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# An Integrative Review with Toolkit for Caregivers of Persons with Dementia

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An Integrative Review with Toolkit for Caregivers of Persons with Dementia

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**Table of Contents**

Abstract .....	4
Introduction and Background .....	5
Problem Statement .....	6
Review of the Literature .....	8
Theoretical Framework .....	12
Methods.....	14
Settings and Resources .....	14
Description of the group, population or community.....	15
Organizational analysis of project site .....	15
Goals, Objectives and Outcomes .....	17
Ethics and Human Subjects Protection .....	17
Results.....	18
Conclusion.....	20
References.....	22

Appendix.....25

A. Lewin’s coping theory/ EBP process

B. IRB approval letter

C. Initial survey questions

D. Final survey questions

E. Caregiver resource pamphlet

### Abstract

*Background:* The risk of burnout among caregivers of people with dementia is on the increase. Dementia is a progressive neuropsychiatric disorder affecting the cognitive function resulting in confusion and disorientation leading to greater demands on the caregiver which can lead to depression, social isolation, stress, worsening personal health, anxiety, fatigue, financial losses, and potential for abuse.

*Methods:* This project focused on creating a toolkit for nursing staff caring for patients with dementia followed by a presentation designed to provide options for caregiver support that can assist the caregiver in decreasing their feelings of stress and burnout. This included strategies for coping with dementia and some of the behaviors that go with it, as well as websites and phone resources.

*Results:* Nine nurses attended the presentation and seven took both pre and post- test. The pre-test allowed for additional strategies to be suggested and the post-test indicated that most nurses had a good idea of strategies to present to caregivers. A toolkit was provided and a brochure to caregivers.

*Conclusion:* The toolkit presentations and caregiver resource brochure were positively accepted by the nine of eleven nursing staff. The nursing staff indicated that this caregiver brochure was a resource that would be sustainable for future use. Nurses caring for persons with dementia are in the best position to educate the caregivers and provide the necessary resources that they may need.

*Keywords: dementia and caregiver burden, Alzheimer's, caregiver support, resource, and interventions, staff*

## An Integrative Review with Toolkit for Caregivers of Persons with Dementia

### **Introduction and Background**

Dementia is a progressive neuropsychiatric disability that can affect the elderly, and requires almost constant monitoring to maintain medication regimens, nutrition, and safety ("Family caregiving," 2011; Takai & Takahashi, 2009). It is well documented that caregivers suffer from burnout and health problems when taking care of ill family members, and dementia is one illness that can be one of the most difficult to deal with (Pinquart & Sorensen, 2007). The World Health Organization (WHO) acknowledges that there is an important need for adequate access to effective caregiver support (Blom & Zarit, 2015).

Caregivers are usually over the age of 50 and may have had to reduce their work hours or quit work altogether to provide care ("Family caregiving," 2011; Messinger-Rapport, 2006). The coping strategies that the caregiver may or may not have will contribute to the level of burnout or burden that they experience. With adequate access to resources there is the potential for improved coping (Fenison, 2011). Limited resources available to the caregiver can add to this stress and anxiety. The Caregiver Burden Inventory (CBI) or the State Trait Anxiety Inventory (STAI-Y1) is currently used to determine the level of stress caregivers are experiencing and, the Coping Inventory for Stressful Situations (CISS) is used to assess coping strategies (Iavarone & Ziello, 2014).

Many times the caregivers are unable to participate in community based programs due to the person with advanced dementia, demographics, or lack of a vehicle (Kwok & Wong, 2013). The caregiver must be viewed as the hidden patient and supportive efforts must be made instead of treating them when they become ill from the burden or begin to have problems with abuse (Quayhagen M. 1997; Lilly, 2012). The goal of this project was to provide some of the available

resources for nurses to share with patient families specific to their geographical area and individualized to the patient and caregiver (Lopez-Hartmann & Wens, 2012). When dementia patients enter the Geri-psychiatric care setting many times the caregiver express their frustration with dealing the dementia related behaviors and lack of support resources.

A needs assessment of a local facility revealed that there was a lack of informational resources available for the nursing staff to provide to assist the caregiver when problems arise at home. The needs assessment and written survey were done with the eleven nursing staff regarding the current discharge instructions being provided to the families. The current discharge instructions contain information about current medications and potential appointments that may need to be scheduled; however, there is no information about support resources that may be available to the caregiver near their geographical area. By providing the nursing staff with the appropriate information they can forward it to the caregivers. The toolkit included a user-friendly education resource notebook for the staff with general caregiving strategies and an easy to read brochure to be given to the caregiver.

### **Problem Statement**

As our population lives longer, the need for caregivers for these persons with dementia is increasing (Fenison, 2011). Many families are attempting to keep their loved ones a home and the burden for caring for them is increasing (Messinger-Rapport & McCallum, 2006; "Family caregiving," 2011). The repercussions of caregiver burden are many; including depression, anxiety, and poor health outcomes which can affect everyone in the family (Blom & Zarit, 2015). How caregiver burden affects family members and their coping mechanisms are dependent on the person and the support systems that may be available (Fenison, 2011). There is a correlation

between coping strategies and the ability to deal with the level of dementia. Women and elderly caregivers have a higher level of stress and increased burden (Iavarone & Ziello, 2014).

