Improving Caregivers’ Perceived Involvement in Care Through Facilitating Communication with Hospital Providers

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Improving Caregivers’ Perceived Involvement in Care Through Facilitating Communication with Hospital Providers

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This Manuscript Partially Fulfills the Requirements for the Doctor of Nursing Practice Program and is Approved by:

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Abstract

Practice Problem: Involvement of family in care-planning for prevention of delirium in acute care settings is crucial, yet remains underutilized in those who are cognitively impaired. Despite the incidence of delirium in acute care worsening during COVID-19, many factors have led to it being placed on the back burner.

PICOT: In caregivers of cognitively impaired individuals, can implementation of an evidence-based, best practice tool that advocates for evidence-based delirium prevention strategies tailored to their loved-one and facilitates family involvement in care planning for these strategies during a healthcare experience as compared to no other intervention improve confidence in, and involvement in, care-planning within 2 months?

Evidence: Overwhelming evidence exists supporting the effectiveness of a non-pharmacological, multicomponent strategy for prevention of delirium in the healthcare setting, to include family involvement.

Intervention: To support family involvement in delirium prevention should a hospitalization occur, the American Geriatrics Society CoCare: Help Program Delirium Prevention Amidst COVID-19 Toolkit was offered to caregivers at an organization that provides support services to families living with Alzheimer’s.

Outcome: There was a statistically significant improvement in caregivers’ perceptions of, and confidence in, involvement in care after having received the Toolkit, as measured by 3 pre/post survey M-PICS/I-PICS questions (n=27, p=.010; p=.017; p=.35). Caregiver intent to use the toolkit to become more involved in care to prevent delirium in acute care situations was very
often to always (76%). Anecdotal feedback suggested that hospitals should look at policies and practices that ensure patients and families feel free to advocate, and work to eliminate fear of repercussion.

**Conclusion:** In the age of COVID-19, it is vital that more of these such efforts by healthcare professionals ensue to protect this population from a worsening crisis, despite the many challenges they themselves face.

**Keywords:** delirium, delirium prevention strategies, delirium detection, Alzheimer’s, dementia, caregivers.

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Improving Caregivers’ Perceived Involvement in Care Through Facilitating Communication with Hospital Providers

The COVID-19 pandemic of 2020 revealed a serious issue concerning the vulnerabilities of cognitively-impaired individuals. When this population experiences illness or injury, or becomes hospitalized, delirium is a real risk and often translates to poor outcomes. In a healthcare experience, this condition remains undetected and untreated up to 81% of the time. (Scott & Mayo, 2018). The evidence is overwhelming that involvement of family in care-planning for prevention of delirium is crucial, yet it remains underutilized (Thomas et al., 2014; Martinez et al., 2017). Additionally, due to the COVID-19 pandemic, caregivers are subject to hospitals’ limitations on visitors, making presence and communication a challenge furthering the lack of involvement of family in care-planning. With this in mind, the importance of good communication with hospital providers and family involvement and in care-planning for delirium prevention strategies is very important. The purpose of this project is to implement an evidence-based tool that improves the caregiver’s involvement in coordinated care with the hospital provider.

Significance of the Practice Problem

Neurocognitive disorders, the most common of which is Alzheimer’s disease (AD), affect at least 50 million people across the world (Gilbert, 2019). At least 5.7 million Americans in the United States live with the condition and, by 2050, that number is projected to double (Gilbert, 2019). The cost in caring for these patients is over $232 billion some of which falls on caregivers, adding to negative mental health outcomes (“2018 Alzheimer's Disease Facts and Figures,” 2018). In Florida, where this project will take place, there are over 580,000 individuals with AD who are cared for by over 1 million caregivers (Gilbert, 2019). Delirium is a common
complication among this population when they fall ill, experience increased stress, routine
complications, or are given certain medications, to name a few risk factors (Johansson et al., 2018;
Grover & Avasthi, 2018; Goodman, 2015).

Up to 40% of the cases of delirium are preventable, and early detection and prevention is
crucial (Goodman, 2015). Overall, the key symptoms include alterations in sleep-wake cycles,
delusions and hallucinations, hyper/hypoactivity, out of the ordinary behavior, and alterations in
emotional behaviors (Inouye et al., 2014). With this in mind, obtaining an accurate and updated
history from family or caregivers to gain a baseline cognitive status to help differentiate
dementia from acute delirium and begin early detection is important (De & Wand, 2015; Inouye
et al., 2014; Thomas et al., 2014; Young et al., 2012).

This is worthy of attention because when a person develops delirium there are significant
consequences to the patient, as well as significant caregiver distress (Johansson et al., 2018;
Grover & Avasthi, 2018). One of the greatest of these consequences is their increased risk of
falls (Pendelbury et al., 2015; Johansson et al., 2018). Delirium increases a patient’s risk of
falling substantially and has significant impacts on mortality, morbidity, and quality of life
(Doherty et al., 2014; Johansson et al., 2018). The rate of hip fractures secondary to delirium-
related falls is up to 70% and, more than any other injury, has a mortality rate for this population
of 36% (Mosk et al., 2017).

Additionally, from a financial perspective, falls are deemed a “never event” so the cost,
up to $30 billion a year, extends to the facility rather than Medicare (ARHQ, 2020; Felhberg et
al., 2017). Outside of the impact of falls, delirium alone costs society and the system $143 billion
annually and increases the patient’s hospital stay by at least 12 days (Goodman, 2015).

Prevention, early screening for an individual’s behavior indicative of delirium, and early
identification of individual risk factors is crucial to improving outcomes (Mosk et al., 2017; Goodman, 2015; Johansson et al., 2018).

A lack of standard screening for cognitive impairment has resulted in undetected and untreated delirium up to 81% of the time (Scott & Mayo, 2018). Additionally, although copious amounts of evidence exists supporting its efficacy, there is currently a significant disparity in consistent strategies to prevent delirium, including involvement of family. Involvement of family in care-planning for prevention of delirium is crucial yet remains underutilized (Thomas et al., 2014; Martinez et al., 2017). As it relates to the prevention of delirium in the healthcare setting, there is a wealth of evidence supporting a non-pharmacological, multicomponent strategy that is infrequently enough implemented for this population (Hsheih et al., 2015; Ludolph et al., 2020). Family and caregiver involvement are vital to this process (Hsheih et al., 2015; Ludolph et al., 2020; Young et al., 2012; Oberai et al., 2018; Abraha et al., 2015; Martinez et al., 2017; De & Wand, 2015; Thomas et al, 2014). Despite its incidence worsening in the age of COVID, dwindling resources and staffing shortages have put delirium prevention on the back burner prompting more healthcare professionals to work together to implement delirium prevention strategies which include family involvement (LaHue et al., 2020).

**PICOT Question**

This project sought to answer the PICOT question: (P) In caregivers of cognitively impaired individuals, (I) can implementation of an evidence-based, best practice tool that advocates for evidence-based delirium prevention strategies tailored to their loved-one and facilitates family involvement in care planning for these strategies during a healthcare experience (C) as compared to no other intervention (O) improve confidence in, and involvement in, care-planning (T) within 2 months?
Evidence-Based Practice Change Framework & Change Theory

Decisions to implement a change project should always be guided by evidence and sound theory or frameworks (Cody, 2006). The goal of this project was to develop a sustainable and effective change in practice. It is for this reason that this project was guided by Havelock’s Change Model. Havelock motivates the change agent to focus on six things that will poise the intervention to be a sustained one. These are caring about the need, building appropriate relationships, diagnosing the problem and collaborating for a solution, disseminate the solution and monitor for continued sustainability and efficacy (White, K. et al., 2020). The organization’s mission and vision and shared passion from this author drives the desire for change, the evidence guides the solution (involving the family in care-planning to prevent delirium), and the project’s efforts to follow-up with caregivers after hospitalization to sustain the intervention and monitor efficacy, meld with this theory. The intervention will begin to be put into practice immediately with all existing and new caregivers. Evidence-Based Practice Change Framework utilized for this project is the John Hopkins Nursing Evidence-Based Practice Model and is outlined in greater depth later in this paper.

Evidence Search Strategy

In an attempt to gather unbiased evidence, a systematic review of literature was performed using the keyword “delirium diagnosis”. The search was limited to only peer-reviewed articles written in English between 2011 and 2020, and to maximize results additional limitations were established for highest quality articles. The following databases’ limiters were utilized: Pro-Quest allowed for a search limited to articles and literature reviews; CINAHL Complete offered a filter which was utilized to focus on articles in the subject areas of dementia, risk assessment, patient safety, outcomes, and nursing assessment; and Pub-Med offered a limiter
of top tier meta-analyses and systematic reviews. Excluded from the list were studies on children. Inclusion criteria were articles addressing patients in or out of the hospital (attention primarily to non-intensive care unit [ICU] patients, but included some in ICU), those with or without dementia, Confusion Assessment Method (CAM), prevention methods, and screening tools. To avoid bias, the search strategy did not limit results to only full-text articles. Quick internet searches using Google and Google Scholar were also utilized.

**Evidence Search Results and Evaluation**

The results of using the above search strategy revealed an abundant full-body of literature. Pro-Quest offered 844 articles, CINAHL Complete resulted in 1,070, and Pub-Med revealed 176 articles. This totaled 2,090 relevant pieces of literature. Also included were articles from quick internet searches using Google and Google Scholar. For the purposes of this evidence-based practice (EBP) proposal, nine articles were chosen that evaluated the effects of non-pharmacological, multicomponent delirium prevention strategy (see figure 1). Although two studies on ICU patients were selected since this population may likely need to seek services of a critical care unit, most articles chosen were studies in non-ICU hospitalized patients at risk for delirium. The widely used Strength of Recommendation Taxonomy (SORT) tool for grading evidence was used to determine quality of the literature (Ebell et al., 2004). Of the studies: eight were given a high-quality grade of SORT 1, seven of the works are Level 1 systematic reviews (SR) and/or meta-analyses (MA) of high-quality studies; one study was given a SORT 1 and Level III but was a well-designed study across multiple ICU’s within a hospital chain that had previously validated studies of its kind; and one Level IV, SORT 2 study was chosen as, although only a survey, it highlighted the need for further education related to delirium detection assessments, namely the CAM (see Appendix A). A final study, a 10th study, was found by
Jonsdottir et al. (2013) adequately validating the Modified Patients Perceived Involvement in Care Scale (M-PICS/I-PICS), a tool which will be utilized in the pre/post-survey as a measurement tool, as the questions on patient involvement are in line with project goals.

