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Assessment of Caregiver Burdens: A Screening Tool development for the improvement of Caregiver Health

BY

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A doctoral thesis submitted to the faculty of the Medical University of South Carolina in partial fulfillment of the requirements for the Post Professional Occupational Therapy Doctoral degree in the College of Health Professions

1.0 Introduction

1.1 Caregiver needs

This project investigates the needs of informal caregivers for home health patients in upstate South Carolina. An informal caregiver is defined as "Those untrained and unpaid people who provide care to an ill person because of their relationship with them" (IAHPC Pallipedia, 2022). Caregivers in the home may be responsible for basic needs such as bathing, dressing, feeding patients, and incontinence care, but also in some cases includes performing procedures such as wound care, feeding tube maintenance, catheters etc. Despite attempting to create time to care for their loved ones, caregivers sometimes run out of time causing things to get missed in patient needs or in their own lives. Caregivers sometimes have a poor understanding of or ability to complete skills needed to care for their loved one such as catheter care or medicine management.

Over the past 14 years, as an Occupational Therapist (OT) working in home health in the upstate of South Carolina, I have witnessed consequences in the health of caregivers. These consequences include increased stress, decreased quality of life, decreased health and financial status and even hospitalization. Many caregivers report a rise in anxiety as caregiver burden rises. Caregivers in the home are continuously experiencing decline in health and quality of life while taking care of recently discharged loved ones (Del-Pino-Casado et al., 2021). If we want to provide optimal care for clients in home health, we must consider their environment and the health/well-being of those primarily in charge of providing their care.

Caregivers in the home may be responsible for basic needs such as bathing, dressing, feeding patients, and incontinence care, but also in some cases includes performing procedures such as wound care, feeding tube maintenance, catheters etc. These consequences include increased stress, decreased quality of life, decreased health and financial status and even hospitalization. Many caregivers report a rise in anxiety as caregiver burden rises.

A meta-analysis with 74 studies shows a large positive association between subjective caregiver burden and anxiety symptoms. (Del-Pino-Casado et al., 2021). Several studies also include physical, psychological, and financial consequences with increased caregiver burden. (Talley, K et al., 2019 and Thana, K et al., 2021) There is a need to identify the stressors of individual care givers in the home health environment with a screening tool because when these unique set of problems are identified, it will allow the whole patient/caregiver picture to be recognized and interventions to be developed and implemented by the home health team.

Many caregivers in South Carolina show a wide range of burdens which cause stress. Some are common, others are unique to their situation. So, what are the caregiver activities which may cause the burden? The main sources of burdens fell into a few major categories.

- Managing Medical Needs of Loved Ones- Caregivers showed a heavy caregiver burden in those “caring for an older family member with advanced techniques in the home with far less training than those medical professionals who perform them daily” (Lee, et al., 2019). A review from 1980-2018 found that 67% performed nursing techniques such as management of medications, wound care, feeding tubes, catheter care, etc. which increased the challenge of caregiving. (Lee et al., 2019).
- Managing Self-Care Tasks- Many of the health needs of home health patients result in decreased independence for that individual due to physical or mental limitations. A 2021 study by Del-Pino-Casado, et al highlighted that these seemingly simple tasks were a

major source of stress and burdens associated with daily caregiving routines for patients. Specifically, this study identified bathing, dressing, feeding, incontinence care, and managing appointments as major sources of strain.

- Limited Support-. Rodríguez-Madrid et al., 2021 asserts when support for caregivers is lost, the burden for the remaining caregiver increases. In my observations of caregivers over the years, I have noted that single caregivers appear less satisfied with their situation, more stressed by care instructions and increased worry about getting everything done and doing it right. In a search using solo, one, single, multiple, caregivers in all different orders and combinations no studies were found on the effects of being a single caregiver versus having multiple caregivers, but one study showed that when support for caregivers was lost, the burden for the remaining caregiver was greater and reported health was worse. (Rodríguez-Madrid et al., 2021).
- Financial Strain- Finally, Talley, K., 2019 describes financial strain as a source of burden. As caregivers attempt to care for others, many times their hours of work must be reduced, some must take time off from work (many times with no pay), and there are almost always increased costs incurred when caring for others.

