Combatting the Inevitable: Stress Reduction and the Informal Caregiving Role

Jessica C. Winski

Edson College of Nursing and Health Innovation, Arizona State University

Author Note

Jessica C. Winski is an Edson College of Nursing and Health Innovation graduate of Arizona State University. She has experience as a teaching assistant at Arizona State University and in at-home care for medically fragile children.

She has no known conflict of interest to disclose.

Correspondence concerning this article should be addressed to Jessica C. Winski, Edson College of Nursing and Health Innovation, Arizona State University, 550 N. 3rd Street, Phoenix, AZ 85004. email: jfarrone@asu.edu

Abstract

The purpose of this quality improvement project is to determine if preparation for the caregiving role reduces stress. The community of caregivers in Arizona have expressed to a caregiving agency that not knowing how to prepare for a personal emergency related to their caregiving duties led to increased stress. The agency created an emergency respite guide and booklet through grant funding regarding this issue. The Transactional Model of Stress and Coping will be the guiding theory for this project. Participants for the study were recruited through flyers in the agency newsletter. Human subject protection was accomplished, and subjects had to be over 18 years old, have no prior caregiving training, have not filled out a respite booklet previously, and be a primary Caregiver for someone. Subjects completed two validated pre-booklet questionnaire tools. The booklet was then sent to the participants to complete, then completed the same two questionnaires after filling out the booklet immediately post, and then 30 days later, along with an evaluation questionnaire. The scores were input into intellectual statistics then analyzed using descriptive statistics. Results for an *n* of four displayed an overall decrease in stress symptoms and perceived stress after completion of the booklet. If stress is reduced with preparation using an emergency respite booklet, then as a community, we know that preparation for the caregiving role is necessary to reduce stress and improve quality of life.

Keywords: Informal caregiver, stress, preparation, quality of life

Combatting the Inevitable: Stress Reduction and the Informal Caregiving Role

Some individuals cannot fully care for themselves at home but do not require hospital or nursing-level care; this dilemma leads to needing assistance from a family member, friend, or someone else in the community to help care for them. Caregivers without previous experience can face many challenges when caring for someone. There are issues in caregiving— caregiver burnout, increased caregiver stress, and poor quality of care, to name a few—that arise in the informal caregiver situation that is important to address to ensure that both parties are supported. This role comes with many unknowns and responsibilities all piled on instantly. Feeling prepared to care for someone makes the role more manageable. This quality improvement project used an emergency respite booklet to prepare for the unknown and its relation to stress in informal caregivers measured using questionnaires. Stress in this role is inevitable, but it should not be unbearable.

Problem Statement

Initiating taking care of someone at home without any preparation is daunting; some need help knowing where to start or how to take care of someone best. When an informal caregiver feels equipped to take on this role in only some aspects, it adds to the stress that they may experience as a caregiver. This culmination of stress can lead to a high burnout rate among this population. Mental health struggles such as anxiety and depression can lead to burnout, which is defined as long-term stress causing exhaustion, reduced desire, motivation, and fulfillment to perform (Rotenstein et al., 2018). This issue of burnout has been researched exponentially in formally trained healthcare workers but needs more for informal caregivers (Rotenstein et al., 2018).

The prevalence of informal caregivers is growing today and will continue in the years to come. In a month, about 23% of adults in the United States express that they have cared for someone before; 22% of adults in Arizona care for someone in the home setting. About 14.5% of adults who provide care in the United States report that they experienced two weeks of poor mental health over the previous month, with about 17% in Arizona stating that their mental health is inadequate. The increased demand for informal caregiving will grow nationally in the next two years (Centers for Disease Control and Prevention, 2018). This growing role will require more awareness, research, and support than ever to battle this population's struggles.

Purpose and Rationale

As informal caregiving plays a vital role in healthcare, addressing burnout is imperative for long-term positive outcomes. Caregiving is a demanding role to take on and for which to feel prepared. If proper preparation to care for someone is not accomplished, this causes unneeded stress and can quickly lead to burnout. Determining where most support is needed is crucial to ensure they successfully care for someone. If someone is being managed by another person who is struggling mentally and feels burnt out, the person receiving care is also subject to their health suffering. This project aims to determine if stress and burnout are related to informal caregiver preparedness using an emergency respite booklet (see Appendix B).

Background and Significance

Problems involving caregiving can be complex and multifaceted and are more readily examined piece by piece. Determining who is interested in this widespread issue, what can be done to prevent burnout different from what is already being done, and what are the outcomes are integral parts of understanding the problem.

Population

The population that was explored is informal caregivers who care for someone in the home setting. Informal caregivers are all around us in the community and play a significant role in caring for one's well-being and health. Informal caregivers are unpaid and do not have any formal education to care for someone medically but provide in many areas of one's life and well-being (Centers for Disease Control and Infection, 2018; Koller et al., 2022). The problem addressed is this population's high caregiver stress and burnout rate. The burden of caring for an individual's medical and personal needs can put much strain on a caregiver's finances, personal life, relationships, and health; this can lead to increased stress and burnout (Alves et al., 2019; Fenstermacher et al., 2022; Gérain & Zech, 2022; Parry et al., 2023).

Intervention(s)

To battle burnout and high stress in informal caregivers, emergency respite preparation can help these individuals have peace of mind when caring for someone. Sometimes emergent situations arise for a caregiver, and the person they care for requires emergency respite. Planning for these situations using the emergency respite booklet to have all needed information in one place is the goal of the project site; they have found that only a few caregivers have this information prepared or even know what respite is or means. A literature search found that preparation in any capacity for this role positively benefits the caregiver's life (see Appendix A, Table A1-A3). Respite care is care provided by someone other than the sole caregiver equipped with the knowledge and information to care for the individual appropriately (Phillipson et al., 2019; Roberts & Struckmeyer, 2018). Respite care improves caregivers' well-being by giving them a reprieve from this role to care for themselves or other obligations. Informal caregivers spend a significant amount of time throughout the day managing activities of daily living and medical needs, including appointments and household chores; the reduction in time for the

caregivers' needs becomes an issue. Respite care resources and planning can help reduce the stress and burnout rate one might experience when juggling one's life and someone else's (Phillipson et al., 2019; Roberts & Struckmeyer, 2018).

Comparison/Current State

Many people are discharged from the hospital with many comorbid conditions that need to be managed, and the education and support for those who will be caring for the patient at home is lacking. There can be a short time to prepare to care for someone with an illness that presents quickly (Lieshout et al., 2020). In an outpatient setting, a provider may need help identifying caregiver needs or how and what to address, often leaving the caregiver needing informed education or resources (Holliday et al., 2022). Furthermore, respite care is not utilized to its full potential. The low incidence of caregivers finding respite care can be attributed to many factors: feeling like there will be a lack of quality care, guilt of leaving the person to be cared for, and poor follow-through with resources (Phillipson et al., 2019). A change in knowledge and use of respite services is an intervention that can be addressed, which also goes hand in hand with preparation for becoming a caregiver.

Outcome(s)

The ideal outcome of improving preparedness would be reducing stress and burnout rates and improving mental health. A national strategy aiming for this outcome is the RAISE Family Caregiving Act which includes five primary goals to support the caregiver to aid in the most success (Administration for Community Living, 2022). Another outcome would be improved preparation of care planning and education about what is available to caregivers (Holliday et al., 2022). Lastly, increased respite opportunities and connections likely increase caregiver satisfaction (Holliday et al., 2022). The burden of caregiving can also manifest as physical

symptoms of pain and fatigue, so improving stress in these caregivers could also enhance their health (Koller et al., 2022).

Background/Significance Summary

Overall, informal caregivers are highly susceptible to stress and burnout. When underprepared and stretched thin, these caregivers need the proper tools to provide care effectively. Respite care necessary to ensure their health is optimal to continue giving care; if they are not healthy, the individual being cared for cannot receive the care and supervision they need. Preparation and role relief are currently overlooked as interventions to diminish stress. The goal is to improve the caregiver's satisfaction and personal well-being.

Internal Data

The organization is a non-profit located in Downtown Phoenix called the Arizona Caregiver Coalition that serves the greater Phoenix area and other areas across Arizona; the agency supports caregivers of all types. Their mission is to improve the lives of caregivers around Arizona with support, advocacy, and resources. The key stakeholders are the executive director of the organization and the program development coordinator. The issue at hand was discovered due to the numerous caregivers in the community who would reach out to the organization for help to prepare for caregiving or what to do in times of stress. The coalition saw a continuing pattern of people who were over-stressed or burnt-out in the caregiver role due to lack of preparation and utilization of respite. This unaddressed issue could impact the care that someone gets due to the stress and burnout of the caregiver. This problem is significant to the Arizona Caregiver Coalition because its goal is to maximize the quality of life for caregivers—increased tension in this role has the opposite effect of what the organization is trying to accomplish in its mission.

PICOT Question

Are informal caregivers who care for an individual at home with chronic conditions who receive preparation tools for this role compared to the current practice of no preparation tools show reduced overall stress?

Search Strategy

Compiling the most relevant research on informal caregiving started with an extensive search of PsychINFO, PubMed, and the Cumulative Index of Nursing and Allied Health (CINAHL). These three databases provide peer-reviewed journals and reliably produce medically driven research to aid in preparedness to reduce informal caregiver stress. Preparation through training, classes, and education was the focus of this search to look to commonly studied forms of preparation and translate this to preparation using education and materials for emergency respite; the search yields, as mentioned in the following sections, did not demonstrate current research in emergency respite preparedness and the effects of this on caregiver stress. The search strategies and levels of evidence of the included articles are discussed in more depth in this section.

Keyword Selection

Refined keyword selections for the search yielded the most applicable articles for the PICOT question. The keywords used in each initial search were *informal caregivers* and *stress.* This search produced many articles in PubMed and a manageable amount in CINAHL and PsychINFO, but the yield needed to be narrower and fit the inclusion criteria stated below. A second search of *informal caregivers, family caregivers, emergency respite, preparation, reduced burnout,* and *reduced stress* yielded no articles. A third search of *informal caregivers, family caregivers, family members, chronic conditions, preparation, class, training, reduced*

burnout, and *reduced stress* yielded a minimal number of articles; the term *chronic condition* was removed in the final search. This adjustment caused a more condensed and suitable culmination of research to be examined.

Initial and Final Search Yields

An initial search of *informal caregivers and stress* yielded 348 results on PsychINFO, 263 on CINAHL, and 4,557 on PubMed. The final search with the keywords of *informal caregivers*, *family caregivers, family members, preparation, classes, training, reduce burnout,* and *reduce stress* yielded 23 on CINAHL, 96 on PsychINFO, and 1,862 on PubMed. After inspecting each yield from all three databases, ten critically appraised articles were extracted; of the ten articles, four were randomized control trials (RCT), two pre-post experimental design, one pilot (non-randomized, non-controlled) trial, one Likert scale interview, one descriptive exploratory study, and one longitudinal descriptive study. Boolean phrases and Mesh terms were included in the searches to have all possible results, and gray literature from the Centers for Disease Control and Prevention and the Administration for Community Living was examined.

Limitations, Inclusion, and Exclusion Criteria

The inclusion criteria of the articles included those published between 2018 and 2023, peer-reviewed, and written in English. They also needed to be focused on informal caregivers and exclude any capacity of educationally prepared caregivers. Any medical condition or illness of the one receiving care and any age or gender was included in the search. Almost half of the articles chosen were RCTs to have the highest level of evidence. Articles were also excluded if the proposed intervention did not discuss the relation to caregiver stress. Articles were included if they discussed caregiver depression or burdens related to stress.

Critical Appraisal and Synthesis of Evidence

The Rapid Critical Appraisal (RCA) tool by Melnyk and Fineout-Overholt (2019) was used to acquire the highest levels of evidence. The studies included were determined to be of relatively high quality and strong evidence; many of the studies used a randomized control trial as its design. Though most studies selected were high-quality quantitative studies (see Appendix A, Table A1), there are two notable qualitative studies included (see Appendix A, Table A2) in the evidence tables and synthesis table (see Appendix A, Table A3). The qualitative studies facilitate the use of personal accounts of caregivers' thoughts and feelings about their role—namely regarding stress and burden—which adds significant substance to the evidence.

Demographically, the mean age of participants in the studies was 50, and they consisted mainly of females. The research took place in hospital/clinic settings or the community. Sample sizes ranged from small at 13 to large at 370. As stated, most of the study's participants were female caregivers, but in one study, male caregivers comprised most of the participants. This outlier of the ten studies determined their sample through inclusion criteria of the patient rather than the caregiver. The tools used in many studies, such as the Zarit Burden Scale (ZBD), were valid and reliable. Crucial dependent variable outcomes examined in the studies were caregiver stress and burden, which improved overall in each intervention. There was heterogeneity of the study samples and measurements, and homogeneity of the demographics, outcomes, and variables. A weakness of the studies overall was that about half were conducted outside the United States; this allows less local evidence related to the issue.