**Themes from the Evidence**

An abundance of evidence supporting the effectiveness of multicomponent non-pharmacological strategies to prevent delirium in hospitalized patients both in and out of the ICU, can be found. Multi-component non-pharmacological strategies address risk factors associated with delirium and are aimed at prevention; a number of studies suggest this approach is effective (Oberai et al., 2018). While the strategies included may differ slightly, overall, they all include the same minimum criteria: staff education, little to no use of delirium-inducing medications, early mobilization, early detection, bowel and bladder regimen, sensory enhancement (use of glasses and hearing aids), assistance with meals, frequent orientation, and family involvement (Siddiqi et al., 2016). The common theme is that, despite profound evidence, these delirium-prevention strategies are not consistently put in place, including involvement of family in care-planning. This project seeks to implement a new policy at adult day centers wherein the Family Nurse Counselors (FNCs) will embed into practice the utilization an evidence-based tool that improves the caregiver’s involvement in coordinated care with the hospital provider and their family member.

**Effectiveness of Delirium Prevention Strategies**

Six of the nine pieces of evidence (Level 1 SORT 1) were done on non-ICU older hospitalized individuals (see Appendix A). One meta-analyses of 39 randomized control trials (RCT’s), along with another systematic review of 31 primary studies, showed moderate evidence supporting the use of multicomponent non-pharmacological interventions, including family
involvement in care-planning, as compared to usual care (Abraha et al., 2015; Siddiqi et al., 2016). The other four were meta-analyses or systematic reviews looking at a total of 41 primary studies, all showing strong evidence confirming the effectiveness of multi-component non-pharmacological interventions to include family involvement in care-planning, as compared to usual care, in reducing the incidence of delirium (Oberai et al., 2018; Thomas et al., 2014; Hseish et al., 2015; Ludolph et al., 2020). There was an abundance of evidence supporting these interventions in ICU patients as well. One (Level IV SORT 1) was chosen as it was done across several ICUs in one facility. Martinez et al. (2017) agreed with other studies showing significant reduction in delirium when implementing multi-component non-pharmacological interventions, again to include family involvement in care-planning (Martinez et al., 2017). Overall, a significant amount of evidence exists supporting this strategy over usual care.

**Early Detection of Delirium**

A second theme, as mentioned, is the importance of early detection of delirium. One well-validated and frequently adopted delirium assessment method is the CAM. The aforementioned studies used CAM as part of the interventions. This is likely due to the abundance of evidence speaking to the efficacy of this assessment. One study was chosen as it was a systematic review (SORT 1, Level 1) of 39 primary high-quality studies performing a comparison of several delirium assessments. The outcome agreed with other studies showing that the CAM has a 95% sensitivity to delirium, higher when compared to other assessment methods (De & Wand, 2015). This validates their use of CAM for delirium detection, as drives home the need for delirium detection methods. One notable survey of 147 providers (Level IV, SORT 2), found most participants had never used or heard of the CAM, but agreed delirium diagnosis is often delayed due to not knowing patients' baseline cognitive status and misinterpreting delirium
for dementia. Young et al. (2012) study is useful in validating why inclusion of family is valuable in detecting and preventing delirium.

**Importance of Family Involvement**

A final theme, and the basis of this project, is the importance of involving the family caregivers in the care planning for these patients. The importance of involving the family in care planning for delirium prevention strategies, act as valuable members of the healthcare team, work with hospital staff to communicate vital information about their loved one, and being present when appropriate for their loved one while in the hospital, cannot be overstated (Martinez et al., 2017; Hsheih et al., 2015; Ludolph et al., 2020; Oberai et al., 2018; Siddiqi et al., 2016; Thomas et al., 2014; Abraha et al., 2015). This recurring theme, along with the others as stated above, provide the strong evidence to support this practice change.

**Practice Recommendations**

There are significant amounts of high-quality evidence supporting the efficacy of delirium prevention strategies in hospitalized patients. Specifically, these include a multi-component nonpharmacological group of interventions: assistance with meals, ensuring hearing aids and glasses are in use, toileting schedules, minimal use of delirium-inducing medications, early ambulation, early delirium detection, frequent orientation, and family involvement in care planning (see Appendix A). The practice recommendation of this project was to implement a family-support best-practice tool within an organization that provides services and resources to caregivers of patients living with Alzheimer’s and related disorders. This family support tool included these best-practices for delirium prevention in acute care settings. Prior to the project, caregiver resources were only given at their expressed need and after an initial needs assessment. However, since every family would be eligible for and benefit from the intervention, the resource
would now be offered to 100% of new caregivers and existing caregivers. This involved creating a new workflow for the organizations FNCs. The project manager created a new standardized, sustainable workflow wherein the FNCs would embed into practice offering the tool to all caregivers at the time of acceptance into the organization, during their routine Annual Caregiver Reviews, and during support groups (see Appendix B). Additionally, the FNCs would now anticipate caregivers reaching out in the event of a hospitalization, should the caregiver desire, in order to assist them in implementing the tool. This tool will improve the caregivers’ ability to be an effective member of the hospital care-planning team during their loved one’s hospitalization by implementing a delirium-prevention care plan that is specific for that patient.

**Project Setting**

The location where this EBP project occurred is a non-profit organization that provides community-based services in Florida (almost 2 million residents in 2019). Their clients are patients and families (caregivers) living with dementia, Alzheimer’s disease, and related disorders within those counties. Its mission surrounds advocating for the health and well-being of community members living with Alzheimer's through care that is community-based and family-centered. In 1996, with a shared vision to advocate for patients and their families, a group of Florida residents started the organization with the intent to assure all funds go to assisting these families, working together with them to provide a safety net for these they serve. Services provided include 11 adult day centers specializing in Alzheimer’s care, FNCs, Identification (ID) locater services, professional and community education, case management, 24-hour crisis line, and advocacy and community outreach through law enforcement and legislators to promote change.
Organizational Support

Organizational support for the project was obtained by the vice president (VP) of the organization (see Appendix C). The project manager performed a Strengths, Weaknesses, Opportunities, and Threats analysis, commonly referred to as SWOT, to determine the interplay between the setting and the project; strengths include the organizations’ history of success in advocating for change and support for others seeking to work through them to achieve better outcomes; weaknesses, while minimal, may only lie in funding, as it comes primarily from donations rather than the broader financial resources that may be more inherent in a for-profit organization; opportunities are plentiful due to the consistent research and evidence-based practice changes the organizations engages in; and threats likely lie in COVID-19 impacting utilization of services by patients and families and changes in planned projects.

Project Overview

The purpose of this project was to embed a standardized practice with the FNCs to begin to implement, with all caregivers, the Delirium Prevention Amidst Covid-19 Toolkit (AGS Toolkit) as developed by The American Geriatrics Society (AGS) CoCare: Help Program (American Geriatric Society CoCare: HELP Program [AGS], 2020). The American Geriatric Society (formally known as the Hospital Elder Life Program) is an organization with a delirium-prevention program that is based-solely on evidence, has been well studied, and has been proven effective in controlled trials (AGS, 2019). Their website includes a list of all such relevant articles (AGS, 2019). They have recently adapted their widely-used Delirium Prevention Toolkit to further assist hospitals and families in integrating delirium prevention strategies into care when the patient is on isolation, such as for COVID-19, and have limitations on visitors.
Permission to use the toolkit was acquired by the AGS for the purpose of this project (see Appendix D).

The AGS Toolkit (see Appendix E) is a tool that facilitates caregivers and hospital staff in incorporating evidence-based delirium-prevention strategies into care of older adults (AGS 2020). These strategies include: staff education, patient and family education, early mobilization, a bowel and bladder regimen, sensory enhancement (use of glasses and hearing aids), assistance with meals, frequent and appropriate orientation, and family involvement (see Appendix E). It allows for the caregivers to interact with the staff at a hospital to collaboratively implement these evidence-based delirium prevention strategies. Importantly, it encourages and facilitates family involvement which was the ultimate goal of this project, as family involvement has been proven to significantly impact efforts to prevent delirium in hospitalized patients, as described earlier.

Prior to the project, resources were only given to the caregiver at their expressed need and after an initial needs assessment. However, since every family would be eligible for and benefit from the intervention, the practice recommendation was to implement the AGS toolkit with 100% of new caregivers during admission and existing caregivers during support groups and annual reviews. The new workflow was implemented by adding the toolkit as an addendum to the new caregiver’s acceptance paperwork packet, adding it to the agenda template for the support groups, and adding it to the paperwork packet reviewed between the FNC and caregiver at the Annual Caregiver Review. Embedding the intervention into several processes sought to ensure sustainability long after completion of the project and ensure all current and new caregivers receive the tool.

The FNCs were also to begin providing assistance with completing the document during admission, during the annual review, and at support groups. As part of the toolkit, the caregiver
can contact the FNC should they desire in the event of a known hospitalization to have assistance in the use of the AGS Toolkit, with the goal of involving them in care planning for delirium prevention strategies. Potential risks and unintended consequences were minimal but included the FNCs’ need for re-education on the toolkit as well as challenges getting the toolkit to caregivers if COVID-19 necessitated virtual interactions.

