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Nurse Practitioner Intervention in Palliative Care Settings Benchmark Project

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The University of Texas at Tyler School of Nursing

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Contents

Acknowledgements

Executive Summary

Benchmark Study

1. Rationale for the project

1.1 Project Goals

2. Literature synthesis

3. Stakeholders

4. Implementation

5. Timetable/Flowchart

6. Data collections methods

7. Cost/benefit discussion

8. Results

9. Recommendations

Conclusion

References

Appendix

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Executive Summary

Palliative care is an area that continues to grow in the United States annually, as chronic disease becomes more prevalent related to numerous factors. According to the Center of Advance Palliative Care (2018), while the continued growth of palliative care in the nation reflects a great example of healthcare innovation, there is still much work to do to assure patients with serious illness have access to healthcare needs. Because change and necessity in resources are lacking in palliative care, many gaps in care exist in community-based settings that directly affect patients, families, and organizations poorly. Examples of poor outcomes are symptom management, quality of life, advanced care planning, caregiver burnout, and unnecessary utilization of emergency departments (ED) and hospitalizations. Various end of life symptoms, such as shortness of breath, pain, anxiety, and depression, present in chronic disease processes like congestive heart failure, chronic obstructive pulmonary disease, and cancers. Poor symptom management influences poor quality of life. In addition, lack of in-home management can increase caregiver burnout and neglect advanced care planning. Use of ED and hospitalizations by chronically ill patients can lead to financial burdens and loss for organizations; from a patient perspective, temporary relief of chronic illness in the hospital can cause furthermore unmanaged feelings in the home and repetitive ED visits for care. Because innovation is required for change to influence optimal health outcomes, strategic implementation of a single provider is essential in palliative care settings to bridge gaps. Therefore, in palliative care settings, it is recommended to utilize nurse practitioner (NP) interventions to influence optimal outcomes.

Nurse Practitioner Intervention in Palliative Care Settings

Palliative care is a specialty of healthcare that focuses on chronic and severe disease. As chronic disease continues to rise annually related to genetics, sedentary lifestyle, and environmental factors, the need for interventions will increase to meet demands of patients, families, and organizations. Therefore, implementation of a nurse practitioner in the palliative care setting is ideal for optimal patient outcomes.

1. Rationale for the Project

Annually, chronic disease is held accountable for causing seven out of ten deaths in the United States, killing over one million Americans each year (Raghupathi & Raghupathi, 2018). Because the specialty of palliative care consists of healthcare for the chronically and severely ill population, the prevalence and increase of disease pushes rationale for effective palliative care measures. Lack of providers, unplanned pandemics, and geographical location heavily influence poor outcomes for patients in community-based palliative care settings. The current lack of interventions for optimal outcomes furthermore leads to bothersome outcomes for patients and families as well as poorly impacts stakeholders and organizations. When using innovation to understand how gaps in care could be bridged from a healthcare and business model to influence best outcomes, utilizing a single provider in the community has suggested optimal outcomes from a variety of studies. According to Schelin et al. (2018) in a cohort study, superior quality of care was present in patients who received specialized palliative care during the last week of life compared to patients in other settings who lack the specialized care. While several different in-home programs exist to promote safety and optimal health, such as tele-medicine, hospice, and home health companies, the lack of an advanced practice registered nurse (APRN) can lead to failure. The scope of practice for the nurse practitioner exceeds the registered nurse scope of

practice that is commonly used in those specific programs. As an APRN, education from a pathophysiological standpoint, immediate intervention in the home, continuation of in-home care, and expertise in areas of social services can lead to prompt intervention and immediate coordination of care for the vulnerable population. In addition, APRNs may close gaps in community-based settings at a lower cost for organizations with the necessary credentials versus physicians. Therefore, the rationale for benchmark is not related to a single factor, but rather, encompasses interventions that promote best outcomes for patients, families, and organizations.

1.1 Project Goals

The goal of the benchmark project is to bring awareness and influence change in palliative care settings. With having experience in hospice and palliative care, nurses witness gaps in care that influence negative results. Many gaps in care revolve around lack of education on disease process, prognosis, symptom management, and medication regimen. These gaps have led to ED visits and hospitalizations for short term management on irreversible disease. Another project goal is to reflect how in-home NP intervention improves bothersome symptoms. By results of adequate management, the intervention can be a strategy to meet demands and needs of all involved and create a pathway for future chronic disease.

2. Literature Synthesis

Evidence based practice (EBP) developed through qualitative and quantitative studies suggest that several gaps in care exist in palliative care resulting in poor patient outcomes. Furthermore, specific outcomes, such as hospitalizations, symptom management, advanced care planning, quality of life, and caregiver burnout, can be positively targeted by NP intervention in the palliative care setting to better serve patients, families, and corporations.

A cohort study by Miller et al. (2016a) focused primarily on how NP interventions in patients who qualify for palliative care services in nursing homes improved patient outcomes by decreasing hospital mortality as well as end of life hospitalizations. According to the study outcomes, NP interventions reflected a three percent decrease in hospitalization in the last thirty days of life versus no nurse practitioner intervention. In addition, hospital mortality rates decreased by two percent for deaths overall by implementation of NP interventions versus lack of NP interventions (Miller et al., 2016a).

A randomized control trial (RCT) by Miller et al. (2016b) reflected a decrease in hospitalizations and emergency department visits related to symptom management and/or exacerbations in patients who qualified for palliative care services in nursing home settings. Study outcomes suggested that lower rates of hospitalizations occurred with patients who had palliative care consultations via NPs; also, there were less emergency room visits and hospitalizations reflected for those who received NP palliative care sooner rather than later in the chronic disease process. Bothersome or burdensome transition rates appeared to be lower with patients who had NP consultations within three to six months from the date of death.

In a quality improvement project by Mitchell et al. (2016), the study suggested positive outcomes related to the implementation of NP interventions in palliative care in rural areas. Of the areas of positive influence, depression rates among patients were decreased related to NP interventions, influencing overall better quality of life. In addition, anxiety decreased among patients related to NP influences. Hospital mortality, hospitalizations in general, and emergency department visits all decreased in patients on palliative care services in rural areas related to direct NP consultation and intervention, affecting not only the patient and families but also organizations for better outcomes.

