

Respite Care: Who Cares for the Caregiver?

Joe Haralson

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Approved by:

<i>Dr. Kathryn Lawrence</i>	Project Team Leader
<i>Alveda Person</i>	Project Team Co-Leader
<i>Dr. Wanda Williams</i>	DNP Program Director

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Abstract

Background: Respite care is a service that can assist the family member caring for a loved one requiring 24-hour care. Research as has shown that this can positively affect the patient/caregiver relationship by supplying a short relief from the stressors of constant care and social isolation.

Purpose: To increase the awareness of the no-cost respite care service offered by the local Department of Aging, thus increasing the utilization of this service.

Method: During a one-month period in 2023, caregivers of individuals participating in a local rehabilitation clinic were identified as potentially benefiting from respite care. Those caregivers were issued a pamphlet with information on no-cost respite care and contact numbers for the local Department of Aging, by the rehab staff. Analysis was conducted for comparison between the number of new inquiries for the service in 2023 with inquiries during the same period in 2022.

Result: Of the 1200 patients seen in the rehab facility, 18 caregivers were identified as potential beneficiaries of respite care services. Data analysis revealed that in 2022, there were 7 inquiries compared to the same time period in 2023, at 14 new inquires, indicating a 100% increase in inquiries for respite care with the pamphlet intervention compared to the previous year.

Recommendations and Conclusions: It is recommended that a representative from the county's Department of Aging schedule quarterly visits to local inpatient and outpatient rehab facilities, to supply pamphlets and answer questions from the rehab staff, with the purpose of increasing awareness in caregivers, and potentially improve no-cost respite care utilization.

Background and Significance

In our society, there exists a commendable yet often overlooked cadre of individuals who embrace the formidable task of caring for the most vulnerable among our community. These informal caregivers, as identified by the America's Health Insurance Plans (AHIP), number nearly 48 million across the United States. They step up to provide indispensable care for those who are not able to care for themselves (AHIP, 2022). Examples of this vulnerable population include, but are not limited to, frail and demented elderly family members (Reinhard et al., 2023). Frequently, these families prefer to care for their family members in the comfort of their homes over placement in long-term care facilities. Other times it is not a personal choice, but the decision is forced upon the family due to the financial burden of placing the family member into an outside facility (Huang et al., 2021).

Financial Toll

These individuals often work long hours without pay, and most often without the appreciation they rightly deserve. Describing these situations in terms such as “long hours”, “stress filled”, and “without pay” may not seem significant, until these terms are quantified. In 2017, the American Association of Retired People, (AARP), reported that these un-paid caregivers supplied nearly 34 billion hours of services, valued at an estimated \$470 billion (Adler, 2022). This service does not come without additional expenses for the caregiver. The same report from AARP estimates that these caregivers will spend on average \$7000 on expenses, from supplies to home accommodations to transportation (Adler, 2022). These informal caregivers are not only supplying an unpaid service, but many will also miss workdays or are forced to leave the workforce all together, which adds the additional stress of lost wages. It is estimated that 39% of caregivers will leave their jobs due to the added burden of caregiving

and, as a group, lose nearly \$39 trillion in pay and benefits (Family Caregiver Alliance, 2022).

Additionally, consider the situation of elderly couples where one spouse becomes the primary caregiver for the other. These couples, often subsisting on a fixed income, are suddenly confronted with the escalating costs associated with caregiving. This already substantial financial strain intensifies, placing an overwhelming burden on the caregiver's shoulders (Solá, 2023).

Physical and Emotional Toll

The informal caregiver is responsible for the delivery of around the clock care (Vandepitte, 2019). Rain or shine, in health or sickness, these individuals provide the most basic needs such as feeding, bathing, dressing, toileting, safety, and companionship while often neglecting their own health and well-being out of strong feelings of responsibility (Reinhard et al., 2023; Losada-Baltar et al., 2022). Often, elderly couples are in this situation, the healthier spouse caring for the unhealthy, but many times it is an adult child taking care of an elderly parent (Chen et al., 2022).

Unsurprisingly, the patient is the primary focus of attention and care. During health care provider visits, the health and well-being of the caregiver is often overlooked. Unfortunately, practical interventions, such as a standardized checklist for assessing caregivers' needs and risks, are often lacking in many of the healthcare settings (Riffin et al., 2020). Caregiver inclusion is an essential component of patient-centered care for people who are medically vulnerable, however, the health and wellness of the informal caregivers are rarely meaningfully considered when interacting with clinical health care teams (Shepherd-Banigan, et al., 2021).

Informal caregivers also act as advocates for their patients, even though they sometimes felt uncomfortable doing so during medical appointments, nevertheless, the patient's caregivers were also frustrated by the fact that providers often ignore their comments and insights, despite

being the primary caregiver (Raj, et al., 2021). One can only imagine the added stress that this may cause to an already stressful situation.

Additionally, these patients may be at such a diminished condition that they are incapable of self-care (Reinhard et al., 2023). In some instances, the patient may be in such a state of health that they are bed bound or confined to a wheelchair or grappling with conditions such as Alzheimer's disease that render them unsafe to be left unsupervised (Liao et al., 2022). If there is a comparison, it would to a newborn infant. The amount of care and attention a newborn requires is easily imagined even by those without children. It is difficult to imagine a scenario in which a young child would be left alone for any extended period, even by those without children. It is the responsibility of the parents to meet the needs of the newborn because the infant is unable to meet these needs on its own. This scenario may mirror the scenario one might find themselves in when caring for an adult loved one who is unable to care for themselves. This is the challenge of the informal caregiver. Instead of supplying basic needs to a small infant, the feeding, cleaning, clothing, and fostering a safe environment is being supplied to an adult (Reinhard et al., 2023).