Caregivers have vastly different burdens which cause stress. Some caregivers may report stress when assisting their loved ones with bathing or dressing while others may report little stress for that burden. This is also why “catch all” (or one size fits all) interventions do not work (Lauritzen et al., 2015 Parker et al., 2008, Corry et al., 2019). Therefore, a screening tool is needed to assess sources of burden and the associated amount of stress that is causes for that individual.

In my observations of caregivers over the years, I have noted that single caregivers appear less satisfied with their situation, more stressed by care instructions and increased worry about getting everything done and doing it right. In a search using solo, one, single, multiple, caregivers in all different orders and combinations no studies were found on the effects of being a single caregiver versus having multiple caregivers, but one study showed that when support for caregivers was lost, the burden for the remaining caregiver was greater and reported health was worse. (Rodríguez-Madrid et al., 2021).

1.2 Need for improved caregiver assessments

Optimal interventions cannot be advanced until the assessment process is first successful. As one study concludes, specific instruments are needed which can measure the quality of caregiver health (Tyo & McCurry, 2020). Assessments and interventions for caregivers are essential and can affect up to 25% of our population. "More than 1 in 5 Americans are taking care of their elderly, ill and disabled relatives and friends" (Kent & Erin C, 2020, p. 1).

Many interventions are already being tried with varying degrees of success. One study shows that support groups have been shown to be helpful in care givers of older adults with dementia. (Lauritzen et al., 2015) Another review concludes that support groups only, supplying self-help materials and offering only peer support are not successful. (Parker et al., 2008) A third study shows that telephone use only for education of caregivers had little to no effect on caregiver outcomes. (Corry et al., 2019)

There are several caregiver tools being used to measure stress at this time, but they all have limitations which make them less than ideal for the purpose of this project. The Caregiver Strain Index (CSI) (Robinson, B.C., 1983) has 13 items and can be given in a brief time with simple yes/no questions, but only identifies that there is stress present, not the root cause. The Caregiver Strain Questionnaire (CGSQ) is a longer 21 item measure with a 5-point Likert scale (Brannan, A.M., et al. 1997). This would take a little longer to complete and is geared towards families with young people with emotional problems, so it is limited. Also, there is the Caregiver Self-Assessment Questionnaire (Epstein, Lubow, G., et al. 2010) which is an 18-item assessment with yes/no questions which identify the presence of stress or depression, but not the cause. An assessment is needed which can identify the common causes of stress as well as sources of strain unique to each caregiver. This assessment must also be efficient to use to be feasibly integrated into clinical practice.

1.3 Constraints for therapists

Therapists in the home health field face many obstacles when it comes to adding another assessment to perform in the home. These obstacles include limited time in the home, limited access to caregivers at times, productivity expectations, lack of reimbursement for caregiver assessments. Therapists are not addressing caregiver burdens because many times they do not know what they are. The focus is on the patient and teaching the caregiver how to take care of the patient's needs. There is no section in the home health evaluation which covers caregiver stress or burden. A screening tool is needed which is efficient and captures the uncommon burdens of caregivers and those commonly supported by research. The screen should also be filled out by the caregiver while OT evaluates the patient.

Caregivers are an important part of the care team of our patients once they are in the home. A caregiver who gets sick or hospitalized or stressed to the point of not being able to help the patient can contribute to the rehospitalization of the patient and additional hospitalization of the caregiver themselves. Caregiver stress is individualistic in nature (not all burdens are rated the same by each caregiver). We can build more accurate plans and interventions to assist caregivers, but it will all need to begin with an accurate assessment or screen for the burdens unique to each caregiver. A new screening tool is needed that identifies unique burdens, major sources of stress, and is easy for therapists to administer given the constraints of productivity demands and limited visits.

2.0 Methods

This project's purpose was to develop a caregiver screening tool that 1) identified sources of caregiver burden and the associated stress and 2) was feasible for therapists in clinical practice. There were 2 primary aims of this study.

- Aim 1) Determine common sources of caregiver burden and the associated stress caused by the burden.
- Aim 2) Identify critical elements needed by therapists to feasibly utilize a screening tool in clinical practice.

The two aims were accomplished through a multi-phased project. The first phase of the project consisted of a needs assessment involving caregivers and therapists. A preliminary caregiver survey was developed to identify common sources from the caregiver’s perspective. Results of phase one resulted in the development of a pilot screening tool. The pilot screening tool was trialed during phase two of the project. Interviews were conducted with therapists to determine what attributes were most important for therapists for feasible implementation into clinical practice. This feedback was utilized in the development of the pilot screening tool.