A cohort study by Rogers et al. (2017) reflected significance in how NP interventions plus usual care in palliative care drastically improved several areas of outcomes versus only usual care for heart failure patients. First, quality of life and functionality significantly increased in patients who received NP intervention with usual care in trials versus controlled trials without NP intervention. In addition to quality of life, spiritual well-being increased for patients on palliative care services when NP led palliative care was consolidated with usual care versus usual heart failure care alone. Lastly, anxiety and depression scores significantly improved in patients with heart failure on palliative care services related to the combination of therapy and interventions that deviated from the usual care provided (Rogers et al., 2017).

A cohort study by Walling et al. (2017) suggested that NP interventions positively influenced outcomes by reflecting the benefits of long-term support such as advanced care planning, hospice referral, and psychosocial support. Knowingly, NP intervention in multiple settings decreased the risk of hospitalizations; however, NP involvement in oncology proposes that advanced care planning, hospice referral, and psychosocial support were better coordinated and followed through when a nurse practitioner was able to educate, influence, and guide patients and caregivers during the disease process. By early intervention in end of life care, caregivers may feel less pressured in making permanent, major medical decisions for loved ones, and could better honor patient end of life care requests. In addition, this could improve the well-being of each individual patient and caregivers involved (Walling et al., 2017).

In a cohort study by Fedel and Pennington (2019), NP palliative care interventions reflected significance regarding patient care coordination, psychosocial support, and advanced care planning. In addition, the advanced practice nurse (APN) provided insight and care

coordination with the palliative care team by implementing a holistic care approach in palliative care patients that corresponded with the trajectory of the illness.

In a study by Martin and Roeland (2018), a randomized control trial was used to reflect how nurse led palliative care interventions concurrent with oncological care impacted specific patient outcomes. NP intervention along with oncological care showed significant increase in quality of life and depression with patients compared to patients without NP palliative care interventions.

In a qualitative study by Dusseldorp et al. (2018), Colaizzi's seven step method and Metaphor Identification Procedure were used to analyze and present how patients view nurse practitioners and NP interventions in a palliative care (or oncological) setting. Six themes included NP as humans, professionals, providing care, cure, organizing patient care, and significant impact on patient well-being. In addition, metaphorically speaking from the patient perspective, NPs were symbolically trusted. Many patients stated that the NP felt like "a warm nest, a sympathetic ear" (Dusseldorp, 2018, p. 597), and that trust and expertise of the NP was key to relationship. Next, the NP was viewed as a travel aid, with the ability to answer urgent questions and having availability in crisis and/or time of need for patients and families. Furthermore, NPs were viewed as a combat unit. Patients felt metaphorically that the NP was a "partner in crime" and a person that could "fight against cancer" with the patient individually (Dusseldorp, 2018, p.598). Like a chain or link, the NP was also voiced by patients to be the "connector of illness" (Dusseldorp. 2018, p .599) and vital in coordination of patient care. The NP served as a signpost for patients by guiding them in the correct direction to continue life and accomplish daily goals. Lastly, the NP served as a technician by performing maintenance

inspections for patients that varied from lab reviews, head to toe assessments, medication management, or assessment of feelings and empathy (Dusseldorp et al., 2018).

A qualitative study by Bagcivan et al. (2017) evaluated early versus delayed NP palliative care consultations in patients with newly diagnosed advanced cancer in rural areas. According to the outcomes, areas addressed were general evaluations consisting of marital/partner status, spiritual and emotional well-being, and family and/or caregiver support. Also, specific symptoms, such as mood, depression, pain, and cognitive mental status were addressed and managed versus not intervention. General treatment recommendations included counseling, current medications, and new medication regimens. Symptom management involved pain, constipation, and depression. Lastly, advance directives, identification of surrogacy, and trajectory of illness were addressed with patients. Compared to the delayed group, early implementation of palliative care consultation by the NP was significant in evaluation of general pain, hospice awareness, and discussion of hospice for better management of care (Bagcivan et al., 2017).

When focusing on hospice enrollment, a cohort study by Riggs et al. (2016) and a randomized control trial by Hanson et al. (2019) both supported and reflected how nurse practitioner intervention in palliative care settings increased the rate of hospice enrollment and advanced care planning.

Concluding, a randomized control trial by Hoerger et al. (2018) supported that nurse practitioner intervention in palliative care affected outcomes by decreased hospitalizations, improved quality of life, and increased advanced care planning.

3. Stakeholders

When considering change, it is important to identify and consider stakeholders that will be most affected. For the benchmark project plan, the stakeholders include administration of Texas Palliative Care (Pathways), Hospice of East Texas, and major hospitals of East Texas. When poor outcomes arise in the community, such as lack of in-home symptom management, patients have an increased risk of emergency department use and/or hospitalization. The increase in hospitalizations directly affects hospitals by costs of care as well as Hospice of East Texas if the patient chooses revocation of services for curative treatment versus comfort care. In addition, Texas Palliative Care is affected with the need for alternate interventions for care. One reason the implementation is ideal is that the intervention could increase education and lead to prevention of unnecessary hospitalizations that directly affect all stakeholders negatively. In addition, direct staff are also affected by change or lack of interventions leading to poor outcomes, such as nurses and doctors of all organizations. The increase in-patient care requires an increased demand of staff to accommodate. Therefore, considering the stakeholders and using evidence-based practice to suggest change is vital for benchmark success.

4. Implementation

Although the opportunity for implementation was unavailable for nurse practitioner intervention in palliative care, the benchmark project still requires a detailed plan for implementation. Outcomes measured are qualitative or quantitative meaning that the tests or assessments completed for results will vary. For hospitalizations and emergency department visits, quantitative statistics are used in descriptive forms using numbers. These outcomes can be easily assessed as one visit, two visits, and continued.

