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Partnership Between Islam and Palliative Care at Swedish Health Services

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Doctor of Nursing Practice Capstone Project: Executive Summary

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Introduction

The spiritual practice of Islam is considered one of the three major monotheistic religions. Islam is the second largest religion in the world with 1.6 billion followers; about 3.5 million of those live in the U.S.[1] The number of Muslims in the U.S. is projected to double by 2030.[1] Additionally, the number of adults age 65 and older in the U.S. is projected to double from 46 million today to over 98 million by 2060.[2] As the U.S. population ages, many healthcare workers are often too overwhelmed to handle the varying and intricate social, economic, familial, spiritual, and cultural needs of older adults with complex chronic disease or life-limiting illness. A palliative care team that respects and values one's cultural and spiritual needs is vital to not only support providers in day-to-day activities, but also to give patients and families the support of a person with specialized knowledge to help with chronic illnesses as well as the end-of-life transition. Providing culturally sensitive resources such as a palliative care team that understands the needs of their Muslim population is vital to Swedish Medical Center's core beliefs and values which include, compassion, dignity and excellence.[8] More specifically, nurturing each patient's spiritual essence is a goal within the Swedish mission of compassion, which aligns with this project's goal.[8] Thus, this Doctor of Nursing Practice (DNP) project aims to complete a needs assessment and a gap analysis of the use of palliative care services for patients adhering to Islam at Swedish Medical Center's First Hill (FH) and Cherry Hill (CH) locations.

Objectives

The following objectives were met during the implementation of this project:

1. Interview Muslim patients on the palliative care list at FH and CH using a modified faith, importance, community, and address (FICA) questionnaire (see Appendix A).
2. Create 2 surveys (see Appendix B & C) to assess barriers and baseline knowledge faced by the palliative care team (chaplains/providers/social workers) when providing care to patients of the Muslim faith.
3. Analyze surveys and interview responses as well as barriers identified by a Muslim Imam trained in chaplaincy to help group findings into themes and formulate recommendations (educational PowerPoint and pamphlets) to support the palliative care team.
4. Create and implement a plan to provide an Islamic toolkit that will include a prayer rug, a compass, and a dry ablution kit.
5. Develop system/policy recommendations on methods to bridge community and hospital resources to provide an Imam presence when needed and outline next steps in resource development and sustainability of this work after completion of the project.

Background and Significance

Islam differs from other faiths in the belief that Muhammed, Peace be Upon Him (PBUH) is God's last messenger. As a form of respect to God's last prophet, followers must say, "Peace Be Upon Him," after the mention of his name or abbreviate their response as, "PBUH" in written format. The belief in God and Muhammad (PBUH) as the last messenger is the first of the Five Pillars that form the core beliefs and practices of the Islamic faith. The Five Pillars also include praying five times a day facing Makkah (Islam's holiest site), fasting during the month of Ramadan, being charitable to the poor, and lastly, performing a pilgrimage to Makkah in Saudi Arabia once during a person's lifetime, if financially able. The holy text of Islam is called the Qur'an, which Muslims believe to be the word of God as taught by prophet Muhammad (PBUH). The Qur'an is supported by the Sunnah, which are the narrations from the companions and family of the prophet (PBUH) that illustrate his day-to-day dealings throughout his lifetime. This text is a major source of Islamic law. For followers of Islam, their religion dictates specifics

regarding all aspects of life, including the sanctity of life, suffering, death and dying, and even life after death.[3]

Islam forbids hopelessness and lamenting the illness or decisions regarding illness. Often when western medicine falls short, Muslim patients and families rely on spirituality to fill the void.[3] Muslims are reminded in the Quran to be patient and to seek forgiveness as a means of worship and are reminded that time of death is predestined. Predestination is an important concept in Islam which dictates that certain monumental events like birth, death and marriage are predetermined at the time when the soul(ruh') enters the body in the womb; at 6 weeks.[4] Islam supports most of the tenants of palliative care around death and serious illness, including affirming life, easing suffering, and treating the dying with compassion and dignity.[3] However, sensitivity to the type and amount of analgesia provided to a Muslim patient for comfort is essential. Muslim patients might refuse palliative care services due to the belief that it contradicts the Islamic belief of "redemptive suffering" which is the idea that pain and suffering is a means of expiating sins.[5, 6]

In a literature review it was found that because of the limited use of Palliative care in Muslim majority countries, there is minimal research about Palliative care and Muslim patients.[5, 6] Of the few studies on this subject, three major themes emerged that are appropriate in this project's context.[5,6] The themes include improving Muslim patient experience, patient care delivery suggestions for the provider, and cultural and religious barriers to analgesia use.