Besides the financial strain, social relationships can be negatively affected. The relentless demands of caregiving, coupled with the necessity of the constant presence with the patient, caregivers often feel isolated (Bonin-Guillaume et al., 2022). Studies have shown that the unrelenting stress of caring for their loved one, tend to overshadow the personal lives of the informal caregiver, to the point of manifesting into a sixfold increase of feelings of depression anxiety, and sleep disturbances (Bonin-Guillaume et al., 2022). The same study noted that family caregivers were more likely to report a negative impact on relationships or family life and tended to have difficulty in relationships with older adults. Friends and social events tend to take a backseat. The caregiver is no longer going to work and interacting with other people. The

opportunities to meet with friends to see a movie or eat at a restaurant are significantly decreased. These feelings of isolation can start to strain the caregiver's mental well-being (Holliday et al., 2022). These are just one more straw on an already fragile back of the informal caregiver.

The level of responsibility shouldered by caregivers is immense, with the stress of providing round-the-clock care accumulating steadily over time. This constant strain, compounded by the financial impact of lost wages and the expenses associated with caregiving, significantly raises the risk of caregiver burnout (Vandepitte, 2019). This burnout not only affects the informal caregiver's mental and physical health but can also lead to increased emergency department visits and can ultimately result in an early admission into a long-term care facility (Vandepitte, 2019). This issue cannot be overlooked, as each year sees a rise in the number of individuals requiring in-home care, along with the associated increase in informal caregivers (AARP, 2020). This naturally occurring trend of aging underscores the critical need for support systems that address the sustainability of caregiving and the well-being of both the informal caregiver and their patient.

Purpose

The purpose of this project is to increase the awareness of the no-cost respite care service, offered by the local government funded Department of Aging, with the aim of increasing the utilization of the service, by the informal caregivers supplying 24-hour care to family members or friends.

Review of Current Evidence

A general review of current evidence utilized the databases Academic Search Complete, CINAHL, and PubMed. These searches were limited within the years of 2017 to 2022. Search

topics consisted of *caregiver burden, caregiver burnout, cost of respite services, and government provided services*. By narrowing down search parameters by including specific keywords, phrases, and benefits to the caregiver and the patient when utilizing respite care services. Of the articles that were resulted from the search, twenty-four were chosen for this project.

The Caregiver

It is difficult to narrow down what an informal caregiver may look like. Included in this document is the information pamphlet utilized in this project (Appendix C). This information pamphlet from the local county Department of Aging, defines a caregiver as an adult who cares for a family member greater than 60 years old; an adult who cares for a person with Alzheimer's disease or a related disorder, regardless of age; and a senior raising an adult child aged child with a disability. To be sure, there are situations where the caregiver is a friend, but in most cases these informal caregivers are usually family members caring for an aged or disabled parent, or a spouse caring for a disabled partner (Holliday et al., 2022). Caring for a loved one in the home crosses all racial and cultural aspects but research has shown that female family members are more likely than male family members to be placed into the role of caregiver (Solá, 2023).

There are many motivations as to why it is decided to care for a loved one in the home. Caring for a disabled family member in the home has positive benefits to the loved one. They are in a known environment, they are surrounded by familiar faces, and experience less stress when compared to being cared for in a facility (Dombestein et al., 2019). The already overcrowded healthcare system is also positively benefited, because the informal caregiver is able to keep patients in the home (Vandepitte et al., 2020).

The Scandinavian Journal of Caring Sciences published a study in 2019 with the intent of finding what motivates these informal caregivers to participate in a system that is both taxing to

their health and finances. The study attempted to understand their motivations by applying the Self-Determination Theory (SDT) (1985), a seminal work by psychologists Edward Deci & Richard Ryan. This theory suggests that humans are motivated by three main needs; to believe they are doing something by choice and believe in what they are doing, feel they are doing something correctly and confidently, and have a general feeling of appreciation (Dombestein et al., 2019). Having a greater understanding of the informal caregiver's motivation, can allow for a more robust support network (Dombestein et al., 2019).

Caregiver Burden

Informal caregivers generally provide 24-hour, seven days a week care, and typically lack professional training and experience (Holliday et al., 2022). Instead, they typically rely on trial and error or assumptions about what is appropriate. Family care providers are not backed up by teams of care providers who are able to clock out after a shift and then separate themselves from the stress of patient care. (Holliday et al., 2022). Registered nurses, equipped with extensive education, training, and the support of multiple team members, can find themselves nearly overwhelmed after a 12-hour shift caring for a patient requiring constant attention (Anshasi et al., 2020). Unlike these professional caregivers who can leave their work at the end of their shift, home care providers do not have the luxury of "clocking out". For those caring for a spouse in need of constant attention, their commitment is unending. There is no button to press for assistance with tasks like cleaning the patient after an incontinence episode. The informal caregiver shoulders the entirety of care responsibilities and is perpetually on call (Reinhard et al. 2023). Without support the burden of stress may come to a tipping point, which can cause a decline in the caregiver's physical and mental health (Lio et al., 2022, Vanepitte et al., 2019).