For advanced care planning, symptom management, quality of life, advanced care planning and caregiver burnout, questionnaires and qualitative data are used more for results. An

example of a tool used for symptom management and quality of life is the functional assessment of chronic illness therapy- palliative care (FACIT-Pal) (eProvide, 2020). Likewise, the Zarit assessment tool is used primarily for caregiver burnout (Emory University, 2020). Advanced care planning is qualitative and available in forms, such as do not resuscitate orders or advanced directives. It is important to have a foundational knowledge on the differences between the tools, qualitative and quantitative, to understand the plan of implementation will occur. In addition, understanding the tools themselves allows the nurse practitioner to make changes at each visit or telephonic call for optimal outcomes.

Having a foundation of knowledge in the assessment tools brings forth the first step of the plan: educate the practitioner on the use and interpretation of the assessments. The day prior to implementation, the provider can take one hour to review the assessments and ask questions if needed. Also, within this hour, the practitioner can begin to develop ideas for interventions depending on poor scores or decreasing scores. An example would be from the FACIT- pal: “are you having pain?” If pain is present, the practitioner can adjust or add pain medications to better meet symptom management needs for optimal outcomes. For the Zarit assessment, if the caregiver score of burnouts is high, the nurse practitioner can suggest resources for care in the home for optimal outcomes.

After understanding and brief education of the assessments, the flow of the trial should be discussed with the provider. The number of participants ideally would be between five and ten patients for the trial. The patients would be selected on the following suggested criteria: discharged within one month of the hospital or emergency department and enrolled into Texas Palliative Care. Implementation of the plan is divided among weekly increments for a duration of eight weeks as follows:

- Week one, day one: Initial face to face visit to discuss disease specific process, prognosis, and pathophysiology, review medications, and explain what each medication is for. Assess need for DME; assess caregiver support, assess potential gaps in care, such as support in home, availability to receive prescriptions, and diversity. Review insurance benefits and see if home health, or insurance related nursing is available for alternate resources if needed. Stress the importance of compliance to advice and how to manage immediate symptoms of specific disease processes. Educate on ED precautions versus telephonic advice to NP and the palliative care team. Complete FACIT-Pal and caregiver burnout assessments as baseline. Estimate time: two hours.
- Week one, day two: Complete a telephonic call to reassess needs or concerns from initial face to face visit. Re- educate on ED precautions versus telephonic call to the palliative care team. Estimated time: thirty minutes.
- Week one, day five: Complete telephonic call to address needs or concerns. Assess overall condition and symptoms if any are present. Assess caregiver stress. If the patient/caregiver is having issues, assess to see if issues can be managed via telephone with education or if a face to face visit is needed. An example is a congestive heart failure patient who reports shortness of breath and a five-pound weight gain overnight. This would suggest a planned face to face visit rather than telephonic assessment for optimal care. Plan next face to face visit for week two during the call. Estimate time: thirty minutes.
- Week two, day one: complete face to face visit. Complete disease specific assessment and adjust interventions as needed for outcomes. Review medications, concerns, and fears. Encourage the patient and families to call for assistance or needs. Complete

FACIT-Pal and Caregiver burnout assessments and compare to baseline. Estimated time: one hour.

- Week two, day four: Complete telephonic call to assess needs. Discuss changes in condition with disease specific assessment. Assess caregiver. Assess overall needs. If there are needs or symptoms that require management within 48 hours that may affect patient outcomes, anticipate face to face visit for changes and education. Plan next face to face visit. Estimated time: thirty minutes.
- Week three, day one: Complete face to face visit. Discuss needs, changes, and disease specific educational needs. Assess medications. Assess compliance. Assess needs for interventions. Estimated time: one hour.
- Week three, day four: Complete telephonic call to assess needs. Discuss changes in condition with disease specific assessment. Assess caregiver. Assess overall needs. If there are needs or symptoms that require management within 48 hours that may affect patient outcomes, anticipate face to face visit for changes and education. Plan next face to face visit. Estimated time: thirty minutes.
- Week four, day one: Complete face to face visit. Discuss needs, changes, and disease specific educational needs. Assess compliance. Assess needs for interventions. Estimated time: one hour.
- Week four, day four: Complete telephonic call to assess needs. Discuss changes in condition with disease specific assessment. Assess caregiver. Assess overall needs. If there are needs or symptoms that require management within 48 hours that may affect patient outcomes, anticipate face to face visit for changes and education. Plan next face to face visit. Estimated time: thirty minutes.

- Week five, day one: Complete face to face visit. Discuss needs, changes, and disease specific educational needs. Assess medications. Assess compliance. Assess needs for interventions. Estimated time: one hour.
- Week five, day four: Complete telephonic call to assess needs. Discuss changes in condition with disease specific assessment. Assess caregiver. Assess overall needs. If there are needs or symptoms that require management within 48 hours that may affect patient outcomes, anticipate face to face visit for changes and education. Plan next face to face visit. Estimated time: thirty minutes.
- Week six, day one: Complete face to face visit. Discuss needs, changes, disease specific educational needs. Assess medications. Assess compliance. Assess needs for interventions. Estimated time: one hour.
- Week six, day four: Complete telephonic call to assess needs. Discuss changes in condition with disease specific assessment. Assess caregiver. Assess overall needs. If there are needs or symptoms that require management within 48 hours that may affect patient outcomes, anticipate face to face visit for changes and education. Plan next face to face visit. Estimated time: thirty minutes.
- Week seven: Discuss discharge planning and assess needs for home health, hospice, long term care, or in-home assistance. Complete disease specific comprehensive assessment and review medications. Discuss discharge planning and educate on process as well as ED precautions and safety.
- Week eight: Complete discharge with disease specific education, review of medications, refill medications as needed. Educate on safety and emergency room precautions versus primary care visit/phone call. Complete comprehensive assessment. Assure physicians

are in place for continuation of care, at minimal, a primary care physician with a planned follow up appointment.

FACIT- Pal and caregiver burnout assessments are to be completed upon admission, on week two, four, six, and eight. While advance care planning is an important part of palliative care, hospice services and advance directives should be addressed near week six to eight, once the report is built with patients and families prior to the end of the interventional trial.

