcome their worries. The study, a cluster randomized controlled trial, found knowledge regarding pain management improved at 2 weeks after intervention and that families and patients had fewer concerns regarding pain and pain medications, as well as improved patient pain scores. The intervention deployed by Parker Oliver et al. (2010) was the inclusion of hospice patients and their caregivers in interdisciplinary team meetings by videophone. This was a two-phase study, with first phase patients and

caregivers receiving regular hospice services, while the second phase participants received the intervention, attending an average of two meetings and being provided the opportunity to express their concerns regarding pain assessment and management. The results did not show an improvement in outcomes, raising concerns that the limited number attended meetings may not have been sufficient to produce a significant change.

Pain Assessment in Patients with Communication Limitations

The study conducted by Eritz and Hadjistavropoulos (2013) attempted to correlate end-stage dementia patients' pain ratings on the Color Analogue Scale with their informal caregivers' ratings on the same scale. The study determined that informal caregivers did not interpret nonspecific behavioral cues as pain, as correlations between patients' reports and caregivers' reports were not established. De Witt Jansen et al. (2018) examined several clinicians' attitudes towards the use of observational tools, one of them being the Abbey scale, in the pain assessment of dying dementia patients. The responses were unexpectedly mixed, with a large proportion of clinicians expressing their belief that many of the observational tools had no value in pain assessment of this patient population and confessed to not routinely using them.

Strengths and Weaknesses of the Evidence

Despite the limited number of research studies focused on the pain assessment of home-based hospice patients with communication difficulties, valuable information is still revealed in them that can guide further research in an effort to help families navigate pain management. The majority of the studies reviewed explored the challenges of family caregivers with pain assessment and management, highlighting similar themes among the interviewees, although the generalizability of all five studies in this category was limited by geographic location (Kelley,

Demiris, Nguyen, Parker Oliver, Wittenberg-Lyles, 2013; Tarter, Demiris, Pike, Washington & Parker Oliver, 2016; Parker Oliver, Wittenberg-Lyles, & Washington, 2013; McPherson, Hadjistavropoulos, Lobchuk, & Kilgour, 2013; Mehta, Chan, & Cohen, 2013).

There were limitations among the studies that sought to provide solutions to caregiver concerns as well. For example, the Cagle et al. (2015) pilot study on the efficacy of the EMPOWER approach found positive results, however the lack of proper randomization and relying on chart reports for baseline measures threaten the internal validity of the study, while the high mortality by three months forced the researchers to rely on very early measures, which may not reflect the sustainability of the intervention. The only study that had as a goal to quantify the amount of attention paid by informal caregivers to nonverbal cues of pain, the Eritz and Hadjistavropoulos (2013) study, draws concerns that not only some advanced dementia patients may not accurately report pain with the Color Analogue Scale, but also purposefully placing them in possibly painful situations is not warranted and may not be ethical despite the study's ethics discussion. The findings of the De Witt Jansen (2018) qualitative study were surprising and appear in stark contradiction with other current and previous evidence on the topic. One significant limitation lies in the contact index sampling procedure for this study, which is concerning for the motives and bias of both participants and researchers. Please refer to Appendix G for a more detailed appraisal of strengths and weaknesses.

Summary and Gaps in Literature

In conducting this synthesis, it became evident that there is a lack of current, good quality evidence that addresses the problem of pain management in home-based hospice patients, signaling a need for a renewed focus of research efforts on this topic. Many of the recent studies

are qualitative, suggestive of the very real challenge of working with a vulnerable population, and they only outline the fact that family concerns regarding the pain management of their dying loved ones continue to exist and are yet to be effectively addressed (Kelley, Demiris, Nguyen, Parker Oliver, Wittenberg-Lyles, 2013; Tarter, Demiris, Pike, Washington & Parker Oliver, 2016; Parker Oliver, Wittenberg-Lyles, & Washington, 2013; McPherson, Hadjistavropoulos, Lobchuk, & Kilgour, 2013; Mehta, Chan, & Cohen, 2013). The very few researched attempts to address family concerns have been largely unsuccessful (Parker Oliver et al., 2010) or have concerns in terms of validity of results (Cagle et al., 2015). This synthesis points out the need for new approaches aimed at easing the responsibility of family caregivers in caring for their loved ones and managing their pain as they approach the end of life.

METHODS

Study Design

Comfort is always at the heart of holistic nursing efforts and drives many of the interventions that nurses employ in the care of their patients. This is particularly the case for hospice and palliative care, where special consideration is given to the entire family unit as the recipient of comfort care. Although comfort is closely related to quantifiable concepts such as pain and anxiety, it is more complex and more inclusive than such concepts (Kolcaba, 1991). In this sense, comfort is not purely the absence of discomfort—as one can still report comfort despite the perceived presence of discomfort-causing circumstances—and has a more complex, personal meaning to each person (Kolcaba, 1991). Kolcaba's Theory of Comfort, as well as the purpose of the study guiding its design, dictated the descriptive quantitative nature of the methodology selected for this study. The project sought to describe the usefulness of the Abbey

scale in improving the pain assessment of home-based hospice patients by analyzing the answers of a paper-format survey by family caregivers after they have become familiarized with the scale. The advantages of using a survey-based descriptive design are that it reduces researcher bias and it is both cost effective and convenient to use (Polit & Beck, 2016).

Setting

The setting for this study was within the area of operations of Aviant Hospice in Phoenix, Arizona and Globe, Arizona. Due to focus on care for hospice families in home-based settings and caregiver limitations in the ability to travel to a different location, the intervention was introduced in the home of the hospice patient and his or her family caregivers during routine hospice staff visits. A letter of authorization was provided by the agency and attached in Appendix A.

Participants

The participants were family caregivers of hospice patients receiving services from the Aviant hospice agency. Because no family caregivers of hospice patients located in Globe, Arizona, met the criteria for participation, all participants in the project came from the Phoenix, Arizona, metropolitan area. Before meeting with the student, potential participants in the project that met the inclusion criteria were selected by the hospice agency administration based on the available data in their charts. During home visits, the hospice nurses asked permission from family caregivers for the student to visit and explain the focus of the project and recruit participants. This type of sampling strategy is called convenience sampling. Its advantage is its efficiency however caution must be paid when using this strategy as participants who volunteer for the study may have more challenges and possibly different

experiences than the general population they represent (Polit & Beck, 2016). Aligning with the focus of the project and the study question, the criteria for participants to be included in the study were: a) family caregivers of adult hospice patients with limitations in verbal expression; b) over 18 years old; and c) English speaking and reading ability. The target number of participants was 10-20, however only three family caregivers met the criteria of participation and agreed to meet with the student. An incentive for participation was provided to participants in the form of a gift card in the amount of \$10.00 per participant.

Intervention

Participants were introduced to the Abbey Pain Assessment Tool and were instructed in its use, as well as recording the scores, and were encouraged to use the scale for two weeks. The Abbey scale was selected due to its ease to use as well as the availability of clear instructions for teaching. See Appendix F for a depiction of the Abbey scale. The original author authorized the public use and reproduction of the scale as long as acknowledgments remain attached as shown (New South Wales Government Agency for Clinical Innovation, n.d.). The instructions, presented in verbal and written form, were adapted from a training resource by The Australian Government Department of Health (2013). See Appendix E for the written instructions.

Data Collection

After two weeks using the Abbey scale and recording measured scores and pain relief interventions provided, participants were asked to complete the provided questionnaire and their answers were confidentially recorded. The records of the scores and associated interventions were also collected for further analysis of trends in the use of the scale.

Survey Design

The study utilized a 16-item survey with questions formatted to be simple and easy to understand and to eliminate researcher bias and worded to be courteous towards participants in the survey. Appendix C provides a view at the questionnaire. The first set of four questions was demographic in nature, providing a general picture of the participants in terms of age, gender, level of education, and time spent as hospice family caregivers. The fifth and sixth questions specifically targeted the average degree of use of the Abbey scale by caregivers. The following nine questions were Likert-style questions, shedding light on the experience of caregivers with the use of the scale and their perception of its usability. This type of question provides the options of agreeing or disagreeing with the statement in the body of the questions, prompting participants to choose the option that best aligns with their views (University of Wisconsin, 2010). The final question was a short answer type question, allowing participants to make comments and suggestions regarding the scale. This type of open-ended question can provide a more nuanced view of caregivers' experience with the scale, but it can be more difficult to analyze (Polit & Beck, 2016).