**Methods**

**Framework**

The John Hopkins Nursing Evidence-Based Practice (EBP) Model guided the approach to this practice change, as it allows for rapid adoption of EBP projects by using three simple steps: inquiry, finding the evidence for best practice, and translating that to practice improvements (Dang & Dearholt, 2017). During the *Inquiry* step, initial interviews with the organization as well as a great deal of research on delirium, its adverse effects, and gaps in current practice were clear, as was the evidence supporting the need for a standard approach to involvement of family in delirium prevention. From there, internal and external factors were assessed as described earlier, to include the organization, the community, and the participants. It was thus noted that a practice change could be adopted to bridge this gap and a plan for the approach to the evidence-based practice change was developed. The *Evidence for Best Practice* phase led to attainment of the AGS Toolkit, as it mirrors the overwhelming evidence for family involvement in care-planning and evidence-based delirium prevention strategies in the hospital. Then the AGS Toolkit was *Translated into Practice Improvement* by creating a practice change with staff at the facility that includes implementing it with existing and new caregivers, assisting them in completing it and anticipating the caregiver contacting them, should they desire, to facilitate its use during a hospitalization.
Participant Inclusion

Caregivers

Inclusion criteria for participation was any caregiver receiving services with the organization. At the time, due to limited services for translation of the AGS Toolkit and interpreters, anyone who did not read, write, or speak English were excluded. However, in the future, it is the hope that the facility will be able to accommodate multiple languages post project.

Family Nurse Counselors

Three FNCs were chosen by the organization’s VP to participate because their centers have the largest number of families served. There is one FNC per day center, each oversees their own support group and adult day center. Each day center holds support groups on the 1st and 3rd weeks of each month (two meetings each month for each center). The project manager attended those meetings for one month at three different day centers. These support groups are hosted by the FNCs, and it is at these six support groups that the initial roll out of the intervention occurred.

Procedures

Intervention with Family Nurse Counselors

The Evidence-Based Project Review Committee (EPRC) approval was obtained prior to project implementation (see Appendix F). The project manager began promptly, and concluded the project in the first week of January. Immediately upon EPRC approval, the Director of the FNCs and the organization’s VP notified the FNCs involved as to the specifics of the project (see Appendix F). The VP and the director also sent an email to those FNCs containing attachments that included the new addendum to the admission packet (the AGS toolkit), the new agenda template for the support groups (which now included the AGS toolkit), and the updated annual
review packet (which now included the AGS toolkit as an addendum). In the week following approval the project manager met briefly with the three FNCs to ensure they understood the project and to answer any questions. The goal was to ensure they were competent with the concept of delirium prevention in acute care, the AGS Toolkit, and how and when to implement it. The project manager also reiterated that, once implemented, the FNCs should encourage and anticipate the caregivers’ desire to contact them in the event of a hospitalization to facilitate use of the toolkit. The FNCs were also asked to anticipate weekly phone calls from the project manager to address any issues arising with use of the toolkit when and if a new caregiver was accepted into the organization.

To ensure the FNCs began using the new items immediately, the project manager ensured the FNCs had replaced their digital copy of the old packets with the new ones containing the AGS Toolkit as an addendum. To remove additional workload, the project manager offered to personally attach the new items to any printed packets in use. All of these actions by the project manager ensured sustainability long after completion of the project.

*Intervention with Caregivers*

During the week that the project manager met with the FNCs, an email describing the topic of the support group session (introduction to the toolkit) was sent by the project manager to the VP to deliver to all caregivers who used email (see Appendix G). The project manager also sent the VP, to forward to caregivers, a second email to serve as a reminder the day before, a third on the morning of the meeting, and a final email directly after the meeting as a thank you (see Appendix G).

At the support groups, consent by the caregivers was obtained before the meeting began. It was also communicated clearly that there was no penalty for not participating and that they
could opt out at any time. The project manager made clear to the caregivers that they were welcome to stay for the entirety of the session regardless of participation. The first five minutes of the session was set aside to allow caregivers to take the pre-survey, if they desired, which included questions that asked the caregiver to evaluate their current perceived involvement in decision making during a hospitalization.

In the following 20 minutes of the session, the project manager co-demonstrated with the FNC how to implement the AGS Toolkit with caregivers. The project manager ensured that the FNC knew how they would be implementing the toolkit at support group meetings, during annual reviews, and at the time of the caregivers’ acceptance into the organization moving forward. Together, the project manager and the FNC oriented the caregivers to the toolkit, offered instructions on how to complete it, discussed its importance, and described how it would be used to facilitate coordination of care between they and hospital staff to implement evidence-based delirium prevention strategies. During the support groups, the FNC was made aware that the caregiver should be instructed to reach out to the FNC in the event of a hospitalization, should they require assistance in utilizing the toolkit with hospital staff.

The last five minutes was set aside for caregivers to take the post-survey should they desire, which asked the caregivers to rate their confidence in being involved in care-planning now that they had the AGS Toolkit, as well as if they planned to use it. The caregiver was also asked to anticipate a short 30-day follow-up survey in the mail. The number of caregiver participants per support group varied but totaled 27 across all centers. A table with all tests performed on the data collected can be found in Appendix L.
Measures

The goal of the survey was to measure any improvement in caregivers’ perception of, and confidence in, involvement of care and decision making after having received the AGS Toolkit, with a focus on the clinical significance of these data as it relates to delirium prevention. A secondary goal was to determine if the caregivers plan to use the toolkit should a hospitalization occur, to further family involvement in care-planning. This was done as the evidence overwhelmingly demonstrates that family involvement in care-planning, as well as the effectiveness of the prevention strategies in the toolkit, are valuable in detecting and preventing delirium in the hospital setting. Additionally, the organization strongly desired to utilize such an evidence-based tool as an important resource for their families. The largest determinant of whether the organization would do so is if the caregivers felt it would increase or enhance their involvement in care for their loved one. Thus, the organization was interested in the results of these particular measures.

To measure the clinical significance, the pre- and post survey was administered before and directly after the caregivers received the tool. The pre-survey determined the caregiver’s current perception of, and confidence in, involvement in care using the three questions from the previously validated Perceived Involvement in Care Scale (M-PICS/I-PICS) that were specifically related to perceived involvement in care (see Appendix H). Permission to use the three questions from the survey was given by the author (see Appendix I). The post-survey evaluated the caregiver’s confidence in involvement of care after having received the AGS toolkit. All data were collected and provided to the FNCs and to the organization’s leadership to determine if changes needed to be made for continued sustainability at those facilities and others.
The project manager also gathered data on caregivers’ use of the AGS Toolkit during a hospitalization. A question on the post-survey asked how often the caregivers intended to use the toolkit at each hospitalization, examining frequency of responses. The goal was that the toolkit would be used at least 75% of the time (“very often” or “always”, answers 4 and 5 on a 5-point Likert Scale) during an acute care situation. It was during the support groups that the project manager administered the pre- and -post surveys to the caregivers.

To further measure use of the toolkit during a hospitalization, the project manager followed up with caregivers 30 days following the support group roll out to determine if the patient was hospitalized, how many times the patient was hospitalized, and if the tool was used at each hospitalization (see Appendix K). This was done using a two-question survey sent by the VP via postal mail containing a self-addressed stamped envelope which the caregiver was asked to fill out and return promptly, should they desire. These data were gathered to measure if the evidence-based toolkit resulted in the family’s active involvement in care in the event of a hospitalization. There was no identifying information on the 30-day surveys as they were to be reported as a group, examining frequency of responses.

**Protection of Human Rights and Privacy**

In consideration of protection of human rights and to protect privacy, the pre- and -post surveys were handed out in paper format by the project manager, and given to the FNC in an envelope, then given immediately back to the project manager who waited at the site for them. To protect caregiver privacy and to match pre- and -post surveys, respondents were asked to create a code (mother’s initials and their own date of birth) for each survey. The survey data were stored with no identifying information on an encrypted flash drive in a secure location. All
data collected were destroyed after the completion of the project and the drive was reformatted.

All data collected were analyzed in SPSS and reported in aggregate form.

**Financial Impact**

The financial impact of the project and on sustainability was very small. The cost lied only in acquiring Ziplock bags (as required in the toolkit) and printing the AGS Toolkit for the FNCs to utilize with newly accepted caregivers and current patients in the adult day centers. It is for this reason the budget for the project was nearly zero. The interventions occurred during the normal working hours of the FNCs as they host the support groups and/or meet with new and existing families, therefore no additional cost in labor was incurred (see table 1).

**Table 1**

*Financial Impact*

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**Results**

**Descriptive Data**

Demographic data was collected for background information that may be of use to the FNCs moving forward, which reported the self-disclosure of the education level of the caregivers (n=27). Descriptive analysis revealed that 56% of caregivers had completed high school or some
college, and 44% had obtained a college degree. One pre-survey question determined if the loved-one had previously been hospitalized while in the caregivers’ care. Descriptive analysis indicated that 70% of the loved ones had indeed been hospitalized while in their care.

**Caregiver Perception of Involvement in Care**

A Shapiro-Wilk test was performed on the three M-PICS/I-PICS questions. The results indicated that the data were not normally distributed. This led to the project manager performing a non-parametric test, the Wilcoxon Signed-Rank test. The results for these three questions indicated that the median post-survey scores were statistically significantly higher than the median of the pre-survey scores, indicating a statistically significant improvement in confidence in involvement in care after receiving the toolkit (see table 2).