5. Timetable/Flowchart

Project Phases	Project Dates
Pre project Preparation Day	Monday, August 10, 2020
Week one, Day one/Admission	Tuesday, August 11, 2020
Week one, Day two	Wednesday, August 12, 2020
Week one, Day five	Saturday, August 15, 2020
Week two, Day one	Monday, August 17, 2020
Week two, Day four	Thursday, August 20, 2020
Week three, Day one	Monday, August 24, 2020
Week three, Day four	Thursday, August 27, 2020
Week four, Day one	Monday, August 31, 2020
Week four, Day four	Thursday, September 3, 2020
Week five, Day one	Monday, September 7, 2020
Week five, Day four	Thursday, September 10, 2020
Week six, Day one	Monday, September 14, 2020
Week six, Day four	Thursday, September 17, 2020
Week seven, Day one	Monday, September 21, 2020
Week eight, Day one/Discharge	Monday, September 28, 2020

Providing a flowchart or timetable of events during the benchmark project allows visualization of anticipated progress. Each week, as stated in the implementation discussion, is broken down into sub days for nurse practitioner interventions. Interventions and skills may vary based on severity or exacerbation of illness. In addition, hospitalizations, emergency department visits, and/or deaths may change the trajectory of the flowchart. In addition, calls may change to visits if outcomes appear to change for the worse. Anticipated start date of

benchmark will be Monday, August 10, 2020 and continue through anticipated discharge on Monday, September 28, 2020.

6. Data Collections Methods

Understanding the methods of data collection in the benchmark project is a vital part of supporting evidenced based practice. The variation of outcomes and types of methods used to view results causes different approaches to capturing data. The outcomes assessed consist of both quantitative and qualitative data, meaning that the data across the board will not be the same.

For quantitative studies, such as hospitalizations and emergency department visits, descriptive statistics will be utilized. For example, there is simplicity in calculating how many visits each patient did or did not have during the project from admission until discharge. Participants will have zero visits up to unlimited number of visits to count. On the contrary, alternate outcomes, such as symptom management, caregiver burnout, and quality of life, use mixed methods approach, such as qualitative data and inferential statistics for data. Symptom management and quality of life assessments are obtained using the FACIT Pal assessment (eProvide, 2020). Shortness of breath, pain, nausea, emotional well-being, and functional wellbeing are areas addressed that assist providers in understanding needed interventions for optimal patient outcomes. The scale uses a numerical rating that ranges from zero to four, with zero being not at all, up to four, indicating very much. When the patient and family are asked about specific areas of symptom management and quality of life, the patient and/or family can rate the outcomes. Based on the rates during the trial, the nurse practitioner can assess the feedback of the scales to determine further interventions and unmet palliative care needs for

further intervention as needed. Using this tool to collect data can support if specific interventions were therapeutic or nontherapeutic to influence optimal health outcomes.

According to Emory University (2020), several different assessments are available for caregiver burnout. Like the FACIT- pal assessment, the Zarit caregiver stress self-assessment is a tool that is qualitative in nature that allows the caregiver to assess overall stress of caring for the patient in the home. It consists of twenty items that allow the caregiver to assess stress from no stress to severe stress. As the trial progresses, the nurse practitioner can assess the caregiver burnout tool and alternate outcomes to determine if caregiver's stress is responsible for less than optimal outcomes. This tool can assist the provider with interventions and needs in the home for the caregiver to influence optimal patient outcomes in palliative care settings, such as hospice referral, in home care, or other social support needs. Lastly, advance care planning is qualitative, but the data collection can vary. Do not resuscitate orders, advance directives, or verbal consent of curative measures all are data obtained by the patient and/or caregiver, and at any time, are subject to change. Therefore, assessing advance care planning needs as previously mentioned allows the most up to date data and needs for the participant and family.

7. Cost/Benefit Discussion

Although the integrity of healthcare revolves around patient needs and advocacy, costs and benefits are essential for healthcare. Stakeholders, such as Hospice of East Texas, Texas Palliative Care, and major hospitals in East Texas, expect that change and implementation of the benchmark must reflect a benefit and refrain from cost deficit. Hiring a nurse practitioner for palliative care interventions in the community is costly. Financial barriers could be an issue; therefore, proposing the pay for face to face visits on an hourly basis for trial periods could assist in change. Documentation of phone calls and visits can be done by the NP without electronic

record and kept systematically written for review of assessments and interventions. Associated costs for mileage reimbursement for face to face visits and management of patient care will be included. If interventions are significant on outcomes, proposal of a salaried NP for community-based palliative care in the home setting would be needed for ongoing intervention, roughly estimated at 120k-130k per year. According to Jackson et al. (2018), the average cost for one hospitalization for a heart failure patient was \$11,552. If implementation of change is successful, the proposed salary cost of the NP would be beneficial (profitable) if only twelve advanced heart failure patients were better managed in home settings to decrease one exacerbation leading to hospitalization in a twelve-month period. Therefore, having an APRN or NP, that is familiar with palliative care and experienced in the trajectory of illness, is important for positive patient outcomes in the home setting and to decrease costs of necessary training.

Outside from financial benefits and aspects of the capital economy, implementing a nurse practitioner in palliative care also impacts positive outcomes from the patient point of view. According to Wheeler (2016), the nurse practitioner can care for, advocate, and advise patients at every stage of any life limited disease. Relieving suffering is the primary goal of palliative care and allowing patients and families to have interventions in home to improve symptom management, quality of life, and assist with caregiver needs promotes beneficence during the end times of life. Concluding on benefits of the benchmark, community-based palliative care remains in infancy across the United States. Success of the benchmark can lead the way for an expansion of the intervention across the states for optimal outcomes.

8. Results

When considering results for patient outcomes, results will vary due to the diversity of patient outcomes planned to assess. For this specific benchmark, as previously mentioned,

patient outcomes include hospitalizations and/or emergency department visits, symptom management, quality of life, advanced care planning, and caregiver burnout. Because palliative care and severe illnesses significantly impact organizations, providers, patients, and families, this benchmark ideally will support how nurse practitioner intervention can improve multiple patient outcomes, that will in return, alleviate poor outcomes on organizations. Hospitalizations and emergency department visits ideally will be less than two per participant or be nonexistent during the trial. While zero emergency department visits and/or hospitalization in the eight-week trial significantly suggest success of the benchmark project, diversity and patient/family wishes and the autonomy in care are still ethically important to consider. Another example of success on the benchmark planned project, when considering emergency department visits or hospitalizations, is the prevention of financial deficit if twelve participants avoided hospitalizations over the eight week trial, as twelve heart failure patients hospitalization equal an annual nurse practitioner salary (Jackson et al., 2018).