There are other factors that can contribute to the extent of the burden that is experienced by the caretakers including; education level and understanding of the disease process, socioeconomic status, demographics, and the level of the person's dementia behavior (Fenison, 2011). Interventions such as providing websites and phone numbers of resources that are available to families and caregivers is needed to accommodate the increasing numbers of caregivers (Gitlin, Corcoran, & Winter, 2001). Health professionals must be aware of available resources and provide the appropriate information to the families of people with dementia to assist with decreasing the burden of caregiving.

When appropriate resources are made available, the caregiver is supplied with options and education on how to deal with the dementia and where to find help. Some of the interventions that are currently available include; meals on wheels, day care, respite, visiting nurses, home health aides, support groups, telephone support and medication management (Messinger-Rapport & McCallum, 2006). Sometimes families will attempt to resolve dementia behavior problems on their own without success, this is when feelings of distress or failure occur. They may be reluctant to accept assistance or resource information, and interpret the offer of them as a failure to provide appropriate care to the patient. However, with the appropriate information, included in the toolkit, this assumption can be decreased.

Currently, the discharge instructions at the facility includes only: medications and follow-up physician visits. The discharge instructions are general and vague in terms of providing specific local resources and information for the caregiver. The nursing staff will now be able to provide the resource brochure to the families before discharge and provide them the resources and



strategies needed to assist them in coping with the challenges of their loved one's dementia-related behavior.

### **Review of Literature**

The literature search included Google scholar, Baystate online library, the University of Massachusetts online library, Medscape, Medline, Ovid, Cochrane, CINAHL, State of Massachusetts government website, as well as other individual websites from the Internet. The search terms included caregiver burden, dementia, caregiver support, and dementia interventions. The research articles included qualitative studies, meta-analysis, random controlled trials, professional opinions, literature reviews. Although some of the articles were older than five years they still applied to the subject and problems experienced of caregiver burden. The articles reviewed were strongly in support of the need for support and resource availability for caregivers

There are indications that the caregiver burden is dependent on the level of dementia and the level of capability of the caregiver, but with adequate resources and support the risk for depression and anxiety can be lessened. Family stressors come in many different forms; marriage, babies, unemployment, but dementia can place a long term stress on the family.

Dementia affects the cognitive function of the person which can create confusion and disorientation and also cause functional deficits. When progression of the dementia occurs there is a need to increase care and this creates a greater demand on the caregiver. There is the requirement to maintain medication regimens, meet nutritional needs, and maintain the safety of the family member. Dementia can also affect the physical abilities as well, they may become weaker and be unable to ambulate or get out of bed. There may be mood swings and their personality may become labile, or they may not be able to identify family members.

Many persons with dementia go undiagnosed for a long period of time as the disorder can be slow to progress and family does not see the changes until they are obvious or the person becomes aggressive, combative or ill (Lilly, 2012). Since dementia can be slow to progress the “if it ain’t broke-don’t fix it” can occur and the family just plods along with a decreased level of functioning. Other predictors of burden were impairment of activities of daily living, number of hours contributed to caregiving, coping abilities, spousal status, and gender of the caregiver (Kim & Chang, 2011).

Stress or imbalance causes distress in the family and a feeling of helplessness, without assistance this imbalance can break apart the family unit and the person with dementia receives inefficient care and may end up hospitalized. By recognizing the behaviors that the person with dementia is exhibiting and understanding what abilities they may have lost the caregiver can begin to understand the best and most appropriate way to handle the behavior (Snow, 2016).

When the caregiver begins to recognize the signs of worsening behavior or physical problems they can learn to develop new strategies to assist them in providing care. Having new strategies can assist to decrease the burden and create new problem solving abilities and coping skills. Some of the strategies include; approaching slowly to avoid startling the patient, holding hands, not trying to re-orient the patient when they say they are somewhere else, not to argue with them, and most important the caregiver must learn to accept that the dementia process is not going to improve.

### **Women as Primary Caregivers**

Women have frequently been the focus of studies on this topic as they were usually the primary caregiver to the family (Iavarone & Ziello, 2014). When caregivers do not have the

support or the knowledge of available resources there can be a delay in asking for assistance (Lilly, 2012). The caregivers are the hidden patients and supportive efforts must be directed to them before they suffer from stress related illnesses instead of treating them after (Quayhagen & Quayhagen, 1997; Lilly, 2012).

Persons that were born between 1946 and 1964 will make up more than a quarter of the population and will need more resources to care for them as they become older. Many of the caregivers are the spouses of the person with dementia and over the age of 50 themselves (Messinger-Rapport & McCallum, 2006). Caregiver burden can compromise physical, psychological, emotional, or functional health of the caregiver (Kim & Chang, 2011). These caregivers need assistance to avoid coping mechanism failure or negative health problems.