**Table 2**

*M-PICS/I-PICS Questions Results*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre: Mean and (SD)</th>
<th>Post: Mean and (SD)</th>
<th>Z</th>
<th>P (Sig)</th>
</tr>
</thead>
<tbody>
<tr>
<td>M-PICS/I-PICS question #1 “I give my opinion about the type(s) or tests(s) or treatment(s) that my healthcare provider recommended”</td>
<td>2.33 (1.36)</td>
<td>1.63 (.742)</td>
<td>-2.5</td>
<td>.010</td>
</tr>
<tr>
<td>M-PICS/I-PICS question #2 “I suggest a certain kind of medical treatment to my healthcare provider recommended”</td>
<td>2.52 (1.37)</td>
<td>1.37 (.879)</td>
<td>-6.5</td>
<td>.017</td>
</tr>
<tr>
<td>M-PICS/I-PICS question #3 “I insist on a particular test or treatment”</td>
<td>2.70 (1.35)</td>
<td>2.70 (.98)</td>
<td>-28.5</td>
<td>.038</td>
</tr>
</tbody>
</table>
Note. Note statistically significant results. Likert Scale used: 1) Strongly Disagree; 2) Disagree; 3) Neutral; 4) Agree; 5) Strongly Agree.

Caregiver Use of AGS Toolkit During an Acute Care Situation

Out of the 27 respondents, a total of 26 answered the question on the post-survey which asked caregivers how often they intended to use the toolkit at each hospitalization (n=26). Examining frequency of responses, the results showed that 37% answered “very often”, and 37% answered “always” for a total frequency of 74%. While this was just under the goal of 75% answering “very often” or “always”, the mean score was 4.08, indicating that their intent to use the toolkit, on average, fell in the goal range and is thus clinically significant (see table 3).

The 30-day surveys were administered to the 27 participants, and 14 were returned (n=14, a 52% response rate). All 14 surveys indicated that no hospitalizations occurred in the 30 days since the support group roll out, and thus no data could be gathered on actual use of the toolkit during a hospitalization (see table 3). All data collected was provided to the FNCs and the organizations’ leadership to determine if changes need to be made for continued sustainability at those facilities and others.

Table 3

Caregiver Use of AGS Toolkit During an Acute Care Situation

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extent caregiver will be using the AGS Toolkit in the future</td>
<td>4.08 (37% reported they would use the toolkit “very often and 37% reported they would use the toolkit “always”).)</td>
<td>74% (goal was 75% answering “very often” or “always”)</td>
</tr>
<tr>
<td>How many times was your loved one</td>
<td>0 (no hospitalizations occurred)</td>
<td>0 (no hospitalizations occurred)</td>
</tr>
</tbody>
</table>
hospitalized in the 30 days since our meeting?

During how many separate hospitalizations in the last 30 days did you use the AGS CoCare: Help Program: Delirium Prevention Amidst Covid-19 Toolkit? 0 (no hospitalizations occurred) 0 (no hospitalizations occurred)

**Note.** Likert scale used for first question: 1) Never; 2) Rarely; 3) Sometimes; 4) Very Often; 5) Always. Last two questions: all 14 of returned surveys indicated that there were no hospitalizations, thus no data on use of the toolkit.

**Impact**

COVID-19, as well as the news media, are highlighting the risks and dangers of delirium in this population, drawing attention to the importance of family involvement in delirium detection and prevention strategies in acute care settings and citing the need for healthcare workers to utilize them as active members of the care team (Paris, 2020). The emergence of such media coverage drives home the increasingly widespread attention to this problem, and the ease to which it can be resolved. Despite its incidence worsening in the age of COVID, dwindling resources and staffing shortages have put delirium prevention on the back burner, prompting more healthcare professionals to work together to implement delirium prevention strategies which include family involvement (LaHue et al., 2020).

There is clinical significance in the interventions implemented in this project: caregiver confidence to form partnerships with health care professionals and advocate for delirium prevention strategies increased after exposure to the toolkit (p <.05), and should thus have a more widespread use. Of further clinical significance was that caregiver intent to use the AGS
toolkit during an acute care situation was, on average, “very often” or always” and is thus notable; clearly caregivers want to be involved. This evidence-based intervention addressed the practice problem by giving caregivers knowledge, combined with the proper tools, to increase the likelihood they will become more involved in care to prevent delirium, should their loved-one become hospitalized.

During the support group discussion, some anecdotal feedback from caregivers was received that may be of more clinical significance than the data collected here. Overwhelmingly the caregivers did not know: 1) what delirium was, 2) how dangerous delirium was, 3) how easy it was to prevent in hospital settings, and 4) what progressive steps to take to advocate for and ensure prevention strategies were in place. There was an overwhelming expression of gratitude by the caregivers for providing them with this resource. Nearly every caregiver felt very strongly that they already advocated for their loved one, and this was evident in their responses to the presurvey M-PICS/I-PICS questions. The FNCs did a fantastic job of helping the caregivers build confidence for advocacy. However, many caregivers did not see a possibility of working together with hospital staff and providers to become involved in care. When the topic was brought forward to the caregivers that they would be advocating for and insisting on day-to-day care that would prevent delirium in the hospital, many of them felt they were not free to do so. They verbalized fear of pushback from hospital staff, that they and their loved one would be retaliated against, and/or that the staff would simply refuse to implement the strategies into the plan of care and cite “shortage of staff due to COVID-19” as a rationale.

These caregivers’ perspectives should have a great impact on practice. Hospital healthcare professionals should look at policies and practices that make patients and families feel free to speak up, work together as part of the healthcare team, and work to eliminate or reduce
any fear of repercussion if the caregivers do involve themselves in care. Such policies should also ensure the practices are consistently being put into practice at every level, especially at the bedside. This project sought to arm caregivers with knowledge and tools to help hospital staff realize the importance of delirium prevention and simple strategies to prevent it. It is now up to healthcare professionals to welcome caregivers’ attempts at collaboration, even when they themselves are busy and “short staffed due to COVID.” It has been widely ascertained that family involvement of the kind implemented in this evidence-based project is crucial, especially now during the COVID-19 crisis.

**Limitations**

Such a discussion leads to the limitations of this project: the possibility that healthcare workers are reluctant to collaborate with families to implement these strategies when presented during a hospitalization. The 30-day survey was designed to determine if the caregivers had such an opportunity to use the AGS toolkit by advocating for the strategies within. However, the project was constrained to a 2-month intervention window, which limited measurable data to that end. A longer timeframe would be warranted to gather true data on successful use of the toolkit with hospital staff, as well as to offer the FNCs an opportunity to support the caregivers at the time of hospitalization. Qualitative data would also be of value to capture and address the anecdotal feedback noted above.

**Dissemination**

The University of St. Augustine for Health Sciences (USAHS) archives Doctor of Nursing Practice (DNP) projects in the Virginia Henderson Library and at USAHS using SOAR. This DNP manuscript has been produced by the project manager in partnership with their USAHS faculty chair. As described earlier, these data have been collected and provided to the
organization’s leadership, as they collaborated with the project manager, to determine if changes needed to be made for continued sustainability. Due to COVID-19 necessitating that dissemination be a virtual event, a Microsoft Teams meeting was held with leadership and the FNCs. Additionally, this manuscript will be sent to Gerontology and Geriatrics: Research Journal or The Journal of Aging for publication consideration.

**Conclusion**

In the age of COVID-19, it is vital that more of these such efforts by healthcare professionals ensue to protect this population from a worsening crisis, despite the many challenges they themselves face. Until addressing the issues of delirium identification and prevention strategies becomes standard practice in hospitals, it is the hope of this author that this project will be a catalyst for change. The significant amount of evidence pointing to delirium prevention strategies that include involvement of families has driven this project. Its purpose has been to empower caregivers to become advocates for evidence-based care in a hospital setting. Alzheimer’s disease and related disorders touch the lives of so many people. It is worth a discussion on how we can offer our nations’ elders, those who raised the generations before them, the highest quality of care the medical profession can provide.
References


https://doi.org/10.1136/bmjopen-2015-007808

https://doi.org/10.1093/geront/gns161


https://doi.org/10.3810/hp.2012.10.1004
Figure 1

**PRISMA Search Strategy**
### Appendix A

#### Evidence Table

<table>
<thead>
<tr>
<th>Citation</th>
<th>Design, Level</th>
<th>Sample</th>
<th>Intervention</th>
<th>Outcome</th>
<th>Usefulness</th>
</tr>
</thead>
<tbody>
<tr>
<td>De, J., &amp; Wand, A. F. (2015). Delirium screening: A systematic review of delirium screening tools in hospitalized patients. <em>The Gerontologist, 55</em>(6), 1079–1099. <a href="https://doi.org/10.1093/geront/gnv100">https://doi.org/10.1093/geront/gnv100</a></td>
<td>Systematic Review</td>
<td>31 high quality studies investigating 21 varying delirium screening tools, excluding ICU patients</td>
<td>CAM and other widely used and reliable delirium screening tools. Comparisons differed from study to study</td>
<td>Assessment of quality: Standards for the Reporting of Diagnostic Accuracy (STARD) criteria. Data synthesis in comparative narrative format.</td>
<td>CAM shown to be an excellent performance of the tool with sensitivities and specificities greater than 95%. Results confirm that CAM is a valid and widely used instrument to identify delirium but should be used by trained persons. This SR useful for this project in that it advocates for increased awareness of delirium detection</td>
</tr>
<tr>
<td>Siddiqi, N., Harrison, J. K., Clegg, A., Teale, E. A., Young, J., Taylor, J., &amp; Simpkins, S. A. (2016). Interventions for preventing delirium in hospitalised non-icu patients. <em>Cochrane Database of Systematic Reviews.</em></td>
<td>Meta-Analysis of Randomized Controlled Trials (RCT’s)</td>
<td>39 trials that recruited 16,082 non-ICU participants.</td>
<td>Single and multi-component interventions (should include as a minimum: staff education; individualized care (ex: frequent re-orientation,</td>
<td>“Synthesized dichotomous outcomes for meta-analysis and calculated pooled RRs with 95% confidence intervals (CIs)</td>
<td>Delirium can cause poor outcomes in patients and warrants prevention strategies. Moderate quality evidence supports implementing multi-component delirium prevention interventions into routine care. Results indicated no clear evidence for use of various medications. This MA is useful for</td>
</tr>
<tr>
<td>Source</td>
<td>SORT</td>
<td>Study Type</td>
<td>Description</td>
<td></td>
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<tr>
<td>Oberai, T., Laver, K., Crotty, M., Killington, M., &amp; Jaarsma, R. (2018). Effectiveness of multicomponent interventions on incidence of delirium in hospitalized older patients with hip fracture: A systematic review. <em>International Psychogeriatrics, 30</em>(4), 481–492. <a href="https://doi.org/10.1017/s1041610217002782">https://doi.org/10.1017/s1041610217002782</a></td>
<td>SORT 1</td>
<td>Systematic Review</td>
<td>9 high quality RCT’s and observational studies with a cohort of 1,889 participants. Ages of patients were over 65 with hip fractures. Studies evaluating multi-component interventions which can include the use of clinical staff/volunteers, geriatric/psychiatric consultation, staff education, patient orientation, addressing sensory needs, sleep enhancement, medication review, hydration and using random-effects methods. Synthesized continuous outcomes and calculated pooled mean differences, or standardized mean differences with 95% CIs using random-effects inverse variance methods” (Siddiqi et al., 2016, Data Synthesis section)</td>
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</tr>
</tbody>
</table>

