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Utilization of Evidence-Based Telehealth for Routine Follow-Up Visits in Outpatient Palliative Care

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Manuscript

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in Outpatient Palliative Care

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Introduction

In the United States, people are currently living longer and with an increased number of chronic illness and comorbidities that affect activities of daily living. Approximately 90 million Americans are affected by a serious illness and this figure is expected to double by the year 2040 (Center to Advance Palliative Care [CAPC], 2014). In particular, cancer accounts for significant morbidity and mortality in the U.S. with an estimated 1,688,780 new cases of cancer of any site and an estimated 600,920 deaths in 2017, making cancer the second leading cause of death (Murphy, Jiaquan, Kochenek, Curtin, & Arias, 2017; National Cancer Institute [NCI], n.d.). In addition, cancer poses a significant burden to the healthcare system with an estimated 24.6 million office visits for cancer care and an annual national expenditure for cancer care estimated to be about $156 billion by 2020 (Centers for Disease Control and Prevention, 2015; NCI, 2017). A vital part of chronic disease and cancer management is the implementation and integration of palliative care.

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization [WHO], 2014). It is estimated that approximately 6 million people in the U.S. are candidates for palliative care services, however, the number of palliative care providers is inadequate to meet these needs (CAPC, 2014). Utilizing an age-based proxy indicator model, Lupu, Quigley, Mehfoud, and Salsberg (2018) estimated a national need for 7,470 to 16,791

hospice and palliative medicine (HPM) physicians per 100,000 people by 2020 and 10,640 to 23,916 HPM physicians per 100,000 people by 2040. At the current rate, the number of HPM physicians in 2040 will be 8,100 which is far below the estimated need (Lupu et al., 2018).

Access to palliative care services continues to be inadequate. Despite a national push to develop inpatient, hospital-based palliative care programs, the current prevalence of programs is 66.5% of hospitals nationwide and 74% of hospitals in California (Dumanovsky et al., 2016). Furthermore, there is dramatically limited access to outpatient palliative care services, with only 18% of California hospitals that have inpatient adult palliative care programs offering an outpatient program (Rabow, O-Riordan, & Pantilat, 2014).

Currently, the University of California, San Diego (UCSD) Moores Cancer Center Outpatient Palliative Care Team is limited in the number of patients they are able to accept due to a lack of providers, physical clinic space, and clinic hours. Newly referred patients are placed in a "queue" and are on the waiting list to be seen until the service is able to accept an additional patient. This ability to accept is greatly influenced by the aforementioned limitations in the practice. The number of patients in the queue is fluid, however, at the time a needs assessment was conducted, there were about 40 to 50 newly referred patients waiting to be seen. due to the. In addition, patients with advanced cancer attend numerous medical appointments which patients report leads to decreased quality of life and increased fatigue from frequent travel. As a result, new strategies for seeing patients are being developed and implemented, especially the utilization of telehealth.

Proposed Evidence-Based Solutions

To identify the benefits of telehealth consultations/visits with palliative care patients, a literature review was conducted using electronic database sources for articles published between 2013 and 2018. Specifically, PubMed, CINAHL, and the University of San Diego online catalog were utilized using the keywords palliative care, telehealth or telemedicine, palliative care physicians or providers. The articles in the review included randomized control trials, systematic reviews, clinical practice guidelines and alerts, observational reviews of the current evidence, and qualitative studies. The original search yielded 96 articles, a total of 35 references were reviewed, and 7 were used in the final proposal. Each of the references were analyzed and categorized according to the strength of the evidence using the 1 to 6 EBP Levels of Evidence scale in Melnyk & Fineout-Overholt (Melnyk & Fineout-Overholt, 2015).

Palliative care is a relatively new specialty that emerged to fill a very specific role in healthcare. However, timing and the setting (outpatient versus inpatient) of palliative care are both vital elements. The first evidence-based intervention is early initiation of outpatient palliative care referrals. Palliative care implemented early (more than 90 days before death), when compared to late (less than 90 days), leads to improved end-of-life (EOL) quality measures, less aggressive EOL medical care, lower rates of hospital and intensive care unit (ICU) admissions in the last month of life, fewer ED visits, lower rates of inpatient deaths, and fewer deaths within three days of discharge (Blackhall et al., 2016; Hui et al., 2014; Scibetta, Kerr, Mcguire, & Rabow, 2016) In addition, there is a significant financial benefit with early palliative care integration in oncology care, with lower direct costs for inpatient (about $6,687 per patient) and combined inpatient and

outpatient direct costs (about $5,198 per patient) (Blackhall et al., 2016; Scibetta et al., 2016). There is also significant benefit for initiating palliative care in an outpatient setting when compared to an inpatient referral. Outpatient management leads to decreased ER visits, hospital admissions, ICU admissions, inpatient deaths, shorter hospital length of stay, and lower composite aggressive EOL care scores (Hui et al., 2014).

