Spring 5-31-2020

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Digital USD Citation

Sahelijo, Nienke BSN, RN, DNP-FNP Student; Fitzgerald, Kori DNP, FNP-C; and Burkard, Joseph F. DNCs, CRNA, "Utilization of Evidence-Based Telehealth for Routine Follow-Up Visits in Outpatient Palliative Care" (2020). *Doctor of Nursing Practice Final Manuscripts*. 128.
https://digital.sandiego.edu/dnp/128

Utilization of Evidence-Based Telehealth for Routine Follow-Up Visits in Outpatient Palliative Care to Improve Quality of Life

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Abstract

Objectives: Palliative care services constitute a vital part of the oncology treatment plan. Much of the suffering associated directly with cancer itself or as a result of treatments can be mitigated with the early incorporation of palliative services. Unfortunately, access to palliative care remains elusive due to a lack of qualified providers. This evidence-based project was implemented in an effort to address gaps in care for advanced cancer patients. The goal was to provide telehealth visits for routine follow-up of stable patients to address and manage symptoms as well as overcome psychosocial challenges with equivalent or improved satisfaction as compared to their last in-office visit using an anonymous qualitative survey.

Methods: The first intervention was to identify palliative-appropriate patients by encouraging oncologists to initiate palliative outpatient referrals at the time of diagnosis. The second was to enroll patients who were identified as stable at their last in-person visit into the telehealth palliative care program. Lastly, telehealth visits were conducted, and data collected using the post-visit questionnaire.

Results: Data on 7 participants was collected during the pilot phase. An additional 10 participants were included in the second phase of this study. Both the pilot phase of this project as well as data collected during this last interval indicate patient satisfaction that is at least equivalent, if not better than in-person visits because of convenience and positive effect on quality of life.

Conclusion: Palliative telehealth visits have the potential to provide equivalent or improved symptom management and psychosocial needs assessments when compared to in-person visits while alleviating the added stress associated with frequent travel.

Keywords: palliative, telehealth, oncology, outpatient palliative, tele-oncology

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Introduction

The health of a nation is largely determined by the prevalence and severity of illness in the general population. In the United States (US) the demographic shift toward greater numbers of older adults living with multiple co-morbidities continues to increase[1]. According to data released by the US Census Bureau in 2018, the next decade will mark the completion of a demographic transition. By 2030, all baby boomers, individuals born between 1946 and 1964, will have reached the age of 65 comprising 20% of the US population[1]. This has led to the steadily rising costs in healthcare as well. Shortly after the passage of the American Recovery and Reinvestment Act of 2009, it was projected that Medicaid spending would increase to over $450 billion by 2020[2]. However, as of the end of 2017, national Medicaid expenditure had already exceeded $500 billion[3]. Similarly, Medicare costs will continue to increase to an excess of $1.3 trillion by 2020[3]. Although aging will play a factor in the increased use of health services and incurred costs for this population in general, it is the chronic illnesses and comorbidities that will lead to frequent hospitalizations and decreased quality of life[4].

Of these, cancer remains one of the most significant burdens to both patients and family members, with approximately 600,000 deaths attributed to the disease each year[5]. The lifetime incidence of cancer is 38.4% and the expenditure associated with cancer care was around $147.3 billion in 2017 alone[6]. The risk for cancer increases as a person matures. Although more treatment modalities and improved screening techniques mean greater survival rates, the financial, physical, and emotional costs of cancer are detrimental. For the 1.6 million individuals who are diagnosed with cancer each year[7], these added stressors can be mitigated by the early implementation of coordinated and collaborative palliative care[8].

Palliative care is defined as a modality of care provided by trained medical professionals, working in an interdisciplinary fashion, that emphasizes the need to optimize quality of life over prognosis. The interdisciplinary team should include specialists, primary providers, nurses, social workers, and spiritual care[9]. It is appropriate at any stage of illness to reduce the impact of symptoms and stress on both patient and caregivers[10]. Home palliative care has been shown to reduce unplanned hospital admissions and emergency room visits, alleviate symptoms related to cancer or treatments, and increase the likelihood of patients being able to die at home[11–13]. Until recently, the principal goal of management in the oncologic world was the complete remission of cancer; however, literature has shown that patient outcomes are positively influenced by the integration of supportive care services to prevent the negative effects of cancer treatment as well[2].