**Bowel/bladder, early mobilization, staff education** for preventing delirium in hospitalized non-ICU patients. Comparison against usual care, placebo, or different interventions. This SR is useful for this project in that the AGS Toolkit advocates for use of such delirium prevention interventions as part of care. Multi-component intervention strategies addressing a range of risk factors greatly reduces the incidence, and possibly shorten duration of existing delirium. Of significance is the importance of early engagement of staff or geriatricians who address risk factors for delirium upon admission. This SR is useful for this project in that the AGS Toolkit advocates for use of such delirium prevention interventions as part of care.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study Type</th>
<th>Level</th>
<th>Study Design</th>
<th>Study Details</th>
<th>Knowledge and Challenges</th>
<th>Findings and Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providers: 82% had never used or heard of the CAM. Only 1 respondent was able to answer all knowledge items correctly. The respondents also agreed that nurses have an important role in delirium detection (65%), delirium diagnosis is often delayed (68%), and reported that not knowing patients’ baseline cognitive status (53%) and having difficulty separating delirium from dementia or psychiatric illnesses (25%) were important challenges to delirium diagnosis. This study is useful in validating why inclusion of data from family would be valuable in detecting and preventing delirium</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Thomas, E., Smith, J. E., Forrester, D., Heider, G., Jadotte, Y. T., &amp; Holly, C. (2014). The effectiveness of non-pharmacological multi-component interventions for the prevention of delirium in non-intensive care unit older adult hospitalized patients: A systematic review. <em>JBI</em></td>
<td>Systematic Review and meta-analysis</td>
<td>Level 1</td>
<td>SORT 1</td>
<td>10 studies included: RCT’s, quasi-experimental, before and after studies, prospective/retrospective cohort studies and case-</td>
<td>Studies evaluated non-pharmacological, multi-component interventions for the prevention of delirium in the hospitalized older adult when compared to usual care</td>
<td>Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument. P&lt;.05 or a 95% CI.</td>
</tr>
<tr>
<td>“Patients who received multi-component interventions had a 31% lower risk of developing delirium (relative risk 0.69, at 95% confidence interval 0.60, 0.78, p&lt;0.0001). All older adults admitted to non-intensive care units in the hospital should have appropriate non-</td>
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</tbody>
</table>
control studies looking at hospitalized adults 60 and over in a non-intensive care setting, and identified to be at risk for or experiencing delirium

- Pharmacological multi-component intervention initiated. Family members of patients identified as high risk must be made aware of the patient's increased risk of delirium and of the need to prevent its onset to the extent possible. They will need to be educated and included in planning the care of their loved ones” (Thomas et al., 2014, p. 232). This MA is useful in validating why inclusion of data from family, as well as prevention strategies are valuable in detecting and preventing delirium

<table>
<thead>
<tr>
<th>Ref</th>
<th>Title</th>
<th>Study Design</th>
<th>Sample Size</th>
<th>Interventions</th>
<th>Analysis</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hsheih, T., Yue, J., &amp; Oh, E. (2015).</td>
<td>Effectiveness of multicomponent nonpharmacological delirium interventions. JAMA Internal Medicine, 175(4), 512–520. <a href="https://doi.org/10.1001/jamainternmed.2014.7779">https://doi.org/10.1001/jamainternmed.2014.7779</a></td>
<td>Meta-Analysis</td>
<td>RCT’s and high-quality Non-RMT’s-(n=14) related to delirium prevention and impact on falls, length of stay and cognitive status. Mean age of participant 65 and older</td>
<td>Interventions included reorientation, early mobilization, therapeutic activities, hydration, nutrition, sleep strategies, hearing and vision attentions, and involvement of family or staff/volunteers</td>
<td>Linear regression analysis for study quality and effectiveness of the interventions. All surveys were 2-sided. Statistical significance indicated by P&lt;.05 or a 95% CI.</td>
<td>11 of the 14 studies showed significant reduction in incidence of delirium. Also found were significant reduction in falls and length of stay. “Multicomponent nonpharmacological delirium prevention interventions are effective in reducing delirium incidence” (Hsheih et al., 2015, Conclusion section). This MA is useful in validating why inclusion of data from family, as well as prevention strategies are valuable in detecting and preventing delirium</td>
</tr>
<tr>
<td>Martinez, F., Donoso, A., Marquez, C., &amp; Labarca, E. (2017). [Special section]. American Association of Critical-Care Before and after, quantitative</td>
<td>227 critically ill adult patients (mean 63)</td>
<td>“Staff training, early mobilization, physical therapy, reorientation,</td>
<td>2-tailed test (p &lt; 0.5), multivariate logistic</td>
<td>Interventions significantly reduced incidence of delirium (from 38% to 24%: relative risk, 0.62; 95% CI, 0.40-0.94; P = .02). While this</td>
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</tr>
<tr>
<td>Source</td>
<td>Level</td>
<td>SORT</td>
<td>Methodology</td>
<td>Interventions</td>
<td>Study Design</td>
<td>Results</td>
</tr>
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</tr>
<tr>
<td>Nurses, 37(6), 36–47. <a href="https://doi.org/10.4037/ccn2017531">https://doi.org/10.4037/ccn2017531</a></td>
<td>Level III</td>
<td>SORT 1</td>
<td>8 RCT’s with 2,105 adult patients evaluating the effects of non-pharmacologic multicomponent interventions for prevention of delirium.</td>
<td>Interventions “vary but usually consist of physiotherapy, reorientation training, early mobilization, identification and treatment of underlying causes or postoperative complications, pain control, regulation of bowel and bladder function, hydration and nutrition, and oxygen delivery” (Ludolph et al., 2020, Rationale section). CAM used in 5 studies. Compared to usual care. Most</td>
<td>Looking for incidence of delirium in the hospital (Primary) also length of stay, mortality, and falls ST delirium (secondary). Analyses in Review Manager; summary of intervention effects risk ratios (RRs) for dichotomous outcomes and mean</td>
<td>Results “confirm the current guidelines that multicomponent interventions are effective in preventing delirium. Data are still lacking to reach evidence-based conclusions concerning potential benefits for hard outcomes such as length of hospital stay, return to independent living, and mortality” (Ludolph et al., 2020, Conclusion section). Strong evidence (RR = .53; 95% confidence interval [CI] = .41-.69; P &lt; .001; eight studies; 2,105 participants). This SR is useful in validating why inclusion of data from family, as well as prevention strategies are valuable in detecting and preventing delirium.</td>
</tr>
<tr>
<td>Ludolph, P., Stoffers-Winterling, J., Kunzler, A. M., Rösch, R., Geschke, K., Vahl, C., &amp; Lieb, K. (2020). Non-pharmacologic multicomponent interventions preventing delirium in hospitalized people. Journal of the American Geriatrics Society. <a href="https://doi.org/10.1111/jgs.16565">https://doi.org/10.1111/jgs.16565</a></td>
<td>Systematic review and meta-analysis</td>
<td>Level 1</td>
<td>8 RCT’s with 2,105 adult patients evaluating the effects of non-pharmacologic multicomponent interventions for prevention of delirium.</td>
<td>Interventions “vary but usually consist of physiotherapy, reorientation training, early mobilization, identification and treatment of underlying causes or postoperative complications, pain control, regulation of bowel and bladder function, hydration and nutrition, and oxygen delivery” (Ludolph et al., 2020, Rationale section). CAM used in 5 studies. Compared to usual care. Most</td>
<td>Looking for incidence of delirium in the hospital (Primary) also length of stay, mortality, and falls ST delirium (secondary). Analyses in Review Manager; summary of intervention effects risk ratios (RRs) for dichotomous outcomes and mean</td>
<td>Results “confirm the current guidelines that multicomponent interventions are effective in preventing delirium. Data are still lacking to reach evidence-based conclusions concerning potential benefits for hard outcomes such as length of hospital stay, return to independent living, and mortality” (Ludolph et al., 2020, Conclusion section). Strong evidence (RR = .53; 95% confidence interval [CI] = .41-.69; P &lt; .001; eight studies; 2,105 participants). This SR is useful in validating why inclusion of data from family, as well as prevention strategies are valuable in detecting and preventing delirium.</td>
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</tr>
<tr>
<td><strong>Systematic Review</strong></td>
<td><strong>26 SRs or meta-analyses resulted in 31 primary studies that were evaluated</strong></td>
<td><strong>Multi/single-component nonpharmacological interventions: “In surgical setting, early mobilization, nutrition and hydration, regulation of bowel/bladder function, and early prevention of complications were the items that randomized studies had in common; in medical setting, in addition to early mobilization, nutrition and hydration, the interventions that the two controlled trials had in common were staff education, orientation protocol, avoidance of sensory deprivation” (Abraha et al., 2015, Unanswered Questions section)</strong></td>
<td><strong>CH-2 and I-2 (p&lt;0.1). Results of analysis narrative</strong></td>
<td><strong>In older patients, multi-component nonpharmacological interventions and some single-component interventions effectively (moderate quality evidence) prevented delirium in hospitalized older patients, but little evidence exists that it prevents delirium in nursing home patients, or that it treats delirium. This SR useful in validating why inclusion of data from family, as well as prevention strategies are valuable in detecting and preventing delirium</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Jonsdottir, T., Jonsdottir, H., & Gunnarsdottir, S. (2013). Validation of the patients’ perceived involvement in care scale among patients with chronic pain. Scandinavian Journal of Caring Sciences, 27(3), 740–749, https://doi.org/10.1111/j.1471-6712.2012.01066.x | Cross-sectional survey | 146 patients | Survey designed to measure patients perceived involvement in care was sent in two phases: first to patients in a pain clinic, the second to workers at unrelated companies. S compared to no effort to measure | Pearson’s correlations, t-test and ANOVA and Chi Square. Construct validity of I-PICS was examined by performing a confirmatory factor analysis. Reliability, for both subscales and the whole I-PICS questionnaire: Cronbach’s alpha coefficients | “I-PICS is a valid and reliable instrument for measuring communication between patients with chronic pain and their HCPs. It may be used as a research instrument to investigate the relationship between patients’ perceived communication with HCPs, satisfaction with most consulted HCP and perceived treatment effectiveness” (Jonsdottir et al., 2012, Conclusion section). This validation of this tool is useful for measuring outcomes for this project, as goals are in line with the projects’.