When considering the FACIT-Pal assessment for symptom management and quality of life, success can be measured if each patient's score improves in a positive direction by two points from the first assessment on week one to the last assessment discharge on week eight. For example, GP4 on the FACIT-Pal under physical well-being asks if there is pain present. If a patient scores a four upon admission indicating very much pain is present, scoring a two upon discharge FACIT-Pal would suggest success in symptom management for pain. While some areas of the assessment may not improve by two points, this is where the importance of the APRN assessment and interpretation is necessary for each disease specific symptom. Congestive heart failure symptom management would vary from a patient with end stage acquired immunodeficiency syndrome. In addition to symptom management, the same criteria

will be used to measure success on the FACIT-Pal for quality of life. Another example from the assessment is GF3 under functional well-being. The question asks if a patient can enjoy life. Upon admission and post hospitalization, the patient may indicate zero, not at all. However, by week eight, if the patient's score increases from zero, not at all to a two indicating somewhat, this is success of benchmark intervention reflecting quality of life. It is important to also add that the nature of palliative care may determine the scores of the FACIT-Pal to be unsuccessful. For example, if a patient is referred to hospice due to actively dying status, symptoms of congestive heart failure, like pulmonary edema, may not improve; however, specific medications can decrease the pain and shortness of breath from pulmonary edema. Therefore, extensive education may need to be provided to the patient and family on realistic scoring of management.

Caregiver burnout results can be measured as successful if the total score of the Zarit assessment is less than twenty upon week eight of discharge, as a score of twenty or higher is an indication of caregiver burnout (Emory University, 2020). Lastly, advance care planning can be measured as success if the patient and/or family has verbal or written advanced care planning upon discharge of week eight. Examples of advanced care planning may be do not resuscitate orders, advanced directive, appointed medical power of attorney, and/or hospice referral. If any areas are not successful, the lack of success does not indicate failure of the intervention. This may simply be suggestions on what the nurse practitioner can improve on or areas that stakeholders may choose to focus on individually rather than holistically in palliative care. In addition, lack of success in specific outcomes but success in alternate outcomes mentioned may reduce time of visits and calls, in return, decreasing financial means for the interventions.

9. Recommendations

Based on the plan of the benchmark project that was suggested by twelve evidenced based practice articles, it is recommended to implement nurse practitioner intervention in settings in which patients qualify for palliative care. Hospitals, skilled nursing facilities, assisted living facilities, and home patients could all benefit from the project, as poor outcomes lead to increase in hospitalizations, revocations from hospice services, and patient/family dissatisfaction. It is also recommended to educate patients and families on palliative care early in disease processes.. Hospitals may benefit from palliative care referrals in patients who return to the emergency department or hospital for care for the same advanced disease more than once in thirty days in an attempt for palliative care to meet the needs and demands of specific vulnerable patients. The benchmark is focused on palliative care; however, this idea may be useful in all patients who are deemed as high risk with illness, noncompliant patients, or patients who often heavily utilize the emergency department. Managed care organizations that managed Medicaid, such as United Healthcare or Cigna, may also benefit from the intervention as an effort to decrease Medicaid expenses utilized nationwide.

Conclusion

Palliative care is a growing specialty that cares for patients with severe illness. While may gaps in care exist with severe illness, such as bothersome symptoms, lack of providers, and fear of the future, the benchmark project can influence and support change in healthcare by influencing optimal outcomes in palliative care patients. Hospitals and emergency department visits are short term in duration, symptom management, and relief of caregiver burnout; however, implementing a nurse practitioner for palliative care needs suggests optimal outcomes in all areas addressed.

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Appendix A

Evaluation Table

Evaluation Table Template

<p>PICOT Question:</p> <p>In patients that qualify for palliative care (P), how does nurse practitioner intervention (I) compared to no nurse practitioner intervention (C) affect patient outcomes (O) in 8 weeks (T)?</p>
<p>PICOT Question Type (Circle): Intervention Etiology Diagnosis or Diagnostic Test Prognosis/Prediction Meaning</p>

Caveats

- 1) The **only studies** you should put in these tables are the ones that **you know answer your question** after you have done rapid critical appraisal (i.e., the keeper studies)
- 2) Include APA reference
- 3) Use abbreviations & create a **legend** for readers & yourself
- 4) Keep your descriptions brief – there should be **NO complete sentences**
- 5) This evaluation is for the purpose of knowing your studies to synthesize.

Place your APA Reference here (Use correct APA reference format including the hanging indentation):

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Citation: (i.e., author(s), date of publication, & title)	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Strength of the Evidence (i.e., level of evidence + quality [study strengths and weaknesses])
Miller et al. (2016b). Palliative care consultations in nursing homes and reductions in acute care use and potentially burdensome end-of-life transitions.	NONE	Cohort, descriptive, quantitative.	2 PCC; 2 states (NC, RI). Exclusive to 2 counties; 2005 – 2010; MCR enrolled, MDS positive within 180 days; 46 NF, n=477. End point; palliative care deaths prior to end of study related to nature.	IV: NH palliative care consultations by NP with palliative care expertise DV: burdensome outcomes, acute care utilization. (H 7 days, H 30 days, H 60 days; ED 30 days; ED 60 days; BST <7 days, 8-30 days, 31-60 days, 61-180 days.)	CI <i>p</i> value	Multivariate regression (to identify potential outcomes) Wald Chi Square Linear modeling Log link function	H 7 days: <7: 20.8 (16.9–24.6) <i>p</i> =0.008 8-30: 11.1 (9.8–12.4) <i>p</i> =0.002 31-60: 13.1 (10.4–15.7) <i>p</i> =0.014 61-180: 6.9 (5.5–8.4) <i>p</i> <0.001 H 30 days: 31-60: 22.6 (18.6–26.6) <i>p</i> =0.07 61-180: 15.4 (12.6–18.2) <i>p</i> <0.001 H 60 days: 61-180: 26.9 (23.0–30.9) <i>p</i> =0.003 ED 30 days: 31-60: 8.3 (5.4–11.2) <i>p</i> =0.02 61-180: 10.8 (8.5–13.0) <i>p</i> =0.50 ED 60 days: 61-180: 16.2 (13.4–18.9) <i>p</i> =0.26 BST <7: 41.6 (36.5–46.7) <i>p</i> =0.99 8-30: 28.4 (25.8–31.0) <i>p</i> =0.64 31-60: 22.6 (19.4–25.8) <i>p</i> =0.27	Strengths: use of rigorous methods; effect measures and outcomes Limitations: physician biased; conflict of interest; retrospective design Feasible: YES LOE: IV No risk nor harm USPSTF: B LOC: moderate