The World Health Organization (WHO) acknowledged that there must be caregiver support provided in an attempt to avoid negative mental health or physical health problems in caregivers (Blom & Zarit, 2015). The Center for Disease Control and Prevention (CDC) also recognized the need for caregiver support. Information from the CDC website explains that the majority of caregivers are family or friends, unpaid and probably had to decrease work hours or quit working to provide care (“Family caregiving,” 2011). The peer-based support groups can be more beneficial to the caregiver than the formal support groups as they allow the caregiver to vent negative feelings and can provide a more positive support as well as gaining ideas from others on how to deal with the everyday problems (Lauritzen, 2015).

### **Helpful Interventions**

Some of the recommendations included having telephone interviews with the caregiver at routine intervals, to determine the level of stress they were experiencing (Tremont & Davis,

2013). Using predetermined questions the researchers were able to obtain information on caregiver stress and whether the phone calls were helpful, and the data supported that conclusion that telephone contact was helpful to the caregiver.

Another recommendation was to have an occupational therapist come into the home to assist the caregiver and to assist with dementia education and environment alterations (Gitlin et al., 2001). It was implied to have a modest affect with the person with dementia, but did not assist the caregiver with self-efficacy. Other research options were to provide questionnaires to the caregiver; the Caregiver Burden inventory (CBI), the State-trait Anxiety stressful situations (CISS), Zarit Burden Interview (ZBI), and the Montgomery Borgatta caregiver burden scale (Iavarone & Ziello, 2014). These assist with determining the level of caregiver burden or stress that they may be experiencing and to guide providers as to which resources may be helpful. The two interviews that are now a part of evidence based practice are the Montgomery Borgatta caregiver burden scale and the Zarit caregiver burden interview (Iavarone & Ziello, 2014).

## **Summary**

The literature reviewed supported the concern that caregivers need more support and resources than are currently available to them. There are many families that have members with dementia and they are attempting to keep them at home for as long as possible. Caregivers must take care of themselves as much as their family members. When dementia related behaviors escalate, they must be willing to back off or set reasonable limits regarding the things that can be changed. The caregiver can control the environment and make changes accordingly, however, they cannot change the personality or the level of dementia that the person may be experiencing, and this is where a support group or resource can be of assistance (Snow, 2016).

Appropriate resources must be provided to the families of people with dementia to assist with decreasing the burden of caregiving. When appropriate resources are made available, the caregiver is supplied with options and education on how to deal with the dementia and where to find help. Having the strategies listed in the toolkit assists the staff to improve care outcomes and coping strategies, and this will be provided to the caregivers. The toolkit should provide an ongoing educational process for staff and sustainable solution for the caregivers. Caregiver burden is dependent on the level of dementia and the level of capability of the caregiver, and was worse when there were not interventions or resources provided. With adequate resources and support, the risk for depression and anxiety can be lessened (Fenison, 2011).

### **Theoretical Framework**

Theoretical concepts are used to guide practice changes and it allows physician, nurses, and other health care professionals to understand their practice and patients. Theories also assist in planning interventions for improved patient outcomes and to better understand their issues (Zaccagnini & Waud White, 2014, p. 360). By utilizing theory, health professionals can increase autonomy, accountability, improve professional standards and provide a higher quality of care.

Utilizing evidence-based practice improves the process of clinical decisions based on the best available research. The nursing theory system is designed to assess the problem, diagnosis the problem, plan interventions, implement the interventions, and then evaluate the interventions for success or failure. If necessary altering the interventions accordingly, re-evaluating again and again until the goal is reached.

Kurt Lewin's change theory was one of the first change theories in the field of psychology (Zaccagnini & Waud White, 2014). He developed the force field analysis, he theorized that all forces should be in balance, in other words the driving force must be stronger than the restraining

force for change to happen. There are three stages to Lewin's theory; unfreezing, movement, and re-freezing. Un-freezing is the act of letting go of old ways, this is in preparation for the change.

The second step is movement, in which education is provided to encourage a fresh look at the situation, and to prepare to move forward to new ideas. Re-freezing is the act of accepting the change and making it the new status (Zaccagnini & Waud White, 2014, p. 361). This serves to change behavior and reinforce them to become the normal. For example, the caregiver consistently attempts to give the family member medications whole, this is the way they have always taken them. The family member is refusing to take them, education is provided to the caregiver about alternative ways the medication can be given. The acceptance of the new concept is incorporated into the medication regimen and the family member is encouraged to take the medication. The caregiver has learned that the old way was ineffective (unfreezing), but the new way is effective (movement) and the medication is administered successfully (refreeze).

Change theory can be used for assisting in caregiver burden as the burden needs intervention in order for the caregiver to remain healthy and remain in balance with their environment (Zaccagnini & Waud White, 2014, p. 361). However as the dementia progresses this could prove to be impossible, and alternative means of care may be necessary beyond the personal caregiver.

The goal of this project has been to provide the appropriate information to caregivers of persons with dementia to make them aware of the resources and options that were available to them. Health care providers of the persons with dementia and staff members at this locally based Geri-psychiatric setting had been involved with the discussion and implementation process of the resource information using evidence based guidelines.