The second evidence-based intervention is telehealth visits for routine follow-ups with palliative care patients. Telehealth is a practical and realistic option in palliative care and may result in increased quality of care, cost benefits and cost savings, a higher level of communication, and higher levels of user satisfaction (Capurro, Ganzinger, Perez-Lu, & Knaup, 2014; Hoek et al., 2017; Rogante, Giacomozzi, Grigioni, & Kairy, 2016) In one randomized control trial, unmet palliative care, continuity of care, depression scores, and hospital admissions were not statistically different between palliative care patients seen with telehealth compared to usual care (Hoek et al., 2017). In addition, studies have shown positive effects on quality of life scores, significantly lower or similar reports of symptomology severity scores, significantly lower anxiety and depression, fewer inpatient admissions, and decreased hospital care costs (Head, Schapmire, & Zheng, 2017).

Description of the Project

The purpose of this evidence-based practice (EBP) project was to implement telehealth visits with palliative care patients with advanced cancer at the UCSD Moores Cancer Center Outpatient Palliative Care Service. Through the use of telehealth, the palliative care team is able to improve or maintain patient satisfaction with symptom management and the overall visit, adequately address palliative needs, and decrease

travel burden for current patients. All of these outcomes lead to an overall improvement in quality of life. In addition, shifting routine follow-up visits to telehealth allows normal clinic hours to be increasingly available for newly referred patients.

For this project, the telehealth visits were limited exclusively to routine follow-up visits. The selection of patients was determined by an informal set of guidelines and provider clinical judgement. Refer to Appendix I for the "Guidelines" for Telehealth Referrals. A post-visit survey distributed to patients via the electronic health record's patient portal evaluated (a) the patients' satisfaction with the quality of the interaction and his or her care; (b) having his or her palliative needs adequately addressed, and (c) the overall quality of the telehealth visit.

The post-visit survey utilizes a Google Forms anonymous online survey platform and consists of five demographic questions, 17 questions with responses on a rating scale, and space for additional comments. The rating scale was on a 1 to 5 spectrum with the responses (1) Strongly Disagree, (2) Disagree, (3) Neutral, (4) Agree, and (5) Strongly Agree. Each of the questions reference the patient's last in-person office visit as the baseline comparison measure (the "control"). Refer to Appendix II to view the survey.

Evidence-Based Practice Model

As described in Melnyk and Fineout-Overholt (2015), the Iowa model begins by having clinicians identify "triggers" to drive a practice change to improve outcomes. This model provides a logical stepwise flowchart including feed-back loops. The use of triggers is an important element of this model since specific factors are driving this project (Melnyk & Fineout-Overholt, 2015). Utilizing telehealth can address two triggers: a decrease of travel requirements to medical appointments for patient and increased

ability to accept new referrals. UCSD places a priority on increased patient satisfaction, maximized provider productivity, and increased patient census. As a result, the Iowa model suited the needs of the project and was used to guide the overall development and implementation of the project. In addition, the algorithm is intuitive and the utilization of a prescribed project plan is beneficial for doctoral students.

The 5 A's Behavior Change Model includes the elements of Assess, Advise, Agree, Assist, and Arrange (Agency for Healthcare Research and Quality, 2012). This model was utilized to guide the structure of the routine follow-up telehealth visits and ensure these elements were included. In addition, the model was used to develop relevant survey questions. The goal was to provide a platform for patients to adequately reflect and share their opinions about their experience.

Project Development and Implementation

There were multiple steps that needed to be completed to ensure successful implementation of the EBP project. These steps included the proposal of the project to UCSD Moores Cancer Center Outpatient Palliative Care Director, obtaining support, UCSD IRB submission and acceptance, USD IRB submission and acceptance, recruitment of patients eligible for telehealth follow-ups, implementing telehealth visits and phone-follow ups, cleaning of the data and asserting results, dissemination of results at stakeholder presentation and conference, and submission of manuscript for publication.

