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Key informants' perceptions of telehealth palliative care for people living with dementia in nursing homes

Joan G. Carpenter^{1,2*}, Laura C. Hanson³, George Demiris⁴, Nancy Hodgson⁴ and Mary Ersek^{2,4}

Abstract

Background Studies have shown that palliative care delivered to people living with dementia (PLWD) in nursing homes (NHs) improves care quality and reduces potentially burdensome treatments. However, access to palliative care services in NHs is uncommon. Telehealth may extend the reach of specialty palliative care consultation, yet strategies for feasible and acceptable NH implementation remain unknown. During implementation of an embedded pragmatic pilot clinical trial for PLWD, we aimed to describe key informants' perceptions of a NH telehealth palliative care intervention.

Methods Guided by the Practical Implementation Sustainability Model (PRISM), we engaged key informants in 30–60-minute focus groups and individual semi-structured interviews to understand barriers and facilitators to implementation of a NH telehealth palliative care intervention in one NH. Interview prompts addressed contextual factors that influenced outcomes. Interviews were conducted and recorded via videoconference, transcribed, and analyzed using the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework.

Results Participants ($n = 14$) included NH administrators and other leaders, palliative care providers, telehealth representatives, dementia advocates, a care partner, and a PLWD. Identified barriers to implementation included stigma surrounding dementia, palliative care, and NHs; multiple logistical pieces required to implement the intervention; inflexibility of palliative care providers to meet NH needs; and inability to assess residents in person. Facilitators included convenient, user-friendly and readily available telehealth equipment, and NH staff presence during visits. Outcomes most relevant to the key informants were increased goals of care conversations, improved symptom management and quality of life, and decreased health care utilization. Suggested adaptations included increased family engagement in the logistics of the intervention and strong NH advocacy.

Conclusions In this study, key informants provided feedback that barriers to implementing NH telehealth palliative care far outweighed the facilitators for uptake. Future work will focus on employing NH staff in user centered design to overcome barriers such as optimal timing for consults and/or scheduled consult days to fit NH workflow, assessing organizational readiness for implementing change, and identifying dementia-specific and palliative care education needs.

*Correspondence:
Joan G. Carpenter
joan.carpenter@umaryland.edu

Full list of author information is available at the end of the article



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Keywords Telehealth, Nursing homes, Palliative care, Supportive care, Dementia

Background

Alzheimer's disease and related dementias are the fifth-leading cause of death in older adults [1] and up to 80% of nursing home (NH) residents are living with dementia [2]. Research has shown that palliative care consultations can improve the quality of care for people living with dementia (PLWD) in NHs by reducing potentially burdensome transitions [3]. Palliative care delivered to PLWD increases advance care planning, improves patient and care partner satisfaction, and reduces costs and acute care use [3, 4]. However, access to specialty palliative care in NHs is uncommon [5, 6].

Telehealth consults have been incorporated into NH care for over two decades to increase access to care; [7] its use is critical in addressing access to specialist services including psychiatry, dermatology, and neurology [8–11]. Some evidence demonstrates that telehealth is feasible, acceptable, and efficacious in its ability to achieve similar outcomes as face-to-face visits for palliative care, geropsychiatry, and chronic care management [12–14]. Telehealth may be particularly effective for reducing acute care use among NH residents when connected to a consult service that provides urgent medical care [15, 16]. Additional support for telehealth lies in research describing NH resident, family, and staff acceptability of telehealth palliative care services however it is unclear on how to best implement, adopt, and sustain services [17, 18].

Despite its potential benefits, research also documents challenges using telehealth in NHs. Challenges include unreliable video connectivity, difficulty with device setup, and troubleshooting technical issues [19]. Further, in a pilot study that combined a palliative care specialist via live video with case-based NH staff teleconferencing, 70% of family members reported they would prefer to see the healthcare providers face-to-face [18].

Due to the potential challenges integrating telehealth palliative care in NHs and mixed opinions on its use, it is critical to understand the perceptions of key informants involved in NH telehealth, specifically when used for PLWD [7, 20]. Therefore, this article explores the views of palliative care providers, residents and family care partners, and dementia advocates (e.g., community advisors and representatives) regarding barriers and facilitators to adopting NH telehealth palliative care for PLWD during a pilot clinical trial. The single arm trial (ClinicalTrials.gov: ID NCT05001620; registration date: July 27, 2021) aimed to enroll thirty PLWD in one NH with preexisting telehealth services available 24 h/day which were used daily by staff for resident's primary and acute care needs. Participants aged 60 years and over were included if they

had a documented dementia diagnosis and were recently admitted to the NH for post-acute care after a hospitalization. The inclusion criteria were purposely broad to include all stages of dementia because PLWD may exhibit symptom distress and complex care needs after hospitalization [21, 22].