The initiation of early palliative care measures remains elusive in the face of ample evidence because the number of providers cannot keep up with the demand. In the United States there are approximately 6,400 providers who are either subspecialized or who self-identify as hospice and palliative care providers[14]. It should be noted that the estimated incidence of cancer for 2018, regardless of site, stage, gender, race, or socio-economic status was 1,735,350 with 609,640 deaths in the same year[6]. One way to increase access to these supportive therapies and services is to expand the modalities of communication between patient and provider. Access to palliative services through telemedicine has become of increasing interest in the field of oncology[11]. Telemedicine encompasses a myriad of electronic means of communication. The ease of communication between provider and patient or loved ones contributes to improved overall satisfaction as well as outcomes[15].

The efficacy of palliative telemedicine is directly correlated to the amount of time the patient has been enrolled in the program. Literature indicates that oncology patients who receive early referrals (more than 90 days before death) have lower rates of emergency room visits and intensive care admissions in the last month of life as compared to those patients who receive late referrals[16]. In addition, late palliative care tends to be administered in the inpatient setting, whereas established outpatient palliative care is a much more affordable method of care delivery and is individualized to the patient[7]. Similar results were seen in another study which compared hospital-administered palliative care to outpatient, interdisciplinary care. There were notable improvements in end-of-life care measures and reductions in overall cost. Mobilization of early palliative care referrals led to a decrease in inpatient costs of about $6,600 per patient[16].

The foundation of this project is built on the knowledge that the initiation of early palliative care can make a definitive difference in quality of life for both patients and their caregivers. By optimizing symptom control, palliative care generates cost savings by preventing the need for emergency services and unplanned hospital admissions. In order to gauge the efficacy of telemedicine palliative visits, a qualitative survey was distributed to participants after their first or subsequent palliative telehealth visits. This anonymized information was collected and analyzed after a 6month implementation period as described.

Methods

Much of the infrastructure for the project was already in place. Telemedicine visits had been incorporated by one nurse practitioner since early 2018 and initial data collection was performed from October of 2018 to February of 2019. Continuation of this project was feasible thanks to the support of the administration and practitioners at the University of San Diego (UCSD) Moores Cancer Center (MCC) outpatient palliative care clinic. The International

Review Board (IRB) application had been submitted the year prior and the transition into the second phase of data collection required no adjustments to the protocol. Therefore, renewal of IRB for both University of San Diego (USD) and UCSD was filed in the fall and renewal was approved on October 23, 2019.

Subject identification for inclusion in the study was ongoing from the period of October 2019 until February 2020. This interval also included the implementation of further telehealth visits, follow-up messages through the electronic health record, as well as the dissemination of the post-visit survey using the patient portal. Telehealth visits were offered to patients whom had previously been evaluated in clinic and deemed to have stable or well-managed symptom presentations. The requirements for inclusion in the telehealth consultations may be found in table 1. Each visit was structured in a manner similar to an in-person visit, although vital signs were omitted as there was no means to measure these. After the conclusion of the telehealth visit, patients were told to expect a post-visit survey which measured their satisfaction using various metrics such as (a) the quality of the interaction with the provider, (b) video and audio connectivity, (c) opportunity for family participation, and (d) the extent to which symptoms were addressed. Each submission of the Google Forms survey provided anonymized data. This data included preliminary demographic data followed by 22 questions in which patients were asked to rate their telehealth experience in comparison to their last in-office visit. Question 23 was free form for any additional comments or feedback. This varied from the previous 17 question survey in that one “negatively” phrased item was included on this form as well as items relating to the ease with which care givers, family, and loved ones were able to participate in the meeting. However, the 1 to 5 Likert-type scale did not change from the pilot phase in that 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, and 5= Strongly Agree. Please refer to figure 1 for a copy of the survey that was distributed to patients. Values of 3 or higher indicated a response that was at least equivalent or improved from the last in-office visit.

Following data collection, a thorough analysis of the feedback generated results that were presented to stakeholders and university staff. These results were also to be presented at the California Association of Nurse Practitioners Regional Conference; however, due to increasing concern for public safety related to COVID-19, the conference was canceled.