Summary of Implementation Process

The framework used for the project was the Johns Hopkins evidence-based model (JHEBM) using its 19 step practice-evidence-translation (PET) process.[7] This three-phase model addresses and offers the best way to approach the limited research available in this subject. First phase in the JHEBM is to formulate a practice question, refine the question and lastly define the scope of the project. The practice question that defined the scope of the project was: At Swedish FH and CH, are there any gaps in the palliative care services provided to Muslim patients during chronic/terminal illness and end of life transition?

Design and implementation plan

1. Patient interviews (see Appendix A).
    a. Interviews deductively coded using three themes identified from literature.
    b. Collective analysis of each theme for potential recommendations/resource building.
2. Epic Data extraction for all Swedish campuses that provide Palliative Care.
    a. All deceased Muslim patients with palliative care in their problems list from 2017-2020.
    b. All deceased Muslim patients who were seen at Swedish from 2017-2020.
3. Barrier to spiritual practice survey (see Appendix B)
    c. Survey administered electronically to members of the palliative care team.
        - Analysis through average and median scores of the survey's 10 items.
        - Provide recommendations on the top two barriers identified and how these barriers may impact the patient experience.
4. Knowledge of Islam survey (see Appendix C).
    a. Survey was administered to members of the palliative care team electronically.
    b. Results calculated and recommendations targeted for those questions that have scored below 50%.

5. External factors outside of the palliative care team were addressed indirectly through providing resources like Imams and prayer kits for patients of the Muslim faith.
    a. Address regulatory requirements regarding having a designated and available Muslim chaplain.
    b. Infectious diseases have been contacted to provide a path forward for patients to receive the prayer kit during COVID pandemic in a safe manner.
6. A Budget Proposal (see Appendix D) was submitted to Somali Health Board (SHB) to help provide resources like a prayer kit for Muslim patients utilizing Palliative Care at Swedish Medical Center.
    a. Proposal will be sent to Greg Malone, director of Palliative Care Services and all the palliative care Chaplains for additional prayer kits as needed after this project completes.

Outcomes/Deliverables.

All identified patients who met the interview criteria during the project period were COVID positive and non-verbal. Two families declined interviews, and a third patient was incorrectly identified to be Muslim. As a result, only one patient was interviewed for this project. See Appendix F for descriptive table of the results of each survey by discipline. The barriers to spiritual care survey response rate 67% and included five chaplains and three providers, one social worker, and one anonymous response. The knowledge survey, response rate which included five providers, five chaplains and one social worker was 73%. Lastly, prayer kits were delivered to both FH, CH and Edmonds campuses, which was welcomed with overwhelming support by the chaplains. Barriers faced during this project included logistical difficulties in accessing Epic remotely. Another limitation of this project was the limited access to patients and families due to the no visitation rules as a result of the COVID pandemic. A summary of the findings gathered from the only patient interview, survey results, and epic data analysis are described as follows:

Patient Interview Themes

The three major themes identified from literature were used to transcribe patients' interview.

- Improving the Muslim patient experience through:
    - Imam Presence, recognizing redemptive suffering, recognizing the concept of predestination, pork ingredient (i.e., docusate sodium) provided in encapsulated tablets.
- Patient care delivery suggestions.
    - Religious accommodation (e.g., not playing music in OR but rather Quran for patient).
- Analgesia use
    - Consideration for patients religious and spiritual obligation when offering analgesia for comfort.

Survey results: Barriers: Two biggest Barriers.

