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Improving Participation in Advance Care Planning in The Guam/Micronesia Geriatric Community Through Education

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ABSTRACT

The University of Guam (UOG) School of Health (SOH) received a grant in 2019 for the Guam/Micronesia Geriatrics Workforce Enhancement Program (GWEP) funded by the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services (DHHS). The vision of the grant is to transform current health systems serving the elderly and those with Alzheimer's disease and related dementias. The framework of the 4Ms – what matters, medication, mentation, and mobility is being used to help make this vision a reality through the creation of age-friendly health systems for the elderly. The Guam/Micronesia GWEP chose to focus on what matters out of the 4Ms during years 1-3 of its grant cycle. Specifically, advance care planning (ACP) was addressed at the Guam Memorial Hospital Authority (GMHA) Skilled Nursing Unit (SNU) and in the Guam/Micronesia geriatric community. A chart review was done at the GMHA SNU, which showed low participation in ACP, 25% of the census for that time period. Several reasons for this were revealed through discussion with GMHA SNU personnel. They included lack of awareness or knowledge about ACP as well as language and cultural barriers. After training about ACP was conducted by Guam/Micronesia GWEP, chart reviewed showed participation in ACP improved to 100% at the GMHA SNU. Given this success, the intention is to continue with trainings in ACP through grant year 3 in the hopes of helping patients and their families as well as health care personnel in the Guam/Micronesia community understand how ACP helps to ensure that health care systems respect what matters most to geriatric patients and their families, and in doing so works toward establishing a more age-friendly health system.

Keywords: Advance care planning; GWEP; 4Ms; Guam; Micronesia, Age-friendly health system, Elderly, Barriers to participation in ACP

1. INTRODUCTION

In response to the growth in the older adult population and the consequent need for a health care workforce better prepared to care for the elderly, the U.S. Department of Health and Human Services-Health Resources and Services Administration (DHHS-HRSA) established the Geriatrics Workforce Enhancement Program (GWEP). The intent of this program is to develop a health care workforce that maximizes patient and family engagement and improves health outcomes for older adults by integrating geriatrics within primary care [1]. In 2019, the University of Guam School of Health received funding to establish the Guam/Micronesia GWEP.

The Guam/Micronesia GWEP seeks to transform current health systems in Guam and Micronesia that serve the elderly and those with Alzheimer's disease and related dementias into age-friendly health systems. Guam and the Federated States of Micronesia are in Micronesia, a subregion of Oceania, in the Western Pacific [2]. Guam is an unincorporated territory of the United States and is part of the Mariana Islands [3]. The Federated States of Micronesia (FSM) is a freely associated state and a U.S. affiliated Pacific Island (USAPI). The islands of Yap, Pohnpei, Kosrae, and Chuuk comprise the FSM [4].

The Guam/Micronesia GWEP is using the 4Ms framework – what matters, medication, mentation, and mobility from the John A. Hartford Foundation and the Institute for Healthcare Improvement Initiative to help make this vision a reality. For years 1-3 of its grant cycle, the Guam/Micronesia GWEP chose to focus on what matters out of the 4Ms. More specifically, the Guam/Micronesia GWEP chose to focus efforts on improving participation in advance care planning (ACP), for ACP seeks to ensure that patients receive medical care that is consistent with what matters to them. This is supported by an often-used consensus definition for ACP which describes it as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" [5]. Participation in ACP results in patients' values and preferences guiding both their immediate and future health care decisions [6]. Participation in ACP has also been shown to reduce stress, anxiety, and depression in both patients and their families and consequently improve their quality of life and end-of-life (EOL) outcomes [7, 8].

Several studies have shown that ACP is integral to honoring the wishes of dementia patients and what matters to them. Participating in ACP while patients still possess effective communication and decision-making abilities prepares and enables patients, their surrogate decision makers, and their families to make complex and timely medical decisions [9]. Early and ongoing ACP conversations between patients, families, and healthcare professionals can prepare patients for discussing specific goals of care [9]. It also has been observed that many individuals have expressed their preference for EOL discussions to occur sooner rather than later, especially because later is often during a medical crisis and/or the patient's capacity is lost because of illness or treatment [25].

