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Patient behaviors during virtual clinic encounters in palliative care

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Case Report

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Abstract

Telehealth use has accelerated since the COVID-19 pandemic and provided access for palliative care patients often facing challenges with travel and limited specialist availability. Our palliative care clinic at the University of Texas MD Anderson Cancer Center has rapidly adopted telehealth which continues to grow and provide care for patients since the pandemic, becoming a routine part of our center. While we strive to maintain consistency when it comes to compassionate, sensitive verbal and non-verbal communication, we have witnessed both advantages and disadvantages to telehealth services. We have come across unanticipated virtual visit challenges while trying to deliver quality care, surprising us from the other side of the camera. In this paper, we describe three cases of unexpected telehealth etiquette that posed new challenges in being able to complete virtual visits. We propose guidelines for setting patient etiquette for a productive telehealth palliative visit.

Introduction

Telehealth has been an innovative growing resource in the past few years for patients faced with life-limiting illness, long distance to treatment centers, and limited availability of palliative care clinical expertise (Speedie et al., 2008; Langarizadeh et al., 2017; McElroy et al., 2019; Guzman et al., 2020; Watts et al., 2020; Snoswell et al., 2021). However, the COVID-19 pandemic has drastically and rapidly accelerated telehealth (Mann et al., 2020; Lally et al., 2021) due to physical distancing needs to reduce transmission and protect vulnerable populations (Kucharski et al., 2020; Levine et al., 2020; Wu et al., 2020). Our ambulatory palliative care clinic, the Supportive Care Center (SCC) at the University of Texas MD Anderson Cancer Center in Houston, Texas, had also made a rapid transition in one week from 13 to 19 March 2020 toward predominantly providing visits via telehealth which has continued (Reddy et al., 2021). Since adopting telehealth, our SCC had shown an increase in total number of daily visits with most encounters via telemedicine now in the clinic.

Common advantages for our patients, also noted in previous telehealth studies, include a potentially more private and comfortable visit environment, allowing for family and friends attendance, as well as opportunities to observe patients in their natural surroundings, revealing home circumstances and sense of personhood. Additional advantages include cost-savings, minimizing travel for patients, caregivers and healthcare professionals, and improved specialist access "anytime, anywhere," especially for our patients living in rural settings (Kidd et al., 2010; Jess et al., 2019; Read Paul et al., 2019). On the other hand, technical and language difficulties can compromise these advantages (Hancock et al., 2019), while the settings and patient behavior in virtual healthcare can also create unique challenges. "Webside manner" (Mehta and Mathews, 2022) and incorporating standards of telehealth behavior training (Gustin et al., 2020) are assisting clinicians in translating in person skill sets to virtual visits. For many patients, though, exposure to telehealth remains new and without guidelines, leaving appropriate behavior for a virtual clinical encounter unclear.

The benefits of "anytime, anywhere" visits have yet to be thoroughly evaluated as providers of our SCC have noticed that while rapid telemedicine adoption ensured access, patients have felt comfortable in conducting palliative care virtual visits in surprising and at times, concerning environments. Most people do not engage in inappropriate or concerning behaviors during clinic visits. However, informal use of technology for social connections might disinhibit behaviors and possibly even diminish one's ability to pick up on non-verbal cues (Konrath et al., 2011; Gustin et al., 2020). These effects might open the door to the other side of behavioral standards in virtual healthcare. Herein, we present three case examples that demonstrate some of the concerns and issues our clinicians have faced. These cases may indicate a need to establish basic ground rules and guidelines to continue to provide quality palliative care in this new telehealth era.

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Patient 1: Public spaces

A woman in her mid-thirties with advanced breast cancer was seen for her first virtual follow-up at the SCC. She had been seen for the first time as a virtual consult two weeks prior with pain, fatigue, anxiety, depression, and poor well-being. At that time, we prescribed regular opioids, laxatives, metoclopramide, daily walking, and natural light, and conducted expressive supportive counseling.

The patient improved in many symptoms and decided to take her follow-up encounter in a restaurant where she was sitting with several family members and friends. While we were glad to see the improvement in symptom burden, due to noise and lack of privacy, we asked the patient if she could move to a more private area and the patient agreed to complete the encounter in the parking area. We were able to complete the physical and a small part of the psychosocial evaluation. The rest of the psychosocial and family goals of care aspects of the encounter, however, had to be canceled and rescheduled for a later time.

Patient 2: Private spaces and inclusivity

A female in her late fifties was referred to SCC for an evaluation of her pain associated with metastatic pancreatic carcinoma. At the virtual consultation, her husband remained off screen, but his voice was heard throughout the visit. The patient, herself, presented in the bathtub, explaining that the only way she could get any comfort from her severe pain was in the tub while watching TV. Otherwise, she would sleep to get away from the pain. Further review revealed that the patient had declined radiation therapy and celiac plexus block for control of pain and was taking extended release opioids more frequently than prescribed by an outside pain management physician. We counseled her and her husband on the safe, effective use of opioids, adjusted her pain and bowel regimens, and encouraged her to reconsider celiac plexus block and/or radiation for pain relief. Despite some discomfort to conducting session with the patient while she was in a bathtub, her need for comfort and pain relief led us to continue with the visit.