							61-180: 16.2 (13.7–18.6) <i>p</i> =0.004	
Miller et al. (2016a). Palliative care consultations in nursing homes and end-of-life hospitalizations.	None; PC impact on NH is unknown.	Quantitative; cohort descriptive	170 of 286 NH; 4 hospices certified of need states; 24 counties; open <3 years with < 3 years data; under seven providers	IV: NH NP PCC DV: PO, EOLH deaths	CI Coefficient	<i>SD</i> (mean) Multivariate [statistics (NH fixed effects)]	H 30d: <i>SD</i> 0.106 (UN) coef 0.016; 95% CI –0.031, –0.002 <i>p</i> value <0.01 H Deaths: <i>SD</i> 0.079 (UN) coef – 0.009; 95% confidence interval [CI] –0.021, 0.002 <i>p</i> value=0.12	Strengths: introducing palliative care is positive effect on patient; supports cost effective MCR Limitations: no resident level data; many variables, such as staffing ratios. No risk nor harm Feasible: yes LOE: IV USPSTF: B LOC: moderate
Mitchell et al. (2016). Evaluation of a pilot of nurse practitioner led, GP supported rural palliative care provision.	NONE	Cohort design, quantitative	6 patients sampled; based in rural area in Australia; NP led PC provision; 62 patients referred, only 6 per protocol from ineligibility	IV: NP led palliative care provision DV: patient outcomes measured with HADS depression, HADS anxiety, POS.	<i>SD</i> (mean)	<i>SD</i> (mean)	POS: 27.8 (<i>SD</i> 8.3) HADS depression: 14.7 (<i>SD</i> 4.7) HADS anxiety: 11.3 (<i>SD</i> 7.0) H: none ED: NONE	Strengths: short duration, minimal loss, effective outcomes Limitations: few patients, missing date, early deaths. No control groups No risk or harm Feasible: yes LOE: IV USPSTF: B LOC: Moderate
Walling et al. (2017). Effect and efficacy of an embedded palliative care nurse practitioner in an oncology clinic.	NONE	QI criteria, quantitative	2 clinics; 35 controlled clinics	IV: Embedding a NP PCM with oncologists DV: quality measures of supportive care, hospice referral, advanced care planning	<i>p</i> value	<i>t</i> test	IV: ACP <i>p</i> <0.01 HR <i>p</i> <0.01 PS <i>p</i> = 0.02	Strengths: successful visits; quality NP to patient time; addressed complex needs; positive impact of outcomes (ACP, HR, PS). Limitations: under two interventional oncologists; smaller sample size; settings may not be comparable to community settings; no random assignment Feasible: yes

								No risk or harm LOE: VI USPSTF: B LOC: Moderate
Rogers, J.G et al. (2017). Palliative care in heart failure.	AHF= high morbidity and high mortality. UC for AHF is less than desirable for PO	Randomized, RCT	150 total participants; 75 PAL UC, 75 UC. Inclusion based on RA.	DV: patient outcomes (improved quality of life and function (FACIT-PAL), depression (HADS), anxiety (HADS), symptom management (KCCQ), spiritual wellbeing (FACIT-SP) IV1: NP intervention (Palliative care intervention) IV2: no NP intervention (no palliative care intervention)	CI P value SD	Student t test Log rank test Test I error Linear mixed model	KCCQ: 9.49, 95% confidence [CI]: 0.94 – 18.05, P= 0.03 FACIT- PAL: 11.77, 95% confidence [CI]: 0.94— 18.05, P= 0.035 HADS depression: -1.94 95% [CI]: 3.57 to -0.31, p=0.020 HADS anxiety: -1.83 points, 95% [CI]: -3.64 to -0.02; p=0.048 FACIT-sp: 3.98 points, 95% [CI]: 0.46 to 7.50; p= 0.027	Strengths: continued management by NP provider, palliative care certified; ongoing assessment in timely approach; frequent assessment follow up Limitations: single center trial; singular interventional planning; advanced care-controlled study; inability to follow up on some participants in trial No risk or harm Feasibility in practice: hospice palliative care; interventions to improve quality of life LOE: Level II USPSTF: B LOC: Moderate
Fedel, P. et al. (2019). Advanced practice nurse collaboration with an established community-based palliative care model.	Based on IOWA model	Cohort studies	71 participants, CBPC, large Midwest, June 1, 2017 through September 30, 2017 before APN; June 1, 2018 through Sept 30,	IV: PC model that implements an APN DV: patient outcomes: 30 days readmission ED utilization Role of APN in PC	p value qualitative data	t test	SSV: p=0.001 30READ: P=0.286 EDV: p=0.506	Strengths: EHR review, appropriate timelines with and without intervention Limitations: Small data samples; limited APN involvement at times; programmatic changes