### **Methods**

This project started with a review of literature and an assessment of a local Geri-psychiatric unit, which is part of a larger network of hospitals in a medical system. Written pre-presentation survey questions were provided to the nursing staff requesting strategy information that could be given to the caregivers to help them with the person with dementia. They were also asked about the current discharge instructions and whether there should be anything added for the caregiver to better handle the dementia related behaviors. A toolkit was provided to the unit including handouts on local resources for patients and their families or caretakers.

A written post-presentation survey was done at the completion of each presentation of the toolkit and brochure review. This included: questions regarding if the nursing staff considered the brochure an adequate listing of computer resources and phone numbers, if the brochure would be helpful to the caregiver and if there was any missing information that could have been included. There was also a question on whether the presentation was informative to them.

The brochure, which is located in Appendix E, includes information needed by any of the persons admitted to the unit with a diagnosis of dementia and/or behavioral disturbances. The caregiver brochure was then provided to the caregiver prior to discharge from the unit.

### **Settings and Resources**

The location of the project was at a local branch of a large regional hospital, Geriatric-psychiatric unit, located in Massachusetts. This facility included an inpatient psychiatric unit specifically for geriatrics with dementia and Alzheimer's. The unit consists of 16 beds, one of which is an isolation room, so it is not utilized often, so census was usually 15 patients. "Group" occurs twice a day providing the patients distraction, update on the news, games, coloring, or

other activities to encourage interaction with each other. Interdisciplinary rounds occur at 9:30 AM every morning with nurses, occupational therapists, psychiatrist, nurse practitioner, and social workers to discuss behaviors that may have occurred over night, medication compliance, sleep behaviors, and eligibility for discharge.

### **Description of the group, population or community**

The population of the Geri-psychiatric unit was geriatrics over the age of 60 years. The patients resided mainly in the State of Massachusetts and came from multiple socioeconomic backgrounds. The patients are admitted there for behavioral disturbances and problems with worsening dementia, or confusion, as well as medication non-compliance. The Geri-psychiatric nurse practitioner, nursing staff, social workers, and occupational therapist were involved with the project. They assisted with identifying the patients that were admitted from home and what the behavior or psychiatric issue may be and to help evaluate what services were currently utilized by the caregiver. The patients with dementia from nursing homes or group homes were excluded from this project as they have structured locations to return to.

### **Organizational analysis of the project site.**

The unit consists of 16 beds, one of which is an isolation room, so it is not utilized often, so census is usually 15 patients. There are three registered nurses (RN) and two certified nursing assistants (CNA) per shift. The CNA's provide all the patient personal care, assist with eating/feeding, and ambulating. The RN's complete the medication regimens and treatments, with a psychiatric or nurse practitioner in attendance for psychiatric orders. Any medical issues that may arise was covered by the hospitalist on duty from the medical floor. There were also two occupational therapists and two social workers during the day that coordinate the activities



and discharge planning with the psychiatrist or nurse practitioner on duty. The toolkit was presented to the key stakeholder (nurse manager), nursing staff, and occupational therapists. The facilitators of this project were the occupational therapy staff, who were aware of this project and willing to assist with information gathering. They did not have the time to create a process or project that would increase the information given to the caregivers, or to even check with them to determine if there is a need. This need was usually discovered during the time of discharge, when the process was already finalized.

A barrier to the process was be the cost of the written information, however the large regional hospital system has a printing department that will be able to reproduce the brochure at a minimal cost. Although the nurses wanted to provide more information to the caregiver they felt this might create more work for them and they often did not have the time.

To overcome any geographical problems telephone numbers and websites of the following resources were included in the process; Home Watch Caregivers, Compassus Hospice, Quaboag on the Common, Alzheimer's Association, Elder care locator, Caregiver Support Northampton, Mercy Life, Colony care, PACE, Greater Springfield Senior Services, Tri-Valley, Franklin County Home Care, Caregiver Action Network, National Alliance for caregiving, Caregiver Magazine, AARP, Family caregiver alliance, Caring for aging parents, Caregiver information, US Department of Veterans Affairs, Soldiers Home, Holyoke, VA Central Western Massachusetts, Springfield Veterans Outreach Center and Veterans Homestead Inc. Phone numbers were provided for those caregivers that were not computer savvy, and websites were provided for those that are.

### **Goals, Objectives, and Expected Outcomes**

The goals and objectives of the DNP project were identified as:

1. Improve the knowledge of the caregiver support resource information for the nursing staff, utilization of a pre and post-presentation surveys to determine the level of increased knowledge by the end of the project, creation and implementation of an educational resource toolkit for the Geri-psychiatric nursing staff
2. To create an understandable and usable brochure for the caregiver
3. To create a hard copy of the toolkit for continuing use by the staff to give to the caregiver

During the process of the needs assessment, it was determined that an informational survey on dementia behavior strategies would be the most appropriate avenue for data gathering. Pre-project surveys were evaluated to determine the best strategy information to be provided to the caregivers.

