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Provider Recommendations for High Quality End-of-Life Care for Advanced Heart Failure Patients

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PROVIDER RECOMMENDATIONS FOR HIGH QUALITY END-OF-LIFE CARE FOR ADVANCED HEART FAILURE PATIENTS



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Introduction

This capstone is in conjunction with a qualitative research study titled: “Defining High Quality End-of Life Care for Advanced Heart Failure Patients” conducted by Maine Medical Center Research Institute (MMCRI) staff, and led by palliative care attending, Dr. Rebecca Hutchinson. Their study is composed of 25 interviews with cardiologists that will be transcribed, analyzed, and findings will be compiled in a final publication.

The final product for this capstone is a set of recommendations for providers regarding end-of-life care for advanced heart failure patients including a review of common themes and benchmarks for quality improvement. This capstone can serve as a tool for providers who have patients with advanced heart failure recognize barriers and improve the quality and access to palliative care.

Goals

1. To develop a set of provider recommendations for end-of-life care for patients with advanced heart failure.
2. To research background literature and review common themes between the research and interviews with cardiologists.

Methods

Literature Search and Review

This review was completed within the first month of the project. The scope of the literature search for barriers to palliative care includes peer-reviewed articles in the past ten years, between 2008-2018 using databases including: Academic Search Complete, Google Scholar, and PubMed. Additionally, literature that was recommended from CORE research staff was also included. The availability and amount of sources is displayed in Appendix A.

Interviews and Transcripts

For this project, investigators at the Center for Outcomes Research and Evaluation (CORE) are continuing to conduct 25 semi-structured interviews with cardiologists (including advanced heart failure specialists and electrophysiologists)- and primary care physicians at MaineHealth between January and May of 2018. These interviews are still ongoing, and a total of 18 have been completed thus far. These interviews sought to understand how clinicians characterize high-quality end-of-life care for patients with advanced heart failure. Interviews specifically explored how intensity of care, rurality of patient residence, location of death (e.g. home versus hospital), involvement of palliative care and/or hospice care might impact the quality of end-of-life care provided. Interviews also focused on how prognostication might impact patient care. Interviews were recorded, transcribed, and then deidentified by research staff. I was not present for these

interviews, but was involved with reading, analyzing, and participating in coding meetings for three transcribed interviews.

Qualitative Analysis

The qualitative data from this study was analyzed using MaxQDA software. The transcripts were imported into the software to categorize providers' responses for themes and line-by-line assisted coding. Data was analyzed using the grounded theory approach, which involves constant comparative analysis to develop a theory that is grounded in data systematically gathered and analyzed (Strauss & Corbin, 1994).

Institutional Review Board

This capstone was granted an exemption from USM IRB review per Title 45 CFR Part 46. This is because I was only involved with the deidentified transcripts and was not present for the interviews. Therefore, this did not qualify as human subjects' research.

Literature Review

Statement of the Problem

Heart failure affects millions of people across the world, and is unfortunately associated with poor short-term and long-term survival. It commonly results in hospital readmissions and a gradual decline in health and quality of life as cardiac function worsens. Numerous studies show the high impact this has on one's health status and quality of life from distressing symptoms affecting both physical and psychological health (Riley et al., 2016). Few interventions currently exist that address patient's existential needs;- most focus more so on pain and symptom control (Stechuchak et al., 2017). While this is still a critical component, many patients and their families often feel that their end-of-life care may fall short on psychological, social, and spiritual needs. High quality end-of-life care, is of significant need for advanced heart failure patients due to their high rate of symptoms, psychological distress, significant uncertainty in their disease, and prognosis. However, several challenges exist to integrate effective, high quality end-of-life care available for patients. Barriers to this include: lack of knowledge on palliative care, discomfort or lack of confidence in ability to discuss end-of-life concerns, prognostic uncertainty, delayed recognition of end stage disease, lack of awareness of resources/referrals, and confusion on the differences between palliative, end-of-life, and hospice care (Hawley, 2017; Lindvall et al., 2014).

Purpose Statement

The purpose of this review is to understand how physicians caring for patients with advanced heart failure think about end-of-life care, the barriers to high quality end-of-life care, as well as a brief look at the types of efforts currently used to manage this. This will provide further guidance for shaping recommendations for providers on this subject.