Legend:

<table>
<thead>
<tr>
<th>Design Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level I</td>
<td>Systematic review or meta-analysis of all relevant RCTs or evidence-based clinical practice guidelines based on systematic reviews of RCTs or three or more RCTs of good quality that have similar results.</td>
</tr>
<tr>
<td>Level II</td>
<td>Evidence obtained from at least one well-designed RCT (e.g. large multi-site RCT).</td>
</tr>
<tr>
<td>Level III</td>
<td>Evidence obtained from well-designed controlled trials without randomization (i.e. quasi-experimental).</td>
</tr>
<tr>
<td>Level IV</td>
<td>Evidence from well-designed case-control or cohort studies.</td>
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</table>
### Evidence Levels

<table>
<thead>
<tr>
<th>Level</th>
<th>Evidence Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level V</td>
<td>Evidence from systematic reviews of descriptive and qualitative studies (meta-synthesis).</td>
</tr>
<tr>
<td>Level VI</td>
<td>Evidence from a single descriptive or qualitative study.</td>
</tr>
<tr>
<td>Level VII</td>
<td>Evidence from the opinion of authorities and/or reports of expert committees.</td>
</tr>
</tbody>
</table>

*(Research Hub: Evidence Based Practice Toolkit: What is Ebp?, 2020, p1)*

<table>
<thead>
<tr>
<th>Name</th>
<th>Quality Grade</th>
</tr>
</thead>
<tbody>
<tr>
<td>SORT 1</td>
<td>Good Quality; patient-oriented evidence; meta-analysis of high-quality studies and RCT’s, high quality diagnostic studies</td>
</tr>
<tr>
<td>SORT 2</td>
<td>Limited Quality; patient-oriented evidence; meta-analysis of lower quality studies with inconsistent findings; case-control studies</td>
</tr>
<tr>
<td>SORT 3</td>
<td>Other evidence; basic research usual practice, opinion</td>
</tr>
</tbody>
</table>

*(Ebell et al., 2004)*
Appendix B

New Workflow

- Caregiver seeks services of Alzheimer's Community Care
- Enrollment assessment includes psychosocial evaluation
- FNC determines appropriate resources to offer caregiver per evaluation. Resources now include AGS Toolkit (all caregivers are eligible).
- FNC's provide training for caregivers on purpose of toolkit, its importance, how to fill it out, and how to utilize it when their loved one is hospitalized.
- Caregiver Annual Review
  - Available resources offered based on need. AGS Toolkit now available and the FNC explains its purpose and how to use.
- Caregiver wishes to join support group and application is accepted
  - AGS Toolkit now available and FNC provides once a month training for caregivers on purpose of toolkit, its importance, how to fill it out, and how to utilize it when their loved one is hospitalized.
- FNC's follow-up with caregiver in the event of a known hospitalization, of support groups, and Annual Caregiver Review to facilitate use of the AGS Toolkit.
Appendix C

Approval from Facility for Project Topic
Appendix D

Permission for use: AGS CoCare: Help Program: Delirium Prevention Amidst Covid-19 Toolkit

September 22, 2020

Dear Ms. Manolas,

Thank you for requesting permission to utilize the “Delirium Prevention Toolkit Amidst COVID-19,” from the AGS CoCare: HELP™ program (formerly The Hospital Elder Life Program) available for free on the help.agasocare.org website. Your request is to include the Toolkit in your project “Improving Caregivers’ Involvement in Healthcare & Facilitating Communication with Hospital Providers”, which will include strategies for families to use to assist with delirium prevention for their family members should they become hospitalized. This project is for Ms. Manolas’ Doctoral Candidacy in the Doctorate in Nursing Practice Program at University of St. Augustine in Augustine, Florida.

Permission is granted for the above provided that:

1. Permission to utilize and link to “Delirium Prevention Toolkit Amidst COVID-19” is limited to this individual doctoral project, “Improving Caregivers’ Involvement in Healthcare & Facilitating Communication with Hospital Providers”. Rights do not apply to revised editions.

2. Proper citation must be given to the American Geriatrics Society (AGS) CoCare: HELP™ program, including full acknowledgement of the source:
   Direct Link: https://help.agasocare.org/productAbstract/H00107
   © 2020 American Geriatrics Society. All Rights Reserved.
   Disclaimer: No responsibility is assumed by the AGS or the Hospital Elder Life Program, LLC, for any injury and/or damage to persons or property arising out of the application of any of the content at help.agasocare.org.
   “Permission granted by the American Geriatrics Society, 2020.”

3. Upon completion, final project to be shared with AGS CoCare: HELP™ via email to dsandos@americangeriatrics.org.

For more information visit AGS CoCare: HELP™ online at help.agasocare.org.

There is no fee for this request. If you have any questions please feel free to contact me at 212-308-1414 or dsandos@americangeriatrics.org.

Thank you,

Deana Sandos
Manager, Special Projects
American Geriatrics Society
### Preventing Delirium amidst COVID-19: Recommendations and Tools for HELP Programs

Here, we provide information for HELP Programs to assist with delirium prevention when (1) HELP staff are allowed in rooms; (2) no HELP staff are allowed in rooms.

<table>
<thead>
<tr>
<th>Intervention</th>
<th>(1) HELP ELS/ELNS visit allowed</th>
<th>(2) No visits: Provide “Hospital Kit” (materials and instructions) for patients in quarantine/isolation (see next page for instructions on assembling the Hospital Kit)</th>
</tr>
</thead>
</table>
| Early mobilization | • Walking with patient – laps around the room  
• Move regularly from bed to chair  
• Range of motion exercises—instruct patient to augment walking or if walking not possible | • Instructions: (1) Safe Walking and Range of Motion Exercises; (2) Use of stress balls and exercise bands  
• Equipment: Stress balls for squeezing (stress relief and strengthening) and exercise bands |
| Therapeutic activities | • Provide usual choices of therapeutic activities from HELP resources that patient enjoys  
• If feasible, help patients call or FaceTime with family and loved ones | • Activities and Instructions: Word searches and crossword puzzle |
| Orientation | • If none in room, bring in mini-whiteboard with date, location, team members, and schedule  
• Provide calm, orienting communication | • “My Orientation Card” with same info as is on the whiteboard in a HELP patient’s room |
| Vision and hearing impairment | • Use HELP vision and hearing protocols  
For vision-impaired patients, consider verbally reading through handouts in the “Hospital Kit” | • Adaptive equipment such as large button telephone  
Provide magnifying glasses (proper protocol for disinfecting) |
| Feeding assistance/dehydration | • Encourage patients to drink six 8oz glasses of fluids/day | • Note card in Hospital Kit with information on hydration, nutrition, sleep, mobility, etc. |
| Nighttime relaxation and sleep | • Review sleep hygiene (no caffeine after 2 p.m.)  
• Provide warm milk or herbal tea  
• Conduct relaxation exercises from 6-ft distance | • “Relaxation Exercise” notecard  
• “What Should I Know About Sleep?” notecard  
• Eye mask, ear plugs to reduce distractions |
| Addressing agitation and fear (related to delirium or fear of providers with PPE) | Try verbal de-escalation procedures before jumping to antipsychotics or other pharmacological methods. See the handout “Verbal De-Escalation” for your use, includes pocket card. | [Staff only] |

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How to Assemble the Hospital Kit:

Gallon-size Zip Lock plastic bag

Notecards (9): To assemble—please print single-sided on thick paper or card stock. Fold along central line; staple tape to create the note card.

