



Telemedicine in Advanced Kidney Disease and Kidney Transplant: A Qualitative Meta-Analysis of Studies of Patient Perspectives

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Rationale & Objective: While the use of telemedicine has increased dramatically across disciplines, patient perspectives on telemedicine related to chronic kidney disease are not well understood. We systematically reviewed qualitative studies on patients with chronic kidney disease as well as those with kidney transplant to better understand these patients' perspectives related to telemedicine.

Study Design: Qualitative meta-analysis.

Setting & Participants: Pre-dialysis chronic kidney disease and kidney transplant patients that used telemedicine.

Selection Criteria for Studies: English language studies published in the year 2000 and beyond that investigated patient perspectives in a qualitative manner. Works that were not qualitative or did not focus on provider-patient interactive modes of telemedicine were excluded.

Data Extraction: 375 articles were pulled from PubMed, Embase, and Academic Science Premier. After filtering, 8 final articles were selected. These articles were critically appraised for quality and were used in the final analysis.

Analytical Approach: We used a grounded theory approach to develop a codebook to systematically

review each of the selected articles through a qualitative meta-analysis of the included literature.

Results: Telemedicine was seen by patients to have notable strengths as well as weaknesses. These characteristics can be organized into 4 primary themes (autonomy, logistics, privacy/confidentiality, and trust). Within each primary theme, we identified subthemes. Universally, all articles included the subtheme "fewer trips to the health care facility" as a beneficial factor of telemedicine within the primary theme "logistics." A majority (6 of 8) of the articles included positive patient perspectives on the primary theme "autonomy" in terms of telemedicine promoting the subtheme of "engagement." Patients' views on telemedicine were mixed regarding the primary themes of "privacy/confidentiality" and "trust" related to telemedicine.

Limitations: Lack of provider perspectives, non-English studies, and studies published before the year 2000. Articles published after the start of data extraction were also not included.

Conclusions: Telemedicine should continue to be offered to patients with chronic kidney disease and kidney transplant patients to facilitate access. Additional research should focus on ways to decrease negative factors experienced by some patients such as difficulty using the technology.

Complete author and article information provided before references.

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Kidney Med. 6(7):100849. Published online May 24, 2024.

doi: 10.1016/j.xkme.2024.100849

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One group in need of telemedicine services is chronic kidney disease (CKD) and transplant patients. CKD can affect multiple systems of the body, and patients often present with comorbid conditions such as hypertension and diabetes.¹ As such, patients need frequent appointments to manage all related conditions. Similarly, transplant patients need close monitoring of the grafted organ and immunosuppressant therapy.² Telemedicine offers a solution that may protect patients from potential infections while also maintaining the necessary continuity of care with providers.

However, challenges with telemedicine have been noted.³ Prior systematic reviews focused on telehealth and eHealth interventions in dialysis patients have shown conflicting results with potential benefits; however more adequately powered prospective studies are needed.⁴⁻⁶ During the COVID-19 pandemic, the use of telemedicine had drastically taken a forefront stand. Across the globe, countries saw impact from the pandemic and displayed

differing responses with the use of telemedicine.⁷ As the US Department of Health and Human Services ended the Public Health Emergency on May 11, 2023, more data on non-dialysis CKD and transplant patient perspectives are needed to guide future decisions about telehealth in this vulnerable population.⁸ The goal of the current study is to assess perspectives of non-dialysis CKD and transplant patients in terms of telemedicine.

METHODS

Qualitative Systematic Review

A systematic review of qualitative literature was performed to assess the perspectives of patients with non-dialysis CKD and kidney transplant on telemedicine. Prior work on qualitative systematic reviews informed our methodology.⁹⁻¹⁶ The first author (CDM) conducted a literature search on June 22, 2022, using Boolean terms (Item S1), from PubMed, Embase, and Academic Science Premier.

PLAIN LANGUAGE SUMMARY

Telemedicine is the ability to do medical visits using technology such as telephone and video calls. For this study, we researched the experiences and perspectives of patients with chronic kidney disease or kidney transplant, who often require complex, coordinated care. We found 8 articles on this topic from 6 different countries and analyzed the text of these publications to see if there were any common themes across the articles. We found 4 major themes: autonomy, logistics, privacy/confidentiality, and trust. Within each of these themes, there were positive and negative connotations to telemedicine. Overall, we feel that telemedicine should continue to be available for interested patients, and more research should be done to remove barriers to telemedicine.