Content Delivery

Potential participants were informed by the hospice agency of the upcoming invitation to participate in the project. The student then approached participants and provided them with an overview of the project and the question it seeks to answer, explaining the purpose of the study as well as potential risks and benefits of participation. A welcome letter was provided to the family caregivers, with written explanation of the study purpose and procedures and an invitation to participate (Appendix B). The participants were also provided with a copy of the

Abbey scale (Appendix F), a record sheet (Appendix D), and verbal and written instructions regarding the correct use of the scale (Appendix E). The package provided contained a questionnaire (Appendix C) and a pre-stamped, pre-addressed envelope. The student instructed family caregivers to complete the questionnaire and place it, as well as the record sheet, in the provided envelope at the end of two weeks of using the Abbey scale. The envelope was to be then mailed to the provided address. Their voluntary submission of the survey and the score record by placing these documents in the provided return envelope and mailing them to the provided address was considered their consent to participate in the study. The Abbey Pain Scale form itself (Appendix F) was not collected and remained with the caregiver. For confidentiality purposes, caregivers were instructed to not place a return address on the envelope, but to place their address in a provided small blank envelope and mail it along with the two above specified documents. Their address was used in order to send them a gift for their participation and the envelope containing their address was kept and opened separately from the completed surveys in order to maintain confidentiality.

Data Analysis

Demographic data contained in the survey was used to provide a picture of the participant sample. Because this data is nominal or ordinal, percentages sufficed in the analysis of this information (Polit & Beck, 2016). Due to the small number of returned completed surveys, the answers to Likert-style questions were analyzed by comparison between the two surveys. In agreement with the University of Arizona Research Computing Consulting department recommendations, calculating measures of central tendency (mean, mode, standard deviation) was deemed unnecessary and not useful when analyzing the results

from such a small sample. The open-ended question was subjected to content analysis in order to extract specific themes in comments and suggestions provided by participants. The data contained in time and intervention sheets used to track the use of the scale was also analyzed for general trends. Again, due to the small number of participants, individual entries were compared without calculation of measures of central tendency.

Ethical Considerations

In order to ensure the wellbeing of participants in this study, the principles of respect for persons, beneficence, and justice will be followed as described further. Furthermore, the project was submitted to the University of Arizona Institutional Review Board (IRB) for further review and recommendations in order to ensure that the study participants are protected. The IRB review determined that the project did not meet the definition of human research and it did not require further IRB oversight (Appendix H).

Respect for Persons

For the respect for persons principle to be met, participants were treated as independent autonomic individuals with the right to choose what activity and intervention they will and will not participate in (United States Department of Health and Human Services, 1979). In this study, participation was voluntary, without any consequences for abstaining to participate, and participants had the right to withdraw at any time during the period of the study. The participants were independent adults with decision-making capability and were not considered a vulnerable population. Clear and adequate information regarding the study overview was provided to participants (Appendix B).

Beneficence

The principle of beneficence encompasses minimizing harms and maximizes benefits to participants (United States Department of Health and Human Services, 1979). This study was, in its quality improvement nature, focused on maximizing the benefits for families involved in the care of hospice patients by providing a useful tool to be used in pain assessment in the home-based environment. There were no risks associated with this study for its participants.

Justice

Justice as a research principle reflects the fairness of the researcher in selecting participants for the study (United States Department of Health and Human Services, 1979). All family caregivers of hospice patients with communication deficits receiving services from the hospice agency were free to participate in this study and were not discriminated against by gender, age, or socio-economic status. The information provided in this study did not contain personal identifiers and the researcher did not have the ability to match responses with certain respondents, as returned envelopes did not contain participants' names or addresses. The student had also signed a confidentiality agreement with the hospice agency prior to recruiting participants. Additionally, no personal data left the organization during and after implementation of the study. This ensured that the right to privacy was met as a subsection of the justice principle.

RESULTS

Findings

Out of the three family caregivers who agreed to be instructed in the use of the Abbey scale, two returned their completed surveys and intervention records at the end of the two weeks during which they interacted with the scale (n=2, 67%). Demographically, one responding participant was male (n=1, 50%) and the other was female (n=1, 50%), one was aged between 50 and 75 (n=1, 50%) and the other was over 75 (n=1, 50%). Both participants have attended college and one participant had a graduate degree (n=1, 50%). One participant was a caregiver for a hospice patient for a period of 1-3 months (n=1, 50%) and the other for 3-6 months (n=1, 50%). See Appendix I for a bar graph of demographics. They both used the Abbey scale on average once per day (n=2, 100%). One participant used the scale for two days (n=1, 50%), and the other used it for 5 days (n=1, 50%). See Appendix J for a graph representation of Abbey scale use.

Because only two completed surveys were returned, the results were analyzed by comparing answers to questions between the two surveys. Descriptive statistics were found to not be useful in this analysis due to the small number of participants. The participants were asked nine Likert-style questions regarding the usefulness of the tool in helping them recognize and assess the severity of pain in their loved ones. They were asked to respond to statements by selecting from four optional answers ranging from “Strongly Disagree“ to “Strongly Agree.” In response to the first statement, “Prior to using the Abbey scale, I was confident in my ability to recognize whether my loved one was in pain,” both participants selected “Agree” (n=2, 100%). When asked whether they were confident in their ability to recognize the severity of their loved

one's pain prior to using the Abbey scale, both participants answered "Agree" (n=2, 100%).

When asked to answer to the statement "Prior to using the Abbey scale I often felt distressed due to my ability to tell whether he/she was in pain," one participant answered "Agree" (n=1, 50%) and the other answered "Strongly Agree" (n=1, 50%).

The participants answered the statement "I will continue to use the Abbey scale" very differently. One participant answered 4= "Strongly Agree" (n=1, 50%) and the other answered "Disagree" (n=1, 50%). A similar reaction was obtained to the statement "The Abbey scale was easy to use" where one participant answered "Strongly Agree" (n=1, 50%) and the other answered "Disagree" (n=1, 50%). When asked whether they felt the Abbey scale was too complex, both participants answered "Disagree" (n=2, 100%).

Mixed results were obtained when participants were asked whether they felt that the Abbey scale was useful in helping to determine whether their loved one was in pain. One participant answered "Strongly Agree" to this statement (n=1, 50%), while the other participant answered "Disagree" (n=1, 50%). However, when asked whether they thought the Abbey scale helped them recognize the severity of their loved one's pain, both participants answered "Agree" (n=2, 100%). Similarly, when asked to answer the statement "I think I need more detailed instructions or training in using the Abbey scale" both participants answered "Disagree" (n=2, 100%). See Appendix K for a bar graph of answers to Likert-style questions.

The final question on the survey was an open-ended question that asked participants for comments and suggestions on the use of the Abbey scale. The answers were analyzed in search of common themes. No common themes were identified among the answers of the two participants. One participant wrote a short comment on their opinion that the Abbey scale was

“easy to use and figure out the pain scale.” The other participant wrote a short paragraph questioning whether their own health problems at the time of the study implementation may have influenced their ability to use the Abbey scale and follow instructions correctly. One sentence wrote “I was dealing with my own health issues at the time” and “this might not be the most reliable survey due to this fact.” None of the participants identified any suggestions for improvement or commented on what they did not find helpful.

Analysis of the score and intervention records showed that each participant used the Abbey tool at least twice during the two weeks they were encouraged to interact with the scale. The participants were asked to contact their hospice nurse if scores obtained were higher than ‘7,’ considered a mild level of pain. Neither of the records showed scores higher than ‘3’ on the Abbey scale. One interesting phenomenon was noted when comparing the obtained scores with the interventions provided by caregivers to patients based on these scores. It was noted that, even though most of the scores obtained were registered in the 0-2 range, which is marked as “no pain” on the Abbey scale, caregivers provided interventions aimed at relieving pain every time the score obtained was greater than ‘0,’ to include scores between 1-2, which are considered “no pain” on the Abbey scale. No interventions were recorded for ‘0’ scores on the Abbey scale.