Even though the benefits of ACP have been reported, participation in ACP is low both in in the United States (U.S.) and Asia. In the U.S., as per a systematic review of studies published from 2011-2016, one in three adults in the U.S. has completed any type of advance directive, which is a key component of advance care planning [10]. A review of ACP in Asian countries shows that ACP is in its infancy in Indonesia and Japan and that participation is low in Singapore and Taiwan [9]. There is currently a paucity of information about ACP participation in the Western Pacific, specifically in Guam and the rest of Micronesia. However, given that Guam is both a U.S. territory and has a population of diverse cultures including Chamorros, Micronesians, other Pacific islanders, and Asians

[11], it is possible that ACP participation is similar to that discussed for the U.S. and in Asia.

Numerous barriers to participation in ACP have been identified [6, 9, 12, 13, 14, 15, 16, 17, 18, 19, 21, 22]. Lack of and/or limited ACP knowledge or awareness by both the public and health care workers was a cited reason for low participation in ACP [13, 15, 16, 18, 19]. Additional identified barriers to ACP participation included: unpreparedness of the patient and their family to make complex medical decisions [5, 6, 13], limited health literacy, difficulty with both written and oral communication limiting understanding [20], patients' perceived unpreparedness of medical professionals to facilitate and discuss ACP [13], mistrust in the health care system [18, 21, 22], misperception that ACP is irreversible [19], inability to participate because of poor cognition [12], concern for negative emotional impact of such discussions on patients and/or their families [12, 13, 18], cultural beliefs that make discussions about death taboo [9, 12, 15, 17], fear of thinking about or discussing death [17, 23], lack of inclination to plan for the future [12], absence of urgency [22], avoidance, a sense of denial and evasion of discussion about ACP [22], and guilt associated with feeling that participating in ACP would result in not fulfilling one's obligation to do everything for their loved one or family member [17, 24].

The Guam/Micronesia GWEP sought to address the likely low participation in ACP in Guam by providing training about the 4Ms and ACP, as other initiatives have shown that either education has improved participation in ACP [6, 9, 15] or recommended that education would likely be helpful in improving participation in ACP [7, 9, 14, 15, 17, 21, 22, 25]. The aim of this initiative was clinical practice transformation at the GMHA SNU through health care personnel education about ACP.

2. MATERIALS AND METHODS

The Guam Memorial Hospital Authority (GMHA) Skilled Nursing Unit (SNU) identified a need for transformation of the clinical practice environment and collaborated with GWEP to utilize the 4Ms framework to transform the GMHA SNU into an age-friendly medical facility so as to improve patient outcomes for the elderly and those with Alzheimer's Disease and Related Dementias (ADRD). In evaluating the GMHA SNU's areas for improvement, it was determined that it would be beneficial to focus on what matters most to patients and their families, specifically evaluating and improving patient and family participation in ACP. The Guam/Micronesia GWEP and GMHA SNU administration felt that focusing on advance care planning (ACP) would help to improve understanding of patients and their families' values, preferences, and goals regarding their medical care and result in a health facility that delivers care that is consistent with what matters to them.

The US Health Resources and Services Administration (HRSA) requires program impact evaluation for each GWEP, utilizing specific quality measures from the Centers for Medicare and Medicaid Services (CMS) Merit-Based Incentive Payment System (MIPS). The MIPS measures are one component of the CMS Quality Measurement strategic initiative. Quality measures are tools to quantify healthcare processes, outcomes, or system structures that can impact quality of care [26]. One of the required measures to demonstrate program impact for patient quality includes MIPS Measure: Care Plan. The Care Plan measure collects data on "The percentage of patients aged 65 years and older who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan" [27]. Focusing on

participation in ACP at the GMHA SNU and using the Care Plan MIPS measure allowed the Guam/Micronesia GWEP to not only work on transforming the health care facility into an age-friendly place of care, but also fulfill the requirements for program impact evaluation.

In trying to evaluate and improve participation in ACP, a baseline assessment of current participation in ACP at GMHA SNU was needed, as this information was not available at the beginning of this initiative. The GMHA SNU is the only Medicare-certified skilled-nursing facility on Guam, and has a bed capacity of 60. However, the facility is currently licensed for 40 beds due to an ongoing nursing shortage. Since the Fall of 2019, the SNU limited their census to 24 due to staffing limitations. A chart review of GMHA SNU patients was conducted from January through June 2019 to determine base-line participation in ACP. The Care Plan MIPS measure as described above was the basis for the inclusion criteria used for the chart review. Based on an inclusion criteria of age 65 years and older, there were 16 patients at GMHA SNU whose medical records could be reviewed during this stated time period. Using the Care Plan MIPS measure, charts that indicated yes to have a living will, advance directive, or advance care plan as assessed on admission and/or containing documentation of discussion on ACP between patient and his/her care team were considered to be indicative of participation in ACP. The chart review showed low participation in ACP, as 4 patients had documentation in their chart indicative of participation in ACP whereas 12 patients did not have any type of advance care plan or documentation of ACP discussion in their medical records. This amounts to 25% of GMHA SNU patients, who were admitted to the facility at the time of the chart review and who had documentation of their participation in some form of advance care planning (Table 1).