			2018 after APN; 6 PC members for APN role discussion					Feasible: yes, for PC setting No risk, no harm LOE: IV USPSTF: B LOC: moderate
Martin, E. J., et al. (2018). Nurse led palliative care for advanced cancer patients.	NONE	Randomized control trial	322 patients; new DX of AC with 8-12 weeks of dx PTE; NCCC. Outreach clinics in NH*, VA MC in VT.	IV: nurse led palliative care interventions in addition to oncological care DV: patient outcomes: FACIT-PAL ESAS CESD Resource use Survival rate	CI <i>p</i> value	Means, standard deviation <i>t</i> test	FACIT- PAL: (quality of life) <i>p</i> =0.02 ESAS (symptom intensity) = <i>p</i> =0.06 CESD (depressive mood) = <i>p</i> =0.02 Resources use: ED visit= <i>p</i> = 0.53 Readmission to hospital= <i>p</i> =0.14 Survival rate: I: 95% CI 10.6-18.4: 14 months NI: 95% CI 7.0-11.1 months: 8.5 months	Strengths: ENABLE mode. Consistent with participants. Limitations: limited diversity and race; limited to telephonic only Feasibility: No risk, no harm LOE: II USPSTF: B LOC: moderate
Dusseldorp, L. et al. (2018). What does the nurse practitioner mean to you? A patient-oriented qualitative study in oncological/palliative care.	None	Qualitative study	17 patients; 2 urban areas in Central Netherlands; one university, two clinics in oncological or palliative care settings. Dutch speaking; ages 45 to 79 with	IV: support and treatment by the NP in PC setting DV: patient outcomes: experiences and identification of NP themes	Fundamental themes Metaphors of NP.	Colaizzi's seven step method MIP	Themes: (1) human professional (2) providing care (3) cure (4) organizing patient care (5) impact on patient's well being Metaphors: (1) trust (2) travel aid	Strengths: accredited qualitative analysis for identification of outcomes Limitations: All receiving PC, heterogenous in age, same time elapsed and educational level; recruited by participants only NP. Feasibility: yes, in PC setting

			signed consent.				(3) combat unit (4) chain (5) signpost (6) technician	No risk, no harm LOE: V USPTSF: B LOC: moderate
Bagcivan, G. et al. (2017). What happens during early outpatient palliative care consultations for persons with newly diagnosed advanced cancer.	ENABLE palliative care model	Retrospective qualitative coded and frequencies tabulated	207 trial patients; Oct 2010 to March 2013,	IV: early outpatient palliative care consultation by NP DV: patient outcomes: discussion, recommendation, treatment for general evaluations, symptom management, AD, hospice.	Descriptive , percentages <i>p</i> value n value	Coding Schema Means <i>SD</i> <i>t</i> tests Chi Square	General evaluations: martial/partner status (81.7%), spiritual/emotional wellbeing (80.3%), family/caregiver support (79.6%) Symptoms: mood (81.7%), pain (73.9%), cognitive/mental status (63.8%) General treatment recommendations: counseling (39.4%), new medications (23.9%), current medication regimen (34.5%), treatment for pain (22.5%), constipation (12.7%), depression (12.0%) Advance directives: AD completion (43%), identification of surrogacy (21.8%), discussion of illness trajectory (21.1%) less likely to have hospice referral <i>p</i> = 0.003 (advanced care planning) Hospice awareness= <i>p</i> = 0.005 (advanced care planning)	Strengths: the study of early versus delayed PC intervention; insinuates that PC may be needed even earlier than study for qualitative feedback for better outcomes Limitations: in trial studies only; rural cancer center that lacks diversity; transportation issues with participants Feasibility: yes, in PC setting No risk, no harm LOE: V USPTSF: B LOC: moderate

							Needed evaluation for general pain <i>p</i> = 0.035 (symptom management)	
Riggs et al. (2016). Hospice enrollment after community-based specialist level palliative care: Incidence, timing, and predictors.	NONE	Cohort	1505 adults and child MR reviewed. MJHS PC and Hospice affiliation ; NY; Dec 2010 to Sept 2013, CS	IV: community-based PC program DV: hospice enrollment	<i>p</i> value CI N value	Analysis of variance Chi Square Fisher exact test Multivariate analysis Mianalyze	N= 362 enrollees post PC program to HE Additional: (factors of influence) POST to PC for patients admitted HC after PC: Age: <i>p</i> = 0.0087 CI: 1.65 (2.89 to 0.041) LA: <i>p</i> =0,0113 CI: 94.23 (22.13 to 166.33) NES, other than Spanish: <i>p</i> =0.0480 CI: 59.54 (118.56 to 0.52) NDD: <i>p</i> =0.0212 CI: 106.09 (16.11 to 196.07) CHF: <i>p</i> =0.0012 CI: 99.70 (39.27 to 160.13) KPS: <i>p</i> =0.0012	Strengths: Large cohort, variety of factors; consistent with other study findings, comparable Limitations Lack of medical records information; family support or lack of; one organization, question of bias Feasible: YES LOE: IV No risk nor harm USPSTF: B LOC: moderate

							CI: 3.68 (1.48 to 5.89)	
Hanson et al. (2019). Triggered palliative care for late stage dementia: A pilot randomized control trial.	NONE	RCT	Mar 31, 2016 through Aug 31, 2017; > or = to 65 years old; Stage 5-7 of dementia using GDS scale; English speaking; 426 participants with LSD; 137 patients eligible, 62 trialed for RCT, NC state. RS	IV: dementia specific palliative care consultation DV: ED/hospital visits; patient comfort, family distress, ACP, PCA, SPA	<i>p</i> value %	Means (SD) Descriptive Chi squared test <i>t</i> test Mann Whitney test	60d ED/hospital visits: <i>p</i> = 0.415 PCA= <i>p</i> <0.001 SNA= 47% (I) versus 0% (C) ACP= Hospice- <i>p</i> <0.019 NH= <i>p</i> =0.046 DOP= <i>p</i> <0.001 GOC= <i>p</i> <0.001 MOST= <i>p</i> <0.001 MOST60d= <i>p</i> <0.001 ARH= <i>p</i> =0.033 SM= <i>p</i> <0.001	Strengths: geriatric stability, in person assessment/consultation Weakness: short time frame of study; limited statistical power Feasible: YES LOE: II No risk nor harm USPSTF: B LOC: moderate
Hoerger et al. (2018). Defining the elements of early palliative care that are associated with patient-reported outcomes and end of life care.	NONE	RCT	171 participants; May 2, 2011 through July 20, 2015; MGH; within 8 weeks of DX; ILC or INC; 18 years or older. RS	IV: early PC DV: coping, SM, QOL, HADS, HQ, Chemo, hospitalizations, hospice (ACP)	% <i>p</i> value	Descriptive (%) Means (SD) <i>t</i> tests multiple regression	Coping= 64/2% SM= 74.5% QOL= <i>p</i> = 0.002 HADS= <i>p</i> = 0.002 HQ= <i>p</i> =0.004 Chemo decline= <i>p</i> =0.002 Hospitalization =	Strengths: large group, multiple visits, diversity Weakness: Possible influencers such as psychosocial support in home. Verbal perspectives versus recorded audio from PC group Feasible: YES LOE: II No risk nor harm USPSTF: B LOC: moderate