Project Relation to the Literature Search

The role that so many take on for an ill loved one can be debilitating and cause much-unneeded strain in one’s life. When stress levels are addressed, many other facets of life improve, including physical health, quality of life, depression, and coping strategies; as seen in

the evidence synthesis. Along with the benefits experienced by the caregiver, the person receiving care, in turn, is provided with more quality management; when someone is in the most optimal physical and mental space in their role, the job is done exceptionally well. Examining preparation for the caregiver role in all facets—whether training, education, or emergency respite resources—effectively reduces stress; this literature synthesis described is the foundation for the project. The health of both individuals, both mental and physical, is of utmost importance in this situation.

Theory/Theoretical Framework Application

Transactional theory is the concept that the environment and the person are in a reciprocal and dependent relationship; one affects the other and vice versa (Lazarus & Folkman, 1984). When considering stress and this theory, the environment influences the person; therefore, the person's response affects the environment. Lazarus and Folkman's (1984) Transactional Model of Stress and Coping appropriately fits the basis of this topic.

The body responds internally to stress caused by external stimuli seen as damaging; the body then needs to determine how to respond to the stimuli (Lazarus & Folkman, 1984). This model has three steps: appraisal of the stressor, current coping abilities, and using coping strategies (see Appendix C, Figure C1). If a stressor is seen as harmful, the person must look at the coping strategies, such as internal factors of willpower and confidence, or external environmental factors, such as family support and finances. Next, coping strategies, such as problem-solving or emotional response, must be implemented to overcome stressors (Lazarus & Folkman, 1984). Improved psychological well-being and functioning is the intention of these effective coping strategies. Caregiving can induce stress, and how they cope with that stress can make a difference in the effect it has on their life and health.

This model supports the proposed intervention by establishing problem-solving methods through utilizing the emergency preparedness booklet to manage stress in the caregiving role and life in general. When a stressor arises, the booklet can be used to cope with the anxiety that is bound to ensue.

Implementation Framework

The FADE Model for quality improvement will guide the intervention in this project (see Appendix C, Figure C2). This model was created by the Organizational Dynamics Institute in Wakefield, Massachusetts to improve the quality of a process (Wiseman & Kaprielian, 2002). There are four steps to this model: focus, analyze, develop, and execute/evaluate. These four steps encompass determining the process that needs improving, collecting data, developing a plan, and implementing and evaluating the plan (Wiseman & Kaprielian, 2002). This model adequately applies to this project as each step coincides with the project timeline of determining the issue being caregiver stress, gathering data about caregivers, proposing a plan with the emergency respite booklet, and implementing that plan. The plan that will be implemented is the evaluation of preparation tools to determine if they are effective in reducing informal caregiver stress.

Methods

The methods of the project were well developed and thought out with the site stakeholders', students', and mentors' input. Proposed intervention implementation and analysis were deemed the best course to measure the project outcomes. The setting, participants and recruitment, intervention, data collection methods, and analysis plans are outlined below.

Setting and Stakeholders

This project was completed with the Arizona Caregiver Coalition. The key stakeholders are the Executive Director, the Program Coordinator, and the Project Developer. The Executive Director oversaw the project. The Program Coordinator facilitated communication between participants and staff to allow the project to flow smoothly. The Project Developer collaborated to design the project elements, aid recruitment processes, distribute materials and deliverables, and assisted in data collection.

Participants and Recruitment

The participants are enrolled members of the agency who are informally trained caregivers in the community. Inclusion criteria for the participants are that they must be the primary caregiver, caring for anyone with any medical or psychological conditions, take care of the individual in the home for more than 4 hours a day, and be over 18 years old. Exclusion criteria included formally trained caregivers with an emergency respite plan already in place. Formally trained caregivers may be equipped with knowledge of the information designed to be new information dispersed to caregivers for this project. Also, a previously designed plan eliminates the pre-measure of the intervention and could skew the stress scales. Participants will be recruited through fliers at in-person events (See Appendix D, Figure D) or electronically through emails and social media posts.

Project Description

The question evaluated was, “Does planning for emergency respite services reduce informal caregiver stress?” The agency developed a booklet that informal caregivers can fill out to help them be prepared for emergency respite. The goal of the booklet is to help reduce stress caregivers feel knowing that their loved one is cared for when something emergent arises.

Intervention and Timeline

Once approval from the IRB was completed in July 2023, the project intervention and data collection began. To start with, the agency has assessed the needs of the community of informal caregivers; many caregivers enrolled in the agency have expressed concerns about not knowing what to do, where their loved ones will go in times of emergency, and what caregiver respite even is—thus the booklet was developed. Recruitment fliers, mass emails, and social media posts used to obtain project participants were dispersed starting in late August 2023. The potential participants were then screened for eligibility based on the inclusion and exclusion criteria in September 2023. Once the participants were selected, they filled out a consent form sent by email and returned by email stating their understanding of their role and participation in the project in September and into October 2023; after all participants had been selected and signed consent, the intervention and outcome measurement started. All the documents can be completed electronically or in person if the participant opts for this method. At the beginning of October 2023, the participants filled out a demographic questionnaire, Perceived Stress Scale questionnaire (PSS-10), and Subclinical Stress Symptom Questionnaire (SSQ-25) all sent by email and returned as a digital anonymous survey or in-person, to evaluate stress before filling out the booklet (Cohen et al., 1983; Helms & Weierstall, 2016). Then, following the responses to the previously mentioned questionnaires, the participants filled out the booklet which they picked up at the agency office or had mailed to their homes. After completing the booklet, the participants received the PSS-10 and SSQ-25 by email in November and December 2023 and then again at the beginning of December 2023, January, and February 2024, both returned by anonymous digital survey or in-person. In December 2023 and January 2024, they were also asked to fill out an evaluation survey sent by email and returned by digital anonymous survey or in person. The evaluation survey evaluated the booklet and its helpfulness to their caregiving role

and if they have had to use their emergency respite plan. The budget for the project can be found in Appendix E, figure E. All the data was collected and analyzed in Intellectus® Statistics (2022) online software.

Data Collection Plan

To collect data for the project, questionnaires were sent out as a link to an anonymous digital survey in an email or picked up by the participants at the agency in a secured location that has an outbox label and could be returned to the exact secure location in the inbox folder. Protecting the participants' identity and information comprised of a four-digit code that was created by each participant and was filled out for each returned document from the participants. Also, the secured location will allow for data privacy as well. The data will be kept indefinitely in Arizona State University's repository.

Outcome Measures/Measurement

The participants' stress levels and stress symptoms were the outcomes measured in this project. Using stress scale instruments determined if and how much stress was reduced from before filling out the booklet and receiving the respite information to after completing the booklet and education on respite. The goal outcome of the project was to decrease the overall stress of the caregiver and improve stress symptoms to improve life quality and health. This outcome measure relates to the Transactional Model of Stress and Coping by using the booklet as a coping strategy to use as a tool for future stressors such as an unforeseen emergency.

Instruments

The instruments used in this project to measure stress are the Perceived Stress Scale (PSS-10) and Subclinical Stress Symptom Questionnaire (SSQ-25). Validity and reliability have been identified for each tool. For the PSS-10, internal consistency reliability was established in a

review of the tool, and factorial and hypothesis validity were well reported (Lee, 2012). For the SSQ-25, internal consistency reliability was high with Cronbach's α and a factor analysis showed high validity (Konstantopoulou, 2020). An independently developed evaluation tool and demographics were used as well. The demographics collected are age, gender, education level, employment, race/ethnicity, marital status, income, condition of the person being cared for, formal caregiving training, and previous completion of the emergency respite booklet.

Data Analysis Plan

In analyzing the data, the goal was to measure if there was a change in stress from before to after the booklet and if it was significant. Although there are two-time points where a measurement of the same scale variables is required, there were only four subjects, therefore descriptive data analysis was only able to be performed on the outcome data as well as the demographic data (Intellectus®, 2022). Confabulation variables were run in the descriptive analysis as well.

Ethical Considerations

Four ethical principles guided this project: autonomy, beneficence, non-maleficence, and justice. Autonomy is the right of the patient to make a fully informed decision about their health and healthcare (Johnson, n.d.). The project adhered to this principle by providing informed consent and allowing participants to partake or decline. The individuals who filled out an emergency respite preparation booklet and received the information guide for caregiving were given all the information required to participate in the project and must sign consent. Beneficence is the intent to do good for the patients or participants involved (Johnson, n.d.). The project adhered to this principle with good intentions in forming methods and measurements. This project aimed to produce a net benefit for this population by determining if

preparation reduces stress. Non-maleficence not harming the patient or participants (Johnson, n.d.). The project adhered to this principle by using methods without malicious intent. This project did not require any intervention that could be physically harmful to the caregivers. Justice is the final principle and is the idea that all procedures or treatments are equal and fair between groups (Johnson, n.d.). The project adhered to this principle by being honest with intervention distribution. The participants were given the same information and measurement tools to disseminate this project equally. Consent was obtained with a printout of the information regarding the project, its goals, and risks and benefits to the participants, who needed to acknowledge and sign. Participants had the right to decline participation in the study and know the risks associated with being a part of the project. Anonymizing responses will protect human rights and allow participants to stop participation whenever and for any reason. The Principal Investigator and the Arizona State University IRB reviewed the project's methodology.

Results

Intellectus® (2022) was used to complete all data analysis with descriptive statistics for a sample size of 4. Summary statistics were calculated for the variable of age. Frequencies and percentages were calculated for gender, education, employment, race and ethnicity, marital status, insurance, medical condition, training, respite use, and prior booklet completion.

Demographics

The average age for the sample was 52 (*SD* = 12.88), and ages ranged from 35-65. The summary statistics can be found in Table 1. The majority of participants were female (*n* = 3, 75%), with the remainder being male (*n* = 1, 25%). There was an equal number of participants with a bachelor's degree (*n* = 2, 50%) and master's degree (*n* = 2, 50%). The majority of the participants were retired (*n* = 2, 50%), with the remainder being employed part-time (*n* = 1, 25%)

or unemployed (*n* = 1, 25%). Most of the participants were white (*n* = 3, 75%), with the rest being Asian or Asian-American (*n* = 1, 25%). The majority of participants were married (*n* = 3, 75%), with the other being divorced (*n* = 1, 25%). Most of the participants were insured (*n* = 3, 75%), and the remaining had Medicare (*n* = 1, 25%). The participants primarily cared for someone with neurological illness (*n* = 2, 50.00%), while the other cared for someone with a psychological or mental illness (*n* = 1, 25%) or other unspecified illness (*n* = 1, 25%). Most of the participants have not used respite services, (*n* = 3, 75%), while one had (*n* = 1, 25%). Frequencies and percentages are presented in Table 2. All participants did not have prior caregiver training or complete a respite booklet.

Table 1

Summary Statistics Table for Age

Variable	*M*	*SD*	*n*	Min	Max
Age	52.00	12.88	4	35.00	65.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Table 2

Frequency Table for Demographic Variables

Variable	*n*	*%*
Gender		
Male	1	25.00
Female	3	75.00
Education		
Bachelor's Degree	2	50.00
Master's Degree	2	50.00
Employment		
Employed Part-time	1	25.00
Unemployed	1	25.00
Retired	2	50.00
Race or Ethnicity		
White	3	75.00
Asian or Asian-American	1	25.00

Marital Status		
Married	3	75.00
Widowed	1	25.00
Insurance		
Insured	3	75.00
Medicare	1	25.00
Medical Condition		
Neurological	2	50.00
Psychological/Mental Illness	1	25.00
Other	1	25.00
Prior Respite Use		
Yes	1	25.00
No	3	75.00

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

Overall Outcomes

The SSQ-25 does not display range to express stress levels, but the higher the total score, the higher the stress symptoms, with a maximum total of 100 (Weierstall, 2016). The PSS-10 scores the tool with the total in ranges; total scores between zero to 13 are considered low stress, between 14 to 26 is considered moderate stress, and between 27 to 40 is considered high stress (Cohen et al., 1983). The average score of stress symptoms of the participants prior to filling out the booklet was 48 (*SD* = 12.41) and ranged from 33 to 62. After completion of the booklet, the average total stress symptom score was 27 (*SD* = 9.70) and ranged from 16 to 37. The average total stress symptom score in the 30-day follow-up was 45.75 (*SD* = 15.33) with scores ranging from 25 to 60. The average total perceived stress score prior to filling out the booklet was 25 (*SD* = 4.32) and ranged from 21 to 31. The average total perceived stress score immediately post booklet completion was 18.25 (*SD* = 3.20), with score ranging from 16 to 23. The average total perceived stress score in the 30-day follow-up was 20 (*SD* = 3.16), and scores ranged from 17 to 24. The summary statistics can be found in Table 3.

Table 3

Summary Statistics Table for Total Stress Scores

Variable	*M*	*SD*	*n*	Min	Max

Pre-booklet Stress Symptom Score	48.00	12.41	4	33.00	62.00
Post-booklet Stress Symptom Score	27.00	9.70	4	16.00	37.00
Follow-up Stress Symptom Score	45.75	15.33	4	25.00	60.00
Pre-booklet Perceived Stress Score	25.00	4.32	4	21.00	31.00
Post-booklet Perceived Stress Score	18.25	3.20	4	16.00	23.00
Follow-up Perceived Stress Score	20.00	3.16	4	17.00	24.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Outcome by Demographic Variable

Summary statistics were calculated for pre-, post-, and follow-up stress symptoms scores as well as pre-, post-, and follow-up perceived stress scores split by gender, education, race and ethnicity, insurance, employment, marital status, and medical condition.