Table 1. Participation in ACP at GMHA SNU, January 2019 – June 2019, prior to training

Number of SNU patients aged 65 years and older at time of chart review [1]	16
Number of patients with some type of ACP in medical record	4
Percentage of patients with some type of ACP in medical record	25%

[1]The total census for the GMHA SNU varies, depending on the time period during which the chart review was conducted. The prior-to-training chart review was conducted January through June 2019.

To address the low participation in ACP at GMHA SNU as suggested by the chart review, the Guam/Micronesia GWEP offered training entitled "4Ms and Advanced Care Planning" to SNU providers and health care personnel. The core concepts presented were the 4Ms framework, advanced care planning, and explanation of an advanced directive form and living will. An introductory session was conducted in August 2020 with the SNU medical director, 1 nursing administrator and 1 nurse manager. After the introductory session, the administrator recommended to implement ACP training to all licensed staff. In response to this recommendation, electronic flyers on the training were sent to the administrator and the training sessions were scheduled according to the administrator's recommendations. The training for the SNU staff took place in December 2020, and these online training sessions were held via

zoom. Each session lasted for 1 hour and included questions and discussion. Seventeen out of 22 licensed health professionals employed by the SNU participated and attended the training. These included 1 physician, 4 Licensed Practical Nurses, 3 Registered Nurses, 2 Certified Nursing Assistants, 1 pharmacist, 1 dietician, 1 ward clerk, 1 physical therapist, 2 occupational therapists and 1 rehabilitation tech /recreational therapist.

At the end of each training presentation, participants were invited to complete an evaluation and have open discussion about any questions or participants' experiences with ACP. Comments were documented in the zoom chat box during the session. After the session, the comments were compiled and reviewed by the trainer.

In February 2021, a post-training chart review was conducted to evaluate for impact of training on ACP participation. As with the baseline assessment, The Care Plan MIPS measure was the basis for the inclusion criteria used for the chart review. Charts for patients who were aged 65 years and older and that indicated yes to have a living will, advance directive, or advance care plan as assessed on admission and/or containing documentation of discussion on ACP between patient and his/her care team were considered to be indicative of participation in ACP.

3. RESULTS

The post-training chart review showed Care Plan MIPS measure or participation in ACP at the GMHA SNU facility improved from 25% at baseline to 100% post-training (Table 2).

Table 2. Participation in ACP at GMHA SNU, January 2019 – February 2021

	Prior to training	After training
Number of SNU patients aged 65 years and older at time of chart review[1]	16	12
Number of patients with some type of ACP in medical record	4	12
Percentage of patients with some type of ACP in medical record	25%	100%

[1]The total census for the GMHA SNU varies, depending on the time period during which the chart review was conducted. The prior-to-training chart review was conducted January through June 2019 whereas the after-training chart review happened in February 2021. Thus, the total census is different for the different time periods.

Evaluative comments of the trainings were positive, as participants felt the training objectives were met and the topics were clearly presented. Suggestions for improving ACP knowledge and participation included revisiting importance of ACP at staff meetings throughout the year and posting the training in an online media platform such as YouTube to provide expanded access to the public. It also was recommended that training/education would be done for the public in order to increase community awareness about ACP.

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Themes that emerged from the discussions that accompanied the trainings included:

- Many patients and families are not aware about ACP.
- Some health care professionals were unaware about ACP and its importance in health care outcomes.
- Cultural beliefs about elders and death act as a barrier to ACP participation. These included fear of not fulfilling one's responsibility of taking care of a family member and fear of death.
- Language was identified as a barrier, as English is a second language for many patients and their families. Consequently, both written and oral communication in the patients and families' non-native language about medical information can result in patients and their families having difficulty understanding or comprehending the information.
- Disbelief that the patient/family member is dying was another identified barrier to ACP participation.