DISCUSSION

Interpretation

The completed surveys provided significant insight in participants’ feelings of self-efficacy in recognizing the presence and severity of pain in their loved one who was terminally ill and their thoughts on whether the Abbey scale was useful in improving these feelings. Interestingly, in complete discordance with available research on the topic, both participants

agreed that they felt confident in their ability to recognize pain and determine its severity of pain prior to the introduction of the Abbey scale. Also notable was that they both felt some degree of distress related to their ability to recognize their loved one's pain, which is in concordance with current literature. The possible explanation for these seemingly conflicting results may be that family caregivers rely on their instincts and "knowing their loved ones" when looking for signs of existent pain, but may still experience the need the validation that their assumptions are correct.

The complete disagreement between the answers to statements #10 ("I will continue to use the Abbey scale") and #11 ("The Abbey scale was easy to use") was surprising, particularly because both participants disagreed with the statement that the Abbey scale was too complex (statement #12), as well as with the statement that they felt they needed more instructions on the Abbey scale use (statement #15). The clue to this discrepancy may rest in the answers to the open question at the end of the survey. The same participant that mentioned concerns with their own health issues as a barrier to correct use of the scale, also disagreed with the statements #10 and #11. This could signal that using the Abbey scale seemed daunting in the context of personal health circumstances, further indicating that personal factors may play a role in the caregivers' interaction with the scale.

Although the answers were split once again on statement #13 ("Use of the Abbey scale helped me determine whether my loved one was in pain"), both participants agreed to different extent that the scale was useful in helping them determine the severity of the pain (statement #14). This is significant because, even though results regarding the usefulness of the Abbey scale in helping participants recognize pain were inconclusive, the value of the scale in determining

the severity of pain is promising. Further exploration on the usefulness of the Abbey scale in the assessment of the severity of pain could provide a better insight into this relationship.

In examining the answers to the open-ended question, one participant further emphasized some of the choices he made in answering the Likert questions, writing a short note in the value of the Abbey scale in determining the severity of pain. The other participant wrote a self-analytic short paragraph on challenges in interaction with the scale and explained that personal factors affected the ability to correctly and completely use the scale. Interestingly, the same patient used the scale the most (five times) throughout the two-week period when comparing the answers to the survey with entries into the attached score and intervention records. No elaboration on the exact mechanism of how personal health factors were thought to have impacted the use of the scale was provided and no correlation between expectations and reality of interaction with the scale was evident in the short answer.

It was interesting to find that, for both participants, the analysis of trends in use of the scale and interventions provided based on the scores obtained showed that interventions were provided for any scores greater than '0.' Despite being instructed in the different scoring of the Abbey scale, where a score of 0-2 is considered "no pain" and a score of 3-7 is considered "mild pain," caregivers appeared to—maybe unconsciously—associate this more unusual way of scoring with scoring on the numeric pain scale, where a score of 1-3 is considered mild pain. Therefore, scores of 1-3 on the Abbey scale were followed by interventions such as repositioning or distraction. No scores higher than '3' on the Abbey scale were recorded during the two-week period.

The results of the survey showed that the Abbey scale has a promising value in helping family caregivers determine the severity of pain in their loved ones, more so than in helping them recognize whether the patients are in pain. The analysis of the score and intervention record entries showed however, a discrepancy between the Abbey scores and the perceived severity of pain, as both participants provided interventions where they might not have been indicated. The patients were not placed at any risk for adverse events by the unnecessary interventions, as they were provided in the form of distraction, repositioning, or encouraged rest. No medication was provided to any of the patients as indicated by the record entries. The analysis of short answers to the last survey question revealed that personal factors may have an impact in the correct and beneficial use of the Abbey scale by family caregivers, although the mechanism of this relationship is not clear. Although not indicated by any of the participants in the project, further clarification or simplification of instructions may help reduce the difficulty in using the scale by family caregivers with personal health issues.

Limitations

The most obvious limitation of this project was the small number of participants, which affected the ability of reporting strong results. In the hospice field, mortality of patients—and, because the study targeted family caregivers of living hospice patients, subsequent disqualification of caregivers whose loved ones died—is a threat to the validity of many studies who are aimed at this population or their families. Additionally, the hospice agency, which provided the setting for this quality improvement project did comment on a previously observed trend in patient relocation to assisted living settings instead of home settings when communication between patients and family caregivers becomes a challenge. In assisted living

facilities, the hospice patients are provided care by trained caregivers who are experienced in handling communication challenges.

Mortality and relocation to assisted living were the largest factors that affected the number of participants, independent of any efforts to increase participation. The implementation period was extended by three weeks to allow for more possible patients with family caregivers that met the criteria for participation in the project to be admitted, which resulted in one additional participant in training. Only two out of the three participants in training returned their completed surveys. Extending the criteria for participation to formal caregivers would then render the project useless, as these caregivers are assumed to have had training in recognizing pain in patients who cannot self-report. The hope is that reducing the challenges in family caregivers' communication with patients with limited verbalization by finding successful interventions in this aspect will change the relocation trend and allow more patients to die comfortably in their own homes

Doctor of Nursing Practice Essentials

The project aligns with Doctor of Nursing Practice Essential II (American Association of Colleges of Nursing, 2006) as the student had to demonstrate the ability to develop and evaluate a quality improvement initiative that was delivered in a way that was sensitive to the needs of the hospice families. In planning and implementing this project, the student used advanced communication skills, employed not only clinical and scientific knowledge, but also principles of business, leadership, and finance, and utilized concepts specific to hospice systems and organizations.

Dissemination

Currently there is a plan to present the results of this quality improvement project and any recommendations for improvement at the first Aviant monthly staff meeting after the final project defense. The agency will have a choice to further study the intervention in order to possibly obtain stronger and more conclusive results by making participation available to more families over an extended period of time.

Conclusion

In preparation for this project, multiple hospice agencies' reluctance to partner in this quality improvement project became evident. The first recommendation for further improvement is addressed to all hospice agencies and is a reminder that, as long as there is evidence of a need to improve the care aimed at hospice patients, as well as the support provided to their families, the quest for solutions to everyday sources of concern should continue. Hospice agencies should not fear change, but should embrace and test new ideas for improvement. Specifically related to this project, although the results showed a positive impact of the Abbey scale in caregivers' identification of pain severity in their loved ones, the limitations in sample size indicate the need to further investigate the study question at a larger scale and, possibly, for a longer period of time. Using the Abbey scale continues to show potential in meeting the relief and ease forms of comfort as Katherine Kolcaba envisioned them in her theoretical framework (2003). Additional testing of simplified training in the use of the scale may be beneficial as well, particularly in family caregivers who have personal health problems.

APPENDIX A:
SITE AUTHORIZATION LETTER



July 9th, 2019

University of Arizona Institutional Review Board
c/o Office of Human Subjects
1618 E Helen St
Tucson, AZ 85721

Please note that Mrs. Camelia Martin, University of Arizona Doctor of Nursing Practice student, has permission of Aviant Hospice to conduct a quality improvement project with our agency for her project, "Usability of the Abbey Scale in Family Caregivers' Pain Assessment of Hospice Patients without the Ability to Self-Report."

Mrs. Martin will conduct a survey of family caregivers of hospice patients at Aviant Hospice. She will recruit caregivers in person during home visits with the hospice staff. She will provide a verbal and written description of the project, what they will be asked to do, and the time involved. The survey will be sent to participants via mail. Mrs. Martin's activities will be completed by September 30th, 2019.

Mrs. Martin has agreed to provide to my office a copy of the University of Arizona Determination before she recruits participants. She will complete a confidentiality agreement with Aviant Hospice. She will present aggregate results to the hospice staff at their monthly staff meeting.

If there are any questions, please contact my office by calling 480-398-2411.

Sincerely,

A handwritten signature in dark ink that reads "Leslie Cooper". The signature is written in a cursive, flowing style.

Leslie Cooper MSN, RN
Executive Director

APPENDIX B:
STUDY INFORMATION LETTER

Study Information Letter

Dear Family Caregivers,

My name is Camelia Martin and I am a graduate student at the University of Arizona, pursuing a Doctor of Nursing Practice (DNP) degree in the Family Nurse Practitioner specialty. As part of my program, I am conducting a quality improvement project regarding the usability of the Abbey Pain Scale in the pain assessment of hospice patients with limitations in the ability to express their needs by their family caregivers.