Inclusion criteria included English language articles published on or after the year 2000 that were peer-reviewed. English language was used as an inclusion criterion, as the authors wanted to ensure correct interpretation of patient perspectives, given the qualitative nature of this study. The year 2000 was selected as the year for inclusion, as studies before then may include technologies that are less applicable to today's telemedicine environment such as video technology and smartphone use. Exclusion criteria included: studies that focused on dialysis populations; studies that only discussed telemedicine modalities in a theoretical sense (eg, patients making assumptions on telemedicine without relevant experience). Additionally, the authors define telemedicine as the use of a technology where providers communicate directly with patients. Originally, the primary author wanted to investigate all ranges of patients with kidney disease including pre-dialysis CKD, dialysis, and kidney transplant. However, after reviewing the available literature, dialysis patients were not included because several systematic reviews had already been published previously on this patient population.⁴⁻⁶

Qualitative Meta-analysis

A codebook was created to analyze each article through an iterative, grounded theory process. The authors CDM, BJA, ARC, and BLJ independently coded themes and subthemes for a subset of the articles and then met and codeveloped a codebook. Then, 2 of the authors (CDM, ARC) recoded the same articles and reconciled differences in coding through in-person and virtual meetings. The primary author coded the remaining articles and iteratively updated the codebook as needed with further consult from all authors. All coding was performed by NVivo (release 1.7; Lumivero). The organization of information captured was categorized as themes, with subthemes that are more specific categorizations within primary themes. Within subthemes,

additional nuances of the data such as positive and negative connotations were captured as sub-subthemes. Following the completion of coding, a table was created to summarize the quantitative metrics of each code and article. All 8 articles were assessed for quality using the Crowe Critical Appraisal Tool Form (Item S2).

RESULTS

Study Characteristics in Systematic Review

A total of 375 articles were screened and entered into Endnote (Clarivate Analytics) (Fig 1). After excluding duplicates and irrelevant articles based on the primary author's review of titles, 34 articles were more thoroughly reviewed by the primary author by abstract and/or full text. Of these 34 articles, 8 met the inclusion/exclusion criteria and were included in this review (Table 1).¹⁷⁻²⁴ Many of the studies excluded after review by the authors did not meet the definition of telemedicine, included patients undergoing dialysis, and/or did not include qualitative patient perspectives of telemedicine.

Of the 8 studies (N = 8) included, 3 focused on transplant patients and 5 focused on non-dialysis CKD patients. Seven focused on adult patients whereas 1 studied children with CKD with their parents. Of the 8 articles, 3 studied dietary aspects of care and investigated patient perspectives on telemedicine used for dietary coaching. Half were

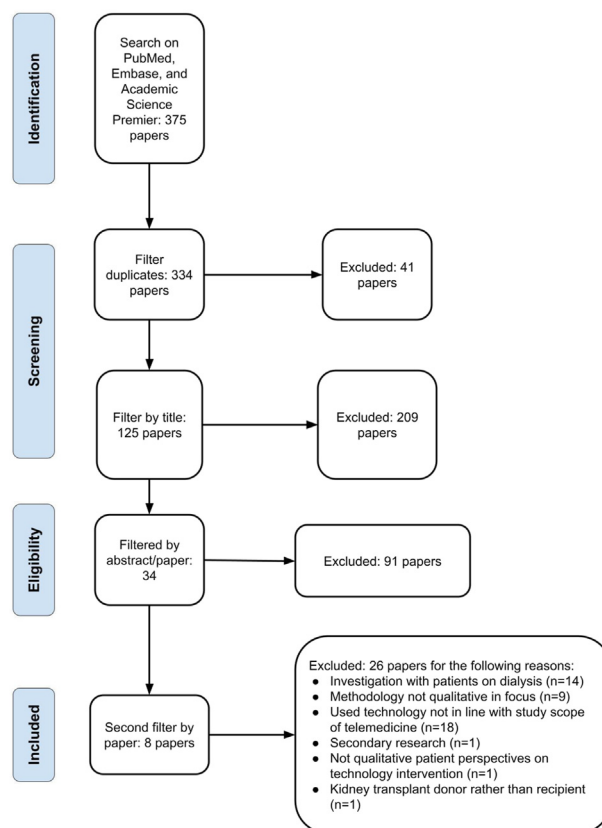


Figure 1. Flowchart of systematic review process.