- “Your Hospital Kit” notecard with blurbs on hydration, nutrition, mobility, sleep, and activities/orientation
- “My Orientation Card” notecard with information that you would find on the whiteboard of a patient’s room enrolled in HELP
- “What Should I Know About Sleep?” notecard with information on why we use non-pharm methods for sleep protocol instead of sleep meds
- “Relaxation Exercise” notecard with information on a relaxation exercise for sleep or calming stress
- Therapeutic Activities: 4 word searches and 1 crossword (3 notecards total)
- Range of motion, safe walking, and stress ball/exercise band instructions (2 notecards total)

Equipment to include:

- Adaptive equipment, if available, such as magnifying glass and/or flashlight
- Exercise band
- Stress ball for squeezing
- Pencil/pen, notepad
- Ear plugs
- Eye mask
- Herbal tea bag (include in kit or make available at bedtime)
Verbal De-Escalation Techniques: Instructions for Clinical Staff

Some patients may be confused or scared in response to the difficult circumstances, unfamiliar environment, and aggravated by personal protective equipment (masks, glasses, protective clothing, etc.) that healthcare providers are using to keep themselves safe during the pandemic. Verbal de-escalation is an important tool for de-escalation in delirious agitated patients (from the ADEPT Tool, https://www.acep.org/patient-care/adept/). You can distribute the following 3x5 pocket card to nurses working with agitated patients:

VERBAL DE-ESCALATION FOR AGITATION

- Respect personal space
- Avoid negative language (“No! You can’t go there!”)
- Use positive language (“I’d like to help you by…”)
- Establish verbal contact
- Be calm, be reassuring, be comforting
- Be concise and use simple language
- Identify the patient’s wants and feelings
- Listen closely to what the patient is saying. Remember they are likely fearful
- Debrief the patient, family, and staff

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AGS-CoCare: HELP

Your Hospital Kit

We understand that this can be a stressful time in the hospital, and you may have to spend time alone during your stay. The following tips and guidelines are to help you stay mentally and physically fit while you are here.

**Activities and Staying Oriented**
- Check out the games and activities to keep your mind active in the hospital.
- Check out the "Orientation Page" to keep you aware of your schedule and staff in the

- Eat and drink well
  - Try to eat 3 meals and drink six 8-ounce cups of water or fluids each day (if OK with doctors).

- Time to Shop!
  - While in your hospital stay, you can use a shopping list and ask your nurse or another staff member if there is any

- Having Trouble Reading
  - Wear glasses or other reading materials if needed
  - Read large print books or audio books
  - Close the window to reduce glare
  - Keep the room well lit
  - Get moving!
Relaxation Exercise

Trouble sleeping? Feeling anxious? Try this relaxation exercise to help you wind down. Get into a comfortable position and start thinking about a relaxing setting in your mind, such as the beach, your comfy bed at home, a beautiful mountain, or anything else that brings you peace.

Establish a steady breathing pattern:
- Breathe in through your nose slowly, hold for 3 counts
- Breathe out through your nose completely, repeat multiple times
- Visualize the stress floating away as you concentrate on each body section. Contract and release, repeating 3 to 5 times each:
  - Your toes
  - Your ankles
  - Knees – imagine the stress draining from your knees
  - Buttocks
  - Spine – arch and straighten
  - Shoulders – shrug and release
  - Slide over to your neck. Drop your chin to chest. Lift it to the ceiling.

Now that you are calm and relaxed, slowly make your body parts:
- Lift your head to the sky
- Move your arms and legs
- Glide your toes
- Wiggle your fingers
- Shrug your shoulders
- Open your eyes

Today is ________ and the weather is ________.

My Orientation Card

I am a patient at ________________ in Room __________

We are located in (city/state): ________________

My doctor is ________________

My nurse and aide(s) are ________________
What Should I Know About Sleep?

Try to go to bed each night at your usual bedtime. Avoid caffeinated beverages after 2 pm, and reduce fluid intake after 6 pm. Do calming activities before sleep.

While sleeping medication may sound like a good idea, these pills can actually harm your sleep health and put you at risk for certain medical conditions, such as delirium. Older adults ages 65 and older should try to sleep without medications. We recommend a glass of warm milk or herbal tea, relaxation exercises, and using a sleep mask or earplugs to avoid distractions.

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Shoulder and Wrist Exercises

Perform 5-10 cycles each

Arms and Hip Exercises

Complete 5-10 cycles each

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### Appendix F

#### Project Schedule

<table>
<thead>
<tr>
<th></th>
<th>Week 1</th>
<th>Week 2</th>
<th>Week 3</th>
<th>Week 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>July</td>
<td>P</td>
<td>P</td>
<td>P-Continue revising Proposal</td>
<td>P- Complete revision of proposal for submission 7/31/20</td>
</tr>
<tr>
<td>Aug</td>
<td>P- Submit Completed Proposal 8/2/20</td>
<td>P- Meet with preceptor about Completed proposal 8/10/20</td>
<td>P- 8/14/20 Communicate final dates of support group intervention to Dr. Gilbert</td>
<td>P- 8/17/20 Begin finalizing plans for whether groups will be in-person, virtual, or over the phone per Dr. Gilbert.</td>
</tr>
<tr>
<td>Sept</td>
<td>9/7/14 Begin NUR7802</td>
<td>A- (EPRC)- Submit 9/10/20 Meet with Mentor RE dates of meetings</td>
<td>A- (EPRC)- Await Approval</td>
<td></td>
</tr>
<tr>
<td>Oct</td>
<td>A- (EPRC)- Await Approval</td>
<td>EPRC Approval Gained</td>
<td>SC- Begin project: Collaborate with staff on logistics of meeting *</td>
<td>I- Support groups * , ** , ***</td>
</tr>
<tr>
<td>Nov</td>
<td>I-Support Groups: * , ** , *** Nov 3, 4, 5</td>
<td>I-Document data from surveys * , ** , ***</td>
<td>I- Support Groups: * , ** , *** Nov 17, 18, 19</td>
<td>I- Document data from surveys * , ** , ***</td>
</tr>
<tr>
<td>Dec</td>
<td>I-Support Groups: * , ** , *** Dec 1</td>
<td>I-Support Groups: * , ** , *** Dec 15, 16, 17</td>
<td>Winter Break 12/18/20</td>
<td>Winter Break</td>
</tr>
<tr>
<td>Jan 2021</td>
<td>Winter Break</td>
<td>1/11/20 Begin NUR7803</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>Feb 2021</td>
<td>Edits</td>
<td>Edits</td>
<td>Edits</td>
<td>Edits</td>
</tr>
<tr>
<td>Mar 2021</td>
<td>Edits</td>
<td>D- Site Teams meeting March 12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apr 2021</td>
<td>D- USA before April 10</td>
<td>April 24- Degree Confirmed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Legend: Planning- P, Approval- A, Staff Collaboration- SC, Implementation- I, Evaluation/Analysis- E, Dissemination- D,
* Send meeting invite email 7 days prior, ** Send reminder email one week prior, *** Send meeting material day of
Appendix G

Emails to Participants

Email #1 (sent one week prior)- I am a doctoral candidate with the University of St. Augustine, seeking a doctorate in nursing practice. As you may have been made aware, I have the honor of participating in your Caregiver Support Group at ____________ on __________ as guest speaker as I discuss the topic “Advocating for My Loved One's Safety: Improving Caregivers Involvement in Care to Reduce Delirium During a Hospital Experience.” This current pandemic is shining a light on delirium as a side effect of your loved one falling ill, and how dangerous it can be. The goal is to discuss ways for you to identify specific signs of delirium in your loved one, and to give you the tools you need to potentially help you communicate with nurses and doctors in the hospital. This includes documentation you can provide that will help them know your loved one better as a person which may be of value due to limitations on visitors currently in place in most hospitals due to COVID-19. Another goal is to help you advocate for simple strategies hospital staff can do to prevent delirium before it occurs, possibly making them safer during their hospital experience.

Please note that this event is being done as part of a doctoral project and by participating you give consent to participate in our efforts to improve quality care for persons and families living with Alzheimer’s and related disorders. To do this you will be asked to fill out a short pre-survey and post survey anonymously and allow the vice-president to mail you a 30-day follow-up with a few short questions. While these 2 short surveys, 30-day follow-up, and attendance at the event are not mandatory, they are truly appreciated as they serve the purposes as mentioned above. Please note that there will no penalty for not participating fully, and you may thus opt-out at any time.

I will send you a reminder email the day before the event, as well as an email the morning of the meeting. Please feel free to reach out to me or the vice-president of ____________ at ____________ with any questions. I truly hope to meet you all at the support group and working with you as we work together as a team to improve the care and safety of your loved one!

Respectfully,
Heather Manolas MSN-ED, RN
Doctorate in Nursing Practice (DNP) Project manager
University of St. Augustine
Cell- 407-765-8503, Email-hethmanolas@yahoo.com
Email #2 (sent day before)- This is a reminder email that I have the honor of participating as guest speaker at your Caregiver Support Group at ____________ on ____________. as I discuss the topic “Advocating for My Loved One's Safety: Improving Caregivers Involvement in Care to Reduce Delirium During a Hospital Experience”.

To recap our topic: This current pandemic is shining a light on delirium as a side effect of your loved one falling ill, and how dangerous it can be. The goal is to discuss ways for you to identify specific signs of delirium in your loved one, and to give you the tools you need to potentially help you communicate with nurses and doctors in the hospital. This includes documentation you can provide that will help them know your loved one better as a person which may be of value due to limitations on visitors currently in place in most hospitals due to COVID-19. Another goal is to help you advocate for simple strategies hospital staff can do to prevent delirium before it occurs, possibly making them safer during their hospital experience.

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Respectfully,

Heather Manolas MSN-ED, RN
Doctorate in Nursing Practice (DNP) Project manager
University of St. Augustine
Cell- 407-765-8503, Email-hethmanolas@yahoo.com

Email #3 -This is a reminder email that I have the honor of participating as guest speaker at your Caregiver Support Group today at ____________, as I discuss the topic “Advocating for My Loved One's Safety: Improving Caregivers Involvement in Care to Reduce Delirium During a Hospital Experience”.