Results

In order to search the evidence on the efficacy and effects of telemedicine in the palliative care setting, a literature search was performed on CINAHL, PubMed, and the Cochrane Database of Systematic Reviews. The search terms utilized included “oncology”, “telemedicine”, “telehealth”, “palliative”, “quality of care”, “quality of life”, “reduced admissions”, “reduced hospitalizations”, “end of life”, “outpatient”, “cancer”, “rural communities”, “teleconsultations”, “tele-oncology”, “terminal care”, “qualitative”, and “reduced emergency services”. Although a majority of the studies that were generated were qualitative studies, the search yielded randomized control trials, systematic reviews, and recommendations for clinical guidelines. The original searches using the above keywords generated 185 articles, of which 44 were reviewed. Of those 44 articles and references, 18 were used in the development of the final proposition. Each article was ranked based on the strength of the evidence presented according to the John Hopkins Nursing Evidence-Based Practice Model (JHNEBP).

The design for this telehealth evidence-based project included video calls using the electronic medical record to complete visits as well as a post-visit qualitative survey to measure the anticipated outcomes of interest. The survey consisted of 22 items each ranked from 1 to 5 as previously described. The patient was meant to compare their last in-office visit to their telehealth encounter when filling in the values. A goal outcome of “equal” or “better” was considered if the patient indicated a value of 3 or higher. The areas of interest included the quality of the communication, the extent to which symptoms were addressed, the degree of comfort with the visit format as a means of discussing sensitive information, the ability of the practitioner to provide adequate teaching and clarification, the ease with which loved ones could be included in the visit, and the perceived difficulty with setting up and utilizing the technology through the patient portal. This survey contributed to the one used in the pilot phase by adding 5 additional items measuring patient satisfaction with regard to including loved ones in the visit as well as a negatively phrased item addressing the flow of the visit.

Data collection extended from October 2019 through February 2020. In that time, twenty-four surveys were distributed and ten were completed. Of the 21 Likert-type items, 19 scored equal to or better than an in-office visit. For a comprehensive table of the results please refer to figure 2.

All of the respondents felt that their provider actively listened to and addressed their symptoms and concerns. It should be noted, however, that item 4 had mixed responses. It states, “The flow of the conversation felt impersonal”. It did not contain easily identifiable negative words such as ‘not’ or ‘no’. If respondents did not read the sentence carefully, they could have simply indicated “strongly agree” and quickly moved on to item 5. It is possible that respondents truly felt the flow of the conversation was impersonal; however, given the positive feedback on most other items, this conclusion is less likely.

It is also worth noting that item 16 which asked respondents if they “felt comfortable having important discussions via telehealth”, had one response of strongly disagree. Many of the conversations that occur during palliative consultations pose questions or address realities that may be jarring to patients if these are being introduced for the first time. Most patients are ready to tackle difficult subjects but there are some that are not.

The last point of discussion focuses on the technology itself. Currently, the palliative team employs iPads for video visits. Patients often use tablets or cellphones to call in. Item 12 asked respondents if the screen “made it easy to include loved ones in the visit. Although 70% of patients responded, “strongly agree”, 20-30% were less enthusiastic about their responses indicating “agree” or “neutral”. The size of the screen limits the number of individuals it can accommodate. Two ways to address this issue going forward is to increase the size of the screen on the provider’s end or to attach a “fish-eye” lens to the iPad/tablet to optically expand the screen. The software was also rated in items 18-20. 80-90% of respondents agreed that the instructions to set-up for the first video call were easy to follow, the technology was easy to use, and the software worked well.

Discussion

In the event of an advanced cancer diagnosis, the integration of early palliative care services is a crucial component of the treatment plan. Unfortunately, the number of patients in need of palliative services vastly outnumbers the dedicated palliative and hospice providers currently registered in the United States[14]. In order the address the gap in care, additional modalities should be made available to expedite access to efficacious care. Providing palliative care through telemedicine is a viable and cost-effective way to improve access to care[17]. This evidence-based project was implemented in an outpatient palliative care setting associated with a large academic hospital in Southern California. The patient population were all diagnosed with cancer and the majority were affected by metastatic disease. At the time the project was implemented, a single provider performed all of the telehealth visits. However, the aforementioned results of ongoing data collection were promising enough to expand the program to include 3 providers. This program is slated to continue growing with the goal of reducing travel burdens and optimizing symptom management for patients suffering with cancer.