2.1 Preliminary work/needs assessment.

The first step in this project's development was to conduct a needs assessment. The needs assessment consisted of 3 key components. The first component was a literature review which was completed to gain knowledge of the existing research of current caregiver burdens, how they are being identified and who is at greater risk for stress. The second component compared what was seen in the literature with the current experiences of caregivers in upstate South Carolina. Surveys were completed to gain further knowledge of local caregiver burdens and to compare local answers to research. Lastly, interviews were conducted with local home health Occupational Therapists to determine the logistical factors that would need to be considered when developing a caregiver screening tool. This included information about the ideal time allowance for administering the screen, order of questions, protocols and set up of the screen itself. The screening tool must be respectful of the time and to the schedules of those who will administer them.

This project considered the perspectives of several key stakeholders: home health caregivers, home health therapists, and the administration for Bon Secours/Mercy in Greenville, SC. It was essential to gain insight from these groups to develop a meaningful, clinically practical screening tool. The following sections will describe how insights from each stakeholder group were incorporated into this project.

2.1.1 Literature review: Step one of the project was to identify sources of caregiver stress in the literature. This was done by searching in PubMed for research, Meta analysis and improvement projects concerning caregiver stress. I began by searching for reviews and research for caregiver burdens. The first key phrase “caregiver health” yielded 59,766 results. Search was then narrowed to the last 5 years, reviews which then yielded 2,460 results. English reviews only cut the results to 2,359. Adding the terms “family stress” with “caregiving” yielded 237 results. Excluding psychiatric and hospice care cut down the results to 120. Another search for “home caregiver health” yielded 329 results and using above filters plus exclusion of dementia and nursing yielded 139 results. Other searches included “caregiver burdens” AND “home health” which yielded 35 results. Articles were included in my review if they contained the key words of “burdens, caregivers, interventions, and anxiety.” I also used search terms as stated above for multiple caregiver’s vs single caregivers with no results. The results of these studies gave me the initial list of caregiver burdens included in the initial caregiver survey. Those burdens included the following:

- Financial strain (Talley, K et al. 2019)
- Medication management, wound care, feeding tube care and catheter care (Lee et al. 2019)
- Little/reduced assistance from family/others (Rodriguez-Madrid et al. 2021)
- Little/reduced assistance from community (Rodriguez-Madrid et al. 2021)
- Bathing, dressing, feeding, incontinence care and appointments. (Del-Pino-Casado et al 2021).

2.1.2 Initial survey of caregiver burdens: The second step of this project was to compare the sources of stress found in the literature to the lived experience of caregivers. This project was supported by the administration and therapy staff at Bon Secours/Mercy Home Health. The OT staff person available collected survey data.

Inclusion criteria: During initial Occupational Therapy (OT) evaluations of home health patients, caregivers were identified if they were involved. Caregivers had to be over 18 and a caregiver at the beginning of the episode of home health, and not be a paid non-family member caregiver to participate.

Exclusion criteria: Paid, non-family member caregivers. Caregivers of patients do not wish to have caregiver participation.

Preliminary survey: The survey consisted of items identified in literature as common caregiver stressors and items Occupational Therapists observed while working with patients.

12 burdens were chosen for the initial survey. Those burdens included the following:

- Financial strain (Talley, K et al. 2019)
- Medication management, wound care, feeding tube care and catheter care (Lee et al. 2019)
- Little/reduced assistance from family/others (Rodriguez-Madrid et al. 2021)
- Little/reduced assistance from community (Rodriguez-Madrid et al. 2021)
- Bathing, dressing, feeding, incontinence care and appointments. (Del-Pino-Casado et al, 2021).

Caregivers were asked to check a box identifying activities they performed, and another box if they were stressful. If an activity was stressful, they were asked to rate the stress on a 1-5 scale with 1= minimal stress up to 5 = extremely stressful. Caregivers were also given the opportunity to add any stressors they may have which were not listed through an open-ended question at the end of the survey and rate them. This was a 2-page paper form, front side only.

Survey collection process: The purpose of the project was described to the caregiver, and they were asked to participate. No monetary or other incentives were used other than the survey's goal, and they were assured no consequences would occur by refusing to participate. The burden information was collected via a paper survey by participating caregivers. The surveys were given to the caregivers to fill out during an Occupational Therapy evaluation and collected when finished.