Summary Statistics by Variable

For female gender, the average stress symptom score prior to booklet completion was 46.33 (*SD* = 14.64) and ranged from 33 to 62. The average female stress symptom score immediately after booklet completion was 23.67 (*SD* = 8.62) and ranged from 16 to 33. For female gender, the average stress symptom score at the follow-up was 46.33 (*SD* = 18.72), with scores ranging from 25 to 60. The average perceived stress score for female participants prior to booklet completion was 25(*SD* = 5.29), and scores ranged from 21 to 31. For female gender the aver perceived stress score immediately after booklet completion was 19 (*SD* = 3.46), with scores ranging from 17 to 23. The average perceived stress score for female participants was 19.67 (*SD* = 3.79), with scores ranging from 17 to 24. The summary statistics can be found in Table 4, where male stress scores are also reported.

For participants with a bachelor's degree, the average stress symptom score prior to booklet completion was 38.50 (*SD* = 7.78), and scores ranged from 33 to 44. For participants with a master's degree, the average stress symptom score prior to booklet completion was 57.50

(*SD* = 6.36), with scores ranging from 53 to 62. Bachelor's degree holding participants had an average stress symptom score of 24.50 (*SD* = 12.02) immediately post booklet completion, and scores ranged from 16 to 33. Master's degree holding participants had an average stress symptoms score of 29.50 (*SD* = 10.61) immediately post booklet completion, and scores ranged from 22 to 37. For participants with a bachelor's degree, the average stress symptom score was 42.50 (*SD* = 24.75) at follow-up, with scores ranging from 25 to 60. For participants with a master's degree, the average stress symptoms score at follow-up was 49 (*SD* = 7.07), and scores ranged from 44 to 54. Participants who hold a bachelor's degree had an average perceived stress score of 26 (*SD* = 7.07) prior to booklet completion, and scores ranged from 21 to 31. Participants who hold a master's degree had an average perceived stress score of 24 (*SD* = 1.41) prior to booklet completion and ranged from 23 to 25. For bachelor's degree holding participants, the average perceived stress score was 20 (*SD* = 4.24) immediately after booklet completion, and scores ranged from 17 to 23. For master's degree holding participants, the average perceived stress score immediately after booklet completion was 16.50 (*SD* = 0.71), and scores ranged from 16 to 17. Participants with a bachelor's degree had an average perceived stress score of 21 (*SD* = 4.24) at follow-up, with scores ranging from 18 to 24. Participants with a master's degree had an average perceived stress score of 19 (*SD* = 2.83) at follow-up, and scores ranged from 17 to 21. The summary statistics can be found in Table 5.

Participants identifying with a race or ethnicity of White had an average stress symptom score of 43.33 (*SD* = 10.02) prior to booklet completion with score ranging from 33 to 53. For White identifying participants, the average stress symptom score immediately after booklet completion was 28.67 (*SD* = 11.15), with scores ranging from 16 to 37. Participants who identify as White, the average stress symptom score at follow-up was 43 (*SD* = 17.52), and scores ranged

from 25 to 60. Participants identifying with White as their race or ethnicity, had an average perceived stress score of 25.67 (*SD* = 5.03) prior to booklet completion, with scores ranging from 21 to 31. For White identifying participants, the average perceived stress score was 18.67 (*SD* = 3.79) immediately after booklet completion, and scores ranged from 16 to 23. Participants who identify as White race or ethnicity, the average perceived stress score was 21 (*SD* = 3.00) at follow up, with scores ranging from 18 to 24. The summary statistics can be found in Table 6, where Asian or Asian-American stress scores are also reported.

For insured participants, the average stress symptom score was 49.33 (*SD* = 14.84) prior to booklet completion, and scores ranged from 33 to 62. Insured participants had an average stress symptom score of 25 (*SD* = 10.82) after booklet completion, with scores ranging from 16 to 37. For Insured, the average stress symptoms score at follow-up was 41 (*SD* = 14.73), and scores ranged from 25 to 54. Insured participants had an average perceived stress score prior to booklet completion of 23 (*SD* = 2.00), and scores ranged from 21 to 25. For insured participants, the average perceived stress score after booklet completion was 16.67 (*SD* = 0.58), with a range of scores between 16 and 17. Insured participants had an average perceived stress score of 18.67 (*SD* = 2.08) at follow up, and scores ranged from 17 to 21. The summary statistics can be found in Table 7, where Medicare covered participants stress scores are also reported.

For retired participants, the average stress symptoms scores prior to booklet completion were 48.50 (*SD* = 6.36), and scores ranged from 44 to 53. Retired participants had an average stress symptom score of 35 (*SD* = 2.83) after booklet completion, and scores ranged from 33 to 37. For Retired participants follow-up stress symptoms score was an average of 52 (*SD* = 11.31), and scores ranged from 44 to 60. For retired participants, the average perceived stress score prior to completing the booklet was 28 (*SD* = 4.24), and scores ranged from 25 to 31. The retired

participants had an average perceived stress score of 19.50 (*SD* = 4.95) after booklet completion, with scores ranging from 16 to 23. For retired participants, the average perceived stress score at follow-up was 22.50 (*SD* = 2.12), and scores ranged from 21 to 24. The summary statistics can be found in Table 8, where part-time employed and unemployed stress scores are also reported.

For participants who are married, the average stress symptoms score prior to booklet completion was 49.33 (*SD* = 14.84), and scores range from 33 to 62. Married participants had an average stress symptoms score of 25 (*SD* = 10.82) after booklet completion, with scores ranging from 16 to 37. Participants who are married had an average stress symptom score at follow-up of 41 (*SD* = 14.73), and scores ranged from 25 to 54. For married participants, the average perceived stress score before booklet completion was 23 (*SD* = 2.00), and scores ranged from 21 to 25. Participants who are married had an average perceived stress score of 16.67 (*SD* = 0.58) with scores ranging from 16 to 17. For married participants, the average perceived stress score at follow-up was 18.67 (*SD* = 2.08), and scores ranged from 17 to 21. The summary statistics can be found in Table 9, where widowed stress scores are also reported.

Participants who take care of someone with a neurological condition had an average stress symptom score of 43 (*SD* = 14.14) prior to completing the booklet, and scores ranged from 33 to 53. For participants who take care of someone with a neurological condition, the average stress symptoms score after filling out the booklet was 26.50 (*SD* = 14.85) with scores ranging from 16 to 37. Participants who take care of someone with a neurological condition had and average stress symptom score at follow-up of 34.50 (*SD* = 13.44), and scores ranged from 25 to 44. Participants who take care of someone with a neurological condition had an average perceived stress score of 23 (*SD* = 2.83) prior to booklet completion, with scores ranging from 21 to 25. For participants who take care of someone with a neurological condition, the average

stress symptom score after booklet completion was 16.50 (*SD* = 0.71), and scores ranged from 16 to 17. At follow up, the average perceived stress score by participants who care for someone with a neurological condition was 19.50 (*SD* = 2.12), with score ranging from 18 to 21. The summary statistics can be found in Table 10, where psychological and mental health and other medical conditions stress scores are also reported.

Table 4

Summary Statistics Table for Stress by Gender

Variable	*M*	*SD*	*n*	Min	Max
Pre-Booklet Stress Symptoms Score					
Male	53.00	-	1	53.00	53.00
Female	46.33	14.64	3	33.00	62.00
Post-Booklet Stress Symptoms Score					
Male	37.00	-	1	37.00	37.00
Female	23.67	8.62	3	16.00	33.00
Follow-up Stress Symptoms Score					
Male	44.00	-	1	44.00	44.00
Female	46.33	18.72	3	25.00	60.00
Pre-Booklet Perceived Stress Score					
Male	25.00	-	1	25.00	25.00
Female	25.00	5.29	3	21.00	31.00
Post-Booklet Perceived Stress Score					
Male	16.00	-	1	16.00	16.00
Female	19.00	3.46	3	17.00	23.00
Follow-up Perceived Stress Score					
Male	21.00	-	1	21.00	21.00
Female	19.67	3.79	3	17.00	24.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Table 5

Summary Statistics Table for Stress by Education

Variable	*M*	*SD*	*n*	Min	Max
Pre-Booklet Stress Symptoms Score					
Bachelor's Degree	38.50	7.78	2	33.00	44.00

Master's Degree	57.50	6.36	2	53.00	62.00
Post-Booklet Stress Symptoms Score					
Bachelor's Degree	24.50	12.02	2	16.00	33.00
Master's Degree	29.50	10.61	2	22.00	37.00
Follow-up Stress Symptoms Score					
Bachelor's Degree	42.50	24.75	2	25.00	60.00
Master's Degree	49.00	7.07	2	44.00	54.00
Pre-Booklet Perceived Stress Score					
Bachelor's Degree	26.00	7.07	2	21.00	31.00
Master's Degree	24.00	1.41	2	23.00	25.00
Post-Booklet Perceived Stress Score					
Bachelor's Degree	20.00	4.24	2	17.00	23.00
Master's Degree	16.50	0.71	2	16.00	17.00
Follow-up Perceived Stress Score					
Bachelor's Degree	21.00	4.24	2	18.00	24.00
Master's Degree	19.00	2.83	2	17.00	21.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Table 6

Summary Statistics Table for Stress by Race and Ethnicity

Variable	*M*	*SD*	*n*	Min	Max
Pre-Booklet Stress Symptoms Score					
White	43.33	10.02	3	33.00	53.00
Asian or Asian-American	62.00	-	1	62.00	62.00
Post-Booklet Stress Symptoms Score					
White	28.67	11.15	3	16.00	37.00
Asian or Asian-American	22.00	-	1	22.00	22.00
Follow-up Stress Symptoms Score					
White	43.00	17.52	3	25.00	60.00
Asian or Asian-American	54.00	-	1	54.00	54.00
Pre-Booklet Perceived Stress Score					
White	25.67	5.03	3	21.00	31.00
Asian or Asian-American	23.00	-	1	23.00	23.00
Post-Booklet Perceived Stress Score					

White	18.67	3.79	3	16.00	23.00
Asian or Asian-American	17.00	-	1	17.00	17.00
Follow-up Perceived Stress Score					
White	21.00	3.00	3	18.00	24.00
Asian or Asian-American	17.00	-	1	17.00	17.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Table 7

Summary Statistics Table for Stress by Insurance

Variable	*M*	*SD*	*n*	Min	Max
Pre-Booklet Stress Symptoms Score					
Insured	49.33	14.84	3	33.00	62.00
Medicare	44.00	-	1	44.00	44.00
Post-Booklet Stress Symptoms Score					
Insured	25.00	10.82	3	16.00	37.00
Medicare	33.00	-	1	33.00	33.00
Follow-up Stress Symptoms Score					
Insured	41.00	14.73	3	25.00	54.00
Medicare	60.00	-	1	60.00	60.00
Pre-Booklet Perceived Stress Score					
Insured	23.00	2.00	3	21.00	25.00
Medicare	31.00	-	1	31.00	31.00
Post-Booklet Perceived Stress Score					
Insured	16.67	0.58	3	16.00	17.00
Medicare	23.00	-	1	23.00	23.00
Follow-up Perceived Stress Score					
Insured	18.67	2.08	3	17.00	21.00
Medicare	24.00	-	1	24.00	24.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Table 8

Summary Statistics Table for Stress by Employment

Variable	*M*	*SD*	*n*	Min	Max
Pre-Booklet Stress Symptoms Score					
Employed Part-time	33.00	-	1	33.00	33.00
Unemployed	62.00	-	1	62.00	62.00

Retired	48.50	6.36	2	44.00	53.00
Post-Booklet Stress Symptoms Score					
Employed Part-time	16.00	-	1	16.00	16.00
Unemployed	22.00	-	1	22.00	22.00
Retired	35.00	2.83	2	33.00	37.00
Follow-up Stress Symptoms Score					
Employed Part-time	25.00	-	1	25.00	25.00
Unemployed	54.00	-	1	54.00	54.00
Retired	52.00	11.31	2	44.00	60.00
Pre-Booklet Perceived Stress Score					
Employed Part-time	21.00	-	1	21.00	21.00
Unemployed	23.00	-	1	23.00	23.00
Retired	28.00	4.24	2	25.00	31.00
Post-Booklet Perceived Stress Score					
Employed Part-time	17.00	-	1	17.00	17.00
Unemployed	17.00	-	1	17.00	17.00
Retired	19.50	4.95	2	16.00	23.00
Follow-up Perceived Stress Score					
Employed Part-time	18.00	-	1	18.00	18.00
Unemployed	17.00	-	1	17.00	17.00
Retired	22.50	2.12	2	21.00	24.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Table 9