On a scale of 1 (the highest ranked barrier) to 10 (the lowest ranked barrier)

- Time was the biggest barrier with a mean of 3.2 (standard deviation [SD] 3.4, median 2.0)
- The belief that spiritual care is better done by others in the health care team was the second biggest barrier with a mean of 3.4 (SD 2.0, median 4.0)

Survey results: Knowledge survey

- Purification for prayer in which 9% answered correctly.
- Question asked if Islam forbids care by a member of the opposite sex during hospitalization in which 27% answered correctly.

- Of note two other areas regarding the Islamic rules about grief and the name of ritual purification prior to prayer received scores of 63% and 55%, respectively.

Interestingly, three of five chaplains felt patients did not want spiritual care from providers, rather patients needed sensitivity and understanding about their faith. Arguably this can be viewed as a form of spiritual engagement.

Epic Data Analysis

From the Epic data, 37% (n = 126) of Muslim patients who died as inpatients between 2017-2020 had palliative care as part of their quality metrics. When this data is further examined by year, palliative care usage had been steadily increasing starting with 2017 in which 2 patients utilized palliative care services, 5 patients in 2018, 22 patients in 2019 and 18 patients in 2020. Furthermore, when percentages are examined between 2019 and 2020, 69% (n = 26) of patient in 2020 had palliative care as part of the quality metric compared to only 30% (n = 74) in 2019.

Recommendation and Discussion.

The implementation of this project reveals knowledge, system, and resource gaps.
Knowledge gaps as identified in knowledge survey:

- Islamic ritual purifications, how Muslims grieve and lastly whether caregivers of the opposite sex can provide care.

Recommendations:

- On 1/27/2021, power point presentation to Swedish First Hill, Cherry Hill, and Edmonds.
- Will create an education binder for the palliative care team; and have a yearly review of the binder with Imam Qasim who is currently known to Swedish chaplains.

System gaps as identified in the barrier to spiritual care (SC) survey:

- Lack of time and lack of training as the first and second reason identified.

Recommendations:

- Monthly meetings to specifically discuss particular cases and learnings through mechanisms like palliative grand rounds.
- Utilize a 5-Part communication framework that questions how family and patient make decisions, how the illness is understood, information regarding the patient's religious and spiritual beliefs and lastly how the provider should share the information and negotiate any conflicts (see Appendix E).[8]

Resource gaps:

Recommendations:

- Continue use and availability of prayer kit as well as extending resources to all campuses.
- Imam to be trained and credentialed specifically for Swedish Health Services. This person to be a volunteer for Swedish but reimbursed through the community and tied to a local Mosque.

Finally, this project has implications for practice including better outcomes for patients by increasing patient satisfaction and providing care that values spirituality. The knowledge gaps and barriers perceived by providers must be addressed in order to provide spiritual/cultural-concordant care to those facing serious/terminal illness. From the Epic data, we can see that the number of Muslim patients needing palliative care is increasing. Thus, it is important to engage in the kind of internal assessment of palliative care provision to Muslims within the setting. It is not simply enough to care about pain control and symptom palliation, this project reinforces that spirituality must be central to the palliative care of every patient that desires it.

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Appendix A: Modified FICA assessment tool patient interview

F – Faith, Belief, Meaning

1. What is your faith or belief?
2. Is this your first time utilizing palliative care.
3. Do you consider yourself spiritual or religious?
3. What things do you believe in that give meaning to your life?

I – Importance and Influence

1. Is it [faith or belief] important in your life?
2. What influence does it have on how you take care of yourself?
3. How have your beliefs influenced your behavior through/during this illness?
4. What role do your beliefs play in regaining your health?

C – Community

1. Are you part of a spiritual or religious community?
2. Is this of support to you and how?
3. Is there a person or group of people you really love or who are important to you?
4. Do you have a spiritual leader? Would you like this person to be involved?
5. How do you feel about community support? Is it ok for community to give support? How would this look?
6. How would you explain palliative care to a friend? Do you know about hospice? How is it different than palliative care?
7. How would you like family involved in terms knowledge about your diagnosis and treatment plan? Is there a specific designated person(s) that you would like to be present for decisions regarding care?