To recap our topic: This current pandemic is shining a light on delirium as a side effect of your loved one falling ill, and how dangerous it can be. The goal is to discuss ways for you to identify specific signs of delirium in your loved one, and to give you the
tools you need to potentially help you communicate with nurses and doctors in the hospital. This includes documentation you can provide that will help them know your loved one better as a person which may be of value due to limitations on visitors currently in place in most hospitals. Another goal is to help you advocate for simple strategies hospital staff can do to prevent delirium before it occurs, possibly making them safer during their hospital experience.

Please recall that this event is being done as part of a doctoral project and by participating you give consent to participate in our efforts to improve quality care for persons and families living with Alzheimer’s and related disorders. To do this you will be asked to fill out a short pre-survey and post survey anonymously and allow the Vice president to mail you for a 30-day follow-up with a few short questions. While these 2 short surveys, 30-day follow-up, and attendance at the event are not mandatory, they are truly appreciated as they serve the purposes as mentioned above. Please note that there will no penalty for not participating fully, and you may thus opt-out at any time.

Respectfully,

Heather Manolas MSN-ED, RN
Doctorate in Nursing Practice (DNP) Project manager
University of St. Augustine
Cell- 407-765-8503, Email-hethmanolas@yahoo.com

Email #4 (sent just after meeting)- I would like to personally thank you for your participation in my presentation during your Caregivers Support Group: “Advocating for My Loved One's Safety: Improving Caregivers Involvement in Care to Reduce Delirium During a Hospital Experience”. I am grateful for your collaborative efforts as we seek to improve quality care for persons and families living with Alzheimer’s and related disorders.

I wish you and your loved one the best,

Heather Manolas MSN-ED, RN
Doctorate in Nursing Practice (DNP) Project manager
University of St. Augustine
Cell- 407-765-8503, Email-hethmanolas@yahoo.com
Appendix H
Pre-Survey

PreSurvey: Advocating for My Loved One's Safety: Improving Caregivers Involvement in Care to Reduce Delirium During a Hospital Experience.

By completing this survey, you agree to participate, anonymously, in data collection and evaluation aimed at improving care for individuals and families living with Alzheimer's Disease and related disorders. You also agree to a follow up in 30 days with 2 follow-up questions.

While this survey is not mandatory, your participation is very much appreciated.

For the first 3 questions: Think about a time when your loved one was in the hospital and how involved in the daily day-to-day care and decision making for them you were. If they have never been hospitalized, think about how comfortable or confident you would feel, if they were hospitalized, to be involved in the daily day-to-day care and decision making for them.

1. Please choose a response to the question that best describes how you feel: I give my opinion about the type(s) or test(s) or treatment(s) that my Healthcare Provider recommended
   A. Strongly Disagree
   B. Disagree
   C. Neutral
   D. Agree
   E. Strongly Agree

2. Please choose a response to the question that best describes how you feel: I suggest a certain kind of medical treatment to my Healthcare Provider
   A. Strongly Disagree
   B. Disagree
   C. Neutral
   D. Agree
   E. Strongly Agree
3. Please choose a response to the question that best describes how you feel: I insist on a particular kind of test or treatment for my symptoms
   A. Strongly Disagree
   B. Disagree
   C. Neutral
   D. Agree
   E. Strongly Agree

4. Has your loved one been in the hospital while you were the primary caregiver?
   A. Yes
   B. No

5. What is your highest level of education?
   A. Did not complete High School
   B. High School diploma or GED
   C. Some college
   D. Associate Degree
   E. Bachelor's degree
   F. Master's Degree
   G. Doctorate Degree

6. To be sure we match your Post-survey Survey to your Pre-survey; we need an identifier that keeps you anonymous. The code will please be your Mother's Initials and Your Birthday. For example: My Mothers' name is Ruth Leigh and MY birth month and day is 5/31, so I would enter the code RL531. Please enter your code in the space below. Remember your code so you can enter it when taking the Post-survey.
Appendix I

M-PICS/I-PICS Permission by Author and Creator

To: Thorbjorg Jonsdottir <torbj@unak.is>
Subject: RE: Request for Permission to use the Modified Patients' Perceived Involvement in Care Scale (M-PICS)

Good Morning Dr. Jondottir

Thank you so very much for your reply! The 3 questions I would love to use are: "I give my opinion about the type(s) or survey(s) or treatment(s) that my Healthcare Provider recommended", "I suggest a certain kind of medical treatment to my Healthcare Provider", and "I insist on a particular kind of test or treatment for my symptoms".

Respectfully,

Heather Manolas

---

RE: Request for Permission to use the Modified Patients' Perceived Involvement in Care Scale (M-PICS)

To: hethanolas

Dear Heather

Sorry I haven’t answered your last e-mail, I have been very busy this week.

Your are welcome to use these questions but I would ask you to cite my article: Jonsdottir T, Jonsdottir H, Gunnarsdottir I. Validation of the patients’ perceived involvement in care scale among patients with chronic pain. Scand J Caring Sci 2013 Sep;27(3):740-749 in your publications.

I look forward to follow you work.

All the best,

Thorbjorg Jonsdottir
Appendix J
Post-Survey

**Post Survey: Advocating for My Loved One's Safety: Improving Caregivers Involvement in Care to Reduce Delirium During a Hospital Experience.**

By completing this survey, you agree to participate, anonymously, in data collection and evaluation aimed at improving care for individuals and families living with Alzheimer's Disease and related disorders. You also agree to allow the vice president to send a short 2-question follow-up survey to you via postal mail in around 30 days.

While this survey is not mandatory, your participation is very much appreciated.

You have participated in the Guest Speakers' presentation and received the AGS CoCare: Help Program: Delirium Prevention Amidst Covid-19 Toolkit. The goal is to help you communicate with the hospital doctors that you would like to advocate for, and intend to be involved in, delirium prevention strategies, as well as give them 24-hour access to important information unique to your loved one.

Now, for the first 3 questions: Think about a future hospitalization of your loved one, and how confident or comfortable you would feel being involved in decision making now that you have the AGS CoCare: Help Program: Delirium Prevention Amidst Covid-19 Toolkit.

1. Please choose a response to the question that best describes how you feel: I give my opinion about the type(s) or test(s) or treatment(s) that my Healthcare Provider recommended
   - A. Strongly Disagree
   - B. Disagree
   - C. Neutral
   - D. Agree
   - E. Strongly Agree

2. Please choose a response to the question that best describes how you feel: I suggest a certain kind of medical treatment to my Healthcare Provider
   - A. Strongly Disagree
   - B. Disagree
   - C. Neutral
D. Agree
E. Strongly Agree

3. Please choose a response to the question that best describes how you feel: I insist on a particular kind of test or treatment for my symptoms
   A. Strongly Disagree
   B. Disagree
   C. Neutral
   D. Agree
   E. Strongly Agree

4. To what extent do you believe you will use the AGS CoCare: Help Program: Delirium Prevention Amidst Covid-19 Toolkit in future hospital experiences?
   1. Never
   2. Rarely
   3. Sometimes
   4. Very Often
   5. Always

5. To be sure we match your responses to this survey with the Pre-Survey; please enter the anonymous code you created for the pre-survey in the space below (it was your Mother's initials and Your birthday). For example: My Mothers' name is Ruth Leigh and MY birth month and day is 05/31, so I would enter the code RL531
Appendix K

30-day Follow-up Questionnaire - Postal Mail

I would like to personally thank you for your participation in my presentation during your Caregivers Support Group: “Advocating for My Loved One's Safety: Improving Caregivers Involvement in Care to Reduce Delirium During a Hospital Experience”. I am grateful for your collaborative efforts as we seek to improve quality care for persons and families living with Alzheimer’s and related disorders.

As we discussed, this is the 30-day follow-up to help get an idea of how or if you used, or had the opportunity to use the AGS CoCare: Help Program: Delirium Prevention Amidst Covid-19 Toolkit

Please recall that by completing this survey, you agree to participate, anonymously, in data collection and evaluation aimed at improving care for individuals and families living with Alzheimer's Disease and related disorders.

While this survey is not mandatory, your participation is very much appreciated.

Please graciously fill out your response to these 2 short questions and return the page in the self-addressed stamped envelope included. Due to COVID-19 the postal mail has been rather slow, so returning this survey promptly is important so that I can receive your very valuable response in time. Thank you!

My two questions are:

1. How many times was your loved one hospitalized in the 30 days since our meeting?
   A. 0 (my loved one has not been hospitalized in the 30 days since our meeting)
   B. 1
   C. 2
   D. 3
   E. 4
   F. 5 or more

2. During how many separate hospitalizations in the last 30 days did you use the AGS CoCare: Help Program: Delirium Prevention Amidst Covid-19 Toolkit?
My Loved one was NOT hospitalized in the last 30 days
   A. 0 (my loved one has not been hospitalized in the 30 days since our meeting)
   B. 1
   C. 2
   D. 3
   E. 4
   F. 5 or more

I wish you and your loved one the best,

Heather Manolas MSN-ED, RN
Doctorate in Nursing Practice (DNP) Project manager
University of St. Augustine
Cell- 407-765-8503, Email-hethmanolas@yahoo.com
## Appendix L

Variables and Statistical Survey/Evaluation Method

<table>
<thead>
<tr>
<th>Variable</th>
<th>Survey/Evaluation Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>M-PICS/I-PICS questions</td>
<td>Wilcoxon Signed Rank.</td>
</tr>
<tr>
<td>Education Level</td>
<td>Descriptive Frequency for each level</td>
</tr>
<tr>
<td>Extent caregiver will be using the AGS Toolkit in the future</td>
<td>Mean average score</td>
</tr>
<tr>
<td>Has your loved one been in the hospital while you were the primary caregiver?</td>
<td>Percentage of yes/no</td>
</tr>
<tr>
<td>How many times was your loved one hospitalized in the 30 days since our meeting?</td>
<td>Frequency. Reported as a group</td>
</tr>
<tr>
<td></td>
<td>Frequency. Reported as a group</td>
</tr>
</tbody>
</table>