Summary Statistics Table for Stress by Marital Status

Variable	*M*	*SD*	*n*	Min	Max
Pre-Booklet Stress Symptoms Score					
Married	49.33	14.84	3	33.00	62.00
Widowed	44.00	-	1	44.00	44.00
Post-Booklet Stress Symptoms Score					
Married	25.00	10.82	3	16.00	37.00
Widowed	33.00	-	1	33.00	33.00
Follow-up Stress Symptoms Score					
Married	41.00	14.73	3	25.00	54.00
Widowed	60.00	-	1	60.00	60.00
Pre-Booklet Perceived Stress Score					

Married	23.00	2.00	3	21.00	25.00
Widowed	31.00	-	1	31.00	31.00
Post-Booklet Perceived Stress Score					
Married	16.67	0.58	3	16.00	17.00
Widowed	23.00	-	1	23.00	23.00
Follow-up Perceived Stress Score					
Married	18.67	2.08	3	17.00	21.00
Widowed	24.00	-	1	24.00	24.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Table 10

Summary Statistics Table for Stress by Medical Condition

Variable	*M*	*SD*	*n*	Min	Max
Pre-Booklet Stress Symptoms Score					
Neurological	43.00	14.14	2	33.00	53.00
Psychological/Mental Illness	62.00	-	1	62.00	62.00
Other	44.00	-	1	44.00	44.00
Post-Booklet Stress Symptoms Score					
Neurological	26.50	14.85	2	16.00	37.00
Psychological/Mental Illness	22.00	-	1	22.00	22.00
Other	33.00	-	1	33.00	33.00
Follow-up Stress Symptoms Score					
Neurological	34.50	13.44	2	25.00	44.00
Psychological/Mental Illness	54.00	-	1	54.00	54.00
Other	60.00	-	1	60.00	60.00
Pre-Booklet Perceived Stress Score					
Neurological	23.00	2.83	2	21.00	25.00
Psychological/Mental Illness	23.00	-	1	23.00	23.00
Other	31.00	-	1	31.00	31.00
Post-Booklet Perceived Stress Score					
Neurological	16.50	0.71	2	16.00	17.00
Psychological/Mental Illness	17.00	-	1	17.00	17.00
Other	23.00	-	1	23.00	23.00
Follow-up Perceived Stress Score					
Neurological	19.50	2.12	2	18.00	21.00
Psychological/Mental Illness	17.00	-	1	17.00	17.00

Other	24.00	-	1	24.00	24.00

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Evaluation of Emergency Respite Booklet by Participants

Frequencies and percentages were calculated for evaluation questions regarding the booklet's usefulness, preparation capabilities, ease of readability, and content, among others. Questions were answered by participants with strongly agree, agree, neutral, disagree, or strongly disagree. An *n* of three completed the evaluation of the emergency respite booklet, one participant did not fill out the evaluation survey.

Outcome of Evaluation Questions

Most of the participants felt neutral about the helpfulness of the booklet (*n* = 2, 67.66%), with the remainder agreeing (*n* = 1, 33.33%) with it being helpful. A majority of the participants agreed that they felt prepared for a personal emergency (*n* = 2, 67.66%), and the remainder felt neutral (*n* = 1, 33.33%). Most participants agreed that the booklet had all the required elements for the caregiving role was (*n* = 2, 67.66%), with the remainder feeling neutral about this (*n* = 1, 33.33%). The majority of participants disagree that they have used this booklet since its completion (*n* = 2, 67.66%), and the rest felt neutral about using the booklet since completing it (*n* = 1, 33%). There was an equal number of participants who answered, neutral (*n* = 1, 33.33%), agree (*n* = 1, 33.33%), and disagree (*n* = 1, 33.33%) to knowing what respite is and how to find it after completing the booklet. All the participants agreed that the booklet was easy to understand (*n* = 3, 100%) and all felt neutral that the booklet affected their life in a positive way (*n* = 3, 100%). Frequencies and percentages are presented in Table 11.

Table 11

Frequency Table for Evaluation Questions

Variable	*n*	*%*
The booklet has been helpful for my role as a caregiver.		
Neutral	2	67.66
Agree	1	33.33
I feel prepared for a personal emergency.		

Neutral	1	33.33
Agree	2	67.66
The booklet has all the required elements for this role.		
Agree	2	67.66
Neutral	1	33.33
I have used this booklet in some capacity since filling it out.		
Disagree	2	67.66
Neutral	1	33.33
I feel like I know what respite now and can determine how to find it.		
Neutral	1	33.33
Disagree	1	33.33
Agree	1	33.33

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

Clinical Significance

The average demographic of participants was a 52-year-old White, retired, married, educated, insured female. Stress symptoms and perceived stress reduced when looking at pre booklet completion to post booklet completion; there was a three-point decrease in the average for stress symptoms and five-point decrease in the average for perceived stress. When looking at the average of stress scores by demographic majorities, female participants had a six-point net decrease in perceived stress and stress symptoms, bachelor's holding participants had a one-point net decrease in perceived stress and stress symptoms, master's holding participants had a 13-point net decrease in perceived stress and stress symptoms, White identifying participants had a four-point net decrease in perceived stress and stress symptoms, insured participants had a 13-point net decrease in perceived stress and stress symptoms, retired participants had a two-point net decrease in perceived stress and stress symptoms, married participants had a 13-point net decrease in perceived stress and stress symptoms, and participant who take care of someone with a neurological condition had a 12-point net decrease in perceived stress and stress symptoms.

When examining the minority demographic participants in this project from before and after booklet completion, it was found that the male participant had a 13-point net decrease in perceived stress and stress symptoms, the Asian or Asian-American participant had a 14-point net decrease in perceived stress and stress symptoms, the employed participant had a 11-point net decrease in perceived stress and stress symptoms, the unemployed participant had a 14-point net decrease in perceived stress and stress symptoms, and the participant caring for someone with a psychological or mental health condition had a 14-point net decrease in perceived stress and stress symptoms. The remaining minority demographics in the project showed that the participant with Medicare had a nine-point net increase in perceived stress and stress symptoms, the widowed participant had a nine-point net increase in perceived stress and stress symptoms, and participant who cares for someone with another medical condition had a nine-point increase in perceived stress and stress symptoms. Between all demographics, there was a net decrease in perceived stress and stress symptoms.

Of the seven questions on the evaluation form, most participants answered “agree” to three of the questions, the questions being: the booklet was easy to understand, I feel prepared for a personal emergency, and the booklet had all the required elements for the role. Three other questions were majority answered with “neutral”, and one question had a split answer of “disagree”, “neutral”, and “agree”. Overall, the participants’ responses were positive to the booklet regarding their experience.

Project Impact

The portrayal of a decrease in stress can greatly affect the community, including patients, providers, entire systems, and policies. Decreasing caregiver stress can improve the individual’s physical health, and when their mental and physical health are optimized, they have the ability to

provide the best care to their loved one; when the person receiving care has the most effective care possible, their health will be more managed. Providers can then focus on medical management without stress playing a major role in their patients' health if stress is reduced. From the perspective of having a plan and reducing worry about if something were to happen to the caregivers, facilities can be more available to individuals who truly need the services, rather than those being cared for at home that just need somewhere to go last minute in an emergency. Also, hospital systems can be less crowded with patients who do not have properly managed health as mentioned previously due to poor mental health and extreme stress of caregivers. Lastly, policies can be positively affected for caregivers with the evidence that preparation benefits all of these individuals and systems; policies could eventually be put in place of more regulated and available preparation support for caregivers to reduce stress.

Sustainability

Emergency respite preparedness planning is the intervention of this project, and after completion, stress was examined and measured. The overall reduction of informal caregiver stress was the goal of this project. This form of quality improvement is ever-changing, evolving, and growing, and more can always be done—even after the end of this project—to produce a significant overall effect. When the project is complete, the site should be able to use the information gathered in this project to continue and revise the booklet to allow for even further stress reduction for caregivers. The site champion of the caregiving agency is the Executive Director. The site champion will be responsible for maintaining the presumed positive outcome of this project for the future. Any new additions, changes, or ideas that stem from this project will be initiated by the agency's Executive Director. With the sustained use of this booklet, even

if stress reduction is limited, it is at least one adjustment; each small change can snowball into a more significant effect when other processes are adjusted.

Discussion

The utilization of an emergency respite booklet as a form of caregiver role preparation displayed an outcome of reduced stress in this population. Participants overall found the booklet and guide to be useful and easy to understand, which are imperative components of a largely distributed material. As a first run and draft of this booklet and plan there are continuation pieces that can be built upon to see an even greater reduction in stress of caregivers.

Barriers and Limitations

Barriers that occurred throughout the project include a small sample size due to a lack of participant response, poor recruitment outcome, and incomplete booklet and questionnaires by participants. Some of these barriers were addressed by phone/text and email to follow up with the participants if questionnaires needed to be returned or filled out. Expression of the direct benefit to the individual and the community could be used to aid in the recruitment of participants. Two participants were lost to follow up, in an already small sample size. There was also not much diversity in demographics for this project. Lastly, outside factors that impact stress levels could not be controlled and may influence stress levels.

Relation to Literature

It is no surprise that when looking at past literature that the caregivers in this project were middle-aged females, as this is the demographic of a majority of literature searched for this project (Bektas Akpinar et al., 2022; Brunet et al., 2021; Cheng et al., 2018; de Araújo Freitas Moreira et al., 2018; Easom et al., 2018; Nemati et al., 2018; Sousa et al., 2021; Zimmerman et al., 2018). Like the project, six studies examined that also showed a reduction in stress, which

also showed increased coping as a part of stress reduction, after some form of caregiver preparation intervention (Bektas Akpinar et al., 2022; Brunet et al., 2021; Cheng et al., 2018; de Araújo Freitas Moreira et al., 2018; Easom et al., 2018; Sousa et al., 2021; Zimmerman et al., 2018). Looking back at the Transactional Model of Stress and Coping by Lazarus and Folkman (1984), this booklet could be seen as a method of coping to reduce stress. Though this study did not focus on physical health, physical symptoms of stress were examined and had decreased, including depression, as well as in six of the previous studies (Bektas Akpinar et al., 2022; Brunet et al., 2021; Cheng et al., 2018; Easom et al., 2018; Raj et al., 2018; Zimmerman et al., 2018). All of this evidence culminated improves the argument for preparation for caregivers to reduce stress.

Future Research

This project focused on the English version of this booklet and its effect on the stress of English and speaking caregivers; future assessment of this booklet can be centered around other language versions, such as Spanish, which all tools have been translated into already, to examine its impact on the tension of these caregivers. This project did not have a need for the Spanish versions of the materials, as all participants who partook in the project were English-speaking. Also, other cultures as well may be affected differently by caregiver stress and would aid in the research regarding preparation for caregivers. Finally, a demographic that was not evaluated that would be important for future research is social class and the burdens that come with the increased financial strain of some of these populations and their stress levels related to caregiving.

The agency could also eventually start to partner with local primary care offices where their booklet and guide could be offered to patients. Stress could be evaluated in office visits in a

similar fashion to this project. The correlating physical health to stress levels could be evaluated further in this setting.

Conclusion

Demonstration of preparedness planning and training for informal caregivers reducing stress levels and overall life and role satisfaction should be an example for all other forms of preparation that will have the same effect in the long term. Decreasing stress in caregivers can improve their experience with caregiving, improve their health and the health of the individual being cared for, and create an overall happier community of caregivers and the ones they care for. As more individuals take care of someone else at home, the stress and health of the caregiver will be a valuable focus for healthcare.