A – Address

1. Is it important for you to discuss your spiritual issues or your beliefs with your doctor?
2. Why is it important to discuss your spiritual beliefs with your doctor?
3. Is it important for you to receive assistance or help with prayer? (e.g. facilities or accompaniment or materials)
4. Is it important for you to speak to a chaplain of the same spiritual beliefs? Why or why not?
5. How do you view psychological illness?
6. Would you like to treat pain right away? Would you rather experience more pain to have a clear mind? Why?
7. How much pain is too much pain?
8. How do you view illness in general?

Appendix B: Barrier to spiritual questions survey response

Below is a list of reasons spiritual care might not be performed by providers (doctors, APPs) with patients even when ideally it would be performed; identified in Balboni et al 2014.

Question 1.

Please **rank order** each of the following factors in how you think **they limit** your provision of spiritual care to your palliative care patients. Choose **1 as being the reason most** likely **for you,** and **10 being the least likely factor.** Each item should receive a rating, and each number 1-10 should only be used once.

This **survey is completely anonymous,** and your answers will be used to help assess if there are any gaps and provide recommendations that will improve the partnership between Islam and palliative care.

Not enough time

Lack of private space to discuss these matters with my patients and or family.

I have not received adequate training.

I am personally uncomfortable discussing spiritual issues

Religion/spirituality is not important to me personally.

I believe that spiritual care is better done by others in the health care team.

I do not believe palliative care patients want spiritual care from providers.

I am worried that patients will feel uncomfortable.

I worry that the power inequity between patients and (providers) makes spiritual care inappropriate.

I feel uncomfortable engaging these issues with patients whose religious/spiritual beliefs may differ from my own.

Question 2.

I am a…

Provider

Chaplain

Other

Question 3.

If the survey did not accurately capture barriers to providing spiritual care, please write in the box below. Feel free to write in any additional information that would be helpful.

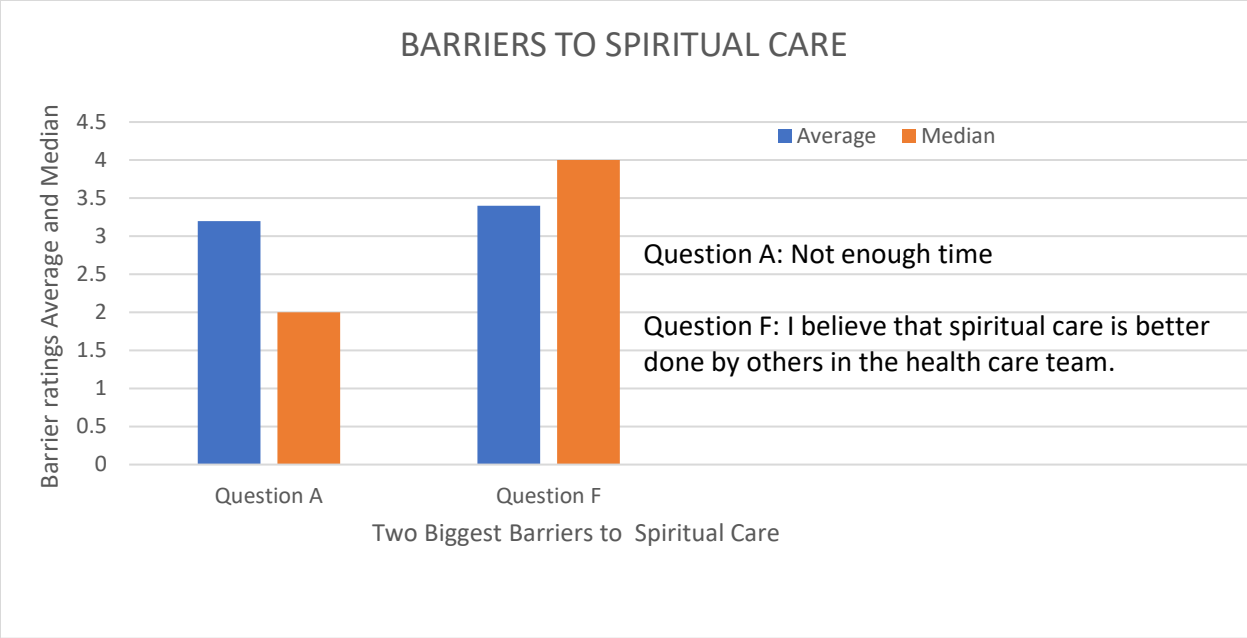
Appendix B: Barriers survey results. (N=10)