Table 1. Study Characteristics

Study	Study Design	Study Population	Recruitment	Time Period
Heyck et al ¹⁷ (2022)	Cross-sectional observational survey	235 Canadian patients 18+ y of age with CKD	Nephrology/kidney clinic	December 2020-April 2021
Huuskes et al ¹⁸ (2021)	Focus groups	34 Australian patients 18+ y of age with kidney transplant	Transplant society, transplant network, and social media	August 2020
Kelly et al ¹⁹ (2019)	Mixed methods in randomized control trial	77 Australian patients 18+ y of age with stages 3-4 CKD	Tertiary nephrology Units	November 2016-November 2017
Ladin et al ²⁰ (2021)	Semi-structured interview	60 US patients 70+ y of age with stages 4-5 CKD	Nephrology clinic	August-December 2020
Nielsen et al ²¹ (2020)	Semi-structured interview and focus group	36 Danish patients 18+ y of age with kidney transplant	Transplant center in University Hospital	September 2018-April 2019
Trace et al ²² (2020)	Semi-structured interview	18 UK patients aged 9 mo-14 y with parents	Outreach clinic	January-May 2018
Varsi et al ²³ (2021)	Semi-structured interview	18 Norwegian patients 18+ y of age with kidney transplant	Outpatient clinic	June 2018-April 2020
Warner et al ²⁴ (2019)	Semi-structured interview	21 Australian patients 18+ y of age with stages 3-4 CKD	Teaching hospitals	November 2016-November 2017

Abbreviation: CKD, chronic kidney disease.

investigated during the COVID-19 pandemic and the other half were pre-pandemic. Countries represented in studies included Australia (n = 3), the United States, Canada, Denmark, the United Kingdom, and Norway. Characteristics of the studies are shown in Table 1.¹⁷⁻²⁴ Three studies used telephones as their method of telehealth, 2 studies explored general experiences relating to telemedicine, 2 studies evaluated patient experiences with hospital telemedicine applications, and 1 study evaluated use of a telehealth app.

Primary Themes, Subthemes, and Sub-subthemes

Of the included studies, we identified 4 primary themes—autonomy, logistics, privacy and confidentiality, and trust. Table 2 displays illustrative quotes and indicates which themes and subthemes were present in each article included in the final analysis.¹⁷⁻²⁴

Autonomy

Autonomy had 3 subthemes; “engagement” (which was further classified using the sub-subthemes “positive” [n = 6] or “negative” [n = 2]), “motivation” (n = 4), and “personalization” (n = 3). “Autonomy” is defined as a patient’s ability to take part in their health care. As such, being engaged, being motivated, and receiving personalized medicine are aspects that contribute to a patient’s ability to have autonomy in their own care. The subthemes are defined as follows: (1) “Engagement” is defined as a patient taking an active part in their health care; (2) “Motivation” is a patient’s desire to be engaged in their health and health care; and (3) “Personalization” is the

care a patient receives being tailored to their specific needs and/or goals.

Logistics

“Logistics” is defined as the ease or difficulty of receiving and/or taking part in one’s own health care. We classified the primary “logistics” theme into subthemes of “facilitators” and “barriers.” The sub-subtheme, “fewer trips to the health care facility,” was classified under the subtheme “facilitator” and was found in all 8 articles. This sub-subtheme is defined as patients not needing to go to the hospital or clinic as often because of telehealth. Other “facilitator” subthemes included “comfort at home” (n = 5) and “technology” (n = 6). “Comfort at home” is defined as a patient’s view of telehealth being beneficial to that care is received at home. “Technology” as a facilitator is defined as technology making health care feel more accessible for the patient. The subtheme “barrier” was further classified into the sub-subthemes of “medical care” (n = 4) and “technology” (n = 5). The sub-subtheme “medical care” refers to patients that viewed telehealth negatively compared to in-person care because there are limitations in terms of the physical examination. The sub-subtheme, “technology” barriers included obstacles such as lagging and disrupted connections.