References

Administration for Community Living. (2022). *RAISE Family Caregiving Act: Progress toward a national strategy to support family caregivers*. ACL. Retrieved February 3, 2023, from https://acl.gov/sites/default/files/RAISE_SGRG/RAISE%20Family%20Caregiver%20Act_Progress%20Report_23%20April%202020.pdf

Alves, L. C. de S., Monteiro, D. Q., Bento, S. R., Hayashi, V. D., Pelegrini, L. N. de C., & Vale, F. A. C. (2019). Burnout syndrome in informal caregivers of older adults with dementia: A systematic review. *Dementia & Neuropsychologia, 13*(4), 415–421. https://doi.org/10.1590/1980-57642018dn13-040008

Bektas Akpinar, N., Beduk, T., & Cay Senler, F. (2022). The effect of caregiver educational program on caregiver reactions and lifestyle behaviors for caregivers of colorectal cancer patients: A quasi-experimental study. *Supportive Care in Cancer, 30*(5), 4389–4397. https://doi.org/10.1007/s00520-022-06862-5

Brunet, H. E., Banks, S. J., Libera, A., Willingham-Jaggers, M., & Almén, R. A. (2021). Training in improvisation techniques helps reduce caregiver burden and depression: Innovative practice. *Dementia: The International Journal of Social Research and Practice, 20*(1), 364-372. https://doi-org.ezproxy1.lib.asu.edu/10.1177/1471301219869122

Centers for Disease Control and Prevention. (2018). *Caregiving for family and friends — A public health issue*. CDC. Retrieved February 3, 2023, from https://www.cdc.gov/aging/agingdata/docs/caregiver-brief-508.pdf

Cheng, H. Y., Chair, S. Y., & Chau, J. P. C. (2018). Effectiveness of a strength-oriented psychoeducation on caregiving competence, problem-solving abilities, psychosocial

outcomes, and physical health among family caregiver of stroke survivors: A randomized controlled trial. *International Journal of Nursing Studies, pp. 87*, 84–93. https://doi.org/10.1016/j.ijnurstu.2018.07.005

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior,* 24(4), 385–396.

de Araújo Freitas Moreira, K. L., Ábalos-Medina, G. M., Villaverde-Gutiérrez, C., Gomes de Lucena, N. M., Belmont Correia de Oliveira, A., & Pérez-Mármol, J. M. (2018). Effectiveness of two home ergonomic programs in reducing pain and enhancing quality of life in informal caregivers of post-stroke patients: A pilot randomized controlled clinical trial. *Disability and Health Journal, 11*(3), 471–477. https://doi.org/10.1016/j.dhjo.2018.01.003

Easom, L. R., Wang, K., Moore, R. H., Wang, H., & Bauer, L. (2018). Operation family caregiver: Problem-solving training for military caregivers in a community setting. *Journal of Clinical Psychology, 74*(4), 536–553. https://doi.org/10.1002/jclp.22536

Fenstermacher, E., Owsiany, M., & Edelstein, B. (2022). Informal caregiving burnout among the sandwich generation. *Innovation in Aging, 6*(Supplement_1), 872–872. https://doi.org/10.1093/geroni/igac059.3115

Gérain, P. & Zech, E. (2022). A harmful care: The association of informal caregiver burnout with depression, subjective health, and violence. *Journal of Interpersonal Violence, 37*(11-12), NP9738–NP9762. https://doi.org/10.1177/0886260520983259

Helms, E. & Weierstall, R. (2016). Subclinical stress symptom questionnaire (SSQ-25). Retrieved from osf.io/n9asd

Holliday, A., Quinlan, C., & Schwartz, A. (2022). The hidden patient: The CARE framework to care for caregivers. *Journal of Family Medicine and Primary Care, 11*(1), 5–9. https://doi.org/10.4103/jfmpc.jfmpc_719_21

Intellectus Statistics [Online computer software]. (2022). Intellectus Statistics. https://analyze.intellectusstatistics.com/

Johnson, A. (n.d.). *What are the basic principles of medical ethics?*. Medical ethics 101. https://web.stanford.edu/class/siw198q/websites/reprotech/New%20Ways%20of%20Making%20Babies/EthicVoc.htm

Koller, E. C., Abel, R. A., & Milton, L. E. (2022). Caring for the caregiver: A feasibility study of an online program that addresses compassion fatigue, burnout, and secondary trauma. *The Open Journal of Occupational Therapy, 10*(1), 1–14. https://doi.org/10.15453/2168-6408.1847

Konstantopoulou, G., Iliou, T., Karaivazoglou, K., Iconomou, G., Assimakopoulos, K., & Alexopoulos, P. (2020). Detection of subclinical stress symptoms with the new SSQ-25 questionnaire. *European Journal of Public Health Studies, 3*(1).

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer.

Lee, E. (2012). Review of the psychometric evidence of the perceived stress scale. *Asian Nursing Research, 6*(4), 121–127. https://doi.org/10.1016/j.anr.2012.08.004

Lieshout, K., Oates, J., Baker, A., Unsworth, C. A., Cameron, I. D., Schmidt, J., & Lannin, N. A. (2020). Burden and preparedness amongst informal caregivers of adults with moderate to severe traumatic brain injury. *International Journal of Environmental Research and Public Health, 17*(17), 1–12. https://doi.org/10.3390/ijerph17176386

Melnyk, B. M., & Fineout-Overholt, E. (2019). *Evidence-based practice in nursing and*

healthcare: A guide to best practice (4th ed.). Lippincott, Williams & Wilkins.

Nemati, S., Rassouli, M., Ilkhani, M., & Baghestani, A. R. (2018). Perceptions of family caregivers of cancer patients about the challenges of caregiving: A qualitative study. *Scandinavian Journal of Caring Sciences, 32*(1), 309–316. https://doi.org/10.1111/scs.12463

Parry, M., Beleno, R., Nissim, R., Baiden, D., Baxter, P., Betini, R., Bjørnnes, A. K., Burnside, H., Gaetano, D., Hemani, S., McCarthy, J., Nickerson, N., Norris, C., Nylén-Eriksen, M., Owadally, T., Pilote, L., Warkentin, K., Coupal, A., Hasan, S., … Peter, E. (2023). Mental health and well-being of unpaid caregivers: A cross-sectional survey protocol. *BMJ Open, 13*(1), e070374–e070374. https://doi.org/10.1136/bmjopen-2022-070374

Phillipson, L., Johnson, K., Cridland, E., Hall, D., Neville, C., Fielding, E., & Hasan, H. (2019). Knowledge, help-seeking and efficacy to find respite services: An exploratory study in help-seeking carers of people with dementia in the context of aged care reforms. *BMC Geriatrics, 19*(1), 2–2. https://doi.org/10.1186/s12877-018-1009-7

Raj, S. P., Shultz, E. L., Zang, H., Zhang, N., Kirkwood, M. W., Taylor, H. G., Stancin, T., Yeates, K. O., & Wade, S. L. (2018). Effects of web-based parent training on caregiver functioning following pediatric traumatic brain injury: A randomized control trial. *The Journal of Head Trauma Rehabilitation, 33*(6), E19–E29. https://doi.org/10.1097/HTR.0000000000000388

Roberts, E. & Struckmeyer, K. M. (2018). The impact of respite programming on caregiver resilience in dementia care: A qualitative examination of family caregiver

perspectives. *Inquiry (Chicago), 55*, 46958017751507–46958017751507. https://doi.org/10.1177/0046958017751507

Rotenstein, L. S., Torre, M., Ramos, M. A., Rosales, R. C., Guille, C., Sen, S., & Mata, D. A. (2018). Prevalence of burnout among physicians: A systematic review. *JAMA : The Journal of the American Medical Association, 320*(11), 1131–1150. https://doi.org/10.1001/jama.2018.12777

Sousa, L., Sequeira, C., Ferré-Grau, C., & Graça, L. (2021). "Living together with dementia": Preliminary results of a training program for family caregivers. *Scandinavian Journal of Caring Sciences, 35*(1), 86–95. https://doi.org/10.1111/scs.12821

Wang, C.-L., Kuo, L.-M., Chiu, Y.-C., Huang, H.-L., Huang, H.-L., Hsu, W.-C., Lu, C.-H., Huang, T.-H., Huang, S., & Shyu, Y.-I. L. (2018). Protective preparation: A process central to family caregivers of persons with mild cognitive impairment. *International Psychogeriatrics, 30*(3), 375–384. https://doi.org/10.1017/S1041610217001764

Wiseman, B., & Kaprielian, V. S. (2002). *Methods of Quality Improvement*. What is Quality Improvement? Retrieved April 30, 2023, from https://josieking.org/patientsafety/module_a/methods/methods.html

Zimmerman, S., Sloane, P. D., Ward, K., Beeber, A., Reed, D., Lathren, C., Matchar, B., & Gwyther, L. (2018). Helping dementia caregivers manage medical problems: Benefits of an educational resource. *American Journal of Alzheimer's Disease and Other Dementias, 33*(3), 176–183. https://doi.org/10.1177/1533317517749466

Appendix A

Evaluation and Synthesis Tables

Table A1
Evaluation Table for Quantitative Studies

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
Bektas Akpinar et al., (2022), The effect of caregiver educational program on caregiver reactions and lifestyle behaviors for caregivers of colorectal cancer patients: A quasi-experimental study	No framework addressed. Implied Framework: Transactional Model of Stress and Coping	**Design:** pre-test-post-test, quasi-experimental intervention with a control group **Purpose:** To evaluate the effects of the educational package provided to enhance family caregivers'	**N=** 105 **Demographics:** M age of the caregivers in the control group was 39.34±1.34 (18–69), M age of the caregivers in the experimental group was 38.87±1.45 (18–69). M age of the patients in the control group was 61.4±1.64 (31–80), and M age of the patients in the experimental group was 62.4±1.44 (41–81). It was observed that the patients included in the study had a	**IV1:** caregiver educational program **DV1:** Healthy lifestyle **DV2:** Caregiver reaction **Definitions:** None described	**Tools:** the Healthy Lifestyle Behaviors Scale-II, and the Caregiver Reaction Assessment **Validity/ Reliability:** the scale was reported to be valid and reliable	**Statistical Tests Used:** Kolmogorov–Smirnov and Shapiro Wilk tests. Student t-test and Mann Whitney U test. The Wilcoxon test. Chi-square or	**DV1:** interpersonal relationships-p p<0.001, nutrition-p<0.001, health responsibility-p<0.001, physical activity-p=0.689, stress management-p=0.021, spiritual growth-p=0.002 **DV2:** self esteem-p<0.001, lack of family support-p<0.001, financial problems-p=0.007, interruption of daily life-p=0.002, health problems-p<0.001	**Level of Evidence**: Level 1 **Strengths**: Focus on colorectal cancer caregivers **Weakness**: Small population sample **Feasibility**: Feasible as done in an interview type **Application**:

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
Country: Turkey **Funding**: none **Bias**: No conflicts of interest		experience of colorectal cancer patients receiving chemotherapy on healthy lifestyle and caregiving reactions	lower education level in the control group (p=0.004) and had more advanced diseases (p=0.045). **Setting:** oncology service and outpatient chemotherapy units in two different hospitals **Exclusion:** Patients without a 1st degree relative to care, patients with a colostomy, family members who do not want to participate in the study, and patients who have previously received chemotherapy. **Attrition:** 5 participants lost in follow-up			Fisher exact tests Spearman correlation coefficient		Applicable to determine caregiver stress for this population and generalizability

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
Brunet et al., (2021), Training in improvisation techniques helps reduce caregiver burden and depression: Innovative practice **Country**: United States **Funding**: Director's Innovation Fund. Center of Biomedical and Research Excellence (COBRE) grant **Bias**:	No theoretical/conceptual framework addressed. Implied framework: Transactional Model of Stress and Coping	**Design:** Pilot non-randomized, non-control trial **Purpose:** To determine if an improvisation course will improve caregiver stress and anxiety.	**N=** 15 **Demographics:** Majority female, mean age ~67, well-educated and provide full-time care **Setting:** Improv course participants at Cleveland Clinic Lou Ruvo Center for Brain Health **Exclusion:** Not directly caring for family member **Attrition:** 7 lost in follow-up	**IV1:** Improv for Care skills course **DV1:** caregiver depression **DV2:** caregiver burden and stress **DV3:** family members neuropsychiatric symptoms **Definitions:** Neuropsychiatric symptoms: irritability, apathy, appetite changes, nighttime behaviors, disinhibition, agitation, and depression	**Tools:** BDI-II, ZBI, and NPI-Q **Validity/ Reliability:** Validity and reliability of tools confirmed	**Statistical Tests Used:** Wilcoxon signed ranks tests	**DV1:** "caregivers' mean baseline depression severity was minimal (BDI-II total score M = 12.8, SD = 6.99)"; "There were significant declines in depression symptoms (Z = –2.64, p = .008)" **DV2: "**baseline level of caregiving stress was mild to moderate (ZBI total score M = 40.0, SD = 10.41)"; significant declines in caregiving stress (Z = –2.16, p = .031)" **DV3:** prior scores "NPI-Q (Z = –2.10, p = .036). There was not, however, a significant increase in caregiver NPI-Q total	**Level of Evidence**: Level 4 **Strengths**: Initial results of Improv course **Weakness**: Small sample size, no randomization or control **Feasibility**: Feasible but more difficult to keep participants in person. **Application**: Can be used as a tool for caregivers to improve stress

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
No conflict of interest							distress scores (Z = –1.12, p = .265)"	and depression of caregivers.
Cheng et al., (2018), Effectiveness of a strength-oriented psychoeducation on caregiving competence, problem-solving abilities, psychosocial outcomes and physical health among family caregiver of stroke survivors: A randomised controlled trial **Country**: China	The relational/problem-solving model of stress; an integration of the transactional theory of stress and social problem-solving theory	**Design:** A prospective multi-center and single-blinded randomized controlled trial **Purpose:** To evaluate the effectiveness of a strength-oriented psychoeducational program on the caregiving competence, problem-solving coping abilities,	**N=** 142 **Demographics:** The majority of caregivers were female (75%). In this trial, the caregivers were relatively young (age: 49.1 ± 12.5 years, range: 19–80 years) and had low educational attainment (71.1% received ≤12 years' formal education). Half of them were children of the survivors (57.3%, son: 24.2%, daughter: 32.8%) and employed (54.7%) **Setting:** Medical wards of a regional acute and two rehabilitation	**IV1:** psychoeducational program **DV1:** caregiving competence **DV2:** problem-solving coping abilities **DV3:** depressive symptoms **DV4:** Caregiving burden **DV5:** social support satisfaction **DV6:** family functioning	**Tools:** Caregiving Competence Scale, Problem Solving Inventory, 10-item Center for Epidemiological Studies Depression, Caregiving Strain Index, Six-item Social Support Questionnaire, General Functioning subscale of the Family	**Statistical Tests Used:** chi-square test with Bonferroni adjustment for multiple comparisons independent t-tests for continuous variables	**DV1:** improved at each follow-up **DV2:** declined at each follow-up **DV3:** improved at each follow up **DV4:** improved at each follow up **DV5:** Improved at each follow up with slight decline at last follow up **DV6:** declined at each follow up **DV7:** improved to last follow up	**Level of Evidence**: Level 1 **Strengths**: Focus on stroke survivors **Weakness**: Specific population **Feasibility**: Less feasible, intensive interventions **Application**: Applicable to caregivers who care for stroke survivors, and could be generalized