Please **rank order** each of the following factors in how you think **they limit** your provision of spiritual care to your palliative care patients. Choose **1 as being the reason most** likely **for you,** and **10 being the least likely factor.**

	A	B	C	D	E	F	G	H	I	J
Chaplain	2	3	6	8	7	5	1	9	4	10
Chaplain	1	4	10	7	9	6	5	2	3	8
Chaplain	10	4	2	1	8	3	5	7	6	9
Chaplain	2	1								
Chaplain	3	7	8	9	4	1	2	5	6	10
Provider	2	4	3	6	10	1	7	8	5	9
Provider	1	2	3	9	10	4	7	6	5	8
Provider	9	8	10	7	6	1	5	2	3	4
Social worker	1	4	7	9	6	5	2	8	3	10
Anonymous	1	2	3	4	7	5	6	8	9	10
Average Answers	**3.2**	**3.9**	**5.8**	**6.7**	**7.4**	**3.4**	**4.4**	**6.1**	**4.9**	**8.7**
Standard Deviation	**3.4**	**2.2**	**3.2**	**2.5**	**2.0**	**2.0**	**2.2**	**2.6**	**2.0**	**1.9**
Median	**2.0**	**4.0**	**6.0**	**7.0**	**7.0**	**4.0**	**5.0**	**7.0**	**5.0**	**9.0**

Legend: Questions of Survey.

Not enough time.	A
Lack of private space to discuss these matters with my patients and or family.	B
I have not received adequate training.	C
I am personally uncomfortable discussing spiritual issues.	D
Religion/spirituality is not important to me personally.	E
I believe that spiritual care is better done by others in the health care team.	F
I do not believe palliative care patients want spiritual care from providers.	G
I am worried that patients will feel uncomfortable.	H
I worry that the power inequity between patients and (providers) makes spiritual care inappropriate.	I
I feel uncomfortable engaging these issues with patients whose religious/spiritual beliefs may differ from my own.	J


BARRIERS TO SPIRITUAL CARE
Barrier ratings Average and Median
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
Average
Median
Question A
Question F
Two Biggest Barriers to Spiritual Care
Question A: Not enough time
Question F: I believe that spiritual care is better done by others in the health care team.

Appendix C: Islamic Knowledge results

This is a general knowledge quiz about Islam. It is sourced from an article titled; How Islam Influences End-of-Life Care: Education for Palliative Care Clinicians by Leong et al (2016).

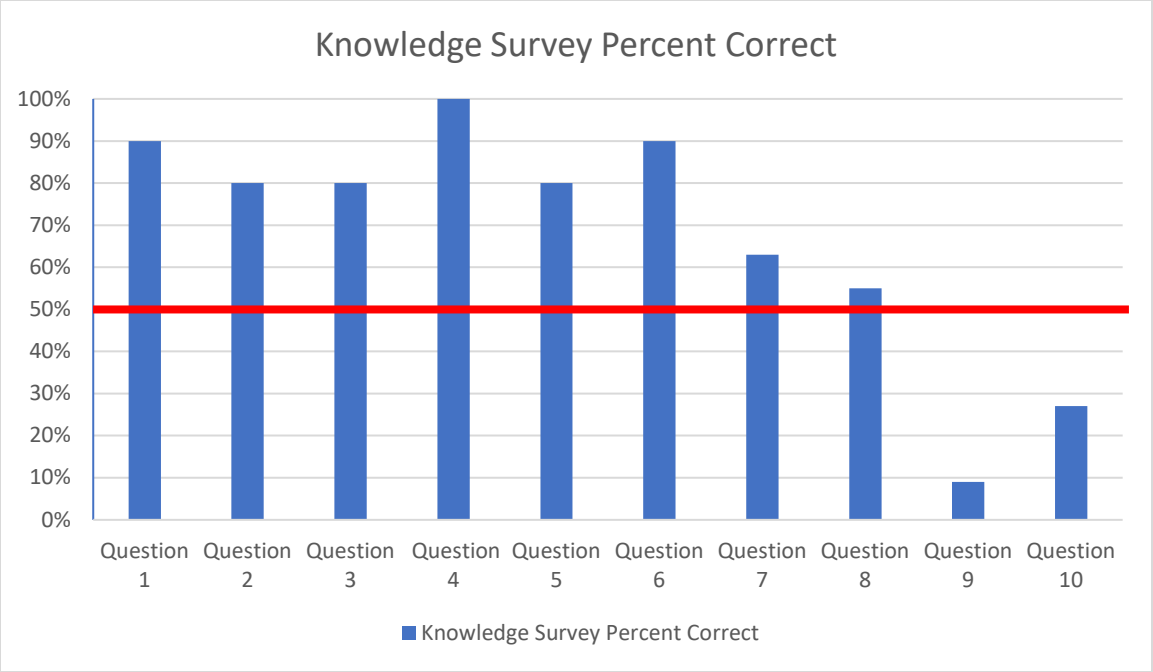
Instructions: Please take without the help of outside resources. Thank you.
This **survey is completely anonymous,** and your answers will be used to help assess if there are any gaps and provide recommendations that will improve the partnership between Islam and palliative care.