Privacy and Confidentiality

The primary theme “privacy and confidentiality” was further classified into the subthemes “positive experiences” and/or “negative experiences.” A “positive experience” (n = 2) is defined as the feeling that private health

Table 2. Table of Primary, Subthemes, and Sub-subthemes of Selected Studies

Primary Theme	Subtheme	Sub-subtheme	Article	Illustrative Quote
Autonomy	Engagement	Positive	Huuskes et al ¹⁸ Kelly et al ¹⁹ Ladin et al ²⁰ Nielsen et al ²¹ Trace et al ²² Warner et al ²⁴	“When I go into the hospital the whole thing is distracting, and sometimes I forget something. But if I’m sitting in front of a computer I’ve got lots of time and I usually have a list of things right by me.” (Huuskes et al ¹⁸)
		Negative	Huuskes et al ¹⁸ Trace et al ²²	“Pre-school children were not anticipated to have direct involvement and when one tried, the result was a chaotic VC, disengaging the parent.” (Trace et al ²²)
	Motivation	Kelly et al ¹⁹ Nielsen et al ²¹ Warner et al ²⁴ Trace et al ²²	“If I didn’t have the phone calls from [my coach] once a fortnight I probably wouldn’t have taken it as seriously as I have” (Kelly et al ¹⁹)	
	Personalization	Kelly et al ¹⁹ Trace et al ²² Warner et al ²⁴	“It’s given me simple tasks, simple methods, or methodologies, to improve the situation, and they’re not a whole lot of gobbledygook, just basic stuff that we can understand” (Kelly et al ¹⁹)	
Logistics	Barriers	Medical Care	Heyck et al ¹⁷ Huuskes et al ¹⁸ Ladin et al ²⁰ Varsi et al ²³	“If there were physical changes in my condition, I would rather attend the physical clinic with the MD. So that she could see the changes, such as swelling in my legs or listening to my chest.” (Heyck et al ¹⁷)
		Technology	Huuskes et al ¹⁸ Ladin et al ²⁰ Nielsen et al ²¹ Trace et al ²² Varsi et al ²³	“We attempted the video, but I was not sophisticated enough...to get it to work.” (Ladin et al ²⁰)
	Facilitators	Comfort at home	Kelly et al ¹⁹ Ladin et al ²⁰ Trace et al ²² Varsi et al ²³ Warner et al ²⁴	“[At home] was the best way to do it... you’ve got the book in front of you if she wants to refer to something it um, it’s quieter and peaceful so the speak.” (Warner et al ²⁴)
		Fewer trips to the health care facility	Heyck et al ¹⁷ Huuskes et al ¹⁸ Kelly et al ¹⁹ Ladin et al ²⁰ Nielsen et al ²¹ Trace et al ²² Varsi et al ²³ Warner et al ²⁴	“This has meant that I don’t have to set aside so much time. I have to go all the way to the hospital. It takes, as I said, three to four hours, back and forth, and so on. So I can do it in ten minutes, which means that I have time to do other things instead, or plan other things. So for me it has been absolutely superb.” (Varsi et al ²³)
		Technology	Huuskes et al ¹⁸ Kelly et al ¹⁹ Ladin et al ²⁰ Trace et al ²² Varsi et al ²³ Warner et al ²⁴	“I was panicking, thinking oh, like, I don’t do technology, I’m rubbish!... I don’t even know how to switch a computer on! When it was like...download an app... go to this email, I was thinking ‘oh no’, but actually it went really smoothly.” (Trace et al ²²)
	Privacy and confidentiality	Positive experiences	Trace et al ²² Warner et al ²⁴	“feelings of enhanced privacy were reported, compared to: ‘...corridor conversations in clinic’; ‘...anyone walking in [referring to other staff entering the clinic room].’” (Trace et al ²²)
Negative experiences		Huuskes et al ¹⁸ Trace et al ²² Varsi et al ²³	“So I don’t think I would have liked, even if it may be my spouse, I would not have liked to carry it out if the spouse was sitting in the living room, or in the same room as me.” (Varsi et al ²³)	

(Continued)

Table 2 (Cont'd). Table of Primary, Subthemes, and Sub-subthemes of Selected Studies

Primary Theme	Subtheme	Sub-subtheme	Article	Illustrative Quote
Trust	Comfort	Positive	Ladin et al ²⁰ Trace et al ²² Warner et al ²⁴	"maybe the doctor is more committed to providing his time because of [telehealth]...we're able to have a greater dialogue...than at the office." (Ladin et al ²⁰)
		Negative	Huuskes et al ¹⁸ Ladin et al ²⁰ Nielsen et al ²¹	"I need to see the doctor...her facial expressions. She should be able to see me and tell whether I'm okay with whatever she's saying or not. [You cannot] really do that over the telephone." (Ladin et al ²⁰)
	Relationship	Positive	Ladin et al ²⁰ Trace et al ²² Warner et al ²⁴	"[My coach] supported me over the weeks, the phone calls every now and again, every couple of weeks or so, which I think's brilliant... just to have someone there to pat you on the back every now and again and explain different things and things you don't think of... I looked forward to the phone calls to tell you the truth! Because there's nothing better than talking to people." (Warner et al ²⁴)
		Negative	Heyck et al ¹⁷ Huuskes et al ¹⁸ Ladin et al ²⁰ Nielsen et al ²¹	"There's always an occasional technical glitch. You can't connect for some reason. All this technology, it's basically dehumanizing us. I think it does take away...the personal contact. I do miss that. Especially meeting with the staff." (Ladin et al ²⁰)