An educational toolkit was created from the strategy information obtained from the initial surveys. Once this was collected a hard copy of the information was provided to the unit and nursing staff for review and use. A resource brochure was then created to give to the caregivers. The brochure contained websites, and phone numbers of associations that provide assistance as well as visiting nurses and other resources. Strategies suggested from the initial survey was also included in the brochure to assist the caregiver in understanding some of the different interventions that may be helpful when behavior problems occur.

### **Ethics and Human Subjects Protection**

The application to the UMASS IRB Human Subjects determination explaining the purpose of the toolkit and resource brochure was submitted and waiver of the project was received as a quality improvement project. A copy of the waiver is included in Appendix B. The target

population was the nursing staff of the Geri-psychiatric unit caring for the dementia patients and caregivers. There were no ethical issues for consideration. Health Insurance Portability and Accountability Act (HIPPA) is of utmost importance in this facility and all rules and regulations with confidentiality were maintained.

### Results

Of the eleven nurses that were presently employed (n=11), seven completed the initial pre-project strategy informational survey. This resulted in a 64% response rate, only one nurse responded no to the question regarding whether they understood why patients sundown. Listed on the table below is the survey response for strategies that would be helpful for the caregiver.

Table 1. Initial Survey of Nursing Staff on Dementia Knowledge

Knowledge/Strategies Dementia	Yes	No	Unanswered
Knowledge of sundowning	6	1	4
Re-orient or meet them where they are	6	1	4
Does staff know about PACE	6	1	4
Consistency/routines	7		4
Positive approach	7		4
Substitute not take away/distraction	6	1	4
Medication as a last resort	6	1	4
Current d/c instructions helpful	3	4	4

Of the eleven nurses currently working on this unit (n=11), nine attended the presentations and responded to the final survey resulting in an 82% response rate. The unit secretary and four of the nurses' aides attended, did not complete the survey. However, they provided verbal input regarding the knowledge needs of the families and the appropriateness of the resources in the

brochure including phone numbers and interventional strategies. They do interact with the families and found the brochure to be a helpful resource for the caregivers.

Table 2. Nurses Response to the Brochure on Dementia

Nurse's Response to Brochure	Yes	No	Unanswered
Presentation informative	9	0	2
Brochure helpful to caregiver	9	0	2
Brochure sustainable for future use	9	0	2
Missing information in brochure	1	9	1

The resource brochure was accepted by the nine nurses that attended, and had answered “yes” to the possibility of sustainability into the future. This same group agreed that the brochure was a fairly complete listing of resources regardless of geography. The two power-point presentations outlining the strategies that the initial survey identified were well received. Additional sessions could not be scheduled, and the nurse manager did not want to pay staff to attend separate sessions, so they were held at change of shift. While this was not ideal for gaining the best post-presentation data, it was the most convenient for the nursing staff. The strategies listed were also consistent with the ones currently used on the Geri-psychiatric unit. All nine respondents agreed that this brochure would be helpful to the caregiver, and that they would like to continue it into the future.

### **Discussion**

Despite the continuous planning that was done to get nursing involved with the process of obtaining caregiver strategy and resource information, there was resistance. There were eleven nurses that work on the Geri-psychiatric unit and only seven completed the pre-project initial survey. The survey was left on the unit for three and a half weeks, with many visits to the unit to remind them to complete it, there was only a 64% response rate. With each visit to the unit the

nurses expressed positive verbal response to the project, but did not feel they had the time to complete the questionnaire. Attending a staff meeting might have made the initial survey response go smoother.

The number of questions was kept to ten, with blank space for open-ended responses, but due to poor wording on two of the questions there was some confusion. The strategy information obtained was parallel to what the staff were placing in the dementia care plans. This provided many strategies that could be listed in the brochure such as; keeping a positive approach with validating the person's feelings or behavior, maintaining routines and being consistent, keeping appointments in the morning when offices are quieter and less stressful, to avoid loud situations and music, play music from their era, and to allow them to be wherever they are in time-not to try to re-orient them to the present. Data gathered for the phone numbers and websites was obtained from the Internet and occupational therapists.

### **Conclusion**

Our population is living longer and many wish to stay at home for as long as possible. Where once the older adult was the parent with children, now the children are the caregivers of the parents. Dementia is increasing with the elderly population and they require additional care as the disease progresses. This is a neuropsychiatric disability that affects cognition as well as physical attributes. Persons with dementia can be very challenging as their thought processes change and their behaviors with it. If the caregiver does not understand the disease process or the strategies to deal with it, they will experience increased stress and burden.

Caregivers frequently neglect their own health and mental well-being to care for the family member. This leads to depression, anxiety, and worsening health conditions. There have been many evidence based studies done regarding caregiver burden. The caregiver is the hidden

patient; nurses and physicians are in an ideal position to address this problem and assist with providing resources to them. The problem of caregiver burden is well known and written about, the purpose of this project was to provide the caregiver with a listing of resources that would be available to them.

By utilizing Lewin's change theory nurses can attempt to unfreeze the caregiver stress, by providing them the appropriate information. The hope is to have the caregiver decrease their stress level by realizing that there are resources available to them. When the caregiver is given appropriate information then the feeling of "being alone" decrease and they can realize that there is assistance for them.