Caregiver Burnout

As stated earlier in this project, providing constant care for an adult patient has the potential of taking a physical and mental toll on the body, due to the day-to-day duties involved with supplying 24-hour care. This can be compounded even further if the caregiver is also elderly or in experiencing the fall-out of their own co-morbidities. This day-to-day toll has shown that many caregivers, especially caregivers of dementia patients, have increased levels of depression (Holliday et al., 2022). Depression has the potential to then manifest into physical ailments and if the caregiver's health declines to the point where they can no longer care for the patient, the result may be premature placement into a long-term care facility. Addressing the needs of the caregiver can have a positive impact on the care of the patient (Lio et al., 2022).

It is important to realize that there is a direct association between the levels of stress and general well-being of the caregiver as well as an association to the overall health of the patient (Holiday et al., 2022; Lio et al., 2022). It can be assumed that the longer the caregiver is able to care for the patient at home, the longer the patient will go without being hospitalized or institutionalized, which is the intent of caring for the patient at home (Vandepitte et al., 2020).

Moreover, as care is focused on the patient, the caregiver is sometimes neglected. Studies have shown that family caregivers have increased rates of both physical and emotional ailments (Manzini & Vale, 2020). The National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) conducted a seminal study in 2015 that discussed the strain and stress of caregivers. The report demonstrated that the informal caregiver is more prone to increased risk of mental health issues such as emotional strain, burnout, and social isolation (NAC & AARP, 2015). The researchers also found that along with an increase in psychological ailments, there is a physical toll that comes with providing constant care in the home, which includes increased muscular skeletal injuries, inadequate sleep, and a general neglect in caring

for oneself (NAC & AARP, 2015). The results from this report indicate that complaints of mental and physical stress increase, as the support of their loved ones continue. Informal caregivers put their lives on hold when they begin caring for patients who need constant attention. The amount of time and effort that caregivers put into their responsibilities, can feel overwhelming at times. Every aspect of daily living is affected because of their involvement in the 24-hour care and can lead to feelings of isolation, resulting in a desire to just throw in the towel (Huang et al., 2021; Vandepitte et al., 2019). There is no doubt that the family caregiver plays an important role, and the sacrifices of the informal caregiver cannot be overstated. They are committed to the patients' around the clock care and management of their daily needs, and many times these sacrifices go unrecognized to the outside public, furthering the feelings of isolation (Lio et al., 2022). This supports the idea of the importance of having a system that supports the informal caregivers through their daily challenges (NAC & AARP, 2015).

Respite Care

According to the *Oxford English* dictionary, “Respite” is defined as “a short period or rest or relief from something difficult or unpleasant” (Oxford University Press, 2024). The purpose of respite care is to allow the care giver a short break from the responsibility of the care of the patient. This short break may include hours or multiple days, depending on the service. The caregiver can use the time to run errands do something as simple as go to a park and sit on a bench or watch television. The goal of respite care is to relieve some of the stress of patient care and allow the caregiver to reestablish a sense of normalcy (Holliday et al., 2022). Research has shown that even small amounts of time away from the stress of caregiving, can have positive effects on the health of the caregiver (Riekkola et al, 2018). These short breaks in responsibility have shown to reduce stress levels and the feelings of isolation, which in turn benefits the mental

and physical health of the caregiver and reduces the chances of the patient being institutionalized (Huang et al., 2021; Vandepitte et al., 2019).

Underutilization of Respite Services

Many informal caregivers do not use respite care services, not only because they do not understand what respite care is, but because they are unaware that it is an option (Huang et al., 2021). Another reason for the underutilization of a respite care service is the cost (Huang et al., 2021). One type of respite care service is In-home respite care service. In-home respite care service is a type of respite care that can assist with homemaking tasks, personal care needs, and a degree of medical care (Hoyt, 2023). The type of care and the length of time will determine the cost. The average cost of in-home care is \$26 per hour (Hoyt, 2023). This may not sound like much but when you assume that an informal caregiver who is supplying 24-hour care for a loved one, may require a few hours of relief per week, the costs can add up quickly. The website SeniorLiving.org gives an example whereas a caregiver uses the respite care service for four hours a day, three days per week (Hoyt, 2023). When you multiply this number times 52 weeks, it very quickly adds up to around \$16,000 per year (Hoyt, 2023). That \$26 per hour no longer sounds so inexpensive. This cost can be a deterrent for caregivers needing assistance from a respite care service and Medicare and Medicaid may not be the answer for most situations (Hoyt, 2023). This brings back the purpose of this project, which is to increase the awareness and the utilization of the no-cost government service offered by the county's Department of Aging (Moore County Department of Aging, 2022).

Government Services

The Department of Aging, a local county government office, was established for the purpose of caring for the elderly (Moore County Department of Aging, 2022). This department is

funded by governmental grants that allow them to supply dietary supplements; offer the use of an exercise facility at a reduced cost; and respite care services at no cost. In a discussion with the staff at the Department of Aging, members believe that the services they offer are underutilized because of a general lack of knowledge of their existence (Alveda Smith [Moore County Department of Aging], September 2022).