Abbreviation: VC, videoconsultation.

information is protected when using telemedicine. A "negative experience" (n = 3) is defined as the lack of privacy and confidentiality regarding health information.

Trust

Trust was organized into 2 subthemes, "comfort" and "relationship." Both included the sub-subthemes, "negative" and "positive," to highlight the nuances of various patient perspectives. Positive views on "comfort" (n = 3) included patients being comfortable receiving medical care from the team via telemedicine, whereas a negative view (n = 3) of comfort might indicate patient discomfort related to telemedicine. A positive view on "relationship" (n = 3) indicated that patients felt telemedicine facilitated the patient-provider relationship, whereas "negative" views (n = 4) suggested it hindered it.

DISCUSSION

Our analysis demonstrates that telemedicine offers several advantages among patients experiencing CKD and/or kidney transplantations; however, it has its limitations. We found 4 primary themes through our qualitative meta-analysis: (1) autonomy; (2) logistics; (3) privacy and confidentiality; and (4) trust.

As a strength, the positive aspects of telemedicine, such as the primary theme "autonomy" (and the sub-themes motivation and personalization, and the sub-

subtheme positive engagement), indicate that telemedicine provides an opportunity for patients to take an active part in their care. During an in-person visit, patients may feel overwhelmed and distracted by the hospital environment, making it difficult for patients to focus on their visit.¹⁸ Via telemedicine, some patients (ie, young adults) may stay more engaged with their care team in the comfort of their home. Additionally, Kelly et al¹⁹ found supportive text messages and phone calls encouraged patients to take more accountability for their diet. The sub-subtheme "negative engagement" within the primary theme of "autonomy" was present in the reports of Trace et al²² and Huuskes et al¹⁸ indicating that telemedicine did, at times, negatively affect patients' engagement with care. In the Trace et al²² report, it was noted by parents that pre-school children being involved in their telemedicine meetings understandably had a chaotic effect. This suggests it is worth considering the age of the population that would benefit most from telemedicine. Notably, prior work has shown younger adult patients to be more satisfied with telemedicine compared to older adults.²⁵ Therefore, the age of pediatric patients and adult patients should be considered when deciding to implement telemedicine. Additionally, environment can negatively affect engagement with telemedicine. For example, in Huuskes et al,¹⁸ one patient indicated potential for distraction when using telemedicine. Thus, before telemedicine is used, providers should discuss aspects that

contribute to negative engagement, such as age and environment, with their patients.

This meta-analysis identified the subthemes of “barriers and facilitators” regarding the primary theme “logistics” of telemedicine use. The most common “facilitator” was fewer trips to the health care facility, a sub-subtheme found in every article included in the analysis. This indicates one of telemedicine’s greatest strengths for patients with CKD or kidney transplant was tackling the issue of distance to and from the hospital or clinic. By having a virtual session at the comfort of home or work, patients could save a significant amount of time, which was appreciated by patients that lived both near to and far from the hospital.²³ “Technology” was included as a sub-subtheme within the “logistics” parent theme under both the “barrier” and “facilitator” subthemes. As a “barrier” for example, in Nielsen et al,²¹ patients indicated virtual communication was challenging because of a lack of non-verbal cues such as “...body language and visual input.” Trace et al²² found that technology could be a facilitator by being designed in an easy-to-use fashion. The sub-subtheme “medical care” within the primary theme of “logistics” and subtheme of “barriers” reflects concerns patients may have with telemedicine about not being able to have a proper physical examination.¹⁷ They felt that by not being seen in-person, the physician could not directly observe any issues that patients may present with physically such as edema.¹⁷ Patients also felt taking measurements at home such as blood pressure may not be as accurate as in the office.²⁰ Alternatively, as a “facilitator,” the sub-subtheme “comfort at home” represents how patients felt telemedicine provided the opportunity to connect with the medical team in a more comfortable environment.