Barriers to High-Quality Palliative Care

Lack of Knowledge

There is recognition that many providers and patients do not understand the benefits of palliative care. Through 18 semi structured interviews with providers, Kavalieratos and colleagues found that nearly all primary care and cardiology providers were unaware that palliative care can be implemented early on in a patient's diagnosis in conjunction with life-prolonging therapy, rather than being dependent on prognosis. Many failed to see palliative care as an actual clinical service and saw hospice as the appropriate approach to maximize quality of life. There was also a noted misconception on the difference between "hospice" and "palliative care"- several nonpalliative care providers admitted that they didn't know how to access palliative care or know what they do. Conversely, the literature supports that patients can experience a similar lack of awareness of palliative care and how to access it (Boyd et al., 2004). If providers do not initiate a discussion around end-of-life care-or provide education on the benefits of palliative care- patients are not able to adequately express their wishes, values, and treatment choices for future care. Furthermore, patients frequently fail to recognize the severity of their disease when it's not explicitly discussed by their providers (Browne et al., 2014 and Seymour et al., 2010).

Delayed Recognition of End Stage Disease

Due to the unpredictable trajectory of heart failure, there is often limited time to provide high quality end-of-life care before it is too late. Health professionals have agreed that they lack the knowledge related to the opportunities and adequate support to improve this situation (Browne et al., 2014). Literature shows that recognizing prognostic signs that a patient is moving into the last stage of their disease is a major challenge for both the provider and patient

(Kavalieratos et al., 2014 and Glogowska et al., 2016). It is evident that providers may rely on subconscious reasoning to determine this as opposed to a thought out reasoning process. Some providers may look for signs such as reoccurring hospital admissions, exhausting treatment options, comorbidity, or worsening renal function (Taylor et al., 2017; Greener et al., 2014; Glogowska et al., 2016). Uncertainty in prognosticating heart failure is very prevalent among providers and results in a hesitance to initiate conversations with patients (Matlock et al., 2010).

Reluctance to Refer

Although palliative care can be helpful throughout the disease trajectory, there remains a reluctance to referrals. The literature shows that much of this is due to a lack of resources, poor understanding of the condition and the services of palliative care, fear of upsetting patients and their family, not understanding the benefits, or fear of feeling that they are “giving up” on the patient (Hawley, 2017; Lindvall et al., 2014; Browne et al., 2014). It’s suggested that providers feel much more strongly about fixing and treating a patient’s condition, rather than spending time addressing other concerns, such as sources of psychological or spiritual distress, that are common as the disease advances. Several studies have suggested that an earlier integration of palliative care is helpful in improving the quality of life of advanced heart failure patients without compromising length of life. (Kavalieratos et al., 2014 and Glogowska et al., 2016).

Several qualitative studies have identified “triggers” used by providers to initiate palliative care. This includes: specific symptom presence, functional decline in disease status, multiple hospitalizations, device implantation or automatically when transitions in care are documented. However, much of this varies by hospital as well as a providers individual readiness to act upon these triggers. Without a set of mutually agreed-upon triggers, there is opportunity to

act on inappropriate triggers, such as active dying, which could result in a late referral- or none at all (Kavalieratos et al., 2014; Glogowska et al., 2016, Hawley, 2017; Dionne-Odom et al., 2014).

Lack of Communication

The literature indicates that a providers lack of communication with a patient and their family regarding the severity of the patient's condition can be a major barrier for high quality care. This specifically relates to the need to start thinking about the goals and values for a patients care early on- rather than solely being linked to end-of-life care- which could lead to inappropriate treatment, and is associated with adverse outcomes and increased suffering (Glogowska et al., 2016 and Metzger et al., 2014). Specifically, the uncertainty and challenge of predicting prognosis in conjunction with possessing the necessary skills to assess patient readiness as well as helping those reticent patients engage in these important conversations are all barriers having timely goals of care conversations (Dionne-Odom et al., 2014). Incorrect language used during these conversations can be another obstacle. It is evident that "hospice" and "palliative care" are sometimes used interchangeably which may influence patients and their families to have negative associations and think of it only as getting them ready to die. It is suggested that some providers may lack the communication skills to sensitively inform a patient about their condition and prognosis, without sounding too hopeless (Hawley, 2017; Dionne-Odom et al., 2014; Kavalieratos et al., 2014). Additionally, a lack of continuity in providers can make it difficult for patients to develop trust and confidence to share their care goals (Ryan et al., 2009 and Bernacki et al., 2014). Furthermore, inadequate communication around a patient's anticipated end-of-life period early on in their care can greatly hinder palliative care acceptance among a patient and their family while still in the early stages (LeMond et al., 2011).