There are different types of respite care services. Different locations offer different types of services, as well of length of services. Some services will offer an in-home option, and some will be off site. Some may offer transportation services and others will be a drop off site (Hoyt, 2023). Many respite care services are age related and may offer camps or activities for younger people. The services can be community based while others may be more medically weighted. As the pamphlet in Appendix C explains, the not-for-cost services supplied by the local Department of Aging are more focused on emotional support for the informal caregiver as well as a companion for their loved one while the caregiver steps away from their responsibility, ensuring their continued safety.

Conceptual Framework

For the purposes of this DNP project, the Health Belief Model (HBM) was utilized as the conceptual framework. This model was first developed by social scientists in the United States in the 1950s (BUMC, 2022). The Health Belief Model consists of four main points. These points were used to recognize patient behavior. Integrating knowledge of these behaviors, helped guide this project in the implementation of the planned intervention The constructs of the HBM are (1) perceived susceptibility, (2) perceived severity, (3) perceived barriers, and (4) perceived costs (Raingruber, 2017). Along with an information packet detailing the services offered, the clinical

staff also utilized the concepts of Irwin Rosenstock's Human Belief Model to promote the use of the respite care services offered through the local government agency (Hochbaum and Rosenstock, 1952). These constructs were further broken down, specifically referencing the purpose of this project, as follows:

Perceived susceptibility: The caregiver may not believe that the negative aspects of providing 24-hour care can happen to them personally.

Perceived severity: A caregiver may not perceive the burdens and stress of caring for a loved one to be too great.

Perceived barriers: The caregiver may believe that they do not qualify for respite care or believe that it is too hard to navigate the process.

Perceived cost: The caregiver may think that the service is too expensive (BUMC, 2022).

These barriers can be mitigated by the information packet issued to them after they are identified by the clinic staff. Many questions may be answered by the information packet once the caregiver reviews the material. Additional concerns can be addressed when caregivers are in contact the Department of Aging.

Design

This DNP project was a quality improvement initiative using a convenience sample of patients in a local physical therapy center in central North Carolina; with the focus on improving awareness and utilization of no-cost respite care services offered by the local county government, through the Department of Aging. The PI identified, through discussions with the staff at the Department of Aging, that informal caregivers who need respite care may not be aware of this supportive service.

Transitional Framework

This quality improvement project was guided by the Plan-Do-Study-Act (PDSA) method. This method assisted in organizing and guiding the project through the quality improvement process (AHRQ, 2020). The PDSA method was developed as a step-by-step guide in order to research and test changes in a systematic way, before implementing the change (AHRQ, 2020). This was the methodology that guided this quality improvement project.

What the Project was Attempting to Improve

The problem identified is that the no-cost respite care service is underutilized due the general lack of awareness. The project aimed to improve the awareness of the no-cost respite care service provided by a local governmental agency.

Plan

A literature review was conducted concerning informal caregivers, respite care utilization, and the impact respite care services have on the informal caregiver. The literature references indicated that respite care services decrease caregiver burnout, decrease early admittance into long-term care facilities, and decrease emergency room visits. This project plan was focused on the patients and the caregivers who utilized the services of a local rehabilitation center. This center was chosen due to the proximity to the Department of Aging and its high patient population. Written permission was obtained from the rehabilitation facility (Appendix A), and from the Department of Aging (Appendix B), prior to the beginning of the project. The projected number of patient visits during the month of the study was 1200. Not all 1200 patients would be candidates for the respite care services. It was decided that 30 information pamphlets (Appendix C), which were provide to the PI by the local Department of Aging, would be delivered to the rehabilitation center at the beginning of the study, with an additional 30 pamphlets in reserve to resupply the rehabilitation center during each weekly visit. Each visit to

the rehabilitation site was prefaced with a telephone call, ensuring as little disruption as possible from the PI visit.

IRB. Before beginning the DNP project, the project design was submitted to the UNCG Institutional Review Board (IRB) to ensure that the project met the criteria as being exempt from research classification. There would be no personal identifiable information collected during this project. The project was assisted by the lead physical therapist at a local rehabilitation center. Information collected at this center by the PI was limited strictly by the number of information packets that were issued to prospective users of the respite care service. This information was securely stored at the clinic site until it was presented to the project PI. The project was also assisted by the staff at a local government facility, the Department of Aging. Information supplied to the PI of this project include, and was strictly limited to, the number of inquiries into the Department of Aging, specific to the respite care services offered. No personal identifiable information was shared with the PI.

All documents used in this study were securely stored in a password-protected electronic system to maintain participant confidentiality. Only the PI had access to the documents to ensure the confidentiality of the participant information. The project data remains on file for five years through a UNCG password protected file and will automatically be deleted by an eraser program. The data was not viewed or analyzed in a public place such as a coffee shop or library where confidentiality could not be maintained. Data was reviewed only by UNCG faculty involved in the project including the statistician.