There were certain limitations that presented themselves over the course of the study which made data collection challenging. Initially, gaining access to the electronic health record took several weeks. At the conclusion of each semester, access to this system would lapse and take several weeks to re-institute. Collectively, about 10 weeks were lost attempting to establish or re-establish access. Additionally, this student was unable to obtain off-site access to the electronic medical record, which reduced the time allotted for dissemination and collection of surveys. By the end of data collection, two additional providers had begun performing telehealth visits. Only visits performed by the initial provider are reflected in the data. Subsequent survey distribution should focus on capturing patients being managed by the additional providers.
After running an analysis of the individual items, it became apparent that one of the items discussed above was not sensitive to the data it was trying to capture. The qualitative data is still valuable in its content, but the individual items were not systematically tested for validity prior to dissemination.

Given the limitations above, the data still continued to show that the telehealth video visits are favorably received by patients and their loved ones. A larger sample size through continued data collection from multiple providers is expected to further strengthen the results from both the pilot and subsequent phase of this evidence-based study.

Conclusion

Palliative care is a discipline that strives to prevent and relieve suffering through skilled assessment and treatment of pain. It adeptly tackles physical, psychosocial, and spiritual concerns to improve quality of life for patients with serious chronic illness as well as their families[18]. There is a nationwide shortage of skilled palliative specialty providers and the supply is insufficient to meet the growing demand. In addition, for patients suffering from advanced cancer, the burden of medical appointments is severe and frequent travel can be exhausting. Implementing telehealth visits for UCSD MCC palliative care patients with advanced cancer improves or maintains patient satisfaction with regard to symptom management. The overall visit adequately addresses palliative needs and improves overall quality of life by eliminating the need to be physically present at the clinic. It also reduces the risks patients take to make it to their appointments, especially if they are immune compromised. The utilization of telehealth in palliative care is a relatively new intervention that has the potential to dramatically impact the lives of patients with comorbidities beyond cancer. Increasing accessibility to this specialty service may result in improved outcomes for patients with conditions ranging from heart failure to chronic obstructive pulmonary disease. This, in turn, will result in cost reductions due to fewer emergency room visits, decompensation episodes, and the need for aggressive treatment escalation that can often diminish the patient's quality of life. Palliative care differs fundamentally from other specialties because its team-based approach allows providers to understand the patient as the person they were before their illness. Aligning the team's priorities with those of the patient allows the patient to feel heard and understood. Palliative telehealth takes this approach one step further by allowing patients to have direct access to their provider from the comfort of their own homes.

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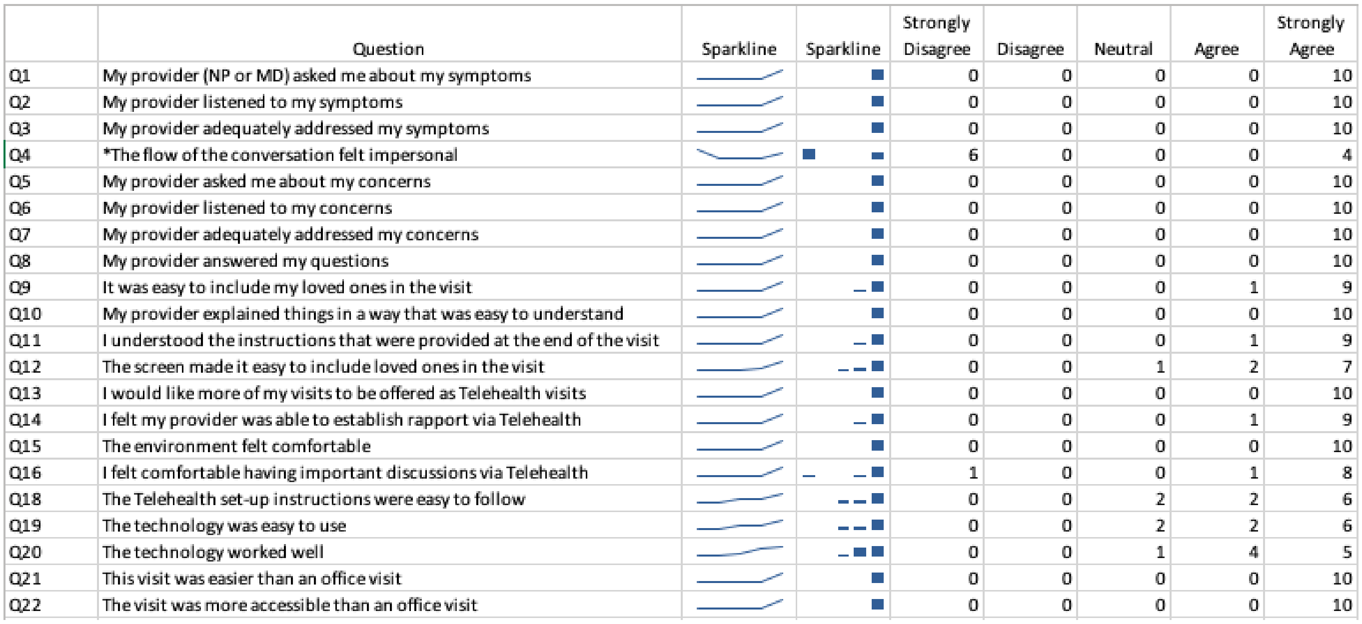
Table 1: Criteria for Telehealth Referrals provided to the outpatient palliative care team to increase patient recruitment