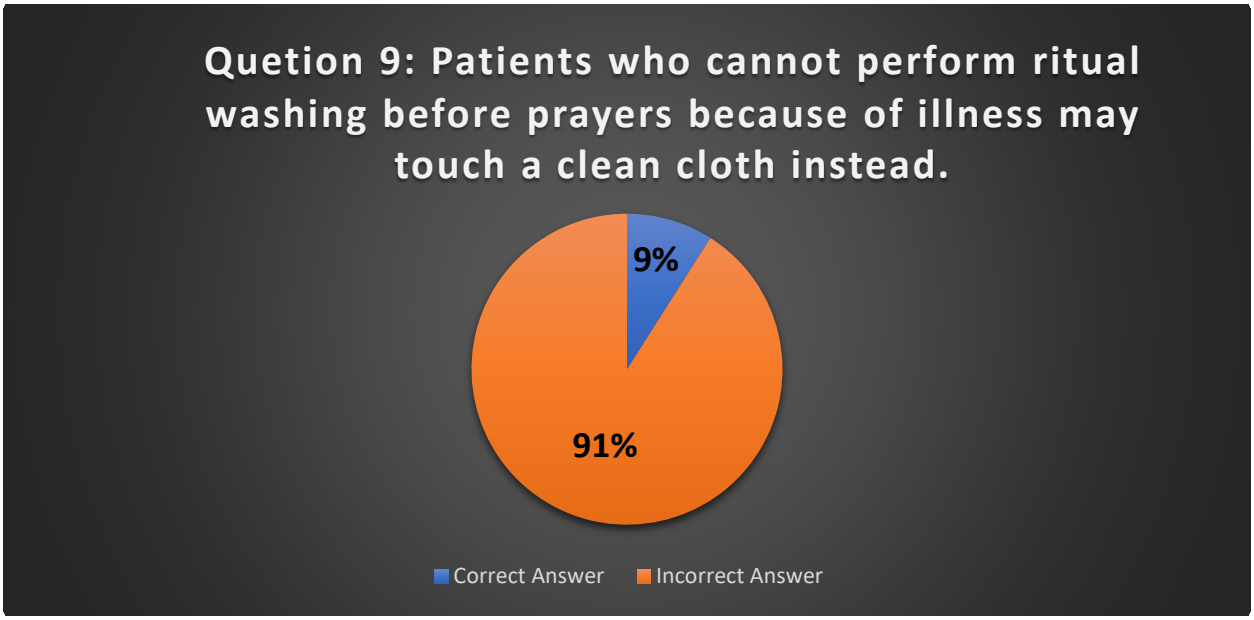
1. According to Islamic teachings, Muslims should seek treatment when they fall ill. TRUE or FALSE.
2. According to Islamic teachings, suffering may be viewed as a way to gain grace and mercy. TRUE or FALSE.
3. According to Islamic teachings, relieving suffering is virtuous. TRUE or FALSE.
4. According to Islamic teachings, serious, treatable, communicable diseases should be treated. TRUE or FALSE.
5. According to Islamic teaching, a patient who is bed-bound is not required to pray daily. TRUE or FALSE.
6. According to Islamic teachings, cremation is acceptable. TRUE or FALSE.
7. According to Islamic teachings, grief can and should be expressed with obvious emotion, such as wailing and lamentation. TRUE or FALSE.
8. The ritual washing of the face, forearms, and feet before prayers is called:
Sunnah, Wudu, Tayammum, Shahadah.
9. Patients who cannot perform ritual washing before prayers because of illness may touch a clean cloth instead. TRUE or FALSE.
10. According to Islamic teachings it is forbidden for caregivers to be of the opposite gender. TRUE or FALSE.