Methods

Design

Guided by the Practical Implementation Sustainability Model (PRISM) and Reach, Effectiveness, Adoption, Implementation and Maintenance Outcomes (RE-AIM) framework (Fig. 1) [23], this qualitative descriptive study used focus groups and individual, semi-structured interviews to collect data from key informants before, during, and after an Imbedded Pragmatic Alzheimer's Disease and AD-Related Dementias Clinical Trials Collaboratory (NIA IMPACT Collaboratory) pilot clinical trial. The pilot clinical trial was designed to evaluate the implementation outcomes of a telehealth palliative care intervention for PLWD.

Data were collected from August 2021 through December 2022. Due to multiple factors related to COVID-19 delays, we conducted a combination of focus groups (before intervention implementation) and individual interviews (throughout implementation). The project was approved by the Advarra Institutional Review Board.

Intervention

The trial intervention consisted of a structured telehealth palliative care consultation delivered by a nurse practitioner, specialty trained and certified in palliative care, via videoconference to PLWD and/or their care partner/surrogate. Figure 2 details the consultation protocol.

The participating NH organization site leadership requested that a social work (SW) champion lead the implementation. The SW was responsible for reviewing a roster of potentially eligible PLWD with the nurse practitioner weekly, determining ability to participate in a goals of care discussion, communicating decision-making status, and where needed, notifying a care partner/surrogate as necessary. The SW also facilitated securing a consultation order from the primary care provider, gaining permission for the consult from the PLWD or care partner/surrogate, and scheduling the palliative care consult. The SW and nurse practitioner set up a mutually agreed upon consultation day/time with the PLWD and/or care partner/surrogate who was asked to join the consult in person, if possible. The nurse practitioner was credentialed by the NH, accessed the electronic medical record for clinical information, and documented the palliative care