Data storage: The surveys were then kept in a secure location with no identifying characteristics present. The results were recorded and later analyzed. The assessment was to determine the burdens of caregivers and the level of stress perceived.

Analysis of surveys: Each survey item was counted as to whether it was checked as a burden by the caregiver and the average of the ratings for each item calculated. Multiple caregiver answers were compared to that of single care givers to show the identified gap in care. The average stress rating of single care givers and multiple care givers were also compared. Lastly, the number of burdens added to the list by the caregivers and the number of caregivers who listed additional burdens were calculated by percentage. This is important because it identifies caregivers who are at greater risk of stress related issues and to show that there are additional burdens not identified in the research.

2.1.3 Using the survey results to develop a pilot tool: After analyzing the data from the initial surveys of the caregivers, burdens which were scored 1) a stress rating of 4 or 5 OR 2) burdens with more than 30% of caregivers identifying as stressful were added to the pilot version of the Caregiver Screening Tool (CST). These sources of stress were included as individual question items on the screening tool. The surveys were formed as a checklist for participation in burdens followed by a 0-5 rating scale for each item. On the back of the form there are blank item lines for the caregivers to include burdens completed, but not listed on the front of the form. There is also a space for each item to be rated.

2.2 Needs/Constraints for therapists

The second aim of the needs assessment was to identify critical characteristics a screening tool would need to be feasibly used by therapists. Once a preliminary version of the screening tool was developed, the tool was modified to improve the user experience for caregivers and clinicians. This was an essential step if the tool is going to be utilized in clinical practice. Modifications were made based on feedback from other OTs who used the tool. Feedback from therapists was obtained by phone interviews with 5 area home health OTs. Answers from interviews were transcribed to blank forms. Interviews were 10 to 15 minutes in length on average. They provided feedback on length, how it would be administered and the flow and appearance of the form itself.

2.2.1 Therapist input:

Inclusion/Exclusion: The criteria for inclusion in the interview process consisted of being an OT working in the state where the survey would take place, being an OT for at least one year in home health and agreeing to the interview.

*Interview process***:** Interviews with therapists were completed over the phone. Therapists were asked the following open-ended questions.

1. How long should the survey take?
2. Do you feel better about doing a survey on the computer or on paper? Why?
3. Would you rather ask the questions to the caregiver or have them fill out the survey while you are performing your patient evaluation?
4. If the caregiver is not present, would you rather call back when they are available or mail them the survey or leave it in the home for them to fill out and send to us?

Are there any other important features we need to address when creating this screening tool?

*Data analysis process***:** Responses were recorded on separate forms for each therapist interviewed with the questions listed and answers to follow. The most common responses were adopted into the form.

2.2.2. Survey formatting: Survey structure is particularly important for feasible use in the clinic. Input from the therapist interviews was used to structure the formatting of the pilot tool. Once the initial version of the screening tool was created, the tool was distributed to the other OT at Bon Secours/Mercy Home Health for pilot testing. This pilot testing was to gain feedback from the therapists about the pros and cons of the tool and to refine it based on suggestions from them.

2.3 Caregiver Screening Tool (CST) pilot

2.3.1 Administrative buy-in: First, the CST Pilot screens were drafted. I met with the management of Bon Secours/Mercy Home Health to inform them of the plan for training, dissemination, and timeline for the project. Management gave their approval for the plan and training/information meeting was set up for management, OTs and office staff who may need to answer questions from calls by patients and/or caregivers. I met with staff including management, front office personnel and OT. The CST was introduced and recommendations for further improvements to the tool were suggested. Changes to the appearance of the tool and making it one page (front and back) as opposed to two pages were made.

2.3.2 Staff training: I met with the other full-time OT from Bon Secours and instructed her to use the screen during OT evaluations with caregivers present. She was instructed to explain the purpose of the screen and ask the caregiver's age and if they were a single caregiver or if there were multiple caregivers. She was then instructed to give the screen to the caregiver to fill out while she (the OT) conducted the evaluation with the patient. Once completed, she was to collect the screen and drop it off with others at a secured location in the Bon Secours/Mercy office. In the event the caregiver was not present, she was instructed to call the caregiver after the evaluation visit and perform the screen manually over the phone while recording the answers on the form. Instructions to add any burdens not mentioned and rate them were included. OT verbalized understanding and agreement of instructions. The same process was completed with a PRN OT in another location on another date due to PRN OTs availability.