Participation in this DNP project involves completing a confidential survey about your experience using the Abbey Pain Scale after having the opportunity to familiarize yourselves with it over the past two weeks. The survey will be mailed to you along with a pre-stamped, pre-addressed return envelope. The survey will take approximately 5 minutes to complete and will consist of demographic questions as well as both closed-ended and open-ended questions. You will have one week to complete the survey, place it in the provided return envelope, and mail it back to me. After the conclusion of the study, recommendations for improvement will be developed based on the aggregated results.

Responses from this survey will remain confidential and will be used solely for the purpose of this study. Participation in this study is voluntary and you may withdraw participation at any time without any consequences. There are no unforeseeable risks that have been identified in the participation of this quality improvement project. You will receive a gift card in the amount of **\$10** as appreciation for your time and effort if you choose to do so. Submission of this survey means that you are consenting to the participation in this project.

This quality improvement project has been reviewed by the University of Arizona Institutional Review Board and has been deemed acceptable in meeting the requirements intended to protect the wellbeing of its participants.

Should you have any questions or concerns please contact Camelia Martin at cammartin@email.arizona.edu

Thank you for your time and consideration.

Respectfully,

Camelia Martin, RN BSN
DNP Student

APPENDIX C:

ABBEY PAIN ASSESSMENT TOOL USE QUESTIONNAIRE

Abbey Pain Assessment Tool Use Questionnaire

The following survey will be used for study purposes and is designed to provide the researcher with information regarding the usability of the Abbey scale in pain assessment of hospice patients by family caregivers. The first set of questions is related to demographics. There are no right or wrong answers. The responses are anonymous and will remain confidential.

Multiple Choice:

1. Age in years:

- | | | |
|----------|---------|-------|
| 1. 18-30 | 4.51-60 | 7.>80 |
| 2. 31-40 | 5.61-70 | |
| 3. 41-50 | 6.71-80 | |

2. Gender:

1. Male
2. Female
3. Other

3. Highest completed level of education:

1. less than 8 grades
2. high school
3. some college
4. undergraduate degree
5. graduate degree

4. Time spent as a caregiver for your loved one during his or her enrollment in hospice services

- | | |
|--------------------|--------------|
| 1. <1 week | 4.1-3 months |
| 2. 1-2 weeks | 5.3-6 months |
| 3. 2 weeks-1 month | 6.>6 months |

5. The average number of times per day I used the Abbey scale over the past two weeks:

- | | | | | |
|-----|-----|-------|-------|------|
| 1.0 | 2.1 | 3.2-3 | 4.4-6 | 5.>6 |
|-----|-----|-------|-------|------|

6. Prior to using the Abbey scale, I was confident in my ability to recognize whether my loved one was in pain

1. Strongly Disagree
2. Disagree

3. Agree
 4. Strongly Agree
7. Prior to using the Abbey scale, I was confident in my ability to recognize the severity of his/her pain:
1. Strongly Disagree
 2. Disagree
 3. Agree
 4. Strongly Agree
8. Prior to using the Abbey scale, I often felt distressed due to my inability to tell whether he/she was in pain
1. Strongly Disagree
 2. Disagree
 3. Agree
 4. Strongly Agree
9. I will continue to use the Abbey scale
1. Strongly Disagree
 2. Disagree
 3. Agree
 4. Strongly Agree
10. The Abbey scale was easy to use
1. Strongly Disagree
 2. Disagree
 3. Agree
 4. Strongly Agree
11. The Abbey scale was too complex
1. Strongly Disagree
 2. Disagree
 3. Agree
 4. Strongly Agree
12. Use of the Abbey scale helped me determine whether my loved one was in pain
1. Strongly Disagree
 2. Disagree
 3. Agree

4. Strongly Agree

13. Use of the Abbey scale helped me determine the severity of my loved one's pain

1. Strongly Disagree
2. Disagree
3. Agree
4. Strongly Agree

14. I think I need more detailed instructions or training in using the Abbey scale

1. Strongly Disagree
2. Disagree
3. Agree
4. Strongly Agree

Short answer:

15. Comments and suggestions regarding the use of the Abbey scale:

APPENDIX D:
ABBEY PAIN SCORE AND INTERVENTION RECORD

APPENDIX E:
HOW TO USE THE ABBEY PAIN SCALE

How to Use the Abbey Pain Scale*

The Abbey pain scale is for measurement of pain in people who cannot verbalize.

How to use the scale:

While observing the patients, score questions 1 to 6.

Q1. Vocalization (e.g., whimpering, groaning, crying)

Absent 0 Mild 1 Moderate 2 Severe 3

Q2. Facial expression (e.g., looking tense, frowning, grimacing, looking frightened)

Absent 0 Mild 1 Moderate 2 Severe 3

Q3. Change in body language (e.g., fidgeting, rocking, guarding part of the body, withdrawn)

Absent 0 Mild 1 Moderate 2 Severe 3

Q4. Behavioral change. (e.g., increased confusion, refusing to eat, alteration in usual patterns)

Absent 0 Mild 1 Moderate 2 Severe 3

Q5. Physiological change (e.g., temperature, pulse or blood pressure outside normal limits)

Absent 0 Mild 1 Moderate 2 Severe 3

Q6. Physical changes (e.g., skin tears, pressure areas, arthritis, contractures, previous injuries)

Absent 0 Mild 1 Moderate 2 Severe 3

Scoring: Add the scores for 1 - 6 and record total pain score

Now check the box that matches the total pain score:

0-2 No pain	3-7 Mild	8-13 Moderate	14+ Severe
------------------------------	---------------------------	--------------------------------	-----------------------------

Finally, check the box that matches the type of pain:

Chronic	Acute	Acute on chronic
----------------	--------------	-------------------------

*Adapted from The Australian Government Department of Health (2013).

APPENDIX F:
THE ABBEY PAIN SCALE

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of resident:

Name and designation of person completing the scale:

Date: **Time:**

Latest pain relief given was.....**at****hrs.**

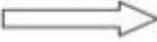
Q1.	Vocalisation eg. whimpering, groaning, crying <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q1	<input type="text"/>
Q2.	Facial expression eg: looking tense, frowning grimacing, looking frightened <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q2	<input type="text"/>
Q3.	Change in body language eg: fidgeting, rocking, guarding part of body, withdrawn <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q3	<input type="text"/>
Q4.	Behavioural Change eg: increased confusion, refusing to eat, alteration in usual patterns <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q4	<input type="text"/>
Q5.	Physiological change eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q5	<input type="text"/>
Q6.	Physical changes eg: skin tears, pressure areas, arthritis, contractures, previous injuries. <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q6	<input type="text"/>

Add scores for 1 – 6 and record here  **Total Pain Score**

Now tick the box that matches the

Total Pain Score

	0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe
---	------------------	---------------	--------------------	---------------

Finally, tick the box which matches the type of pain 

Chronic	Acute	Acute on Chronic
---------	-------	------------------

Dementia Care Australia Pty Ltd
 Website: www.dementiacareaustralia.com

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
 Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002
 (This document may be reproduced with this acknowledgment retained)

APPENDIX G:
TABLE OF APPRAISED ARTICLES

Table of Appraised Articles

Reference	Study Purpose	Design	Sample/Setting	Methodology	Findings	Limitations
Cagle, J. G., Zimmerman, S., Cohen, L. W., Porter, L. S., Hanson, L. C., & Reed, D. (2015). EMPOWER: An intervention to address barriers to pain management in hospice. <i>J Pain Symptom Management</i> . 49(1), 1-12.	Determine the efficacy of the effective management of pain: Overcoming worries to enable relief (EMPOWER) intervention in addressing hospice caregivers' barriers to pain management	Cluster randomized controlled trial	N=126 Caregivers of hospice patients receiving home services Four hospice agencies in North Carolina Intervention n=55 Control n=71	Intervention deployed at the time of admission Interviews at 2 weeks after admission to hospice services and after 3 months Outcome measures: Caregiver Pain Medicine Questionnaire Caregiver Self-Efficacy in Pain Management Scale Family Pain Questionnaire Knowledge Subscale EMPOWER Pain Barriers Measure Patient Pain Ratings	At two weeks, intervention group scored better in terms of knowledge about pain management (p=0.001), had fewer concerns about pain medication (p=0.008), and had improved reported patient pain ratings over the past week (p=0.014) At 3 months, the intervention group continued to score better on all outcome measures. However, the only two statistically significant outcome measure results were for knowledge regarding pain management on the Family Pain Questionnaire Knowledge Subscale (p=0.012), and better scores on the fatalism item on the EMPOWER Pain Barriers Measure (0.032)	Baseline pain rating measures obtained from the chart not directly from patient or caregivers Randomization occurred at agency level (caregivers related to two hospice agencies were randomly assigned to the intervention group) High mortality rate by 3 months (63%)