4. DISCUSSION

Currently, there is a paucity of information about ACP in Guam and the rest of Micronesia. Working on the premise that ACP participation in Guam would be similarly low to the participation observed in the U.S. and Asia, the Guam/Micronesia GWEP sought to improve participation in ACP through education, as other initiatives have shown that either education has improved participation in ACP [6, 9, 15] or recommended that education would likely be helpful in improving participation in ACP [7, 9, 14, 15, 17, 21, 22, 25]. The post-training chart review findings showed that ACP participation at the GMHA SNU improved to 100% with training health care personnel in the 4Ms and ACP. This supports that education is an effective means of clinical practice transformation and can result in improved participation in ACP.

In addition to demonstrating how education can be an effective means of improving participation in ACP, the Guam/Micronesia GWEP initiative at the GMHA SNU helped to reveal some possible insight into community and cultural barriers in Guam to participation in ACP. They included lack of ACP awareness by patients, their families, and some health care professionals; cultural beliefs about elders and death; language; and disbelief that the patient/family member is dying. Although this information was collected through an informal process, it may prove insightful in further understanding the knowledge and attitudes toward ACP in Guam and possibly Micronesia. The is supported by the observation that these findings are quite similar to the findings of others. Other initiatives have shown how lack of ACP knowledge or understanding [5, 6, 13, 15, 19] cultural barriers [17, 21], and denial and evasion [22] contribute to low participation in ACP.

Additional feedback for the training included expanding the training beyond health care personnel to the public so as to improve community awareness and knowledge of ACP. Again, although this information was collected through an informal process, it is consistent with or similar to the observations of others for the need for community-based strategies and interventions for ACP [7, 17, 25, 28]. It also has been suggested that a multi-disciplinary or interprofessional approach toward raising ACP awareness and knowledge would be helpful [15, 25, 29].

4.1 Current work and recommendation for further research and interventions

Based on the training feedback to provide education to the public and building on the possible benefit of a community-based multi-disciplinary strategy as recommended by others, the Guam/Micronesia GWEP has currently expanded ACP education to the community level

and is doing so in collaboration with the Guam Department of Public Health and Social Services Division of Senior Citizens and the Elder Justice Center. Currently the ACP education sessions for the public are advertised through both virtual and paper flyers. Due to local restrictions on gatherings because of the COVID-19 pandemic, the presentations are done over zoom and cover the core concepts of an age-friendly health system, the 4Ms, advance care planning, advance directives, and barriers to ACP. The sessions are 1.5 hours long and include questions and discussion. Given that this is being done on a community, island-wide scale, there is no current means for assessment of impact on these sessions on ACP participation in Guam, as no baseline data exists for ACP participation. A possible future study may seek to assess both baseline data for ACP participation in Guam and change over time with different community-based multi-disciplinary strategies.

Another possible future initiative that could possibly be quite beneficial would be one that formally assesses the knowledge, attitudes, and barriers in Guam toward ACP. Understanding these could prove helpful in designing both community and culturally appropriate interventions aimed toward increasing awareness, knowledge, understanding, and participation in ACP. This has been observed and recommended in other initiatives [9, 17, 21, 25]. Additionally, a consideration for these community and culturally ap-propriate interventions would be translating the materials into the native language of the audience, tailoring the information to each cultural group, and/or training people who are part of the respective cultures in ACP counseling/education, as this has been recommended by other initiatives [17, 21, 25]. This likely would be beneficial for Guam, which has a culturally diverse population.

5. CONCLUSIONS

The findings of this clinical practice transformation initiative are that education is effective at increasing participation in ACP and that education is recommended for both health care professionals and the public using community-based strategies and a multi-disciplinary approach. Incidental and preliminary findings were barriers to ACP in Guam, which included lack of knowledge and awareness; cultural beliefs about elders and death; language; and a disbelief that the patient/family member is dying. The recommendation is to further investigate the current knowledge, attitudes, and barriers to ACP participation in Guam and Micronesia so as to tailor effective community-based and culturally appropriate educational interventions aimed at increasing ACP knowledge and participation. The hope is that it will ultimately develop health care facilities in Guam and Micronesia into an age-friendly health system, and result in patients and their families receiving care that is consistent with what matters most to them.

Informed Consent Statement: Not applicable: The International Review Board did not require individual consent from individual participants, as data was de-identified prior to any data analysis.

Informed consent was obtained for evaluation data from participants in educational session.

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Institutional Review Board Statement: The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Institutional Review Board of The University of Guam protocol code: CHRS# 19-157 approval date: 11/23/2019

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