2.3.3 Caregiver Screening Tool: The tool was formed as a checklist for participation in burdens followed by a 0-5 rating scale for each item. On the back of the form there are blank item lines for the caregivers to include burdens completed, but not listed on the front of the form. There is also a space for each item to be rated.

2.3.4 Data collection process: Pilot testing was to be completed by 2 full time Occupational Therapists at Bon Secours/Mercy Home Health during a 3-week period, but due to unforeseen barriers it was extended to 6 weeks. This allowed us to get more responses.

Beginning on January 16th, 2023, OTs completed the screening tool with clients with identical inclusion measures as with the surveys but with no identifying characteristics on the forms. Screens were placed in my box in the home health office. The pilot study lasted 6 weeks and screens were analyzed to identify sources and number of burdens for caregivers. The number of burdens and rating for multiple caregivers versus single caregivers as well as the number of new burdens identified by caregivers compared to the original 12 burdens. OTs and management met to discuss pros and cons of the tools use and any suggestions for improvement.

2.3.5 Data analysis of the Caregiver Screening Tool:

For the survey, the number of each burden chosen was totaled. The total prevalence was then divided by the total number of caregivers in the study, and this was the average prevalence. Each burden rating was then added up and divided by the number of caregivers who rated them (total rating/total of caregivers who gave ratings for that burden) and this was average ratings for each burden. Prevalence and rating numbers/averages for single caregivers were compared to multiple caregivers. CST pilot was then analyzed by adding up the numbers for each burden chosen and dividing by the total of all caregivers (total of each burden choices/47). Then ratings were added up for each burden and divided by the prevalence total. Again, single care givers were compared to multiple care givers for prevalence and average rating. Next survey prevalence and average ratings were compared to pilot numbers. Lastly, the number of new burdens added were totaled for the survey and the pilot. The ratings or average rating for the new burdens were recorded and compared (survey vs pilot). The new burdens were then divided into themes or categories.

3.0 Results

3.1 Initial Survey Results

3.1.1 Participants: The survey was completed with all new home health Occupational Therapy evaluations with Bon Secours/Mercy Home Health during a 3-week time period. Since this project was carried out in a small population in upstate SC there was a need to protect the identities of the caregivers in this study, therefore some demographics have been generalized and an overall profile was compiled. The caregivers for the survey and screens were from the upstate of SC (South Carolina), had orders for Occupational Therapy evaluations for their loved ones for whom they cared. Eight caregivers participated in the initial survey. Caregivers rated burdens very differently from one another as stated in the introduction. Caregivers ranged in average age between late 20s to early 70s with patients' ages ranging between 50 and 100. Single caregivers represented 75% of the caregivers in the survey. Diagnosis of the patients included pneumonia, dementia, respiratory failure, among others. These diagnoses may be limited and uncommonly large due to the time of year in which this survey and screen take place.

3.1.2 Survey Responses from Participants: The below two tables present the survey responses from caregivers rating their sources of burden and the associated levels of stress caused by each burden.

Table 1 Survey results of care givers.

Burdens	**CG1**	**CG2**	**CG3**	**CG4**	**CG5**	**CG6**	**CG7 ***	**CG8 ***
Dressing	**1**			**1**		**1**		
Bathing	**2**			**1**				
Feeding	**4**			**1**				
Medication	**1**	**5**	**4**	**1**	**1**	**1**		
Incontinence	**4**	**3**		**1**		**2**		
Wounds	**1**					**3**		
Finance	**5**					**3**		
Low assist family	**3**	**4**	**5**					
Low community resources		**4**	**1**					
Appointments	**2**	**3**	**1**		**3**	**4**		
Missing social activities						**4**		
Catheter Care							**1**	

* Multiple Caregivers

Table 2 displays the summarized data from the survey.