Reference	Study Purpose	Design	Sample/Setting	Methodology	Findings	Limitations
De Witt Jansen, B., Brazil, K., Passmore, P., Buchanan, H., Maxwell, D., Mcilpatrick, S., ... Parsons, C. (2018). "A tool doesn't add anything." The importance of added value: Use of observational pain tools with patients with advanced dementia approaching the end of the life-a qualitative study of physician and nurse experiences and perspectives. <i>International Journal of Geriatric Psychiatry</i> , 33(10), 1346-1354.	Describe clinicians' experiences with using observational pain assessment tools in assessing pain in dementia patients at end of life	Qualitative: descriptive	N=47 Nurses and physicians with experience in caring for dying patients with dementia Nurses n=24 Physicians n=23 Purposeful contact index sampling to achieve diversity Hospitals, general practices, hospices, and nursing homes across Northern Ireland	Semi-structured interviews	Three themes: Use of observational tools in assessing the pain of dying dementia patients, barriers to the use of observational tools and perspective on practice development and training in pain assessment of dementia patients	Limited to one geographic area Contact index sampling Participants may have chosen or may have been selected to participate in the study because they had strong opinions on observational tool use.
Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? <i>Journal of Pain</i> , 12(3), 331-339.	Examine if nonverbal behaviors are considered by informal caregivers with end-stage dementia	Correlational study	N=81 Patients with end-stage dementia, 65 years or older N=81 Caregivers of patients with end-stage dementia Nine nursing homes in a midsize metropolitan area	Patients were video recorded during a possibly painful activity. Caregivers were asked to evaluate the pain of patients based on the images. Comparison between patient-reported Color Analogue Scale results and caregiver-reported Color Analogue Scale and Pain Assessment Checklist for Seniors with Limited Ability	No statistically or clinically significant association between patients' pain ratings and caregivers' pain ratings. No significant relationship was found between caregivers' pain ratings and trained professionals' scores.	Convenience sampling Limited geographic area Despite IRB approval, purposefully placing a participant in a potentially painful situation is an ethics issue

Reference	Study Purpose	Design	Sample/Setting	Methodology	Findings	Limitations
				to Communicate scores measured by trained professionals		Some end-stage dementia patients might not be able to accurately report pain with CAS.
Han, C. J., Chi, N., Han, S., Demiris, G., Parker-Oliver, D., Washington, K., ... Ellington, L. (2018). Communicating caregivers' challenges with cancer pain management: An analysis of home hospice visits. <i>J Pain Symptom Management</i> , 55(5), 1296-1303.	Describe the ways family caregivers of hospice patients communicated their pain-related concerns to nurses during visits and the ways nurses responded to expressed concerns	Qualitative descriptive Secondary analysis	N=65 Hospice nurse visits recording their communication with family caregivers 63 transcribed audio-recorded visits Multiple locations across the US	Audio-recorded unstructured interviews	Four major themes with subthemes: Themes: Nurses providing validation, nurses not addressing concerns, nurses mixed-type responses, nurses providing information to address concerns Subthemes based on caregiver concerns: communication and teamwork issues, medication skills and knowledge issues, caregiver-centric issues (beliefs, fears), end-of-life symptom knowledge issues, patient-centric issues, organizational skill issues	Sample homogeneity (female, white) Secondary analysis of a larger study Unclear methods of sample selection from the larger sample of the original study Unavailable patient and caregiver demographics
Kelley, M., Demiris, G., Nguyen, H., Parker Oliver, D., & Wittenberg-Lyles, E. (2013). Informal hospice caregiver pain	Describe the challenges of caregivers in assessing and managing the pain of hospice patients	Qualitative: Secondary analysis of the previous study	N=29 Caregivers of patients with cancer receiving home-based hospice services	Semi-structured interviews	Six themes: caregiver-centric issues, caregiver inadequate medication skills and knowledge, end-of-	Small sample size Excluded caregivers of non-cancer patients

Reference	Study Purpose	Design	Sample/Setting	Methodology	Findings	Limitations
management concerns: A qualitative study. <i>Palliat Med</i> , 27(7), 673-682.			Two hospice agencies in the Pacific Northwest		life symptom knowledge issues, communication and teamwork issues, organizational skill issues, and patient-centric issues.	Generalizability: Two agencies in the same general area Secondary analysis Sample homogeneity: mostly white, female, and college-educated
McPherson, C., Hadjistavropoulos, T., Lobchuk, M., & Kilgour, K. (2013). Cancer-related pain in older adults receiving palliative care: Patient and family caregiver perspectives on the experience of pain. <i>Pain Research & Management</i> , 18(6), 293-300.	Describe the experiences with the pain of older adults with advanced cancer receiving palliative care services and their family caregivers	Qualitative descriptive	Older adults with advanced-stage cancer receiving palliative services (N=18) Caregivers of older adults with advanced cancer (N=15) One palliative care agency in an unspecified large urban area	Semi-structured interviews	Three major themes: feeling cancer pain (sensory aspects of pain); reacting to cancer pain (patients' and caregivers' attitudes, beliefs regarding pain and emotional responses to it), and living with cancer pain (individual life changes, social and relationship challenges brought forth by pain)	Small sample Caregiver sample homogeneity (mostly white female) Results from a single agency Excludes non-cancer patients
Mehta, A., Chan, L., & Cohen, S. (2013). Flying blind: Sources of distress for family caregivers of palliative cancer patients	Identify sources of distress related to pain management in caregivers of hospice cancer patients	Qualitative descriptive Secondary analysis	N=24 Family caregiver of hospice cancer patients	Semi-structured interviews	Four sources of distress: "like being in prison" (overwhelmed by responsibilities), "flying blind" (lack of	Sample size relatively small Homogeneity of the sample (mostly women)

Reference	Study Purpose	Design	Sample/Setting	Methodology	Findings	Limitations
managing pain at home. <i>Journal of Psychosocial Oncology</i> , 32(1), 94-111.			Interested caregivers referred to researchers by a teaching hospital in Quebec, Canada		adequate knowledge), “lambs to the slaughter” (lack of adequate support) and “it hurts to watch someone you love suffer” (emotionally affected by patients’ suffering).	Recruitment: interested caregivers may have had more concerns than the average general population
Parker Oliver, D., Demiris, G., Wittenberg-Lyles, E., Porock, D., Collier, J., & Arthur, A. (2010). Caregiver participation in hospice interdisciplinary team meetings via videophone technology: A pilot study to improve pain management. <i>Am J Hosp Palliat Care</i> , 27(7), 465-473.	Determine the efficacy of including hospice caregivers in interdisciplinary team meetings by videophone in improving perceptions and concerns regarding pain management	Non-randomized mixed methods design 2 Phases Pilot study	N=68 Hospice patients receiving home services Control (phase 1) n=38 Intervention (phase 2) n=30 N=75 Caregivers of hospice patients Control (phase 1) n=69 Intervention (phase 2) n=34 Two rural hospice agencies in the Midwest	Patients and caregivers enrolled in phase 1 received regular hospice services. Patients and caregivers who enrolled in phase 2 participated in videophone conferences with the team and completed baseline and post-intervention measures Primary outcomes: Caregiver Perceptions of Pain Medicine Questionnaire (CPMQ) Hospice Quality of Life Index (HQLI) Secondary outcomes: Caregiver Quality of Life (CQLI)	Non-significant differences between baseline and post-intervention measures CPMQ p= 0.569 HQLI p= 0.934 CQLI p= 0.869	Small sample size Non-randomization The 2-phase design may be a barrier to generalization Attrition rate >40%