Future recommendations would include nurses going out to the community with this information to help families that may be suffering in silence. So many families are dealing with these issues on their own. More attention needs to be paid to the caregivers and family members to see how their loved one's dementia is affecting them. More resources need to be made available to these families that take care of their loved ones at home. It is one thing to assess their stress, but it is more important to relieve it.

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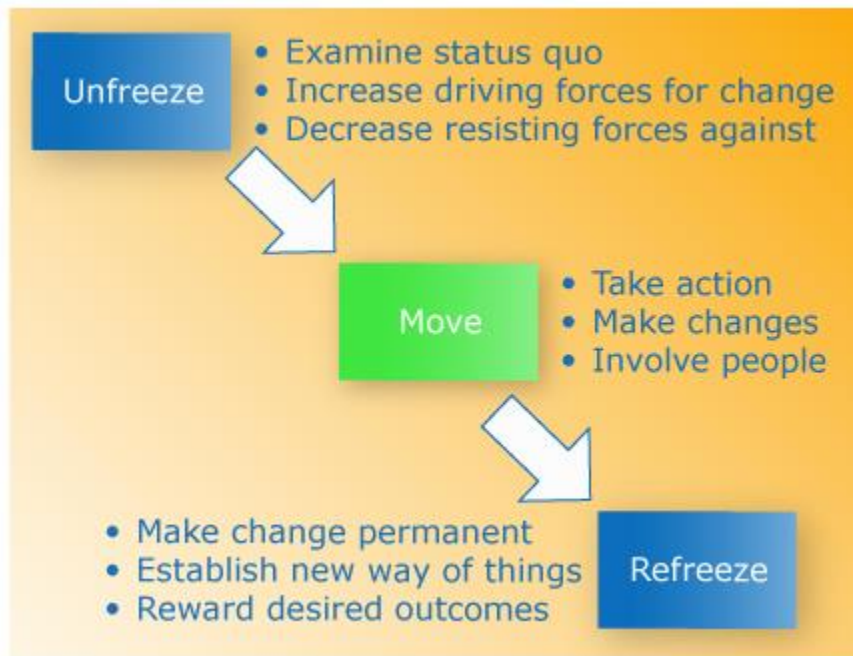
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Takai, M., & Takahashi, M. (2009). The experience of burnout among home caregivers of patients with dementia: relations to depression and quality of life. *Archives of Gerontology and Geriatrics*, *49*, e1-e5. doi 10.1016/j.archger.2008.07.002

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**Appendix A**

# EBP Process

## Practice Question, Evidence, Translation (PET)



Newhouse, R.P., Dearholt, S., Poe, S., Pugh, L.C., White, K (2005) Evidence Based Practice: A Practical Approach to Implementation, Journal of Nursing Administration, 35(1), 35-40.

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(Newhouse et al., 2005)(“JHNEBP,” 2015)

**Appendix B**

University of Massachusetts Amherst      Human Research Protection Office 108 Research  
Administration Building                      Research Affairs                      70 Butterfield  
Terrace    Amherst, MA 01003-9242

Telephone: 545-3428 FAX: 577-1728

**MEMORANDUM**

To:    Lea Grippin, College of Nursing From:    Human Research Protection Office    Date:  
July 28, 2016

Project Title: An Integrative Review with Presentation of an Educational and Resource Toolkit  
for Health Care Personnel and Caregivers of Persons with Dementia

IRB Number: 16-77

The Human Research Protection Office (HRPO) has evaluated the above named project and has  
made the following determination:

The activity does not involve research that obtains information about living individuals.

The activity does not involve intervention or interaction with individuals OR does not use  
identifiable private information.

The activity is not considered research under the human subject regulations. (Research is  
defined as “a systematic investigation designed to develop or contribute to generalizable  
knowledge.)

The activity is determined to meet the definition of human subject research under federal  
regulations and requires submission of applicable materials for IRB review.

For activities requiring review, please see our web pages for more on types of review or  
submitting a new protocol. For assistance do not hesitate to contact the Human Research  
Protection Office at 545-3428 for assistance