Table 2 Prevalence and average stress rating from initial survey

Burdens Identified by research	***Prevalence of Response***	***Average stress ratings***
Dressing	37.5(38)	1
Bathing	25% (2/8)	1.5
Feeding	25% (2/8)	2.5
Medication	75% (6/8)	2.2
Incontinence	50% (4/8)	2.5
Finance	25% (2/8)	4
Low assistance from family	37.5% (3/8)	4
Low assistance from community	25% (2/8)	2.5
Appointments	62.5% (5/8)	2.6
Missing social activities	12.5% (1/8)	4
Catheter Care	12.5% (1/8)	1

3.1.3 Use of survey data for development of pilot tool The survey's results led to the addition of 3 burdens to the CST pilot which were not first seen in the research or by observation of OT in the past. The criteria for adding a burden to the pilot were: the burden had to have at least 30% prevalence of caregiver identification and/or a stress rating of 4/5 or higher on the survey. The burdens dropped from the screen pilot were catheter care, wound care, feeding tube care as they did not meet the criteria for prevalence nor rating. The burdens added were missing social events, home/yard work and the worry of patient falls which all met the criteria for rating.

*3.1.4 Feedback from therapist on survey format***.** Interviews with 5 local OTs indicated that the survey should have the following components to be feasible for clinical use: 5-10 minutes long, completed on 1 sheet of paper (front and back), caregivers to fill out screens while OTs perform evaluations with patients, caregivers not home to be called and asked the questions and OTs to write answers on a survey form.

3.2 Caregiver screening pilot results

3.2.1 Participant description The pilot's participants were from the same area, upstate South Carolina, as the survey. The caregivers ranged in average age of late 20s to early 70s. The age range for patients was 50 to 100. The primary diagnoses were pneumonia, dementia, and respiratory failure. There were 47 total caregivers that participated, 8 multiple caregivers and 39 (83%) single caregivers. All families on the current case load agreed to the screenings during the pilot.

3.2.2 Pilot Screen Responses Five burdens reached over 50% prevalence including bathing, appointments, reduced assistance from family, medication management, and worry of patient fall/health which reached 83%. All ranges of the ratings were 1-5 and the ratings were on a 0-5 scale with 0 meaning no stress and 5 meaning extremely stressful. Four burdens had an average rating of over 3/5 for stress. Those burdens were reduced assistance from the community, financial strain, missing social events, home/yard work and worry of patient fall/health.

Table 3 Caregiver Screening Tool (CST) pilot results.

Burdens Identified by Survey	**Prevalence of Response**	**Average Stress Ratings**
Dressing	48.9 (23/47)	2.7
Bathing	53% (25/47)	2.8
Incontinence	48.9% (23/47)	2.9
Feeding	25% (12/47)	2
Appointments	66% (31/47)	3
Reduced assistance from family	55.3% (26/47)	3
Reduced assistance from comm	21% (10/47)	3.8
Financial strain	38.3% (18/47)	3.7
Medication management	66% (31/47)	2.6
Missing social events	36% (17/47)	3.1
Home/Yard work	38.3% (18/47)	3.2
Worry of patient fall/health	83% (39/47)	3.8

3.2.4 Therapists Feedback I met with OTs involved in the CST pilot to receive input about needed modifications to the CST. The OTs involved in the pilot gave no further modifications to be made to the tool. The pilot, therefore, continued as planned.

3.3 Results comparison between the survey and pilot

The survey results and pilot results show that caregivers consistently choose some burdens more than others. These were management of medicines, making/keeping appointments, and incontinence care (these were the top average in prevalence when combining both survey and pilot of the original 12 burdens). Other burdens had higher average ratings on stress from survey to pilot. These were: Incontinence, medication, and community resources. Two items had higher average ratings of stress and prevalence from survey to pilot. Those were dressing and bathing.

Table 4 Caregiver burdens and associated stress levels.

	Burdens from Survey (Total n=8)	**Burdens from Pilot (n=47)**
*** + Dressing**	37.5%; avg stress rating 1/5	48.9%; avg stress rating 2.7/5
*** + Bathing**	25%; avg stress rating 1.5/5	53%; avg stress rating 2.8/5
+ Incontinence	50%; avg stress rating 2.5/5	48.9%; avg stress rating 2.9/5
*** Feeding**	25%; avg stress rating 2.5/5	36%; avg stress rating 2/5
*** Appointments**	62.5%; avg stress rating 2.6/5	66%; avg stress rating 3/5
*** Family Help**	37.5%. avg stress rating 4/5	55.3%; avg stress rating 3/5
*** Financial strain**	25%; avg stress rating 4/5	38.3%; avg stress rating 3.7/5
+ Medication	75%; avg stress rating 2.2/5	66%; avg stress rating 2.6/5
+ Community Resources	25%; avg stress rating 2/5	21%; avg stress rating 3.8/5

* 7 burdens had an increase in % of caregivers identifying each burden.
* Burdens with higher prevalence of caregiver stress.
\+ burdens had an increase in the stress ratings for the burden.