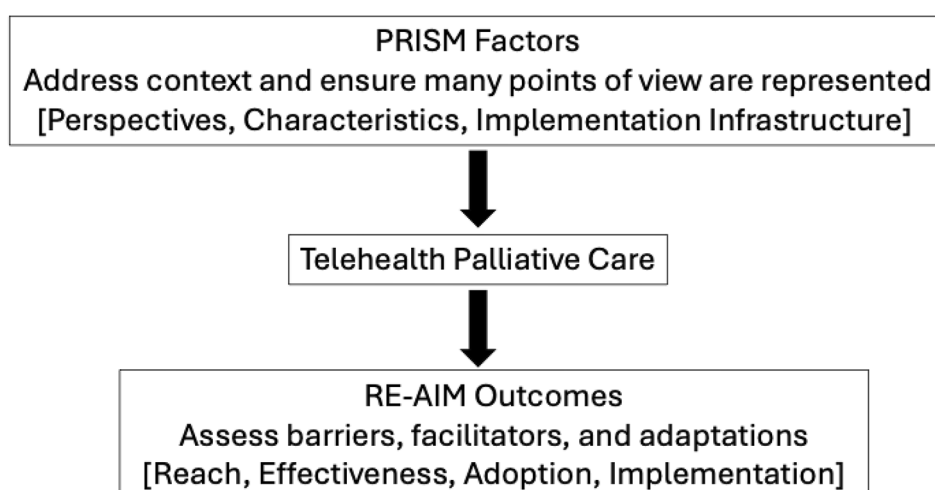


Fig. 1 PRISM/RE-AIM framework for the study

Steps	Actions/Content	Materials
1. Gather Information	<ul style="list-style-type: none"> - Discuss progress since admission with facility social work champion (e.g. improvement, stabilization, decline) - Elicit patient/family/staff input 	<input type="checkbox"/> Electronic Health Record (EHR) PC note template <input type="checkbox"/> Video/tele conference
2. Patient Assessment	<ul style="list-style-type: none"> - Examine patient assisted by facility social work champion (subjective, objective assessments) - Conduct a comprehensive pain and symptom assessment 	<input type="checkbox"/> EHR PC note template <input type="checkbox"/> Primary team notes <input type="checkbox"/> Video/tele conference
3. Goals of Care Conversation	<ul style="list-style-type: none"> - Determine illness understanding/ treatment expectations - Discuss initial transition planning after post-acute care - Elicit goals; explore preferences for type and site of care 	<input type="checkbox"/> Advance care planning education <input type="checkbox"/> Communication scripts/guides <input type="checkbox"/> EHR PC note template <input type="checkbox"/> Video/tele conference
4. Document	<ul style="list-style-type: none"> - Symptom assessment/management - Propose treatment plan, ensure patient/family agreement 	<input type="checkbox"/> Symptom management protocols <input type="checkbox"/> EHR PC note template
5. Communicate	<ul style="list-style-type: none"> - Communicate findings and recommendations to nursing and medical staff; determine agreement - Determine if additional visit or meeting is needed 	<input type="checkbox"/> Preferred communication with primary care provider and staff <input type="checkbox"/> EHR PC note template
6. Follow up	<ul style="list-style-type: none"> - Decide based on continued need for symptom assessment and management and ongoing goals of care discussions 	<input type="checkbox"/> EHR PC note template for follow up

Fig. 2 Telehealth Palliative Care Encounter Protocol (abbreviated)

consult in a note template created specifically for this trial.

Prior to initiating the study, the nurse practitioner and SW champion were oriented to the palliative care consultation protocol and implementation procedures. Additional “check in” calls were provided by study staff as needed. In keeping with a pragmatic trial, the nurse practitioner, SW, and NH staff had flexibility implementing the protocol.

Participant recruitment for the qualitative study

Key informants were identified by the study team networks and NH leadership. We provided information describing study participation for potential participants via email and if interested, they contacted the study team. Eligible participants were palliative care specialists not employed by the NH conducting the consults; NH SWs coordinating the consults; NH staff and providers (including medical directors); NH facility leadership, information technology staff including telehealth representatives; PLWD, care partner(s), and dementia advocates in the community who were connected to the study team through existing professional connections. All participants provided verbal informed consent and were compensated with a \$50 gift card for their participation. PLWD and care partners/surrogates in the trial were not recruited or enrolled in the qualitative study.

Data collection

The interview guide was created and reviewed for face validity by researchers with experience in NHs and dementia palliative care. The questions reflected three of the PRISM internal contextual domains (perspectives, partner characteristics, and implementation and sustainability infrastructure) that are most likely to impact four of the RE-AIM outcomes (Reach, Effectiveness, Adoption, and Implementation). We did not assess Maintenance because it was outside the scope of this study. Interview prompts addressed experiences caring for PLWD; perceptions about NH palliative care; adapting services for telehealth delivery; and planned outcomes. Figure 3 maps PRISM domains to interview questions.

Figure 3. Practical, Robust Implementation and Sustainability Model internal contextual domains mapped to interview guide questions.

Participants were provided with an overview of the structured consult prior to its implementation to provide insights on it (focus groups) or were a part of the professional team implementing it (individual interviews), therefore had hands on experience. Focus groups and interviews were conducted and recorded via videoconference by the research team principal investigator, project manager, or trained research assistant, transcribed verbatim, deidentified, and analyzed using NVivo 12.0.

Data analysis

Guided by the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) outcomes framework we used directed content analysis to analyze the data [23]. We aimed to describe the perceived need for the intervention and its ability to connect with PLWD (reach), the perceived most and least effective components of the intervention including outcomes most important to participants (effectiveness), its acceptance and any suggested adaptations of the intervention (adoption), and barriers and facilitator for its uptake (implementation). The principal investigator and trained research assistant met weekly to organize and review transcripts which familiarized them with the data. Data were coded using a codebook with the predefined categories including reach, implementation, adoption, and effectiveness. We examined coded data to identify patterns, we then summarized categories and used direct quotes to exemplify each summary.

Results

We conducted two focus groups and 6 semi-structured interviews with key informants (none were interviewed more than once). Each focus group was conducted prior to pilot clinical trial onset and lasted approximately 60 min. One group ($n=3$) included a PLWD, a care partner, and a dementia advocate. The other focus group ($n=5$) included NH leadership including a director of nursing, administrator, unit manager, SW, and a palliative care nurse practitioner. Participants ($n=6$) who were interviewed individually (range: 27–60 min) included one dementia advocate, a NH SW, a palliative care nurse practitioner, and three information technology staff including telehealth organization leadership (medical director, lawyer, and chief product officer). Demographic data were not collected as individual identifiers beyond role were not central to the purpose of this study.