							$p=0.005$	
							Hospice=	
							$p=0.03$	

Legend:

30d- 30 days

AC- Advanced cancer

ACP- advanced care planning

AD- Advance Directive

AHF- advanced heart failure

APN- Advanced practice nurse

ARH- Avoid rehospitalization

CBPC- Community based palliative care

CESD- Center for Epidemiological Studies Depression Scale

CHF- Congestive heart failure

CS- Convenience sampling

DX- Diagnosis

DOP- Discussion of prognosis

EHR- electronic health record

EOLH- end of life hospitalizations

ESAS-Edmonton symptom assessment scale

FACIT-PAL- Functional Assessment of Chronic Illness Therapy–Palliative Care scale

FACIT-SP- Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being scale

GOC- goals of care

H- hospital

HADS- Hospital anxiety and depression scale

HCP- Health care provider

HE- Hospice enrollment

HQ- health questionnaire

HR- Hospice referral

I-Intervention

IDT- interdisciplinary

ILC- incurable lung cancer

INC- incurable noncolorectal cancer

KCCQ- Kansas City cardiomyopathy questionnaire

KPS- Karnofskys Performance Score

LA- Lives alone

LOC- Level of certainty

LOE: Level of evidence

LSD- Late stage dementia

MC- Medical center

MGH- Massachusetts General Hospital

MIP- Metaphor identification procedure

MOST- Medical orders for scope of treatment
 MR- Medical records
 NC- North Carolina
 NCCC- Norris Cotton Cancer Center
 NDD- Neurodegenerative disease
 NES- Non-English Speaking
 NH- nursing home
 NH*- New Hampshire
 NI-No intervention
 NP- nurse practitioner
 NY- New York
 PAL- Palliative care
 PC- palliative care
 PCA- palliative care assessment
 PCC- palliative care consults
 PCM- palliative care model
 PO- patient outcomes
 POS- palliative outcomes scale
 POST- predictors of stay
 PS- psychosocial support
 PTE- Prior to enrollment
 QOL- quality of life
 RA- risk assessment
 RCT- randomized control trial
 RI- Rhode Island
 RS- random sampling
 SM- Symptom management
 SNA- spiritual needs assessment
 T- Theme
 UC- usual care
 UN- unavailable
 VA- Veteran Affairs
 VNANYHPC- Visiting nurse service of New York Hospice and Palliative Care
 VT- Vermont

***Prompts for each column – **please do not repeat the headings, just provide the data**
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Appendix B

FACIT-Pal Assessment Tool

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Not at all	A little bit	Some-what	Quite a bit	Very much
<u>PHYSICAL WELL-BEING</u>						
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4
<u>SOCIAL/FAMILY WELL-BEING</u>						
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4

GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
GS7	I am satisfied with my sex life	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

EMOTIONAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

FUNCTIONAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

ADDITIONAL CONCERNS

		Not at all	A little bit	Some-what	Quite a bit	Very much
PAL1	I maintain contact with my friends	0	1	2	3	4
PAL2	I have family members who will take on my responsibilities	0	1	2	3	4
PAL3	I feel that my family appreciates me	0	1	2	3	4
PAL4	I feel like a burden to my family	0	1	2	3	4
B1	I have been short of breath	0	1	2	3	4
PAL5	I am constipated	0	1	2	3	4

C2	I am losing weight	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
PAL6	I have swelling in parts of my body	0	1	2	3	4
PAL7	My mouth and throat are dry	0	1	2	3	4
Br7	I feel independent	0	1	2	3	4
PAL8	I feel useful	0	1	2	3	4
PAL9	I make each day count	0	1	2	3	4
PAL10	I have peace of mind	0	1	2	3	4
Sp21	I feel hopeful	0	1	2	3	4
PAL12	I am able to make decisions	0	1	2	3	4
L1	My thinking is clear	0	1	2	3	4
PAL13	I have been able to reconcile (make peace) with other people	0	1	2	3	4
PAL14	I am able to openly discuss my concerns with the people closest to me	0	1	2	3	4

Appendix C

Zarit Caregiver Burnout Tool

CAREGIVER STRESS SELF-ASSESSMENT (Dr. Steven Zarit, modified version)					
The following is a list of statements that reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.					
QUESTIONS: "Do you feel...	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. ...that your loved one asks for more help than he/she needs?					
2. ...that because of the time you spend with your loved on that you don't have enough time for yourself?					
3. ...stressed between caring for your loved one and meeting other family or work responsibilities?					
4. ...embarrassed over your loved one's behavior?					
5. ...angry when you are around your loved one?					
6. ...that caring for your loved one currently affects your relationship with other family members or friends in a negative way?					
7. ...afraid of what the future holds for your loved one?					
8. ...your loved one is dependent on you?					
9. ... your health has suffered because of your involvement with your loved one?					
10. ... that you don't have as much privacy as you would like because of your loved one?					
11. ... that your social life has suffered because of you are caring for your loved one?					
12. ... uncomfortable about having friends over because you are caring for your loved one?					
13. ... that your loved one seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
14. ... that you don't have enough money to care for your loved one in addition to the rest of your expenses?					
15. ... that you will be unable to take care of your loved one much longer?					

16. ... you have lost control of your life?				
17. ... you want to leave the care of your loved one to someone else?				
18. ... you should be doing more for your loved one?				
19. ... you could do a better job in caring for your loved one?				
20. ... burdened caring for your loved one?				
Total responses per column				
Multiply total by scale (Never = 0, Rarely = 1, Sometimes = 2, Quite Frequently = 3 Nearly always = 4)				
Grand total:				

SCORING: 0-20 = Little/No Stress

21-40 = Mild/Moderate Stress

41-60 = Moderate/Severe Stress

61-80 = Severe Stress