Population. The rehabilitation center sees over 10,000 patients each year. Demographics of the patient population of the local rehabilitation center vary. It is estimated that the average age of the patients seen there is 65 years. The most common patient diagnoses were Parkinson's

disease, dementia, cerebral vascular accidents, cardiovascular disease in need of cardiac rehabilitation, cerebral palsy, and musculoskeletal injuries. The projected number of patient visits during the month of the project was 1200. Not all 1200 patients would be prospective candidates for respite care services. Although the final decision for participation in the respite care service was made by the local government agency, the staff at the rehabilitation facility were given inclusion and exclusion criteria, allowing them to act as the first filtering process of the project. Inclusion criteria included but was not limited to: an adult caring for a family member over the age of 60, an adult who assists a person with Alzheimer's disease (or a related disorder) regardless of age, a senior aged 55+ who is caring for an adult aged child 19-59 years old with a disability. Exclusion criteria generally included patients with short duration disabilities (a patient without comorbidities who has been prescribed short-term rehabilitation after knee surgery). It was made clear to the staff that if there were any question as to the patient's inclusion or exclusion, or if the patient or caregiver requested an information packet, the decision was to err on the side of the patient.

Do

At the beginning of the DNP project, July 2023, a total of 30 pamphlets explaining the government sponsored, no-cost respite care service, were delivered to the participating rehabilitation center. Education was provided to the staff concerning the aim of the project, as well as the inclusion and exclusion criteria. The PI requested the help of the physical therapy staff in identifying potential beneficiaries to respite care. The staff were willing to assist the PI in introducing the project's intervention into the population. When the physical therapy staff identified a patient and caregiver that may benefit from the respite care service, an information pamphlet was given to the caregiver. The therapist would open the pamphlet and briefly explain

the service and point out the contact instructions. On Friday of each week of the project, a visit was made to the center by the primary investigator (PI), to check on progress and replenish the information pamphlets if needed. This phase of the study (intervention phase), ended on 31 July 2023. On the 31st of July, the rehabilitation center was visited by the PI to collect the total number of pamphlets issued.

On 1 September 2023, the PI visited the respite care representative at the project site's county Department of Aging. During this visit the number of new inquiries for the month of August 2023 was collected. For comparative purposes, the inquiries from August of 2022 were also collected.

Study

After processing the information collected at the rehabilitation center, a comparative analysis was conducted, to evaluate the effectiveness of the project's design.

Data Analysis

A pre-and post-data comparison analysis was conducted to ascertain increases or decreases in the respite care inquiries. The goal of matching pre- and post-data was to determine the effectiveness of an intervention by comparing the results with and without the intervention. The with and without analysis provided comparison between the number of new inquiries for the service in July of 2023 with the number inquiries during the same period in July of 2022. The null hypothesis was that there would be no statistical difference between these two numbers of inquiries.

Results

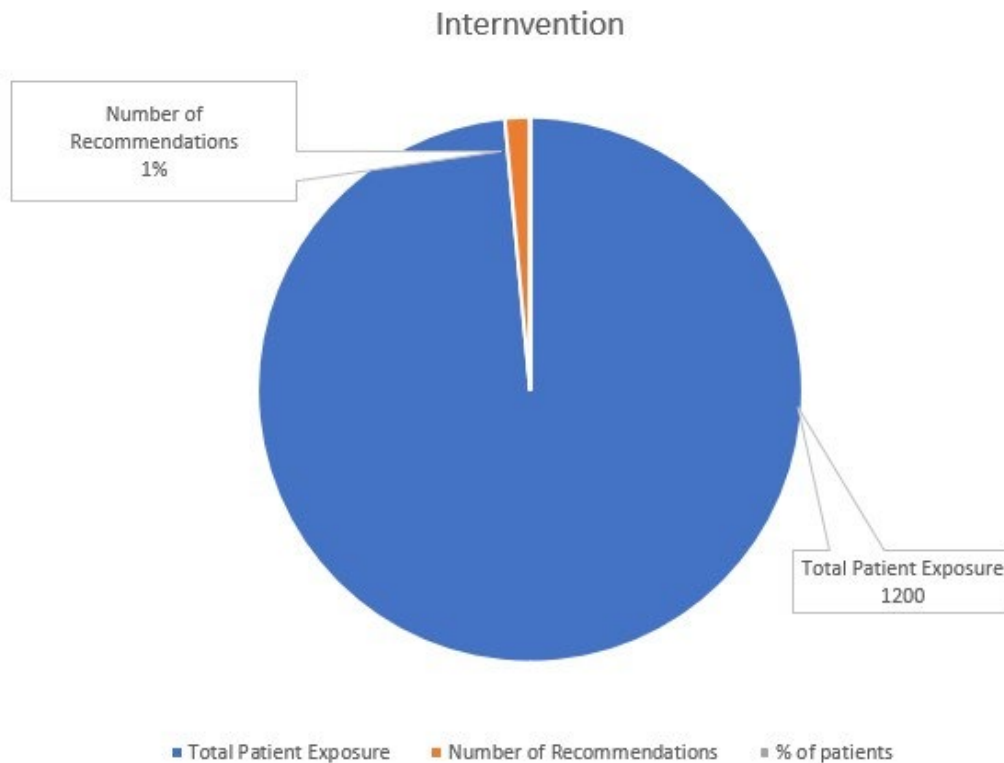
The total number of patients seen at the rehabilitation facility in July of 2023 was 1200. It was determined that 1% of the patient/caregiver population were identified by the staff as

someone who may benefit from respite services and were issued an information pamphlet, based on the project's inclusion and exclusion criteria. The rehab facility received a total of 30 information pamphlets on 30 June 2023, with information on respite services from the Department of Aging. Of the 30 pamphlets, a total of 18 (60%) were issued by 31 July 2023. Of the estimated 1200 patients seen at the clinic, 18 (1%) were exposed to the intervention (**Figure 1**).