Project Approval

This project was implemented at University of California, San Diego (UCSD), which, as a large university medical system, possesses its own Institutional Review Board (IRB). As a result, IRB project approval was required from both institutions: UCSD and

University of San Diego (USD). As stated in the UCSD Human Research Protections Program (HRPP) fact sheet on EBP, Quality Improvement, and Quality Assurance Projects, the HRPP has determined projects meeting the nine criteria to be "certified as not research" will be excluded from IRB review (University of California, San Diego Human Research Protections Program, 2015). However, EBP projects still need to be submitted to the HRPP Director who will certify the project is not research and no IRB review will be required (University of California, San Diego Human Research Protections Program, 2015). UCSD IRB approval was obtained on October 23, 2018 and USD IRB approval was obtained on October 26, 2018.

Project Outcomes

The implementation of telehealth visits for routine palliative care visits and post-visit online survey follow-ups for palliative care patients with advanced cancer had numerous anticipated outcomes. The goal was for patients to report equal or better on all 17 of the measures included in the survey. This is defined as greater than or equal to a 3 or Neutral on the rating scale. The areas of focus included symptom management, addressing palliative care needs, addressing questions and concerns, clearly stating intended interventions, providing patient education, establishing rapport, increasing accessibility, and functionality of the technology.

The use of telehealth for routine follow-up visits in outpatient palliative care at the UCSD Moores Cancer Center achieved the overall project goal on 94.1% of the measures. When compared to the last office visit, the goal of equal or better was achieved on 16 out of the 17 measures. This goal was not met on 1 out of the 17 measures, with

only 1 response less than or equal to 3/Neutral. Refer to Appendix IV for the graphical distributions of the responses.

Limitations of the project included the fact only one provider offers telehealth visits at this time. In addition, this provider had to take unexpected medical leave for the final month of data collection, limiting the sample size. Based on the project data and anecdotal data, it is projected that the responses would follow a similar distribution in a larger sample size.

Anticipated Project Impact

Palliative care is an essential service provided for patients with advanced cancer. Palliative care can increase quality of life, decrease symptom burden, decrease hospital and ICU admissions, decrease hospital costs, and decrease inpatient deaths (Blackhall et al., 2016; Hui et al., 2014; Scibetta et al., 2016). As stated above, there are inadequate numbers of HPM providers and outpatient palliative care sites in California and nationwide. Implementing telehealth statewide and nationwide has the potential to decrease patient wait times while maintaining equal symptom management, patient satisfaction, and quality of care. In addition, there is the potential to decrease travel burden for advanced cancer patients who have to attend frequent medical appointments.

Conclusion

Palliative care is a discipline that strives to prevent and relieve suffering through skilled assessment and treatment of pain, as well as, physical, psychosocial and spiritual concerns to improve quality of life for patients with serious chronic illness and their families (WHO, 2014). 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 with palliative care patients with advanced cancer at the UCSD Moores Cancer Center Outpatient Palliative Care Team improves or maintains patient satisfaction with symptom management and the overall visit, adequately address palliative needs, and improves overall quality of life. The utilization of telehealth in palliative care is a relatively new intervention that has the potential to make dramatic impacts in increasing accessibility to these specialty services not only at UCSD Moores Cancer Center, but nationwide.

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Appendix I: Guidelines for Telehealth Referrals

Table 1: Guidelines for Telehealth Referrals provided to the Outpatient Palliative Care Team in order to increase patient recruitment

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

Appendix II: Post-Visit Survey

Figure 6: Survey Questions Displayed in Table Form

Questions – When compared to my last office visit:	1 Strongly Disagree	2 Disagree	3 Neutral	4 Agree	5 Strongly Agree
1. The provider asked me about my symptoms					
2. The provider listened to my symptoms					
3. The provider adequately addressed my symptoms					
4. The provider asked me about my concern					
5. The provider listened to my concerns					
6. The provider adequately addressed my concerns					
7. The provider answered my questions					
8. The provider explained things in a way that was easy to understand					
9. I understand the instructions that were provided at the end of the visit					
10. I felt my provider was able to establish rapport via Telehealth					
11. The environment was comfortable					
12. I felt comfortable having important discussions via Telehealth					
13. The Telehealth set-up instructions were easy to follow					
14. The technology was easy to use					
15. The technology worked well					
16. The visit was easier than an office visit					
17. The visit was more accessible than an office visit					
Additional Comments:					