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
Funding: None **Bias**: No conflict of interest		caregiver's depressive symptoms, caregiving burden and resources (family functioning, social support) and physical health (such as caregiving-related injury), as well as potential placement of stroke survivors	hospitals in Hong Kong Eastern New Territories. **Exclusion:** (1) do not assume the primary responsibility in caring for the stroke survivor and (2) do not live with the stroke survivor after hospital discharge. Family caregivers or stroke survivors who reported a doctor-diagnosed psychiatric illness were excluded from the study. **Attrition:** 34% rate allowed	**DV7**: Perceived physical health **Definitions:** None expressed	Assessment Device, The Chinese (Hong Kong) SF-12 v2, **Validity/ Reliability:** Validity and reliability stated for each tool			
de Araújo Freitas Moreira et al., (2018), Effectiveness of two home ergonomic programs in	No expressed framework Implied: Theory of Caregiving Dynamics	**Design:** Randomized Control Trial **Purpose:** To evaluate home	**N=** 33 **Demographics:** Caregivers mean age 55 of years old, majority female, majority care for someone for over 3 years, only 9% took	**IV1:** home ergonomic interventions **DV1:** reduce stress	**Tools:** Visual analog pain scale Cohen perceived stress scale	**Statistical Tests Used:** Quantitative	**DV1:** stress was reduced as seen with QoL 95% CI for perceived stress	**Level of Evidence**: Level 1 **Strengths**: No other studies that look at this

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
reducing pain and enhancing quality of life in informal caregivers of post-stroke patients: A pilot randomized controlled clinical trial **Country**: Brazil **Funding**: Research group from Regional Government of Andalusia (Spain) **Bias**: No conflict of interest		interventions effect on stroke caregivers in regard to pain, stress, and QoL.	prior training class for caregiving, and mainly spouse caregiver. **Setting:** Community caregivers in the city of Joao Pessoa **Exclusion:** "be caring for patients with any other neurological disorder; the presence of a comorbid pathology; if the post-stroke patient requires hospital admission during the study; if the patient enters an acute period of stroke" **Attrition:** None lost in intervention or follow-up.	**DV2:** improve QoL **DV3:** reduce pain **Definitions:** Postural and ergonomic intervention: **"**preparation of the patient's environment, postural hygiene during patient transfers, management of the patient during activities of daily life, the caregiver's posture in performing daily activities such as cleaning the	WhoQoL-Bref for QoL **Validity/ Reliability:** Tools valid and reliable.	t-tests for paired samples Wilcoxon signed-rank test Mann-Whitney U test Chi-squared and ANOVA 3 x 3 repeated measures	**DV2:** intervention group showed improved QoL 95% CI for the dimensions of QoL **DV3:** Pain in neck, knees and shoulders were reduced in the intervention group 95% CI for pain intensity	intervention in relation to pain. **Weakness**: Could not blind the participants to the intervention received. Pain was also not addressed prior, so there was no way to know of improvement. **Feasibility**: Can be used for many settings and are interventions that be done easily. **Application**: Applicable to education provided on discharge home

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
				bathroom, among others". Kinesiotherapy intervention: "stretching, flexibility, resistance and relaxation and to train caregivers in bodily awareness and in good practices in breathing".				for a patient being cared of by family.
Easom et al., (2018), Operation family caregiver: Problem-solving training for military caregivers in a community setting	No framework Implied: Caregiving Dynamics	**Design:** Pre-post research design (cross-sectional) **Purpose:** To gain an understanding of how a tailored,	**N=** 370 **Demographics:** Majority of caregivers were female (96%) and White/Caucasian(76%), with a small minority identifying as His-panic (21%). For education, 222(60%) had a college degree or higher education, 68% had an annual household income	**IV1:** Problem-solving training **DV1:** Caregiver burden **DV2:** Caregiver depression **DV3:** Caregiver overall health	**Tools:** ZBS, CESD, PILL, SPSI-R:SF, SWL, SCAS-P **Validity/ Reliability:** Validity and reliability verified	**Statistical Tests Used:** Pearson correlations and two independent sample t-tests	**DV1:** ZBS significantly decreased from baseline to follow-up survey, with a mean of −1.94 ($p<.0001$) **DV2:** CESD significantly decreased from baseline to follow-up survey, with a mean of -7.80 ($p<.0001$)	**Level of Evidence**: Level 2 **Strengths**: identify and addresses the immediate problems of the caregiver **Weakness**:

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
Country: United States **Funding**: none **Bias**: Not addressed		problem-solving training could assist military caregivers, who provide care and assistance to those injured, ill, or disabled as a result of war.	above $30,000, and each caregiver worked an average 21 hours per week **Setting:** Nationally through referrals from the VA, veteran service organizations, VA caregiver support centers, and military family support groups who were familiar with the medical backgrounds of the care recipients **Exclusion:** Not caring for a military service member or veteran with TBI, PTSD, and/or a physical disability, not aged 18 years or older, and not able to understand and speak English **Attrition:** 153 lost in follow-up	**DV4:** Caregiver problem-solving **DV5:** Caregiving satisfaction with life **DV6:** child anxiety **Definitions:** None mentioned		Paired t-tests or non-parametric sign tests	**DV3:** PILL significantly decreased from baseline to follow-up survey, with a mean of −9.69 (p<.0001) **DV4:** SPSI-R:SF significantly decreased from baseline to follow-up survey, with a mean of −6.47 (NPO),and increased 5.16, 5.29 (PPO) (p<.0001) **DV5:** SWL significantly increased from baseline to follow-up survey, with a mean of 3.43 (p<.0001) **DV6:** SCAS-P decreased from baseline to follow-up survey, with a mean of −1.69 (p= 0.070)	Lack of a control group in this study Disproportionate number of female caregivers in the sample, which may limit generalizability **Feasibility**: Feasible to study **Application**: Applicable to determine how a training can improve caregiver burden and stress

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	**Theoretical/ Conceptual Framework**	**Design/ Method/ Purpose**	**Sample/Setting**	**Variables**	**Measurement/ Instrumentation**	**Data Analysis**	**Results/ Findings**	**Level of Evidence; Application to practice; Generalization**
Raj et al., (2018), Effects of web-based parent training on caregiver functioning following pediatric traumatic brain injury: A randomized control trial **Country**: United States **Funding**: National Institute on Disability, Independent Living, and Rehabilitation Research **Bias**:	No theoretical/conceptual framework expressed. Implied framework: Transactional Model of Coping and Stress	**Design:** Randomized Control Trial **Purpose:** To determine whether a web-based training after y (TBI) in a child reduces parental and caregiver stress.	**N=** 148 **Demographics:** Children ages 3-9, mean of 6 years old, and majority male **Setting:** Taken from four large Children's Hospitals and one general hospital around the U.S.-children who had been hospitalized at these hospitals for TBI **Exclusion:** Living in a residence more than a 3-hour drive from the hospital, non–English-speaking, severe cognitive impairment that limited the child's ability to interact, residence in an area without access to high-speed Internet, and other (eg, child not living in the home and parent	**IV1:** I-InTERACT web-based training **DV1:** caregiver depression **DV2:** caregiver psychological distress **DV3:** parenting stress **DV4:** parenting efficacy **DV5:** Child behavior problems **Definitions:** None provided	**Tools:** CESD, GSI, PSI, and CSES **Validity/** **Reliability:** Validity/Reliability tools confirmed	**Statistical Tests Used:** One-way analysis of variance (ANOVA) and $\chi 2$ tests, Analysis of covariance, (ANCOVA), priori power analyses, Hierarchical regression analyses, and Mediation analyses	"Average baseline scores fell within the average range or within normal limits on all measures (eg, GSI: M = 52.55, SD = 12.11; CESD: M = 9.97, SD = 9.91, PSI: M = 51.22, SD = 33.40; CSES: M = 67.45, SD = 7.51)" "intervention effects on caregiver depression was approaching significance (CESD; $F2,101 = 2.89$, $\eta 2 = 0.05$, $P = .06$)" I-InTERACT had "significant relative indirect effect on caregiver stress and self efficacy through changes in the intensity of child behavior	**Level of Evidence**: Level 1 **Strengths**: One of few studies that examines interventions for families who have experienced pediatric TBIs. **Weakness**: Families in the study were wealthy overall and does not account for other families who do not have this privilege. High amount of families lost in follow-up. **Feasibility**:

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
No conflict of interest			psychiatric hospitalization within the previous 12 months" **Attrition:** "There was no significant difference in the number of caregivers who did not complete follow-up measures across the 3 groups (I-InTERACT: n = 14; Express: n = 15; IRC: n = 14; $\chi 2$ = 0.31, P = .86)"				problems (PSI: indirect effect index = −7.28, 95% CI = −15.96 to −0.87; and CSES: indirect effect index = 1.65, 95% CI = 0.35-3.39)."	Feasible due to the convenient use of technology for the intervention and the widespread use of technology today **Application**: Applicable to families who will need to care for a child at home after leaving the hospital who has experienced a TBI.
Sousa et al., (2021), "Living together with dementia": Preliminary results of a training programme for family caregivers	No expressed framework Implied: Theory of Caregiving Dynamics	**Design:** Pilot randomized control trial **Purpose:** To evaluate the effect of the training program, "Living	**N=** 27 **Demographics:** Caregivers average age of 48-55, majority female, typically the child of the individual with dementia, currently employed, average years of caregiving is over 2.5, average hours per day of	**IV1:** training program **IV2:** typical nursing care **DV1:** coping/problem-solving strategies **DV2:** burden	**Tools:** Scale of caregiver burden Caregivers assessment of difficulties index	**Statistical Tests Used:** Qualitative and Quantitative	**DV1:** improved coping/problem solving in intervention group Wilks' lambda = 0.840; F(2,23) = 2.198, p = 0.134, partial eta squared = 0.160	**Level of Evidence**: Level 1 **Strengths**: The participants were interested and found the program to be relatable and useful.

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
Country: Portugal **Funding**: No funding **Bias**: No conflict of interest		together with dementia"	caregiving is more than 6, and majority no prior experience with caregiving. **Setting:** neurology outpatient consultation clinic in a hospital located in Porto **Exclusion:** "The person under care did not have dementia at the early or moderate stage and the person with dementia was experiencing other severe mental pathology" **Attrition:** None lost in follow-up.	**DV3:** satisfaction **DV4:** complications **Definitions:** Living with Dementia Together' Program: "7-week programme comprising 7 weekly individual sessions with an average duration of 60 minutes each as well as two 90-minute sessions [for caregivers]. The sessions addressed many caregiving related topics.	Caregiver assessment of satisfaction index Dementia clinical exam Mini-mental status exam **Validity/** **Reliability:** Program validity addressed from review of studies. Validity/reliability of tools not addressed.	Chi-square test and ANOVA T-test Mann–Whitney U test	**DV2:** decreased caregiver burden Wilks' lambda = 0.455; $F(2,23) = 13.783$, $p = 0.000$ **DV3:** improved satisfaction in caregiving Wilks' lambda = 0.815; $F(2,23) = 2.617$, $p = 0.095$, partial eta squared = 0.185 **DV4:** reduced caregiving complications Wilks' lambda = 0.455; $F(2,23) = 1.407$, $p = 0.265$, partial eta squared = 0.027	**Weakness**: Small sample size. Some participants could not financially travel for the study, so home would have been a better option. **Feasibility**: This is relatively feasible, but there would need to psychiatric nurses trained readily for this. **Application**: This can be used in geropsychiatry as a tool when patients go home with family.