**Appendix D**Capstone proposal 1<sup>st</sup> survey questions

1. Do you know why patients sundown?

Yes            No

2. What information would you want to give to the caregiver?

3. What is currently lacking in the discharge instructions for the caregiver?

4. Is there any information you feel would assist the caregiver?

5. How can the caregiver handle the person with dementia if they get behavioral?

6. Should the caregiver meet the dementia person in their own world or always try to reorient

them?            Yes                            No

7. How do you redirect the person when they are stuck in a worry zone?

8. How does the caregiver assist them to cope with the person not knowing who they are?

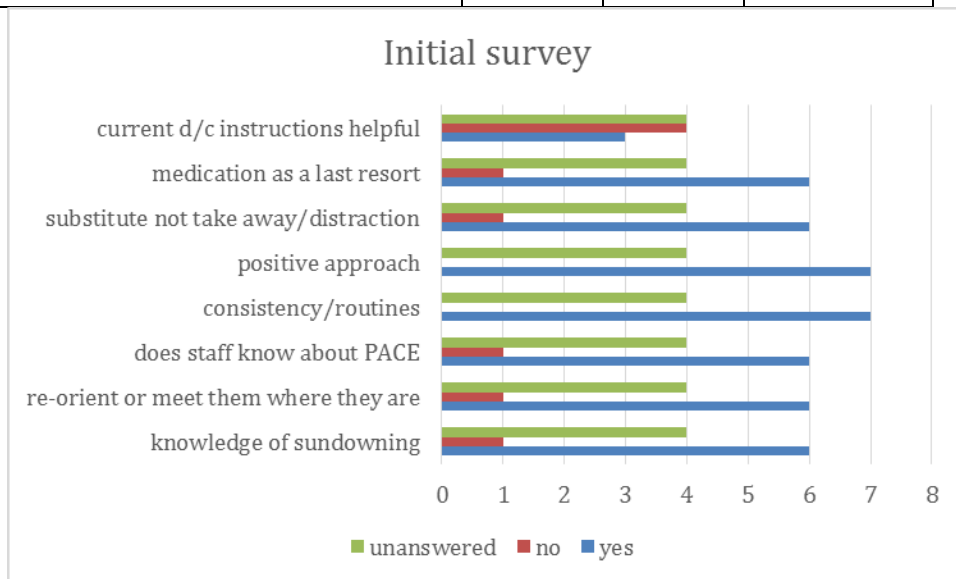
9. What would you suggest to the caregiver if they consistently say “no” or “try to remember”

to the person?

10. Do you know what the PACE program is?    Yes                            No

Table 1. Initial Survey of Nursing Staff on Dementia

Knowledge/Strategies Dementia	Yes	No	Unanswered
Knowledge of sundowning	6	1	4
Re-orient or meet them where they are	6	1	4
Does staff know about PACE	6	1	4
Consistency/routines	7		4
Positive approach	7		4
Substitute not take away/distraction	6	1	4
Medication as a last resort	6	1	4
Current d/c instructions helpful	3	4	4



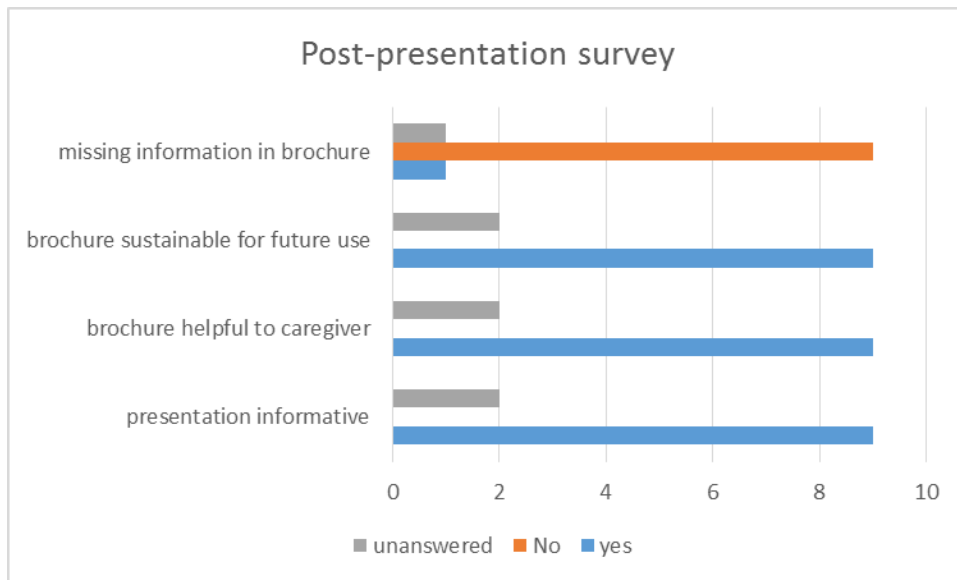
**Appendix D**Capstone proposal final survey questions

1. Do you feel the resource packet for the caregiver will be helpful?  
Yes                      No
2. Did you find the in-service on the toolkit packet helpful?  
Yes                      No
3. Did you feel the length of time for the in-service was appropriate?  
Yes                      No
4. Was the information in the tool kit easy to understand?  
Yes                      No
5. Do you think the information provided on the caregiver pamphlet is clear and concise?  
Yes                      No
6. What other information do you feel could be provided that might have not been provided?
7. Will you be willing to provide this resource pamphlet to the caregiver at time of discharge?  
Yes                      No

Table 2. Nurses Response to the Brochure on Dementia

Nurses Response to Brochure	Yes	No	Unanswered
Presentation informative	9	0	2
Brochure helpful to caregiver	9	0	2
Brochure sustainable for future use	9	0	2
Missing information in brochure	1	9	1