Appendix III: Demographic Information of Participants

Figures 1: Survey Response Data for Age of Participants

Age:
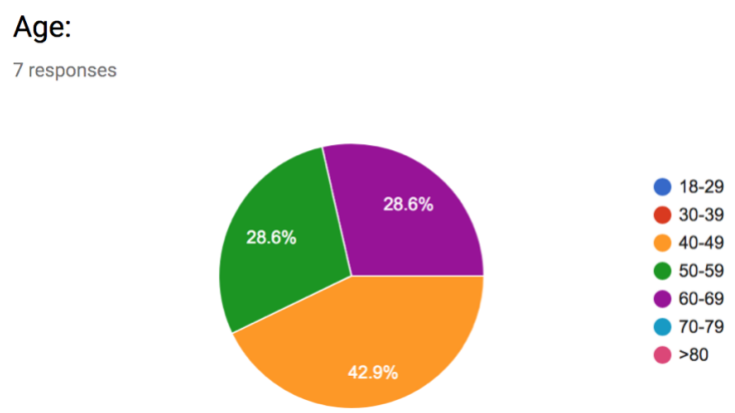
7 responses

Figures 2: Survey Response Data for Gender of Participants

Gender:
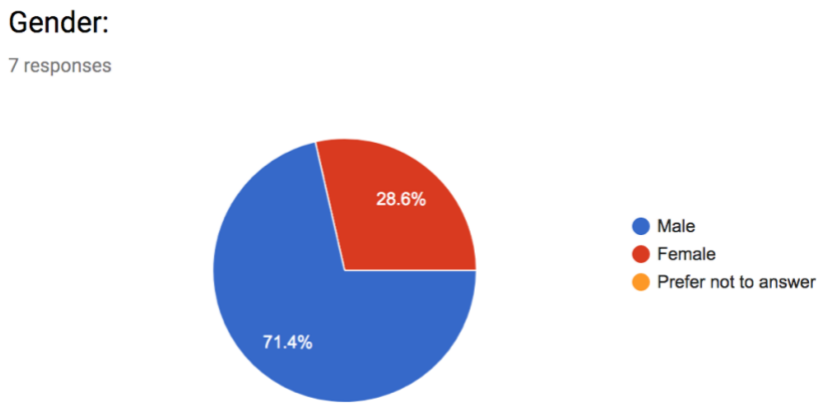
7 responses

Figure 3: Survey Response Data for Race/Ethnicity of Participants
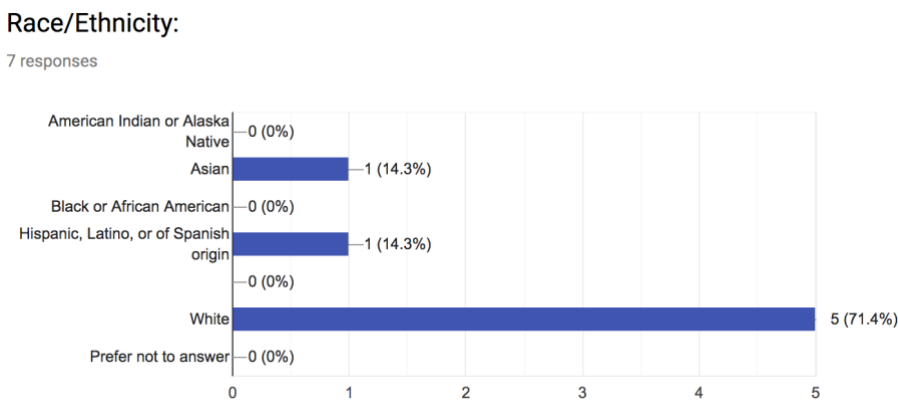
Race/Ethnicity:

7 responses

Figure 4: Survey Response Data for Religion/Spirituality of Participants
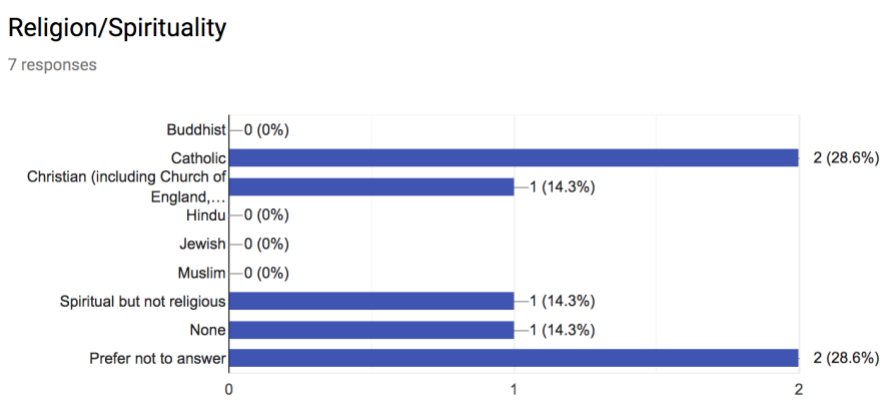
Figure 5: Survey Response Data for Level of Education of Participants
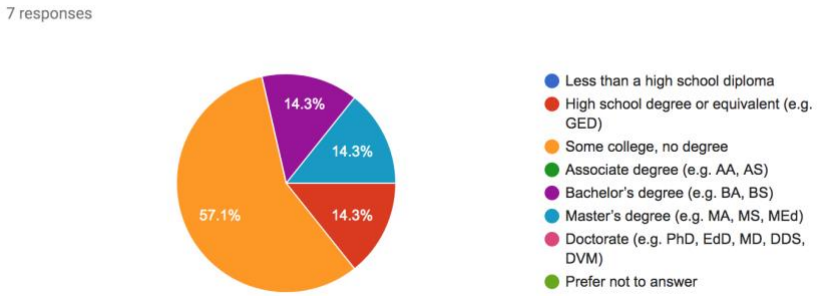
Appendix IV: Results

Figure 7: Distribution of Survey Responses for Questions 2, 3, 4, 12, 13, and 17

    2. The provider listened to my symptoms.
    3. The provider adequately addressed my symptoms.
    4. The provider asked me about my concerns.
  12. I felt comfortable having important discussions over Telehealth.
  13. The Telehealth set-up instructions were easy to follow.
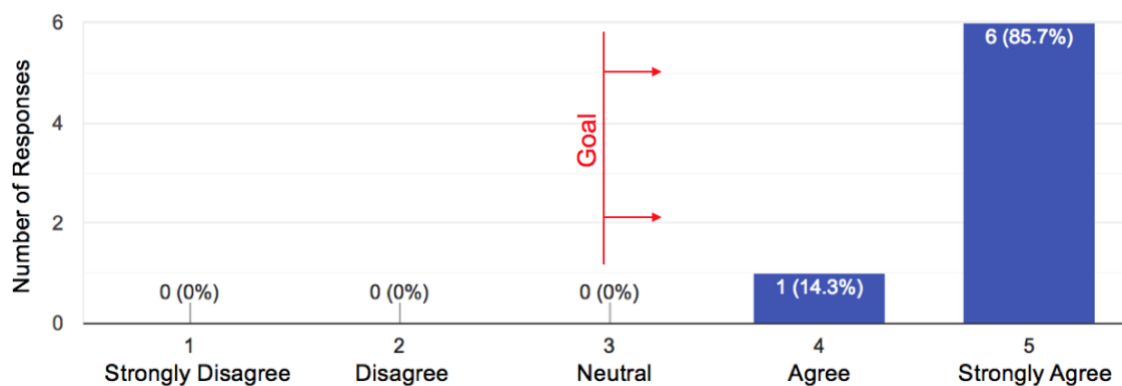 17. The visit was more accessible than an office visit.

Figure 8: Distribution of Survey Responses for Questions 5, 9, 10, 11, 14, 16

    5. The provider listened to my concerns.
    9. I understand the instructions that were provided at the end of the visit.
  10. I felt my provider was able to establish rapport over Telehealth.
  11. The environment felt comfortable.
  14. The technology was easy to use.
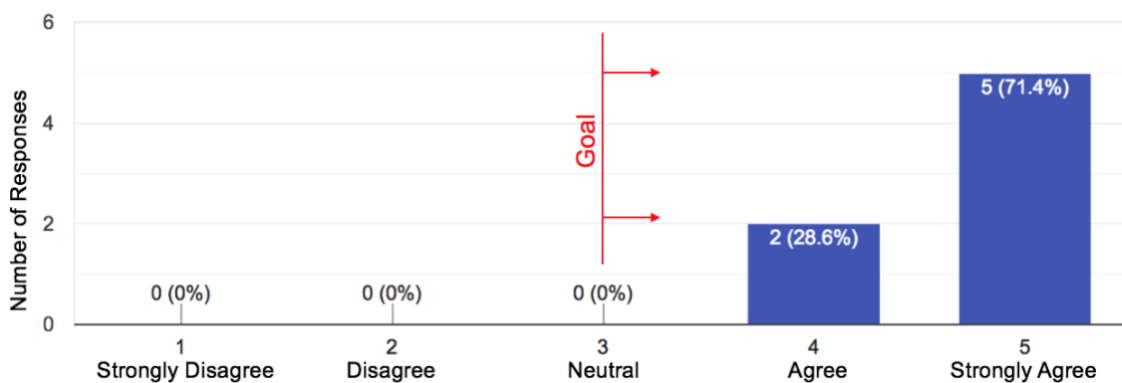 16. The visit was easier than an office visit.