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	**Theoretical/ Conceptual Framework**	**Design/ Method/ Purpose**	**Sample/Setting**	**Variables**	**Measurement/ Instrumentation**	**Data Analysis**	**Results/ Findings**	**Level of Evidence; Application to practice; Generalization**
Zimmerman et al., (2018), Helping dementia caregivers manage medical problems: Benefits of an educational resource. **Country**: United States **Funding**: National Institute of Nursing Research **Bias**: royalties from the book developed from this research	No framework Implied Framework: Theory of Caregiving Dynamics	**Design:** Interview with Likert Scale **Purpose:** To briefly describe AlzMed, and report on change in caregivers' confidence to address medical concerns, as well as change in caregiver burden, anxiety, and depression, following use of AlzMed	**N=** 143 (web-based), 51(book based) **Demographics:** Web-based: Caregivers were primarily white (83%), daughters (48%), who lived with the care recipient (76%) Care recipients were primarily female (61%) and had moderate dementia (61%); 50% or more required assistance with bathing, dressing, and medication use Book based: more minority caregivers (29% versus 14%) and caregivers without a college education (37% versus 10%) than those in the AlzMed website	**IV1:** Web based, or book based education. **DV1:** caregiver confidence **DV2:** caregiver burden **DV3:** caregiver anxiety **DV4:** Caregiver depression **Definitions:** Alzheimer's Medical Advisor (AlzMed) website (and secondarily a book) to help family caregivers assess and manage medical needs at home (as	**Tools:** CCSM, ZBS, GAD-7, PHQ-9 **Validity/ Reliability:** Tools valid and reliable	**Statistical Tests Used:** measures of internal consistency reliability (Cronbach's alpha) were derived for all outcome measures, repeated measures used mixed model with a random effect, Sidak	**DV1:** M of 3.8 (SD 0.6) on a scale of 1–5 (corresponding to between somewhat and moderately confident) **DV2**: M burden score was 22.8 (SD 7.2; possible range 0–48) **DV3:** M anxiety score was 7.9 (SD 5.1; possible range 0–21) **DV4:** M depression score was 5.6 (SD 4.8; possible range 0–27)	**Level of Evidence**: Level 5 **Strengths**: Internet based study **Weakness**: Does not reach those who cannot use internet **Feasibility**: Feasible to complete **Application**: Applicable to providing education to caregivers from their home to reduce, burden and stress

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
			group **Setting:** Residing in the community in North Carolina **Exclusion:** the care recipient had to have a diagnosis of Dementia; reside in the community; not be on hospice or in a comatose state; and not be expected to transition to nursing home, assisted living, or hospice care within six months-if did not meet these criteria, they were excluded. Eligible caregivers had to be at least 21 years of age; the person most involved in care for their relative; and live with or visit their relative at least weekly-if they did not meet these	appropriate) and more effectively work with health care providers.		adjustment. Associations were tested using analysis of variance where the independent variable was categorical and Pearson's r where both variables in the relationship were continuous.		

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Citation	Theoretical/ Conceptual Framework	Design/ Method/ Purpose	Sample/Setting	Variables	Measurement/ Instrumentation	Data Analysis	Results/ Findings	Level of Evidence; Application to practice; Generalization
			criteria, they were excluded. To be eligible to evaluate the web-based version, participants had to use the internet (for any purpose other than e-mail) at least three times a week; book users had to not use the internet more than twice a week-if they did not meet this criteria, they were excluded. **Attrition:** 22 lost in follow-up			Multiple regression analyses		

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Table A2

Evaluation Table for Qualitative Studies

Citation	Theory/ Conceptual Framework	Design/ Method/ Sampling	Sample/ Setting	Major Themes Studied/ Definitions	Measurement/ Instrumentation	Data Analysis	Findings/ Themes	Level/ Quality of Evidence; Decision for/ Application to practice; Generalization
Nemati et al., (2018), Perceptions of family caregivers of cancer patients about the challenges of caregiving: A qualitative study. **Country**: Iran **Funding**: None **Bias**: No conflicts of interest	Transactional Stress Theory	**Design:** descriptive exploratory study **Method:** interviews **Purpose:** to explore the perception of family caregivers of cancer patients about the challenges of caregiving	**Sample:** (*n*=21) **Demographics:** Majority aged between 22-42, female, single, had a university degree, and taking care of their child **Setting:** two oncology referral centers affiliated to Shahid Beheshti University of Medical Sciences in Tehran, Iran, including Shohada Tajrish and Taleghani	• Confusion • Uncertainty • Disintegration • Setback **Definitions:** • Disintegration is taken in this study to indicate a state of helplessness and turmoil in the caregiver's personal, emotional and family system. • Setback refers to the suffering caused by physical–mental	**Data Collection:** Semi-structured in-depth interviews **Data Dependability:** Dependability was enhanced through peer check. So that all interview transcripts, codes and themes were reviewed by three experienced qualitative data analyzers from outside the research team. Credibility was enhanced by data gathering from various sources	MAXQDA-10 was used for conventional content analysis based on Graneheim and Lundman method	(1) Lack of knowledge, Feeling inadequate (2) Feeling instability: Feeling instability and on standby (3) Helplessness, Turmoil (4) Exhaustion: physical symptoms and anxiety. Caregiving tension	**Level of Evidence:** Level 5 **Strengths:** Previous studies have reported a lack of support for family caregivers and lack of attention to their needs, which may be due to the lack of knowledge about the needs and care challenges faced by family caregivers. A comprehensive and in-depth understanding of the family's caregiving experience and their

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

			hospitals ,as well as Seyedal shohada Palliative Care Center in Isfahan, which is the largest palliative care center in Iran **Attrition:** None	exhaustion and the caregiving tension caused by long-term caring for the patient and shouldering the costs incurred, on the one hand, and performing multiple roles simultaneously, on the other.	(interview, and observation in the form of field notes taken during researcher's attendance in clinical wards of the two medical centers), prolonged interaction with the family care-givers and by discussing about the findings among the research team and some of the interviewees so that initial codes were made available to participants to confirmand identify valid codes			subsequent suffering can help healthcare providers in planning training-support programs compatible with their needs and perform effective interventions to obviate these challenges **Weakness:** conducted within an Iranian context, which is different from other cultures. Moreover, none of the caregivers in the present study had experienced caregiving in end-of-life conditions **Feasibility:** Feasible to complete **Application:** Applicable to compile information

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

								of caregivers perceptions of caregiving and how to support them**.**
Wang et al., (2018), Protective preparation: A process central to family caregivers of persons with mild cognitive impairment **Country:** Taiwan **Funding:** Ministry of Science and Technology grant, Chang Gung Medical Foundation, Healthy Aging Research Center, Chang Gung	Grounded Theory by Glaser & Strauss, 1967	**Design:** Longitudinal descriptive **Method:** "longitudinal, grounded theory approach using in-depth face-to-face interviews and an open ended interview guide" **Purpose:** "develop a theoretical model explaining the longitudinal changes in the caregiving process for family caregivers of persons with mild cognitive impairment"	**Sample:** (*n*= 13) **Demographics:** Majority male, mean age of 51, and majority was the spouse as caregiver. **Setting:** Neurological clinics of one northern and one southern medical center in Taiwan **Attrition:** 5 lost over the course of the study	• Ambivalent normalization • Vigilant preparation • Protective management **Definitions:** MCI: "an individual's cognitive decline greater than expected for age-related changes, but does not significantly interfere with activities of daily living" Ambivalent normalization: "The feelings a caregiver experiences when attempting to accept and rationalize the	**Data Collection:** Face-to-face interviews conducted **Data Dependability:** "To avoid interfering with the caregiving interactions, observational notes were used instead of videotaping. After participant 11 had been interviewed four times, it was determined that data saturation had been reached"	Open coding and constant comparative analysis	(1) the caregivers were able to realize in later interviews that the cognitive decline was related to dementia and not just normal aging. (2) the caregivers had a plan for the functional decline of the care receiver and were able to adjust to these changes (3) prevention and safety management was achieved among the caregivers as	**Level of Evidence:** Level 5 **Strengths:** Study shows interventions to monitor symptoms is beneficial **Weakness:** Small sample size, and application only to families in Taiwan. **Feasibility:** Interviews and observation are very feasible. **Application:** "Information technology and improved environmental devices could enhance protection

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

University, Taiwan **Bias:** No conflict of interest				care receiver as normal"			each interview was conducted	strategies available to family caregivers and reduce caregiver burden"

Key: **BD1-II** Beck Depression Inventory, second edition, **CCSM** Caregiver Confidence in Symptom Management, **CESD** Center for Epidemiologic Studies Depression Scale, **CI** Confidence Interval, **CSES** Caregiver Self-Efficacy Scale, **DV** Dependent Variable, **GAD-7** General Anxiety Disorder-7 Questionnaire**, GSI** Global Severity Index of the Symptom Checklist **, IV** Independent Variable, **M** Mean, **MCI** Mild Cognitive Impairment, **NPI-Q** Neuropsychiatric Inventory Questionnaire, **PHQ-9** Patient Health Questionairre-9 Depression Screening, **PILL** Pennebaker Inventory of Limbic Languidness Scale, **PSI** Parenting Stress Index, **PTSD** Post-Traumatic Stress Disorder, **QoL** Quality of Life, **SCAS-P** Spence Children's Anxiety Scale, **SD** Standard Deviation, **SPSI-R:SE** Social Problem-Solving Inventory-Revised Short Form Scale, **SWL** Satisfaction with Life, **TBI** Traumatic Brain Injury, **ZBI** Zarit Burden Interview

Table A3

Synthesis Table

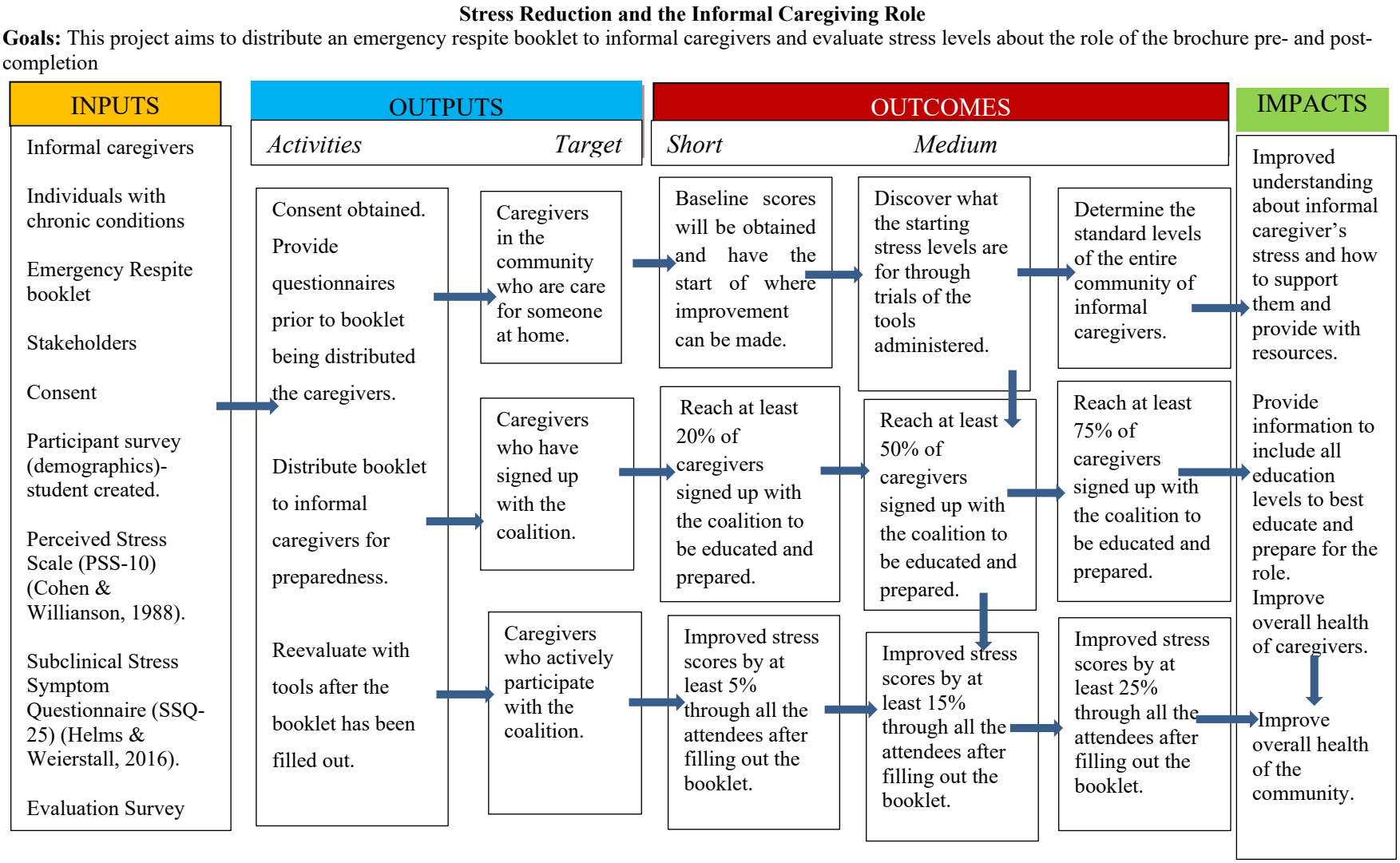
Study (Author, year)	Bektas Akpinar et al., 2022	Brunet et al., 2021	Cheng et al., 2018	de Araújo Freitas Moreira et al., 2018	Easom et al., 2018	Nemati et al., 2018	Raj et al., 2018	Sousa et al., 2021	Wang et al., 2018	Zimmerman et al., 2018
Design LOE	Quasi-experimental level 1	RCT level 4	RCT level 1	RCT level 1	Cross-sectional level 2	Exploratory descriptive level 5	RCT level 1	RCT level 1	Longitudinal descriptive level 5	Interview level 5
Sample										
n subjects	105	15	142	33	370	21	148	27	13	194
M-Age	39 yo	67 yo	49 yo	55 yo	39 yo	22-42 yo	6 yo (patient)	48-55 yo	51 yo	60-68 yo
Gender	F	F	F	F	F	F	M (patient)	F	M	F
Setting										
Hospital/clinic	X	X	X		X		X	X	X	
community				X	X	X				X
Interventions										
Home ergonomics				X						
Training program v. Nursing care								X		
Web-based training							X			X
Improv class		X								
PEP			X							
Educational program	X									
PST					X					
Interview						X			X	
Outcomes/ Themes										
Stress	↓	↓		↓		↑				↓
QoL				↑					↑	
Coping/PSS			↑		↑			↑		
Burden		↓	↓		↓	↑		↓	↓	↓
Satisfaction								↑	↑	
CD		↓	↓		↓		↓			↓
CBP					↓		↓			
PPH	↑		↑		↑	↓				