In September 2023, the PI contacted the Department of Aging to evaluate the effectiveness of the informative pamphlet distribution, on the number of inquiries for respite care services. The data revealed that rehabilitation facility staff members issued 18 information packets ($n=18$), to those who met the inclusion criteria. The PI then inquired about the number of new inquiries for respite care for the month of August 2023. The Department of Aging staff reported that they received a total of 14 ($n=14$) new inquiries for respite care. The number of inquiries for August 2023 was compared to the number of inquiries for the month of August 2022 (pre-test value, $n=7$). The PI used a t -test calculation to analyze the mean values for of the number of inquiries for respite services in August 2022 compared to the mean values of inquiries for respite services in August 2023. The comparative analysis revealed that there was an increase in inquires for respite care by 100% compared to the same period one year earlier (**Figure 2**).

Figure 1

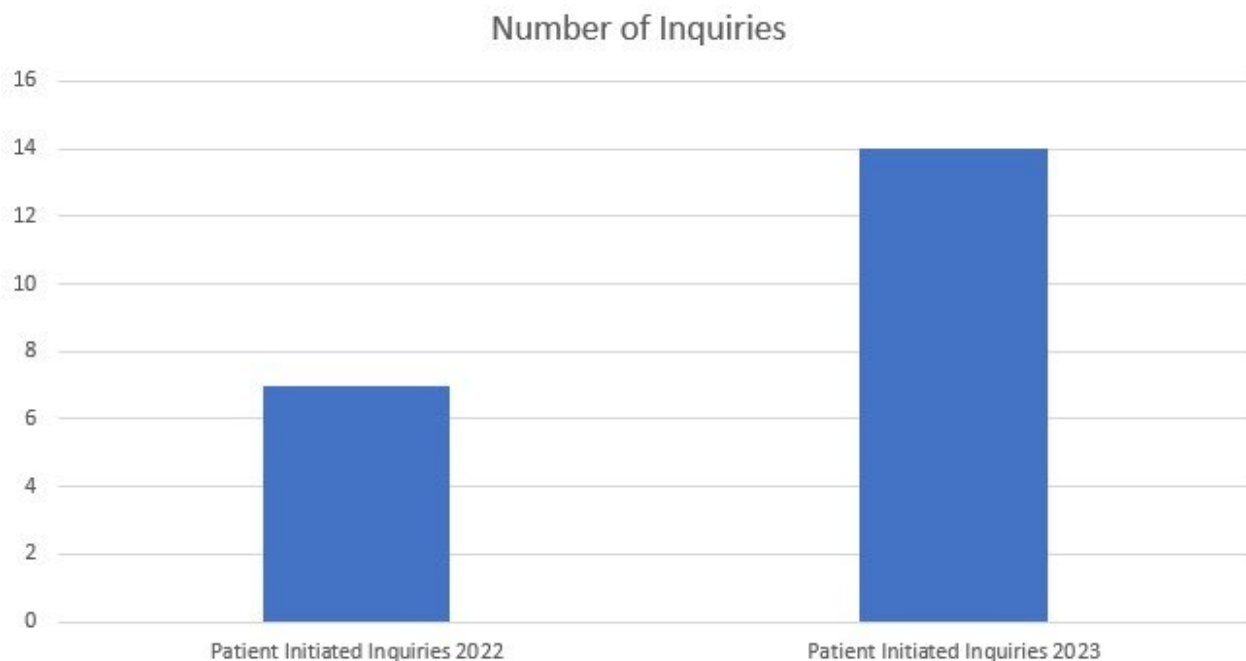
Intervention exposure



Out of the 1200 patients during the intervention phase of the study, 18 individuals were identified as those who could potentially benefit from respite care. The graph illustrates that only 1% of the patient population for the month of July were exposed to the intervention.

Figure 2

Intervention results



There were 14 respite care inquiries to the Department of Aging during the month of August 2023 compared to 7 inquiries during the month of August 2022, demonstrating a 100% increase in the number of respite care inquiries after the intervention.

Barriers and Strengths

One of the barriers of this project was that the intervention was limited to only one of many healthcare facilities in the area. It is not clear whether the increases in the number of inquiries for respite care, can be solely traced back to the intervention conducted at a single site. Therefore, the data results cannot be generalized to all physical therapy sites and departments of aging in other counties.

A second barrier was the time constraints for the completion of this DNP project. The short one-month review of respite care inquiries limited the acquisition of long-term longitudinal data. A greater amount of data could have provided more information on the respite

care inquires if the intervention was continued and followed over a longer period of time.

One of the strengths of the study was the large patient population of the rehabilitation center chosen for this DNP project. This center conducts over 10,000 patient visits each year.

A second strength was that the senior physical therapist, who oversees all patient interactions, was charged with determining whether the patient and informal caregiver may benefit from respite care service. The therapist would then briefly explain the service and give them the information pamphlet. Because there was a trusting relationship already in place, between the therapist and the patient, and also with their family members, the exposure to the intervention was given more weight.

The biggest strength of the project was the motivation of the professionals from both the rehabilitation center and the Department of Aging representative. The individuals of both entities believed in and supported the project's purpose. They were equally motivated to assist the PI with the project any way they could. Particularly evident was the degree to which suggestions for improvement were offered.