Reference	Study Purpose	Design	Sample/Setting	Methodology	Findings	Limitations
				Communication Anxiety Inventory		
Parker Oliver, D., Wittenberg-Lyles, E., & Washington K. (2013). Hospice caregivers' experiences with pain management: "I'm not a doctor, and I don't know if I helped her go faster or slower." <i>J Pain Symptom Manage</i> , 46(6), 846-858.	Describe the experiences of hospice caregivers related to pain management	Qualitative descriptive	N=38 Caregivers of hospice patients receiving home-based hospice services Two hospice agencies in Midwest	Semi-structured interviews, 14-30 days after patients' deaths	Five themes: difficulties administering medication, concerns with medication side effects, insecurities in assessing pain, issues with communication with and between healthcare team members, memories of unrelieved pain.	Sample homogeneity: mostly white, female. Results from just one general area. Interviews took place shortly after patients' deaths, accounts possibly affected by grief
Tarter, R., Demiris, G., Pike, K., Washington, K., & Parker Oliver, D. (2016). Pain in hospice patients with dementia: The informal caregiver experience. <i>American Journal of Alzheimer's Disease & Other Dementias</i> , 31(6), 524-529.	Describe the pain management challenges of caregivers to hospice patients with dementia	Qualitative descriptive Secondary analysis	N=55 Caregivers of hospice patients with dementia, selected from a larger sample of 514 caregivers participating in a larger trial Two hospice agencies in the Pacific Northwest	Semi-structured audio-recorded interviews with caregivers as a part of a large randomized control trial	Four major themes: difficulty in communicating, lack of consistent guidance and support from healthcare professionals, uncertainty about etiology of pain, and secondary suffering	Results from a limited geographic area Participants had already enrolled in a study aimed at supporting informal caregivers and may have had more concerns than the general population Secondary analysis of audio recordings

APPENDIX H:
THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD DETERMINATION
LETTER



Human Subjects
Protection Program

1618 E. Helen St.
P.O.Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
<http://rgw.arizona.edu/compliance/home>

Date: September 09, 2019

Principal Investigator: Camelia Martin

Protocol Number: 1909952343

Protocol Title: USEFULNESS OF THE ABBEY SCALE IN FAMILY CAREGIVERS' PAIN ASSESSMENT OF HOSPICE PATIENTS WITHOUT THE ABILITY TO SELF-REPORT

Determination: Human Subjects Review not Required

Documents Reviewed Concurrently:

HSPF Forms/Correspondence: *C.Martin-Site Authorization Letter.docx*

HSPF Forms/Correspondence: *Determination of Human Research (Revised)-CameliaMartin.pdf*

Regulatory Determinations/Comments:

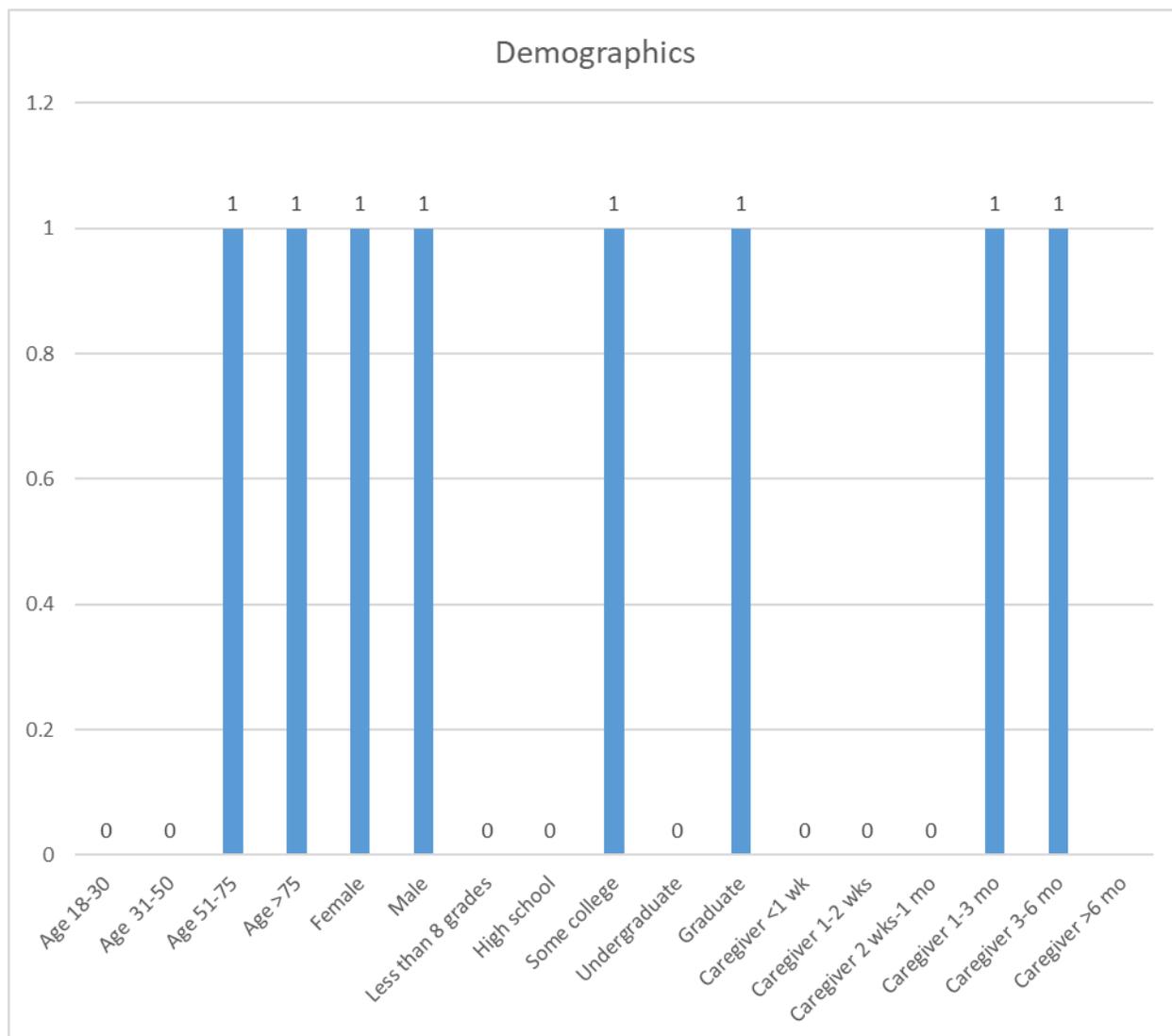
- Not Human Subjects Research as defined by 45 CFR 46.102(e): as presented, the activities described above do not meet the definition of research involving human subjects as cited in the regulations issued by the U.S. Department of Health and Human Services which state that "Human subject means a living individual about whom an investigator (whether professional or student) conducting research: (i) Obtains information or biospecimens through intervention or interaction with the individual, and uses, studies, or analyzes the information or biospecimens; or (ii) Obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens. "

The project listed above does not require oversight by the University of Arizona.