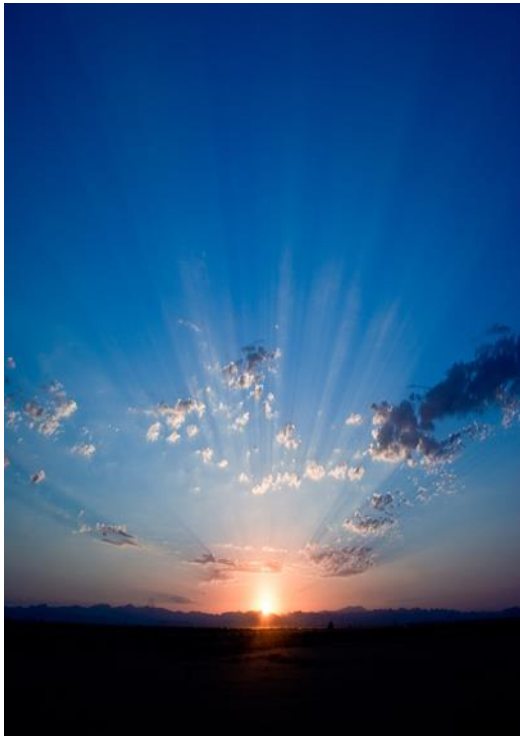
Post-presentation survey





## Appendix E

### Resource Guide for Caregivers of persons with Dementia



#### Dementia care strategies-

Maintain routines

Avoid loud and over stimulating situations

Do not argue or reorient them, follow them where they are in time

Use music from their era to distract and calm them

Use names instead of designations like “your grandson”

Stay in their frontal vision, not from the side

Distract or substitute, do not take away

Offer soft items to hold

Allow them as much responsibility in their care as possible for them

Do not talk about them as if they are not here

Acknowledge their frustration and feelings

***Do not give up-do not be shy***

Look at services in stages-one at a time

Educate yourself about the dementia process

Acknowledge your limitations

Do not blame yourself if gets to be too overwhelming

Seek help when needed

Keep in touch with friends

Get involved in a support group

---

**Websites/Phone Numbers**

Home Watch Caregivers-[www.hwcg.com](http://www.hwcg.com), 413-774-3178

Compassus Hospice-[compassushealthcare.com](http://compassushealthcare.com), 508-845-9670

Quaboag on the Common-[www.quaboagonthecommon.com](http://www.quaboagonthecommon.com), 508-867-7716

Alzheimer's Association-[www.alz.org](http://www.alz.org), 800-272-3900 hotline

Elder care locator, [www.eldercare.gov](http://www.eldercare.gov), 800-677-1116

Caregiver Support Northampton-[www.smith.edu](http://www.smith.edu), 413-582-2722

Mercy Life-MyMercyLife.com, 413-748-7223

Colony Care-[www.colonycareathome.com](http://www.colonycareathome.com), 413-455-1122

PACE- 888-885-0484

Greater Springfield Senior Services-413-781-8800, [www.gsssi.org](http://www.gsssi.org)

Tri-Valley, Inc. 800-286-6640, 508-949-6640

Franklin County Home Care 413-773-5555

Stavros Center 413-256-0473

US Dept. of Veterans Affairs, 855-260-3274

Caregiver Action Network, [www.caregiveraction.org](http://www.caregiveraction.org)

National Alliance for caregiving, [www.caregiving.org](http://www.caregiving.org)

Caregiver Magazine, [www.caregiver.com](http://www.caregiver.com)

AARP, [www.aarp.org/families/caregiving](http://www.aarp.org/families/caregiving)

Family caregiver alliance, [www.caregiver.org](http://www.caregiver.org)

Caring for aging parents, [www.agingcare.com](http://www.agingcare.com)

Caregiver information, [www.aplaceformom.com](http://www.aplaceformom.com)

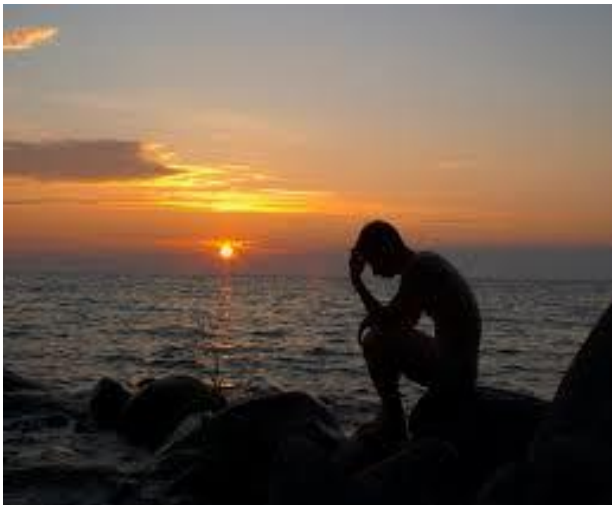
Veterans

Soldiers Home Holyoke Ma, 413-532-9475

VA Central Western Mass, 413-584-4040  
[www.centralwesternmass.va.gov](http://www.centralwesternmass.va.gov)

Springfield Veterans Outreach Center  
413-301-8739  
413-737-5167

Veteran Homestead Inc.  
978-353-0234



You are not alone-  
There is always help-  
There is always hope-