Figure 9: Distribution of Survey Responses for Questions 1, 7, 8, and 15

    1. The provider (Nurse Practitioner or Physician) asked me about my symptoms.
    7. The provider answered my questions.
    8. The provider explained things in a way that was easy to understand.
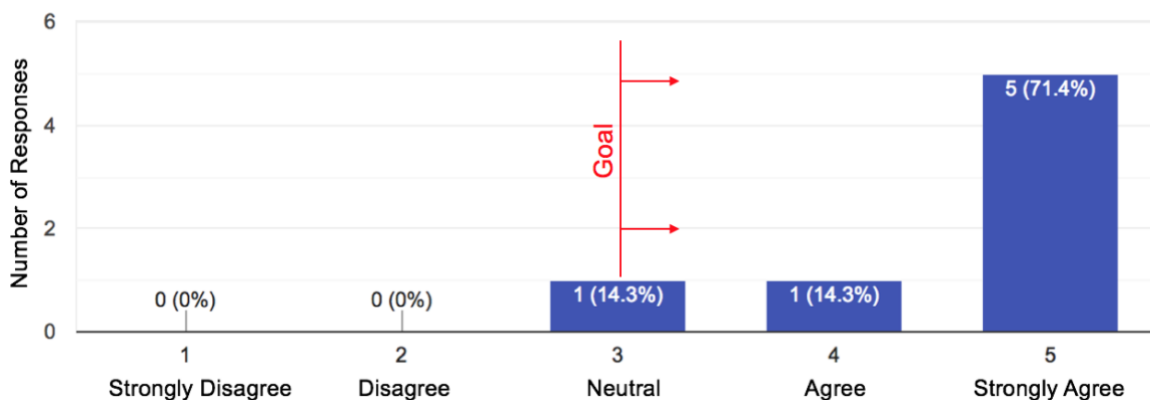   15. The technology worked well.

Figure 10: Distribution of Survey Responses for Question 6

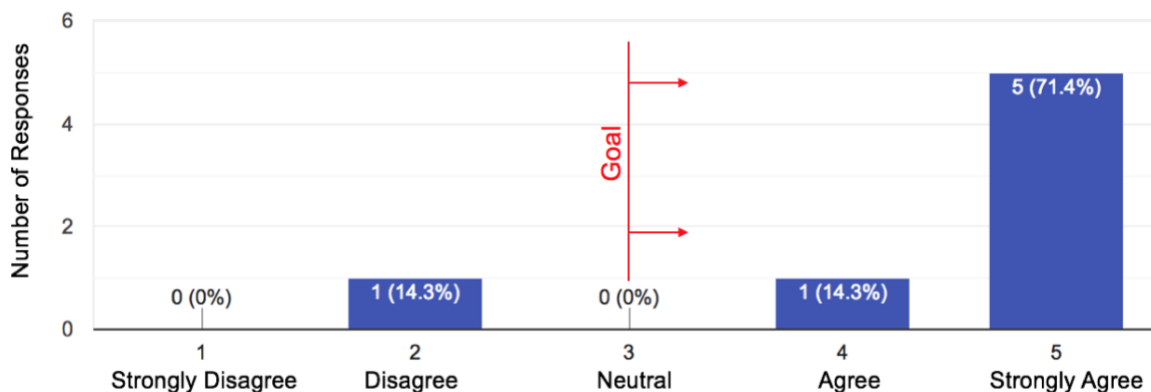   6. The provider adequately addressed my concerns.

Table 2: Additional Comments Submitted into the Optional Free Response Box

Additional Comments
• "We loved telemedicine and would love to continue having these types of visits as often as possible. It was definitely more convenient since the office is a long drive and we're always hitting traffic."
• "In person this visit, on good day, would cost us 4 hours between getting ready, driving, parking and driving home. Leaving at 5:00pm would add another hour. All for about 15 minutes of face time with no need to physically inspect the patient. Could easily be handled over the phone. I am happy to talk to anyone about this subject."