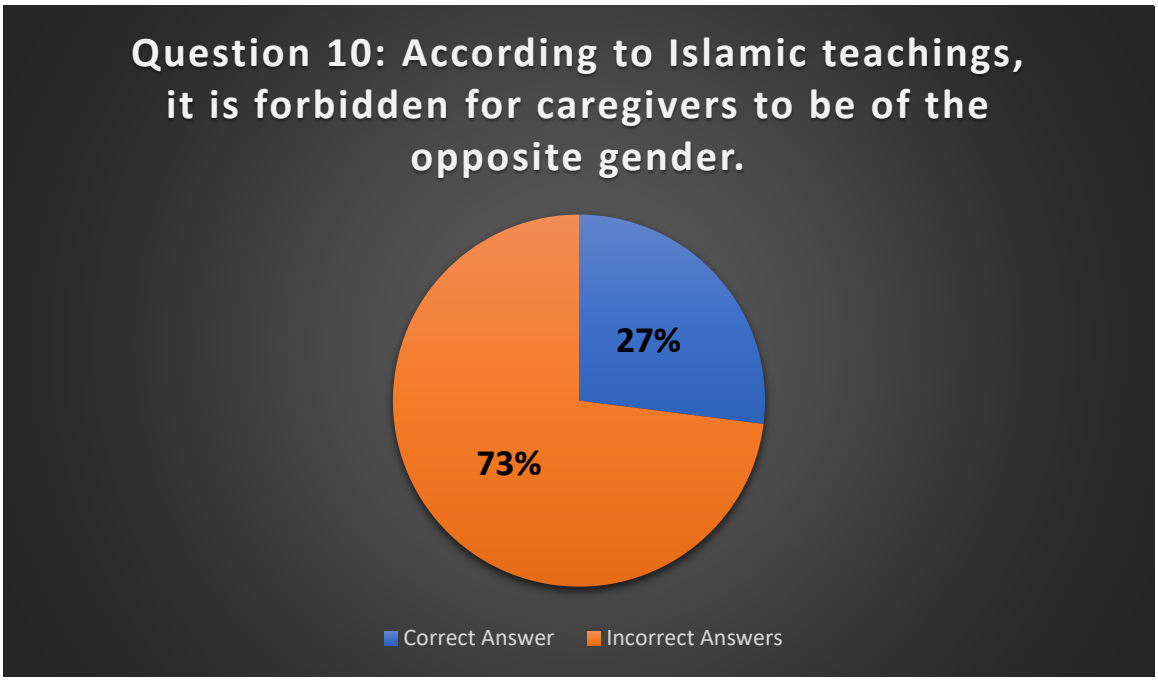
Appendix C: Knowledge questions results (N-11)

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Chaplain	True	False	True	True	True	False	True	Wudu	True	False
Chaplain	True	True	True	True	False	False	False	Wudu	True	True
Chaplin	True	True	True	True	False	True	True	Wudu	True	True
Chaplin	True	True	True	True	False	False	False	Wudu	True	True
Chaplin	True	True	True	True	False	False	False	Wudu	False	True
Provider - MD/PA/ARNP	True	True	True	True	True	False	True	Shahada	True	True
Provider - MD/PA/ARNP	True	True	False	True	False	False	False	Sunnah	True	True
Provider - MD/PA/ARNP	True	True	True	True	False	False	False	Shahada	True	False
Provider - MD/PA/ARNP	False	True	False	True	False	False	False	Sunnah	True	False
Provider - MD/PA/ARNP	True	True	True	True	False	False	False	Wudu	True	True
Social Worker	True	False	True	True	False	False	True	Sunnah	True	True
Correct answer and percentage correct	**True 90%**	**True 80%**	**True 80%**	**True 100%**	**False 80%**	**False 90%**	**False 63%**	**Wudu 55%**	**False 9%**	**False 27%**