The surveys had 2 multiple care givers (25%) who showed lower numbers of burdens and lower ratings of stress reported when compared to 6 single care givers (75%). The Pilot study had 8 multiple care givers (17%) who had an average of 5.1 burdens per cg and an average of 2.5/5 rating for stress. Single care givers (83%) had an average of 6 burdens per caregiver and an average rating of 3.0/5 for stress level caused by the burdens identified.

Table 5 A comparison of the survey and pilot results.

	Surveys	Pilot Study
Number/average of multiple Caregivers	2/33%	8/17%
Average number of burdens reported by multiple caregivers	.5 burdens	5.1burdens
Average number of burdens reported by single caregivers	11.3 burdens	6.0 burdens
Average Rating of stress by Multiple caregivers	1/5	2.5/5 rating
Average rating of stress by single caregivers	2.6/5	3.0/5 rating

Table 6 shows the burdens added by caregivers during the pilot. There were 22 burdens added by caregivers. The added burdens were categorized for easier analysis and to begin the streamlining of the tool. Most burdens added with an average rating of 3/5 or higher indicating that they are a source of high stress to the caregiver.

Table 6 Burdens added by caregivers during the pilot screening.

Medical	Day to Day Strain	Behavior	Relationship	Other's Needs
O2 Management (5/5)	Meal Prep (2/5)	Patient Compliance (4.5/5)	Strain on Relationship (4/5)	Caregiver Health (5/5)
Confusion at Night (4/5)	Laundry (2/5)	Strong Willed Patient (5/5)	Sadness for Pt Condition (5/5)	Multiple Patients (4/5)
Eating & Drinking Concerns (4.5/5)	Home Maintenance (2/5)	Dementia Care (5/5)	Uncertainty for Future (5/5)	
Ambulance/ER (5/5)	Work Balance (5/5)	Patient Behavior (5/5)	Public Outings (4/5)	
Patient Mental Ability for Simple Tasks (5/5)	Constant Care (5/5)	Verbal Abuse (5/5)		
Patient Addiction (5/5)				

4.0 Discussion

4.1 Discussion of Results

Caregivers in the survey and pilot were all unpaid family members or friends who were taking care of the patient (IAHPC Pallipedia, 2022) and had no formal training to perform many of the tasks they were asked to perform. The results show that caregivers are reporting many burdens and highly rated stress. I have witnessed as a practicing home health OT the hospitalization of caregivers due to reported stress by the caregiver themselves. Other OTs in the area confirm my experiences as well.

One study showed that when support for caregivers was lost, the burden for the remaining caregiver was greater and reported health was worse. (Rodríguez-Madrid et al., 2021). Again, pilot screening results support the above study in the prevalence and rating of 2 items (Reduced assistance from family with a prevalence of 55.3% and an average rating of 3/5 and Reduced assistance from community with a prevalence of 21% and a stress rating of 3.8/5.)

Many caregivers in South Carolina show a wide range of burdens which cause stress. Some are common, others are unique to their situation. This was demonstrated by this project in the number of new burdens added (22 burdens, a nearly 200% increase) to the CST pilot. Caregivers in the CST pilot did not show a heavy caregiver burden in those performing nursing techniques as Lee et al., 2019 claimed with exception of medication management. Findings of this study may be different from the findings of Lee et al. (2021) because most wound care, catheter or feeding tube care would be seen by nursing or Physical Therapy (PT) in this particular agency.

We have learned that care givers are different in the burdens they identify and the associated level of stress they report. All 12 burdens listed in the CST pilot were reported as having some level of stress, but the rating varied from 1-5 out of 5. This shows the diversity of perception for stress of each burden. A burden which extremely stresses one caregiver may be a minor stressor to another. Caregiver feedback and observation of caregivers by OTs showed us that a flexible tool was needed that would capture all stressful burdens of all caregivers. The tool created during this project identifies not only the common stressors of caregivers but gives them the ability to report unique burdens which can then be met with an intervention. This is a comprehensive measure of caregiver health which would satisfy the need for having a specific instrument to measure the quality of life of caregivers as stated by Tyo & McCurry in 2020.