Current Efforts for Improvement

Interventions

Patients who are diagnosed with advanced heart failure can often experience a high burden of stress, and may have difficulty accessing palliative care. Home and team-based palliative care interventions may help to mitigate the negative impact of the disease (Diop et al., 2017). While palliative care can be helpful for a patient at any point, a major challenge for clinicians integrating high quality end-of-life care is to identify when they are approaching this stage. However, palliative care teams focus on optimizing quality of life through symptom management and ensuring goal-concordant care, which is beneficial at any stage of the disease process. It's evident that there is a need to initiate timely discussions regarding goals of care with patients and families in order to benefit from this (Lewin, W.H. et al., 2017).

End-of-Life Care Tools

Many tools and resources intended for health care providers regarding goals of care for patients are available online. This includes a virtual course format to learn basic skills to have a conversation about goals of care, frameworks to improve care, a set of frequently asked questions regarding Medicare reimbursements for goals of care conversations, and online modules to raise awareness on ethno geriatrics, (The Conversation Project, 2017). Additionally, there are many resources available intended for patients which providers can promote to families, including: questionnaires regarding goals of care, values worksheets, documents to solidify a consent or refusal of care, information on end-of-life options, and tips on how to interview a hospice (Compassion and Choices, n.d.).

Qualitative Theme Findings

The transcripts revealed a variety of themes present on the topic of high quality end-of-life care for advanced heart failure patients that were consistent with the findings from the literature review. The major themes have been detailed below:

Barriers to High-Quality Care

Several providers identified barriers to care, specifically regarding a patient's health literacy or living in rural areas. Providers also expressed that their colleagues have felt that consulting palliative care would feel as though they are "giving up" on a patient. For those that have consulted, it was noted that it may have been too late and should have been initiated earlier.

Defining High Quality End-of-Life Care

There were several factors suggested that providers felt define high quality end-of-life care. This includes: location of passing, patient knowledge of disease, managing symptoms, respecting patient's values and wishes, the timing of care, effective transition of care, effective therapies, reducing readmission, and using a multi-disciplinary approach.

Palliative Care Experiences

The majority of providers detailed positive experiences they've had working with a palliative care team, and felt that they were an important part of the transition of care. However, providers noted some difficulties navigating patient's negative perceptions of palliative care when it was introduced. It was not evident that this was introduced early on in the patient's course.

Patient Unpreparedness for End-of-Life Conversation

Many providers shared instances where it was clear that a patient was shocked and unprepared for an end-of-life conversation that was initiated by their doctor. It's suggested that this is in the minority of cases, however, there can be a misunderstanding among patients and their families

regarding how sick they are. This may depend on several factors, including how the provider delivers the conversation, the language they use, the patient's level of health literacy, or who the introduction to the conversation is coming from.

Need for Improvement

There was a very clear acknowledgement in all responses that there is a need for improvement in order to optimize end-of-life care for advanced heart failure patients. This was mentioned in regards to consulting palliative care, initiating an end-of-life conversation, recognizing a patient's end stage, reducing wasteful end-of-life care, suggesting palliative care to patients/families, and the delivery of a patient's prognosis.

Conversation Strategy

It was evident that there are varied strategies taken on by each provider regarding how they choose to initiate an end-of-life conversation. Some choose to take the chance to initiate goals of care if the patient suggests it, while others introduce it by going over the patient's recent health decline. Some take a different approach and choose to discuss it on an ongoing basis at different stages of the disease. Others may leave it up to the patient to decide if they would like to participate in further interventions/treatment.

Confidence with End-of-Life Care Conversations

Many providers expressed confidence regarding their ability to deal with planning for end-of-life care. Some didn't fear a patient's negative reaction by initiating planning, or felt confident about being able to identify when a patient is moving into an end-of-life period.

Discussion of Prognosis

Similarly to varied conversation strategies, providers also mentioned two different styles of discussing a patient's prognosis. One is by being vague and only using numbers regarding the

amount of time they have before reaching an end-of-life period in the terms of weeks, months or years, in a way that is graspable for them to understand. The other way is more so by using words and instead being transparent about the situation and what it looks like for that patient. Some providers felt that they should inform the patient about the unlikely success with further interventions rather than give them false hope. It was not evident that providers acknowledged prognostic uncertainty with patients.