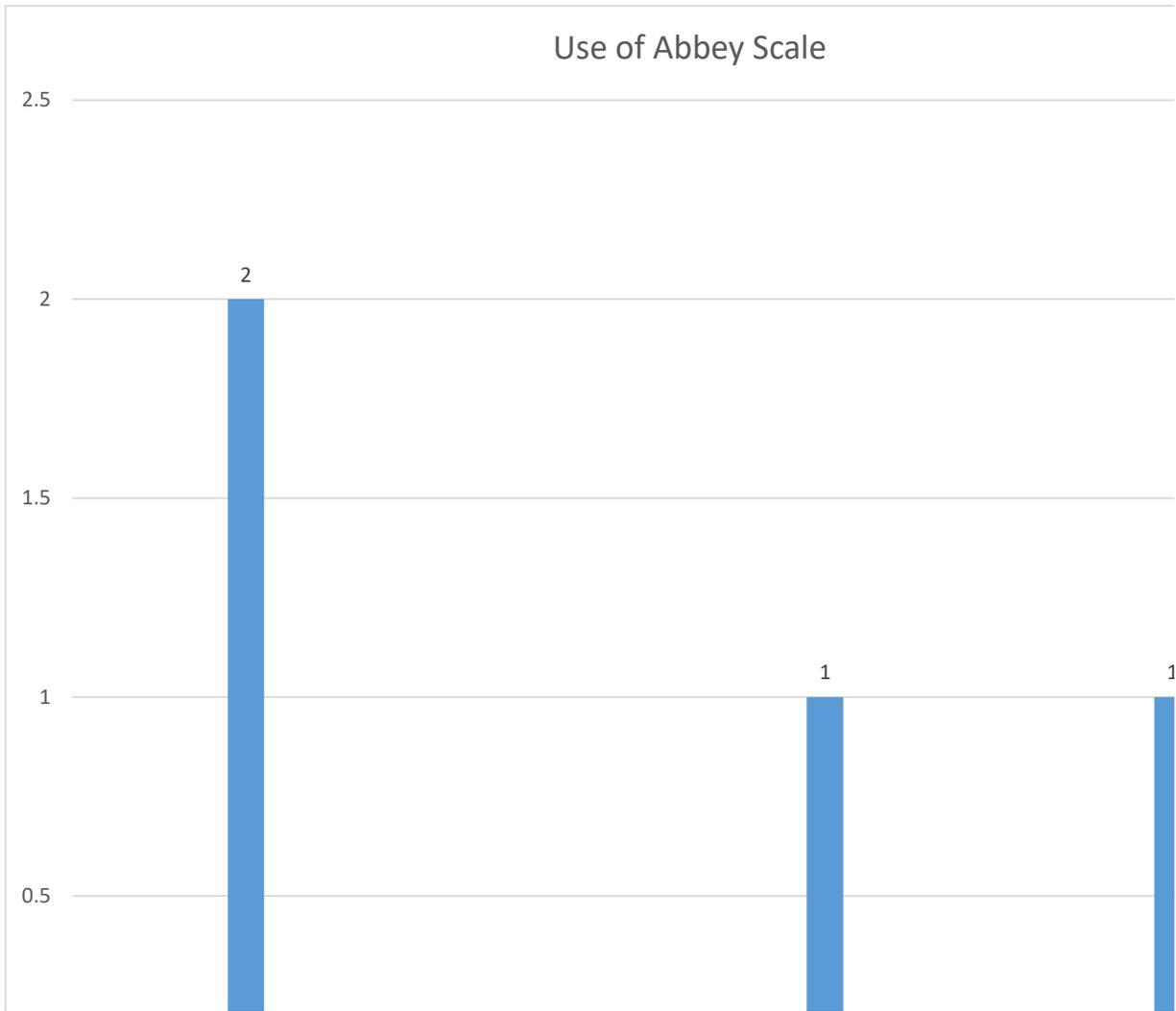
If the nature of the project changes, submit a new determination form to the Human Subjects Protection Program (HSPP) for reassessment. Changes include addition of research with children, specimen collection, participant observation, prospective collection of data when the study was previously retrospective in nature, and broadening the scope or nature of the study activity. Please contact the HSPP to consult on whether the proposed changes need further review.

The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).

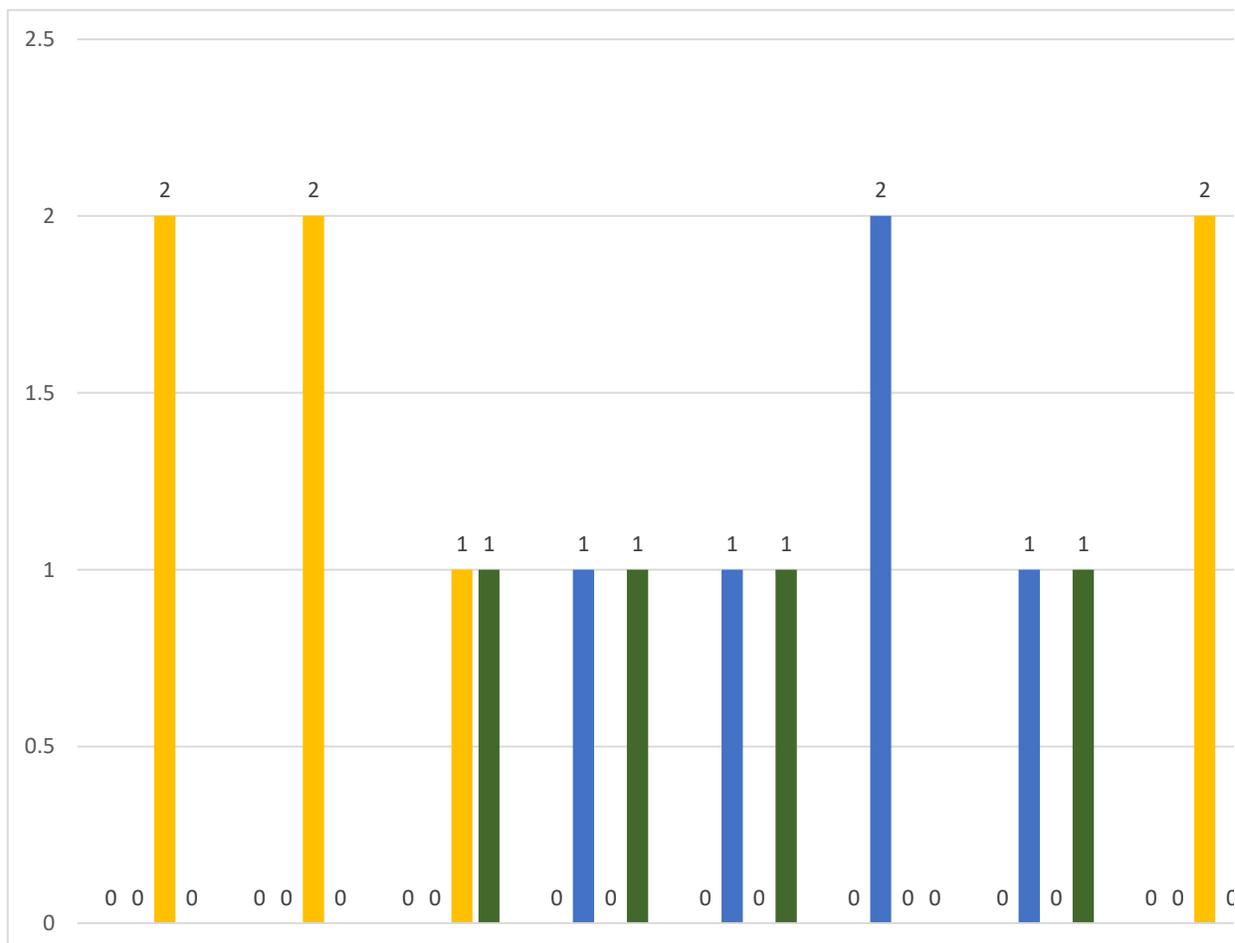
APPENDIX I:
GRAPH REPRESENTATION OF DEMOGRAPHICS



APPENDIX J:
GRAPH REPRESENTATION OF ABBEY SCALE USE



APPENDIX K:
GRAPH REPRESENTATION OF ANSWERS TO LIKERT-STYLE QUESTIONS



REFERENCES

- Abbey, J., Piller, N., De Bellis, A., Esterman, A., Parker, D., Giles, L., & Lowcay, B. (2004). The Abbey pain scale: A 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing, 10*(1), 6-13.
- American Academy of Colleges of Nursing. (2006). The essential of doctoral education for advanced nursing practice. Retrieved from <https://www.aacnnursing.org/DNP/DNPEssentials>
- Ammaturo, D. A., Hadjistavropoulos, T., & Williams, J. (2017). Pain in dementia: Use of observational pain assessment tools by people who are not health professionals. *Pain Medicine, 18*(10), 1895-1907. doi:10.1093/pm/pnw26
- Australian Government Department of Health. (2013). *Abbey pain scale*. Retrieved from <http://www.health.gov.au/internet/publications/publishing.nsf/Content/triageqrg~trriageqr pain~trriageqrg-abbey>
- Cagle, J. G., Zimmerman, S., Cohen, L. W., Porter, L. S., Hanson, L. C., & Reed, D. (2015). EMPOWER: An intervention to address barriers to pain management in hospice. *Journal of Pain and Symptom Management, 49*(1), 1-12.
- Centers for Medicare and Medicaid. (2016). *Medicare hospice utilization by state*. Retrieved from <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/MedicareFeeforSvcPartsAB/Downloads/HOSPICE16.pdf>
- Cheung, C. & Chow, E. (2011). Interpersonal influences between the care provider's burnout and the older care recipient's quality of life. *Administration in Social Work, 35*(4), 425-445.
- Chi, N., Demir, G., Pike, K., Washington, K., & Oliver, D. (2018). Pain management concerns from the hospice family caregivers' perspective. *American Journal of Hospice and Palliative Medicine, 35*(4), 601-611.
- De Witt Jansen, B., Brazil, K., Passmore, P., Buchanan, H., Maxwell, D., Mcilpatrick, S., ... Parsons, C. (2018). "A tool doesn't add anything." The importance of added value: Use of observational pain tools with patients with advanced dementia approaching the end of life: A qualitative study of physician and nurse experiences and perspectives. *International Journal of Geriatric Psychiatry, 33*(10), 1346-1354.
- Eritz, H. & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? *Journal of Pain, 12*(3), 331-339.