Discussion

The purpose of this study was to increase the utilization of the no-cost respite care services, by increasing the awareness of the service. This DNP project was supported by the most recent combined NAC and AARP reports, which demonstrated that only a little over one fourth of informal caregivers utilize any sort of paid service to assist with the day-to-day care of their loved one (NAC & AARP, 2015). The same study also points out that over half of the caregivers get no help at all and feel that they were thrust into the caregiver role, without any choice in the matter. The results of this study suggest that if caregivers are made aware of the respite services available to them, they are more likely to utilize them. In accordance with

studies, assistance services can reduce the negative aspects of informal caregiving if they are utilized (NAC & AARP, 2015).

This DNP project is justified by the fact that respite care is considered a vital aspect of patient care by maintaining the physical and mental health of the caregivers, yet it is typically underutilized (Leocadie et al., 2018). This is not a problem unique to North Carolina or to the United States, but a global problem. In the case of patients with dementia, it has been reported that there are nearly 36.6 million people that are afflicted with this diagnosis and these individuals make up a large portion of the population who are cared for at home (Leocadie et al., 2018). Researchers found that in light of the increasing number of dementia patients, it is imperative not only to quantify the total number, but also to forecast the future numbers, in order to make informed policy decisions, health system planning, and resource allocations (Lancet Public Health, 2022).

Unfortunately, one of the more common reasons for not utilizing a respite care service is a general lack of awareness of this resource (Graaf et al., 2022). During the course of this DNP project, information pamphlets were provided to a patient/family care team through the local physical therapy center, aimed at increasing caregiver awareness of the no-cost respite care service offered by the local county government. The impact of the intervention was seen in the increased number of inquiries to the local Department of Aging.

The PI found that there were multiple ways to spread the awareness of respite care in the planning of this project. Jansen et. al., (2021) found that simply placing pamphlets in a patient waiting area was not an effective way to increase awareness or knowledge about a subject. In order to spread awareness, the PI did not want to rely solely on patients finding the brochure on their own. The PI decided that the best way for this project to be successful was to combine the

distribution of the information pamphlet with a brief discussion of the service by a physical therapy staff member from the rehabilitation center. The staff member first broached the subject of respite care during the therapy encounter and then introduced the pamphlet to the patient and caregiver. The data from this project showed that this combined technique was effective, as seen by the increased numbers of inquiries in comparison to previous months without the intervention.

Although this DNP project only utilized one clinical site, the intervention showed a degree of positive results. Leocadie et al (2018) further suggests an all-out media blitz consisting of pamphlets, newsletters, broadcasts on radio and television, and visits to both in-patient and out-patient facilities. As discussed, this project was limited in its range of influence due to time and financial constraints associated with the academic setting. However, without much additional effort, the effectiveness of the pamphlets at single site could be expanded to encompass multiple sites in the same county. If raising awareness at a single site using the single methodology described in the project, it can be postulated that a full-blown marketing strategy, such as those recommended by Leocadie et al. (2018), could have a massive impact on the awareness of the no-cost respite care service in the county.

Sarah Adler, in a report on behalf of AARP in 2019, refers to the vast number of informal caregivers as an “invisible army.” (Adler, 2022). In other words, they are numerous, and most people are unaware of the levels of emotional and financial stress they endure daily. The next time we find ourselves in a neighborhood grocery, one might consider trying to identify an informal caregiver. Perhaps it is that elderly lady who was speed walking to her car to get home as quickly as she could before her demented husband awoke and attempted to leave. Maybe it’s a co-worker who keeps asking for time off because they are caring for a disabled sibling. Stressors

experienced by the informal caregiver are difficult to fathom. These informal caregivers are more prone to emotional disorders due to the unrelenting stressors that are associated with supplying 24-hour care (Manzini & do Vale, 2020). This reinforces the purpose of this DNP project, which is to promote the benefits of respite care in a more active manner, letting this silent army know they are not alone and that there is help available.

Act

To determine if the intervention of this study was specifically responsible for the increase in the inquiries into the service, it is recommended that the project be repeated in a different county or for a longer period of time. Also, specific information could be gathered when the respite care representative is contacted by the individual. The agent might ask how the caller first heard about the respite care service. This feedback can be used to make changes to the awareness program. This can focus the efforts on the promotion of respite care, by avoiding wasted time and money on ineffective marketing.

Finally, to increase awareness, it is recommended that a Department of Aging representative visit in-patient and out-patient sites throughout the area. This would help to introduce or remind staff of this service; what types of patients would benefit; provide an opportunity to communicate the importance of the respite care services; and have more personal face-to face communication with staff members at the site. Once this is accomplished, the representative would leave the information pamphlets at the facility for distribution to the patients and their caregivers.

Conclusion

As the population ages, it is imperative that we acknowledge the physical and mental burdens placed on the informal caregivers. Respite care allows this invisible army to take a

temporary break from the relentless care that they provide for their family members. This temporary relief will enable these individuals to remain in their role as primary caregivers for an extended period of time. There is supportive evidence that respite care can positively impact the quality of life of both the caregivers and their recipients. When it comes to increasing the utilization of respite care, correctly identifying a patient who would benefit from the service and then informing them of the service is an effective approach. It is important to foster optimal quality of care and develop relationships between the caregivers and respite care resources. The significance of communicating supportive services to the informal caregivers cannot be overstated.