Legend: Questions of Survey.	
According to Islamic teachings, Muslims should seek treatment when they fall ill.	Q1
According to Islamic teachings, suffering may be viewed as a way to gain grace and mercy.	Q2
According to Islamic teachings, relieving suffering is virtuous.	Q3
According to Islamic teachings, serious, treatable, communicable diseases should be treated.	Q4
According to Islamic teaching, a patient who is bed-bound is not required to pray daily.	Q5
According to Islamic teaching, cremation is acceptable.	Q6
According to Islamic teachings, grief can and should be expressed with obvious emotion, such as wailing and lamentation.	Q7
The ritual washing of the face, forearms, and feet before prayers is called:	Q8
Patients who cannot perform ritual washing before prayers because of illness may touch a clean cloth instead.	Q9
According to Islamic teachings, it is forbidden for caregivers to be of the opposite gender.	Q10


Knowledge Survey Percent Correct
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Question 1
Question 2
Question 3
Question 4
Question 5
Question 6
Question 7
Question 8
Question 9
Question 10
Knowledge Survey Percent Correct


Quetion 9: Patients who cannot perform ritual washing before prayers because of illness may touch a clean cloth instead.
9%
91%
Correct Answer
Incorrect Answer


Question 10: According to Islamic teachings, it is forbidden for caregivers to be of the opposite gender.
27%
73%
Correct Answer
Incorrect Answers

Appendix D: Budget Proposal

Budget Proposal: Resource Development for Muslims accessing Palliative Care at Swedish.

Executive Summary:

I am currently a third-year DNP student in the Acute Care Track at the University of Washington and I currently work at Swedish Cherry Hill. As a DNP student, I will be working on a DNP Capstone Project titled Partnership Between Islam and Palliative Care at Swedish. In this project, I envision the following:

1. Perform a needs assessment on the current knowledge of our palliative care team (chaplains and health care providers) to support those of Islamic belief.
2. Using the information from the needs assessment, perform a gap analysis, and develop an educational tool that can support the palliative care team.
3. Provide additional recommendations based on needs assessment and gap analysis.
4. Address bridging community Imams and Swedish Health Care system in providing Imam presence in the hospital when needed.
5. Determine approaches to the next steps in resource development and sustainability of this work after completion of the project.

Item	Price	Number	Total
Tayammum 	$6.95	12	$83.4
	$1:00	12	$12
TOTAL PRICE:			$95.40

I am requesting funding from the Somali Health Board to assist with resource development. I am putting together an initial Kit for the Muslim patients seeking palliative care in the Swedish system that includes a Tayammum and a prayer mat with a compass.

Timeline: I would like to purchase the items before the 10/30/2020. These items will be made available to the palliative care teams at Swedish First Hill and Swedish Cherry Hill before 12/30/2020.

Appendix E: Communication framework[8]

The 5-Part Communication Framework and Example Questions	
Key concept	**Example questions**
Elicit the patient's explanatory model of illness	What do you understand about your illness? What do you think caused your illness? What kind of treatment are you hoping for?
Address the patient's religious or spiritual values	Are you at peace? Do you find comfort in religious or spiritual beliefs?
Determine the patient's desired approach to truth telling	What kind of information about your health would help you make difficult decisions?
Understand how the patient's family is involved in the care	Do you make decisions collectively with your family?
Negotiate cultural conflicts when they arise	What matters the most to you as we think about your illness? Can you tell me more about your values?

Appendix F: Descriptive Table

Descriptive Table: N-15			
Discipline Name	**Number of Each Discipline**	**Response Rate-Barrier Survey***	**Response Rate Knowledge Survey**
Chaplains	5	100% (5)	100% (5)
Providers	8	37% (3)	63% (5)
Social Workers	2	50% (1)	50% (1)
Average	15	67%	73%

*one anonymous included in data analysis in the barrier survey- 10 total took the assessment.

Appendix G: Prayer Kit presentation to Chaplains