Patient 3: Safety first

A man in his early thirties with metastatic pulmonary neuroendocrine tumor involving the thyroid was seen in the supportive care clinic for a scheduled follow-up for symptom management. He was initially seen as a consult 5 months prior for emotional distress and pain. During that time, he was started on mild doses of opioids as needed and seen by our counselor. His stress stemmed from personal reasons and demands of being a new father undergoing cancer treatment. His pain seemed to improve over the months requiring less doses of opioids. He continued to work full time as an EMS provider in order to financially support his family while undergoing treatment. In order to continue working while also accessing medical care he needed, he attended his video follow-up visit with supportive care while working. He wanted to keep his appointment to receive attention and care for his symptoms, and especially share the anxiety he was experiencing, but then received an emergency work call during this time. He had to drive his EMS vehicle to the emergency, and chose to continue the visit while driving, as talking about his anxiety was important. We had felt it was not safe to continue while he was driving, but the patient insisted. His concerns were validated through supportive counseling, and a decision was made to schedule further follow-up with our counseling team at a different time.

Discussion

These cases illustrate the complexity of virtual appointments and some of the unusual circumstances clinicians encounter. They highlight issues of privacy, boundaries, and safety, emphasizing the need to help patients understand the importance of appropriate behavior in a virtual setting. Although clinicians have been navigating telemedicine for decades, it has never been more prominent as it is now, illustrating a need for telehealth education not only for providers, but also for patients, to competently deliver quality care in a virtual setting.

When utilizing telemedicine for sensitive discussions, it is imperative we use both verbal and non-verbal skills, show compassion, and establish a comforting and private environment (Chua et al., 2020; Cocuzzo et al., 2021). Non-verbal communication is one of the most significant factors toward helping to build the relationship between the provider and the patient help to reinforce or contradict verbal comments (Silverman and Kinnersley, 2010). These critical factors are all in jeopardy when a patient or a clinician is not in a conducive environment, fostering private, sensitive communication free from distractions, and able to focus solely on the video visit such as the challenges experienced with the first patient. Patients engaging in other activities in a distracting environment, as noted in the third patient example, run the risk of missing or misunderstanding the information presented during the visit. This could be critical when discussing sensitive material regarding a patient's condition (Levine et al., 2020), conducting thorough symptom assessment, or communicating treatment plans clearly, for example, medication administration such as opioid use in palliative care. These distractions can prolong visits and require additional follow-up calls or messages and unintended consequences regarding side effects and safety.

Isautier et al. (2020) found poor or less effective communication most commonly noted as to why patients perceive telehealth to be worse than those perceive in-person medical care. One would expect, then, for the same to be true for providers finding it difficult to talk to patients who are otherwise multitasking or distracted by others or their environment. Having consistent guidelines across all types of telehealth services for patients is one way we might help minimize risks while upholding standards of care (Watzlaf et al., 2017). Moving forward in the new era of telehealth, we might want to consider the benefits of patient–doctor agreements to assist in maintaining consistency and appropriate standards from both sides once education and guidelines have been established. While past literature has looked at webside manner skills when conducting palliative care visits (Chua et al., 2020), we propose some simple principles and guidelines for patients (Table 1), developed from the above findings, as well as with our own experiences in mind.

The rapid adoption of telehealth by our supportive care center, and other medical specialties, has provided a lifeline of access to medical care for many patients and remains commonly utilized (Demeke et al., 2021; Patel et al., 2021; Reddy et al., 2021). While we value the comfort and convenience it can provide, we hope not to compromise our standards of care. Not only do we want to maintain sensitivity and privacy while providing personhood focused relief to our most vulnerable patients, but we also want to consider the experiences from the perspective of the

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Table 1. Patient instructions for successful virtual encounters

- *Environment.* Treat the visit as you would a clinic appointment in person (appropriate dress, environment, lighting, etc.).
  - Choose a *quiet space* free from distractions.
  - Choose a *private space* to discuss personal and delicate matters.
- *Participants.* Notify family or friends you would like to include of your appointment beforehand. Make sure the doctor is aware of who is in the visit with you.
- *Audio/Video.* Make sure there is enough light for clear visualization and the doctor can hear you clearly. Make sure camera is set to include you and any other persons attending the session.
- *Distractions.* To ensure safety and minimize distractions, do not drive or engage in other activities during a session. Please remember while being comfortable, appropriate attire is helpful for your visit.
- *Assistance.* Ask for help with any technical difficulties.

clinician. Their degree of comfort, confidence, and willingness to practice in this kind of environment is equally important to the success of telehealth moving forward. These challenging experiences are only some of those encountered in our palliative virtual visits and further research can elucidate the effects of patient behavior on an effective telemedicine palliative visit. Despite the ever-evolving landscape of telemedicine, it is important to maintain the same standards of care on both sides of the camera.

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