“Guidelines” for Telehealth Referrals
o Stable at last in-person follow up visit o Well-controlled symptoms o No physical symptoms requiring a physical exam o Residents a long distance away from clinic o Transportation issues to and from appointments o Need for routine titration of long-acting medications (ex: Methadone) o Other “stakeholders” involved who are unable to attend in-person clinic visits (ex: spouses, family members, etc.) o English-speaking only *Ultimately, the decision for referral to telehealth is dependent on the provider’s clinical judgment*

Table 2: Post-Visit Telehealth Survey

Questions—When compared to my last office visit:	**1 Strongly Disagree**	**2 Disagree**	**3 Neutral**	**4 Agree**	**5 Strongly Agree**
1. My provider (NP or MD) asked me about my symptoms					
2. My provider listened to my symptoms					
3. My provider adequately addressed my symptoms					
4. The flow of the conversation felt impersonal					
5. My provider asked me about my concerns					
6. My provider listened to my concerns					
7. My provider adequately addressed my concerns					
8. My provider answered my questions					
9. It was easy to include my loved ones in the visit					
10. My provider explained things in a way that was easy to understand					
11. I understood the instructions that were provided at the end of the visit					
12. The screen made it easy to include loved ones in the visit					
13. I would like more of my visits to be offered as Telehealth visits					
14. I felt my provider was able to establish rapport via Telehealth					
15. The environment felt comfortable					
16. I felt comfortable having important discussions via Telehealth					
17. I was familiar with Telehealth before this visit					
18. The Telehealth set-up instructions were easy to follow					
19. The technology was easy to use					
20. The technology worked well					
21. This visit was easier than an office visit					
22. The visit was more accessible than an office visit					
23. Additional comments:					

Table 2: Results of the Items



	Question	Sparkline	Sparkline	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Q1	My provider (NP or MD) asked me about my symptoms			0	0	0	0	10
Q2	My provider listened to my symptoms			0	0	0	0	10
Q3	My provider adequately addressed my symptoms			0	0	0	0	10
Q4	*The flow of the conversation felt impersonal			6	0	0	0	4
Q5	My provider asked me about my concerns			0	0	0	0	10
Q6	My provider listened to my concerns			0	0	0	0	10
Q7	My provider adequately addressed my concerns			0	0	0	0	10
Q8	My provider answered my questions			0	0	0	0	10
Q9	It was easy to include my loved ones in the visit			0	0	0	1	9
Q10	My provider explained things in a way that was easy to understand			0	0	0	0	10
Q11	I understood the instructions that were provided at the end of the visit			0	0	0	1	9
Q12	The screen made it easy to include loved ones in the visit			0	0	1	2	7
Q13	I would like more of my visits to be offered as Telehealth visits			0	0	0	0	10
Q14	I felt my provider was able to establish rapport via Telehealth			0	0	0	1	9
Q15	The environment felt comfortable			0	0	0	0	10
Q16	I felt comfortable having important discussions via Telehealth			1	0	0	1	8
Q18	The Telehealth set-up instructions were easy to follow			0	0	2	2	6
Q19	The technology was easy to use			0	0	2	2	6
Q20	The technology worked well			0	0	1	4	5
Q21	This visit was easier than an office visit			0	0	0	0	10
Q22	The visit was more accessible than an office visit			0	0	0	0	10