Rather than creating a tool which only measures the presence of stress, (Caregiver Strain Index, The Caregiver Self-Assessment Questionnaire) this tool identifies the cause of stress. It also does not limit the caregiver in identification of burdens to those given validity by research but expands the possibilities of answers to include burdens not supported by research. The CST is also a tool which can be performed efficiently with 12 checkbox predetermined burdens and one open-ended question for adding burdens and rating them unlike the Caregiver Strain Questionnaire which has 21 questions (Brannan, A. M., 1997). After using the survey with this population of caregivers in the home, it was learned that we needed one tool to capture burdens regardless of diagnosis. This tool works for a wide population of caregivers and can be applied to patients with many diagnoses as opposed to focusing on one group. If we use assessments like the CGSQ for youth with emotional problems and another tool for dementia patients and so on, we will make an existing problem even worse for home health clinicians. The problem is that home health clinicians already evaluate patients using many assessments and screens. The CST created here is short enough to be used in the home with therapists but identifies burdens which cause stress and allows other burdens to be added and rated. The amount of stress is recorded on a Likert scale. This is a good fit for caregivers to be assessed in the home as opposed to hospitals or doctors' offices which may be intimidating or uncomfortable for caregivers to freely express their concerns.

Experience in the field shows that therapists and others in home health have limitations and time constraints due to productivity expectations and amount of time to be in the home due to patient fatigue. There is also much to be done while performing an evaluation. This was the reason for OTs being interviewed, and the CST to be created with these limitations and the suggestions of OTs in mind. The tool is easy to use and efficient in the use of the therapist's time. This was supported by OTs who have used the tool.

Caregivers are vital to the care of our patients and need to be assisted in any way possible to take care of themselves and the patient. The first step has been established here by creating a tool which will identify the burdens and measure the resultant stress for at least 25% of our population who take care of another.

4.2 Study Strengths

The strengths of this project are that there is research which agrees with many of the outcomes and trends seen in the results. The purpose and need for a tool to identify and measure caregiver burdens and stress has been documented throughout this paper. There is also much interest in the subject as seen in the amount of research on the subject and by the support given by management of Bon Secours/Mercy and my colleagues and caregivers who participated in the surveys and screenings (no one refused to participate). The project was created with participation of OTs and home health managers who were key due to their feedback to make this tool efficient and easy to use. Caregivers also were asked about the screen and process for gathering information. Caregivers reported during the pilot that the tool and process was not too invasive, and no one turned down the opportunity to participate in the screen.

4.3 Study Limitations

The limitations of this project include the time constraints during the survey and the lack of OTs employed by my company in home health at the time of the survey, untimely delays due to car accident of one OT and vacation time of another during a critical time of the pilot, OTs were the only ones performing the screening due to high patient volume for Physical Therapists, nurses and our social worker (this limited our diversity of diagnosis and burdens observed). The survey and pilot took place in a small area (four counties in the upstate of South Carolina) and during a relatively brief period (6 weeks) which further limited the diversity of people and of diagnoses observed.

4.4 Next steps

- The CST must be streamlined to allow categories of Burdens which can be individualized by the clinician as needed.
- Training for other disciplines to use the tool will create a larger sample size.
- Maintain interest with management and higher administration to expand use of the tool to other home health offices in the company.
- Create a computer database for the coupling of burdens and interventions which can then be easy and efficient to use.

5.0 Conclusion

Caregivers play a pivotal role in the care of patients discharged home from the hospital or other facilities. They perform duties carried out by trained professionals who work in a facility which, unlike their home, was built for taking care of people. Caregivers perform daily tasks, nursing and therapy duties and everything in between. Without our caregivers, many patients would be re-hospitalized.

There is a big need for the identification of stress and the burdens of this stress in caregivers. Research and observation call for a way of identifying stressful burdens which are not only standardized, but also individualized. Before attempting to create interventions for caregivers, we must identify the problems they are having.

Therapists in the home health field have demands on their time which are dictated by productivity, patient fatigue, weather, traffic, and other unforeseen factors. They also have numerous assessments and screens which they perform with patients during evaluations. It is for this reason that an efficient and purposeful screen be created to assess caregivers.

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