Provider Uncertainty

While some providers felt confident with their ability to deal with end-of-life care planning, there were still many who felt uncertain about being able to identify an end-of-life period. This is also true for having a prognostic discussion and who should be the one to deliver that information. Others also expressed uncertainty regarding using telehealth as an option for palliative care.

Recommendations

The following recommendations were developed based on the overlapping themes between the interviews and literature review.

1. Incorporate Collaborative Learning Approach

The literature suggests that promoting education through patient visits and displaying palliative care resources and information in a clinic or hospital may help to initiate end-of-life discussions on the patients side between them and their family (Lindvall et al., 2014). This was echoed in the interviews as well among providers who noted a need for improvement regarding initiating an end-of-life conversation and suggesting palliative care early on.

This approach can allow patients to be more prepared for a conversation and be able to advocate for themselves, and be aware of their options during an end-of-life period.

Additionally, interviewees identified that there is a need for greater effort to incorporate palliative care as frontline staff to define, measure, and improve the quality of palliative care delivery and education within cardiology.

2. Early Identification of End-of-Life Period and Conversation Strategy

Recognizing when a patient is entering an end-of-life period early on can help to ensure that palliative care is integrated early enough to fully understand a patient's wishes and preferences regarding this care. It is important that this stage is not overlooked and, ideally, to have an end-of-life discussion prior to when this period has fully set in. The literature indicates this as a major barrier for integrating early palliative care (Kavalieratos et al., 2014 and Glogowska et al., 2016), and the interviewees acknowledged this as well.

Once recognized, this may require introducing palliative care in a way that implies extra support and comfortable care, rather than using language that may cause a patient or their family to have negative associations. Several interviewees commented on the different strategies used to discuss prognostic conversations, which was either in the context of time (such as weeks, months, years) or through descriptions. This has implied that when delivering this type of prognostic information, there should be a shared language used among all providers with a balance between being honest about a patient's outlook, without giving false hope or being too vague.

3. Utilize Patient-Centered Care

Wasteful care in a patient's end-of-life period appears to stem from efforts to implement further treatments or new interventions which can lead to extended suffering or negative outcomes that are inconsistent with a patient's values and wishes. This was evident in the literature which shows that providers may feel that they are "giving up" if they choose to consult palliative care (Hawley, 2017; Lindvall et al., 2014; Browne et al., 2014).

Interviewees expressed very similar beliefs, and admitted that there have been instances where they realized they waited too long to consult palliative care, and it should have been integrated earlier. Therefore, it is important for providers to utilize patient-centered communication and shared decision making during this time to reduce readmissions and improve their quality of life. Working collaboratively with palliative care could help to facilitate this, since palliative care is patient-centered within itself.

4. Increase Education and Training

The literature strongly indicates that many providers and patients do not understand the benefits of palliative care, or when to access it (Boyd et al., 2004 and Kavalieratos et al.,

2014). While the interviewees did not explicitly admit this, their other statements regarding a need for improvement for integrating palliative care supports the recommendation to increase education and awareness. Incorporating more ongoing education on the benefits of palliative care as well as how and when to consult them could greatly increase positive outcomes for a patient's experience. Additional trainings that focus on implementing patient-centered care and shared decision making could be especially beneficial. Fitzpatrick and colleagues found that this is also recommended for medical school curriculums to integrate more information on palliative care, it's distinction from hospice, how to navigate end-of-life issues, symptom management, and communication skills. However, it is important to be cognizant of overloading medical students to the point of burnout, and to carefully structure this type of education in pre-medical classes.

5. Use a Holistic Approach

Treating a patient with advanced heart failure from a holistic sense throughout their care could help to improve physical, psychosocial, and spiritual needs. The literature reports that many advanced heart failure patients experience a high burden of symptoms that are mostly managed from a physical aspect while mental distress is overlooked (Riley et al., 2016 and Stechuchak et al., 2017). It is not clear from the interviewees that this is recognized on their side, however, they do share experiences where it is implied that these needs were not met. While this is addressed by palliative care, it's important for providers to integrate this from the beginning of their care as well. This will help them to not only better understand the patient and their values, but also bridge the gap for the commonly unmet psychosocial and spiritual need during an end-of-life period.