Results from all focus groups and individual interviews are reported as one dataset. Throughout the interviews, participants talked generally about palliative care, dementia, and NHs but also talked specifically about the intervention that used telehealth to address dementia palliative care in NHs.

Reach

We defined reach as the participants' perceived need for the intervention and the ability of telehealth to connect with PLWD and their care partners/surrogates. In general, participants reported palliative care is needed during dementia care because it had the potential to help with decision-making support and symptom management. They felt it could assist both staff and family caregivers to understand the disease trajectory. They described “good dementia care is palliative” and “palliative care is very

CHARACTERISTICS	Can you give us information about your role [in caring for people living with dementia in nursing homes] and how long you have been in this role?
PERSPECTIVES	<p>Could you start by telling me a bit about your experience with palliative care for people living with dementia?</p> <p>a. When you think of palliative care, what comes to mind?</p> <p>i. PROBE: tell me more about [insert response]</p> <p>b. In what capacity, if any, have you been involved with palliative care?</p> <p>i. If involved with palliative care:</p> <p>1. Can you describe challenges communicating palliative care provider/clinician recommendations to team members?</p> <p>2. What resources do you use within your organization to support palliative care?</p> <p>c. What resources do you have/see a need for palliative care for people living with dementia?</p> <p>d. How does palliative care align with your personal/professional/organizational goals?</p>
ORGANIZATION CHARACTERISTICS; PERSPECTIVES	<p>Next, I would like to ask you about your experience with telehealth consults.</p> <p>a. When you think of telehealth, what comes to mind?</p> <p>b. Have you been involved with telehealth consults?</p> <p>PROBE: Can you tell me about the kind of telehealth consults you have been involved with?</p> <p>c. What resources do you have for telehealth?</p> <p>d. What worked well?</p> <p>e. What did not work?</p> <p>f. Can you describe challenges communicating recommendations from the telehealth consult to other team members?</p>
IMPLEMENTATION AND SUSTAINABILITY INFRASTRUCTURE	<p>I'd like to shift focus and ask if there anything missing from the palliative care consult protocol.</p> <p>a. If so, what?</p> <p>b. Will this protocol work in your facility or practice?</p> <p>i. Why or why not?</p> <p>c. What do you see as a challenge in the protocol?</p> <p>d. How would you change the protocol?</p>
PERSPECTIVES; PATIENT CHARACTERISTICS	<p>This project is designed to be a “real-world” study, which means it will better reflect the experiences and outcomes of those who would receive the palliative care consult during usual care by clinical staff (not researchers). Therefore, every person living with dementia newly admitted for post-acute care and their family/care partner and/or surrogate decision maker is included to participate—but each person has the right to decline a palliative care consult.</p> <p>a. Do you see any concerns raised by this study?</p> <p>b. Can you provide an example of an issue this study might raise?</p> <p>c. What do you think are important outcomes to measure in this study?</p> <p>d. If we were to measure the effectiveness of this project, what do you think is the most relevant outcome to measure when you think about people living with dementia?</p> <ol style="list-style-type: none"> quality of life hospitalization mortality advance care planning conversations medical orders for life sustaining treatments symptom management other
OTHER	During our discussion did anything else come to mind that we haven't talked about, or is there anything you would like to revisit?

Fig. 3 Practical, Robust Implementation and Sustainability Model internal contextual domains mapped to interview guide questions.

important for a whole family to know and understand" (care partner). However, they also reported that some people shy away from palliative care because of stigma or discomfort: *"Everyone just kind of puts off the conversation because it's an uncomfortable conversation and then all of a sudden it's too late to actually have the conversation"* (medical director). They reported misconceptions and that hospice and palliative care are often conflated and considered synonymous which creates additional barriers. *"I think they just have a difficult time grasping it because you know, and often times people compare palliative care to hospice"* (social worker). Further, they reported that some people associate palliative care with chronic symptom management only: *"chronic pain does not equal palliative care... there has to be a serious or advancing illness"* (nurse practitioner).

Participants said telehealth may provide a way to reach people living with dementia sooner who may lack access: *"right now... it's either skilled or hospice, right? So, there's not even an option that we're giving out for palliative"* (nursing home administrator). They also said that telehealth could reach NH residents at the place of their care: *"it brings resource to people where they need it and where they are rather than the other way around which is you come to me. And so I think for particularly vulnerable populations that's even more important"* (medical director). However, they also acknowledged that telehealth may not reach people because of inequities in technology access: *"we have to be careful that we don't end up making our already kind of disparate health system that much more disparate and increasing the distance between the sort of haves and have nots"* (medical director).