- Han, C. J., Chi, N., Han, S., Demiris, G., Parker-Oliver, D., Washington, K., ... Ellington, L. (2018). Communicating caregivers' challenges with cancer pain management: An analysis of home hospice visits. *Journal of Pain and Symptom Management, 55*(5), 1296-1303.
- Hospice Association of America. (2010). *Hospice facts and statistics*. Retrieved from <http://www.nahc.org/assets/1/7/HospiceStats10.pdf>
- Kelley, M., Demiris, G., Nguyen, H., Parker Oliver, D., Wittenberg- Lyles, E. (2013). Informal hospice caregiver pain management concerns: A qualitative study. *Palliat Med, 27*(7), 673-682.
- Koehn, M. (2000). Alternative and complementary therapies for labor and birth: An application of Kolcaba's theory of holistic comfort. *Holistic Nursing Practice, 15*(1), 66-77.
- Kolcaba, K. (2003). *Comfort theory and practice: A vision for holistic health care and research*. New York, NY: Springer Publishing Company.
- Kolcaba, K. (2001). Evolution of the mid-range theory of comfort for outcomes research. *Nursing Outlook, 49*(2), 86-92.
- Kolcaba, K. & Dimarco, M. (2005). Comfort theory and its application to pediatric nursing. *Pediatric Nursing, 31*(3), 187-194.
- Kolcaba, K. Y. & Kolcaba, R. J. (1991). An analysis of the concept of comfort. *Journal of Advanced Nursing, 16*(11), 1301-1310.
- Krinsky, R., Murillo, I., & Johnson, J. (2014). A practical application of Katharine Kolcaba's comfort theory to cardiac patients. *Applied Nursing Research, 27*(2), 147-150.
- Lichtner, V., Dowding, D., Esterhuizen, P., Closs, S., Long, A., Corbett, A., & Briggs, M. (2014). Pain assessment for people with dementia: A systematic review of systematic reviews of pain assessment tools. *BMC Geriatrics, 14*(138).
- Litzelman, K., Skinner, H., Gangnon, R., Nieto, F., Malecki, K., & Witt, W. (2015). The relationship among caregiving characteristics, caregiver strain, and health-related quality of life: Evidence from the survey of the health of Wisconsin. *Quality of Life Research, 24*(6), 1397.
- Lukas, A., Barber, J., Johnson, P., & Gibson, S. (2013). Observer-rated pain assessment instruments improve both the detection of pain and the evaluation of pain intensity in people with dementia. *European Journal of Pain, 17*(10), 1558-1568.
- Macleod, R. (1997). Teaching holism in palliative care and hospice. *American Journal of Hospice and Palliative Care, 14*(1), 12-16.

- McPherson, C., Hadjistavropoulos, T., Lobchuk, M., & Kilgour, K. (2013). Cancer-related pain in older adults receiving palliative care: Patient and family caregiver perspectives on the experience of pain. *Pain Research & Management, 18*(6), 293-300.
- Meeker, M., Finnell, D., & Othman, A. (2011). Family caregivers and cancer pain management: A review. *Journal of Family Nursing, 17*(1), 29-60.
- Mehta, A., Chan, L., & Cohen, S. (2013). Flying blind: Sources of distress for family caregivers of palliative cancer patients managing pain at home. *Journal of Psychosocial Oncology, 32*(1), 94-111.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*(2)
- National Home and Hospice Care Survey. (2004). *Hospice care-data highlights*. Retrieved from https://www.cdc.gov/nchs/nhhcs/nhhcs_hospice_highlights.htm
- National Hospice and Palliative Care Organization (2018). *Facts and figures: Hospice care in America*. Retrieved from https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf
- Nebel, S. (2011). Facing death together: Exploring the conceptualizations of hospice patients and family as a single unit of care. *Journal of Hospice & Palliative Nursing, 13*(6), 419-425.
- New South Wales Government Agency for Clinical Innovation. (2013). *Abbey pain scale*. Retrieved from https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0018/212922/Abbey_Pain_Scale_Final.pdf
- Oliver, D., Wittenberg-Lyles, E., Washington, K., Kruse, R., Albright, D., Baldwin, P., ... Demiris, G. (2013). Hospice caregivers' experiences with pain management: "I'm not a doctor, and I don't know if I helped her go faster or slower." *Journal of Pain and Symptom Management, 46*(6), 846-858.
- Okimasa, S., Saito, Y., Okuda, H., Fukuda, T., Yano, M., Okamoto, Y., ... Ohdan, H. (2016). Assessment of cancer pain in a patient with communication difficulties: A case report. *Journal of Medical Case Reports, 10*(1), 148.
- Orwell, G. (2003). *1984*. New York, NY: Spark Publishing. (Original work published 1949)
- Pace, J. C. & Lunsford, B. (2011). The evolution of palliative care nursing education. *Journal of Hospice & Palliative Nursing, 13*(6 Suppl), S8-S19.

- Parker Oliver, D., Demiris, G., Wittenberg-Lyles, E., Porock, D., Collier, J., & Arthur, A. (2010). Caregiver participation in hospice interdisciplinary team meetings via videophone technology: A pilot study to improve pain management. *Am J Hosp Palliat Care*, 27(7), 465-473.
- Polit, D. F. & Beck, C. T. (2016). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.). Philadelphia, PA: Wolters Kluwer Health Lippincott Williams & Wilkins
- Sheu, E. D., Versloot, J., Nader, R., Kerr, D., & Craig, K. (2011). Pain in the elderly: Validity of facial expression components of observational measures. *The Clinical Journal of Pain*, 27(7), 593-601.
- Spradley, J. (1979). *The ethnographic interview*. New York, NY: Holt, Rinehart & Winston
- Tarter, R., Demiris, G., Pike, K., Washington, K., & Parker Oliver, D. (2016). Pain in hospice patients with dementia: The informal caregiver experience. *American Journal of Alzheimer's Disease & Other Dementias*, 31(6), 524-529.
- Townsend, A., Ishler, K., Shapiro, B., Pitorak, E., & Matthews, C. (2010). Levels, types, and predictors of family caregiver strain during hospice home care for an older adult. *Journal of Social Work in End-of-Life & Palliative Care*, 6(1-2), 51-72.
- The University of Wisconsin. (2010). *Survey fundamentals: A guide to designing and implementing studies*. Retrieved from https://oqi.wisc.edu/resourcelibrary/uploads/resources/Survey_Guide.pdf
- U. S. Department of Health and Human Services. (1979). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. Retrieved from <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>
- Weiss, S. C., Emanuel, L. L., Fairclough, D. L., & Emanuel, E. J. (2001). Understanding the experience of pain in terminally ill patients. *The Lancet*, 357(9265), 1311-1315.
- Whitecar, P., Jonas, A., & Clasen, M. (2000). Managing pain in the dying patient. *American Family Physician*, 61(3), 755-64.
- Wilson, L. & Kolcaba, K. (2004). Practical application of comfort theory in the perianesthesia setting. *Journal of Perianesthesia Nursing*, 19(3), 164-173.
- Woodhouse, J. & Baldwin, M. (2011). *Key concepts in palliative care*. London, UK: Sage Publications.

Zheng, N. T., Li, Q., Hanson, L. C., Wessell, K. L., Chong, N., Sherif, N., ... Rokoske, F. (2018). Nationwide quality of hospice care: Findings from the centers for Medicare & Medicaid services hospice quality reporting program. *Journal of Pain and Symptom Management*, 55(2), 427-432.e1.