This study demonstrates how patients perceived “privacy and confidentiality” in telemedicine both positively and negatively. Positive views included patients feeling an elevated level of security.²² This was because in clinic, patients felt anyone could walk in and out of clinic, and hallway conversations were not as secure. At home via telemedicine, however, patients felt the conversations to be more confidential. However, negative aspects of “privacy and confidentiality” included finding it challenging to locate a quiet area in the home or workplace for the appointment.²³

The parent theme “trust” comprised the subtheme “comfort.” A positive aspect of “comfort” is demonstrated by the report of Warner et al²⁴ indicating that patients felt seen when they received personalized telehealth messages regarding their care, thus helping to establish trust between patients and their provider. They also felt more comfortable discussing fears with the medical team via telephone consultation.²⁴ A second subtheme of “trust” is “relationship,” which was also demonstrated in Warner et al,²⁴ with patients stating they were able to develop meaningful relationships with their coaches during the study. However, Nielsen et al²¹ noted body language added nuance that could only really be done in-person.

The current study shows how telemedicine contains both positive and negative attributes, as noted by the patients and caretakers it aims to serve. Subthemes that were cited in a majority of the 8 articles were deemed to be more meaningful characteristics. Based on the results of this study, it is our recommendation that telemedicine continue to be used and further studied. While some patients may perceive limitations, the benefits found from telemedicine present as an opportunity to better help patients access their care.

There are some important nuances of note regarding this study. First, patient caretakers were considered a part of the study of interest. Given their critical role in caring for the patient, the researchers of this study believed the telemedicine modalities meant to aid patient care directly applies to them as well. Also, across the 8 studies selected, multiple modalities of telemedicine were used, including virtual visits, personalized messages, and telephone consultations. This is important to note, as different modalities have different strengths and weaknesses. For example, while telephone consultations open availability to conversations and saving time to drive to the hospital or clinic, they lack the visual component of a visit. Different software may also have different glitches that need to be addressed. The goal of this study was to focus on broad characteristics of telemedicine, rather than focusing on the nuanced minutia of each potential program.

Strengths and Limitations

The strengths of this study include a broad pediatric and adult population of both CKD and transplant patients, multiple modalities of telemedicine, and high-quality works to assess telemedicine perspectives. Additionally, an enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) checklist found originally in prior work was used to guide the methodology description in the writing of this article (Item S3).^{26,27} Additionally, this study included literature from multiple countries. This offers the additional strength of characterizing telemedicine across a diverse group of settings.

Limitations of this study include a lack of provider perspective, the exclusion of non-English articles, and articles published before the year 2000. Additionally, since the start of this study, other articles have been published in the field that should be considered as telemedicine continues to be used and potentially evolve. Articles published after data extraction began were also not included. Further studies should be performed to understand how the negative views of telemedicine can most effectively be addressed and the most cost-effective way to implement secure telemedicine modalities into the health care setting.

CONCLUSION

In conclusion, telemedicine offers a potential solution to help make medical appointments more accessible for CKD and transplant patients. Telemedicine displays advantages

and disadvantages when compared with in-person consultation. Of all characteristics of telemedicine studied here, “fewer trips to the health care facility” was the most cited view and was found in all 8 articles. The authors recommend telemedicine continue to be used and that negative characteristics of telemedicine continue to be studied for ways to improve the patient care experience. Future research should investigate ways to improve telemedicine use for patients such as improving autonomy, logistics, perceived privacy and confidentiality, and trust.

SUPPLEMENTARY MATERIALS

Supplementary File (PDF)

Item S1: Search Terms for PubMed, Embase, and Academic Science Premier.

Item S2: Crowe Critical Appraisal Tool for all 8 selected articles.

Item S3. ENTREQ Checklist.

ARTICLE INFORMATION

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Support: Christopher D. Manko was awarded a stipend as well as reimbursement for NVIVO subscription from Geisinger Commonwealth School of Medicine for this work.

Financial Disclosure: The authors have no relevant financial interests to disclose.

Acknowledgements: The authors would like to acknowledge Geisinger Commonwealth School of Medicine for its support of this research. Additionally, the authors would like to thank Iris Johnston and Amy Houck for their help with the literature search of this study. Furthermore, the authors would like to thank Dr Lisa Bailey-Davis for her mentorship of the project.

Peer Review: Received December 10, 2023. Evaluated by 2 external peer reviewers, with direct editorial input from the Editor-in-Chief. Accepted in revised form April 19, 2024.

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