I HAVE ABIDED BY THE ACADEMIC INTEGRITY POLICY ON THIS ASSIGNMENT.

Signature: Joe Haralson

Date: 27 March 2024

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APPENDIX

Appendix A

The Office of Research Integrity
 The University of North Carolina at Greensboro
 2714 MHRA Building, 111 Spring Garden Street,
 Greensboro, NC 27412
 (336)- 256- 1482

To the Office of Research Integrity,

I have reviewed the DNP project proposal submitted by Joe Haralson, RN, BSN, and I agree to provide the support requested. This letter provides permission for Joe Haralson, a DNP student at UNCG, to conduct the DNP project that will involve increasing the knowledge of the no-cost care services supplied by Moore County, to family caregivers. Myself and the staff are committed to working with this DNP student and to allow the student to use our facility for this project.

It is my understanding that prior to data collection, the project proposal must first be reviewed and approved by UNCG institutional Review Board for Research Involving Human Participants, and that this support letter is required for the IRB review. It is also understood that our institution may require an IRB or research department review.

Sincerely,

Mary Veit, PT

Name *Mary Veit*
 Site Address *FirstHealth Outpatient Rehab*
 Contact information *mveit@firsthealth.org*
 Job title *PT/OT Supervisor*

Appendix B

The Office of Research Integrity

The University of North Carolina at Greensboro
 2714 MHRA Building, 111 Spring Garden Street,
 Greensboro, NC 27412
 (336)- 256- 1482

To the Office of Research Integrity,

I have reviewed the DNP project proposal submitted by Joe Haralson, RN, BSN, and I agree to provide the support requested. This letter provides permission for Joe Haralson, a DNP student at UNCG, to conduct the DNP project that will involve collecting the number of respite care inquiries into the Department of Aging, from local family caregivers. I am committed to working with this DNP student and to provide assistance for this project.

It is my understanding that prior to data collection, the project proposal must first be reviewed and approved by UNCG institutional Review Board for Research Involving Human Participants, and that this support letter is required for the IRB review. It is also understood that our institution may require an IRB or research department review.

Sincerely,

Alveda Person

Signature

Alveda Person

Name

Site Address *8040 US Hwy 15-501 West End NC 27376*

Contact information *910-947-4186 · aperson1@mecklenburgnc.gov*

Job title

Family Caregiver Advisor

Appendix C

Caregiver Bill of Rights

As a Caregiver,

I have the Right:

- ...to take care of myself...to rest when tired, to eat well, and to take breaks from caregiving when I need them...
- ...to recognize the limits of my own endurance and strength...
- ...to identify support from family members, involved parties, physicians, churches and the community at large...
- ...to socialize, maintain my interests, maintain my health, do things I enjoy (have a life)...
- ...to acknowledge my feelings, whether positive or negative, including frustration, anger and depression, and to express them in a healthy manner...
- ...to take pride in the valuable work I do, and to applaud the courage and strength it takes to meet the needs of my loved one...

Adapted from AARP

Moore County Department of Aging



Family Caregiver Support Program

Due to additional grant funds, caregivers are also eligible to receive the following services:

- Liquid Nutrition
- Supplements (Ensure, Ensure Plus, and Glucerna)
- Incontinence Supplies

The cap for each service provided will be determined on a case-by-case basis.

For additional information please contact

Alveda Person,
Family Caregiver Advisor
8040 US Hwy 15-501
P.O. Box 487

Carthage, NC 28327
Phone: 910-947-4186
aperson1@moorecountync.gov

Helping families one step at a time...

Tel: 910-947-4186
Fax: 910-215-0278

Appendix C

continued

Who's eligible for Respite services?

Funds are intended to assist the caregiver directly, even if there is no direct help for the care receiver. A "caregiver" is eligible for services under the National Family Caregiver Support Program (NFCSP) by meeting one of the following requirements:

- An adult aged 18+ who assists a family member aged 60+; **OR**
- An adult 18+ who assists a person with Alzheimer's disease or a *related* disorder regardless of age; **OR**
- A senior aged 55+ who is a grandparent or other relative (not natural or adoptive parent) raising a grandchild or a family child (aged 0-18); **OR**
- A senior relative (not natural or adoptive parent) aged 55+ who is raising an adult child aged 18-59 with a disability.

What is Respite Care?

According to the National Family Caregiver Support Program:

Respite care services provide periodic support/relief for caregivers from the responsibilities and stress he/she may encounter while caring for a loved one. It allows the caregiver to practice self-care and meet other responsibilities outside of the home.

The Moore Co. Dept. of Aging's Respite Care Program is funded by a state-level grant. Services are contracted with a local home care agency. The agency will not provide hands-on care (such as feeding and dressing) for the client. Their goal is to provide emotional support, improve the quality of life as well as be a companion for your loved one.

The Respite Care Program is based on voluntary contributions only.

Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP) provides grants to States and Territories to fund a range of support that assist caregivers.

The NFCSP offers services like:

- Information to caregivers about available services.
 - Assistance to caregivers in gaining access to the services.
 - Individual counseling, support groups and training to assist caregivers in the areas of health, nutrition and financial literacy.
 - Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities.
 - Supplemental services on a limited basis.
- These services can work in conjunction with other state and community based services to provide a coordinated set of supports.