Key: **CBP** Child Behavior Problems, **CD** Caregiver Depression, **F** Female, **LOE** Level of Evidence, **M** Male, **M-Age** Mean Age, **PEP** Psychoeducation Program, **PPH** Perceived Physical Health, **PSS** Problem-Solving Strategies, **PST** Problem-Solving Training, **QoL** Quality of Life, ↑ Increased, ↓ Decreased

Appendix B

Logic Model

Figure B
Logic Model



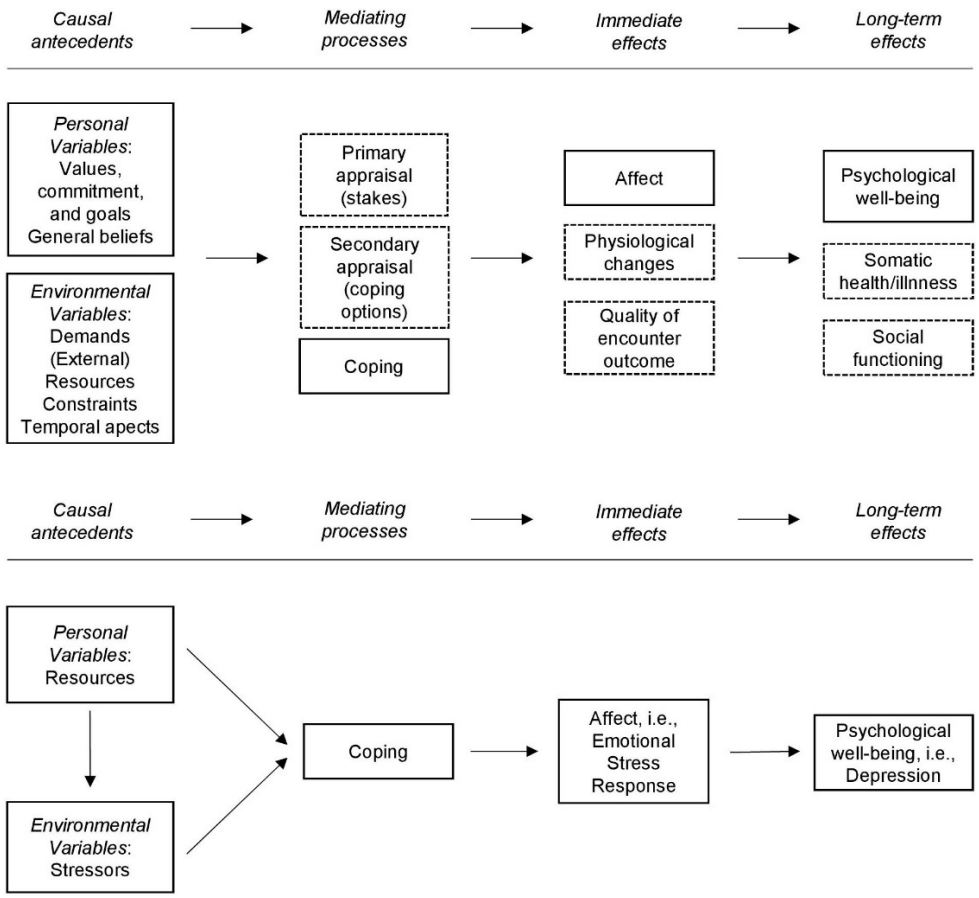
Assumptions: The caregivers will be honest about their stress levels. The caregivers will fill out the entirety of the booklet. All caregivers have some stress related to caregiving. All caregivers have never had formal medical training. Participants will respond and follow up with the questionnaires. Stress will improve with completion of the booklet.

Appendix C

Models and Frameworks

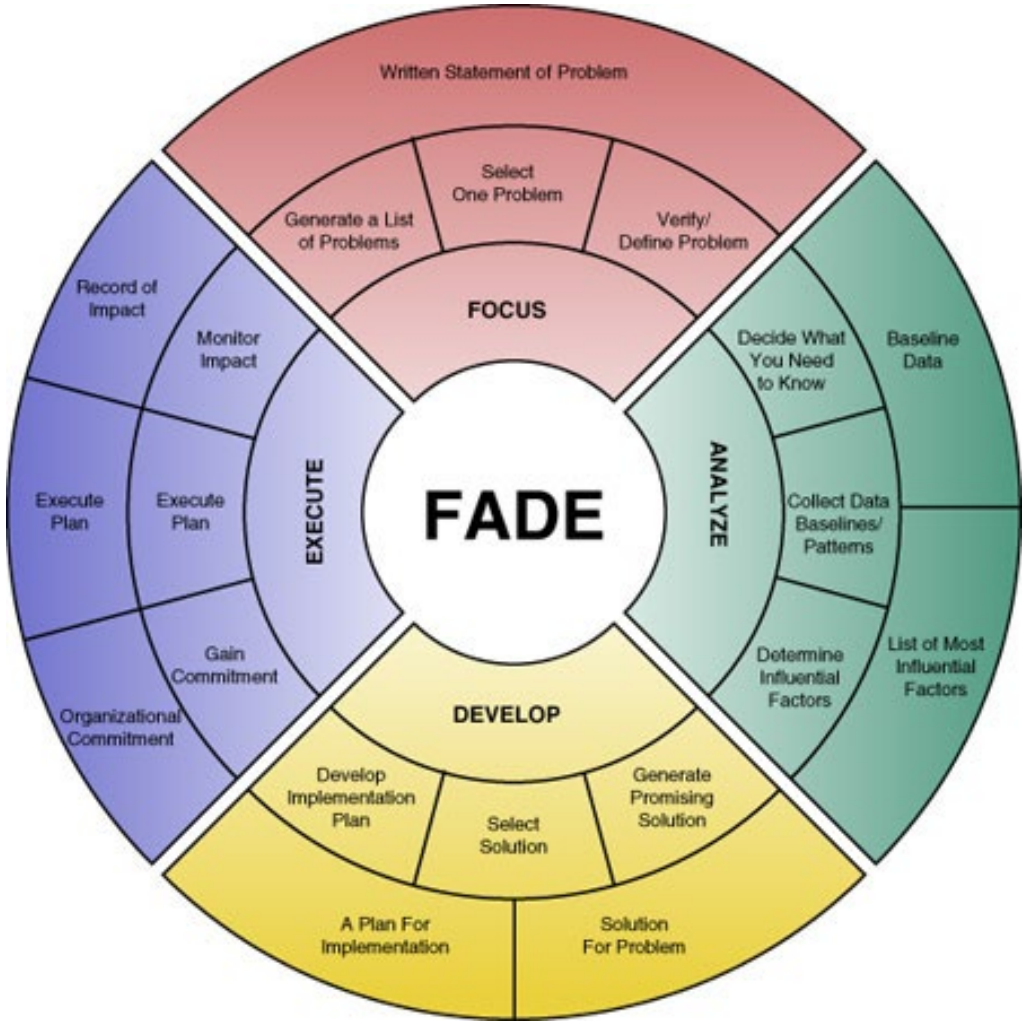
Figure C1

Transactional Model of Stress and Coping



(Lazarus & Folkman, 1984)

Figure C2
FADE Quality Improvement Model

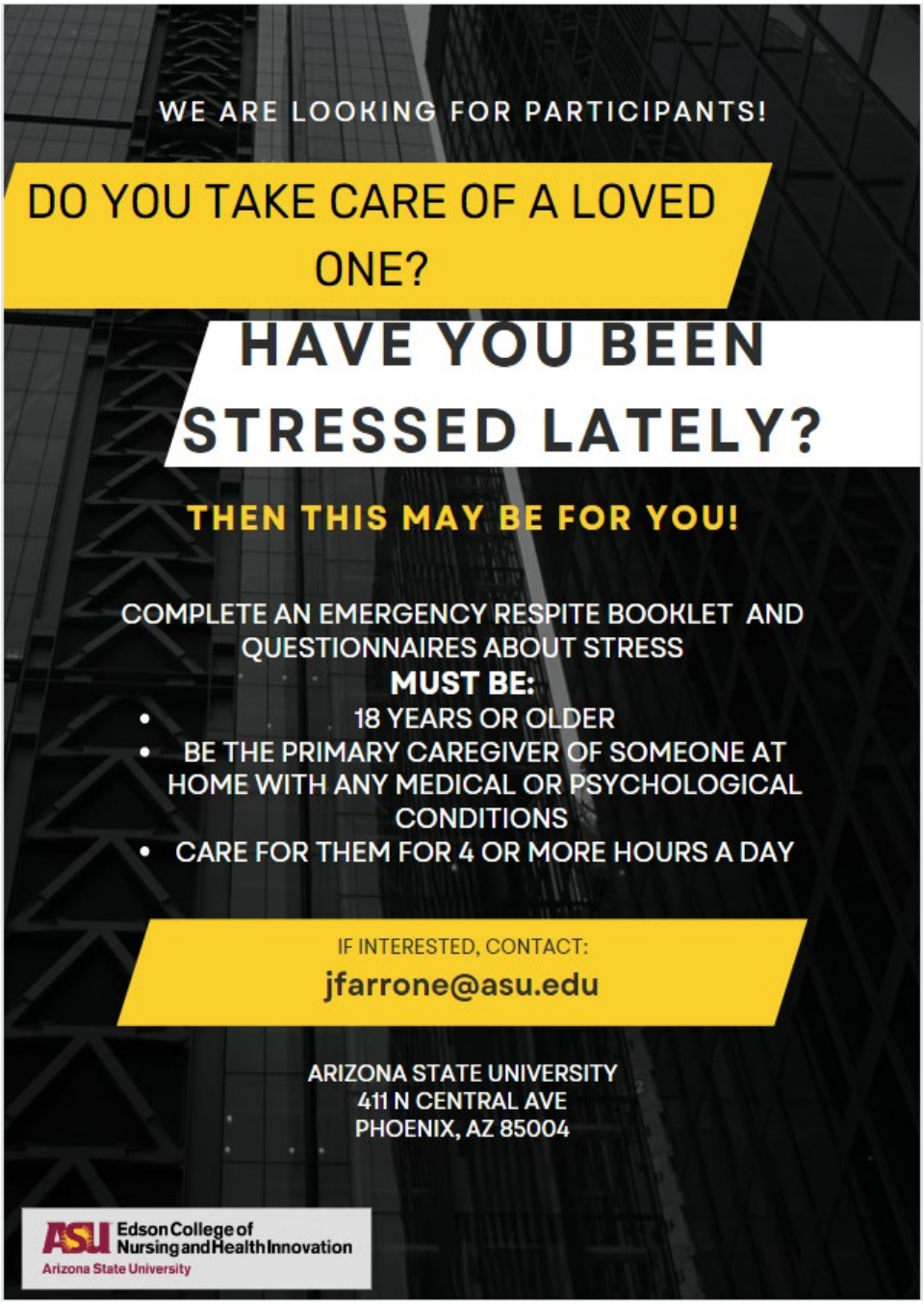


(Wiseman & Kaprielian, 2002)

Appendix D

Recruitment Flier

Figure D
Recruitment



Appendix E

Budget for Informal Caregiving Project

Figure E
Budget

Phase	Activities	Cost	subtotal	Total
Preparation	Design and print emergency respite booklets 20 cents per page x 14 pages each x 20 copies (Direct)-funded by state grant	$2.80 per booklet	$56	
	Design and print emergency respite information guide 20 cents per page x 16 pages x 20 copies (Direct)-funded by state grant	$3.20 per information guide	$64	
	Hire Spanish translator. Estimated 10 hours @ $12/hr to translate materials (Direct)-funded by state grant	$12	$120	
	Provide canvas bag, folder, and wet-erase pen to each caregiver (20 each) (Direct)- funded by state grant	$10	$200	
Delivery	Online Survey Platform (Indirect)-self funded	FREE	FREE	
	Email to disseminate information to Participants (Indirect)-self funded	FREE	FREE	
	Spanish Translator for Spanish speaking participants (Indirect)-funded by state grant. $20/hour for 4 hours	$15	$80	
Evaluation	Email reminders to complete questionnaire	FREE	FREE	

	for 1 month (Indirect)- self funded			
	Analysis of Data on Intellectus® (Direct)- self funded	FREE	FREE	
				$520

Budget Justification:

There is no direct revenue or cost savings to the site. Still, there may be indirect cost savings due to the use of the emergency respite booklet helping to prepare caregivers rather than having workers come in and be paid for hours of assisting the caregiver in finding emergency respite that could be avoided with this plan. This budget is all covered by a state grant for the booklet.