6. Create Standards for Palliative Care Referral

It is evident that there is a need for standards of care regarding what qualifies an end-of-life period, as well as when it is time to consult palliative care. This is identified in both the literature and transcripts that providers may rely on “triggers” to facilitate palliative care involvement which can be a successful way to identify patients who may benefit from a consultation (Kavalieratos et al., 2014 and Glogowska et al., 2016). Interviewees appeared to have varying standards that they used for consulting palliative care, if they had time to do it at all. It was apparent that there was nothing in place for timely referral before a patient is far along in their course. Creating a mutually agreed upon set of clinical triggers between cardiology and palliative care staff could help to mitigate a reluctance to refer.

Discussion

Limitations

One of the limitations to this qualitative analysis was the limited studies available due to the narrow focus of the topic. While I was able to successfully gather enough for a literature review, it did take quite a few different searches and variety of databases to find specific information. Another limitation was that I had originally planned on being present for the interviews with cardiologists to observe the process, but found through my application with the IRB that this would require an additional consent form of my own which could have disrupted both my own timeline as well as the research staff leading the study. Ultimately, the transcripts were still the same information I would have gathered being at the interviews so this was a very minor issue.

Lessons Learned

This capstone experience allowed me to gain new skills and experience relating to qualitative data analysis and creating a set of recommendations based on my own research. Additionally, I have a much stronger understanding on the topic of palliative care and the different factors that affect high quality end-of-life care for patients with advanced heart failure. Specifically, I learned how to navigate MaxQDA software, how to code transcripts for qualitative themes, and experienced the process of working with others to develop a code book for these transcripts. This also gave me experience working with the IRB and how the process works for human subjects research. These lessons will be very beneficial to me as I hope to start a career in the field of patient safety and quality improvement, and has given me a new perspective on what defines high quality end-of-life care.

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Appendix A- Literature Search

Databases Searched	Keywords used	Limits of search	# Articles Retrieved	Additional search refinements	# Articles Retrieved	# Articles Reviewed
PubMed	advanced heart failure or end stage heart failure	2008-present, peer-reviewed articles, humans	7,402	cardiologist	3343	3
Academic Search Complete	advanced heart failure or end stage heart failure, cardiologist, palliative care	2008-present, peer-reviewed articles	8	end of life care	8	3
Google Scholar	advanced heart failure, cardiologist, barrier to palliative care	2008-present, peer-reviewed articles	7,000	none	7,000	5
Google Scholar	patient unawareness, end-of-life care	2008-present, peer-reviewed articles	11,900	lack of palliative care	15,900	4
Academic Search Complete	palliative care for heart failure, triggers	2008-present, peer-reviewed articles	2	none	2	1
Google Scholar	interventions, advanced heart failure, palliative care	2008-present	17,600	none	17,600	4

Appendix B- Coding Map



Provider Recommendations for High Quality End-of-Life Care for Advanced Heart Failure Patients

Common Themes

◆ <u>Barriers to High-Quality Care</u>	◆ <u>Defining High-Quality End-of-Life Care</u>
<ul style="list-style-type: none">➤ Patient's health literacy➤ Living in rural areas➤ Feeling of "giving up"➤ Lack of awareness to resources/referrals➤ Delayed recognition of end-of-life period➤ Unpreparedness to engage in end-of-life conversation	<ul style="list-style-type: none">➤ Location of passing➤ Patient knowledge of disease➤ Managing symptoms➤ Respecting patient's values and wishes➤ Timing of care➤ Effective transition of care➤ Effective therapies➤ Reducing readmission➤ Using a multi-disciplinary approach.

Recommendations

<ul style="list-style-type: none">→ Collaborative Approach<ul style="list-style-type: none">◆ Patient education and embedding palliative care→ Early Identification of End-of-Life Period/Conversation Strategy<ul style="list-style-type: none">◆ Early recognition and integration◆ Shared language→ Patient-Centered Care<ul style="list-style-type: none">◆ Shared decision making◆ Reducing wasteful care or further interventions	<ul style="list-style-type: none">→ Education and Training<ul style="list-style-type: none">◆ Ongoing education/training for providers on benefits◆ Palliative care education in medical school→ Holistic Approach<ul style="list-style-type: none">◆ Treat patient from physical, psychosocial, and spiritual aspect throughout care→ Standards of Palliative Care<ul style="list-style-type: none">◆ Mutually agreed upon triggers for consultation◆ Criteria for end-of-life period
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