Effectiveness

We defined effectiveness as the most and least effective intervention components as well as outcomes that were most important to participants. The most effective component included standardization of the palliative care intervention. One participant said, *"being standardized will make, it will assure that all residents, all patients will get the same care. That's huge. Because so many times, there's so many health disparities you know, based on race and different things, and I just think that if they can see it in that in that way that we are doing this to ensure that all patients are getting this standard"* (advocate). The least effective components included the inability to determine follow through with recommendations, as evidenced by this statement from a nursing home staff member, *"plans can be created, but if plans aren't held and maintained then the whole palliative care plan is sort of thrown out the window, right? And so, I think that would be the biggest concern is, are these, are these plans followed through by the nursing home facility staff?"* (chief product officer). Additionally, participants commented on the lack

of staff buy in which led to challenges coordinating visits, thereby diminishing the intervention's effectiveness.

Outcomes that were cited as most important included better goals of care conversations, symptom management and quality of life. One participant said, *"quality of life and symptom management are going to be like #1"* (advocate) and another commented, *"I also think advanced care planning conversations are, are really important"* (nurse practitioner). Interestingly, participants felt conflicted in prioritizing one outcome over another as the most important: *"a tie between quality of life and symptom management because I think they kind of affect each other"* (director of nursing). Reducing hospital use and advance care planning were also seen as important outcomes, *"dementia folks tend to go in the hospital and there's readmissions a lot of times just because of maybe some change in mental status or or just the, the fact that they're not knowing how to handle whatever situation that has come up and the first thing they think about is, 'Oh well, let's take him to the hospital'"* (advocate).

Adoption

We defined adoption as the acceptability of the intervention and the participants' willingness to adopt the program. Participants stated the implementation of the intervention was complicated for NH staff working in a busy, often short-staffed environment and for clinicians trying to implement the program. *"I think it's really comprehensive. It really touches on all the areas, so umh, but I don't think it needs to be, I mean, it looks a little overwhelming when you look at it"* (nurse practitioner). Another participant suggested to make the intervention as short and focused as possible: *"but you've got you've got to really drill it down to its barest essentials,"* (medical director) and to ensure the intervention included ways to ensure providers were properly using telehealth *"So you have to know. What is acceptable in that realm and what's not, and certain things you have to have, you know a patient care presenter in the room for certain things"* (telehealth chief product officer).

Many made suggestions to refine the intervention to improve its uptake. Participants cited the need for more dementia and palliative care education for staff and family: *"But I think that more and more we're seeing because of the increase of people that are being placed in facilities that has dementia, we are seeing an increase of facilities reaching out to us and providing education not only for staff but for uh, families"* (advocate). Another participant commented, *"So it's going to be most of the families that we're going to be talking with, I think that piece right there, the education for families is pretty key"* (nursing home administrator). Suggestions included the use of video education and key partner input. For example, a medical director said, *"conducting goals of care conversation,*

if you're doing something there, if that's a training, I, I would prefer like a video" and the PLWD commented, "my dream would be to have a training on how to improve communication between staff and people with dementia that be run by us."

Regarding telehealth, suggestions by the nurse practitioner included making the first visit in person, if possible, "The initial consult in person to me gives you a better overall view of things of the patient." Or to build in at least one in person visit: "So, I find that an initial, initial or doing all telehealth without ever meeting them in person can be a challenge." The nurse practitioner also included ensuring strong NH advocacy, "there needs to be a person in the facility who, who is a strong, uhm, who, who will interact with the provider on the outside of the facility. There has to be a person inside to help make it happen." Participants also talked about resistance to technology. "There's no doubt about that, but there are still plenty of folks out there, and I would actually say there are more doctors who are a little bit, you know, like, "oh, I don't really believe that works, or that's not really a doctor is it?" So I think I think we still struggle a little bit with that" (medical director).

Implementation

We defined implementation as the barriers and facilitators to integrating the intervention into workflow and its "fit" or alignment with routine practice. Several participants reported one barrier is that palliative care providers may not be equipped to address the changing clinical challenges over the dementia trajectory. However, they perceived palliative care as "filling a void of a missing piece we have right now" (director of nursing) and viewed it as is as a "bridge between skilled, long-term care, and also hospice care" (nursing home administrator).

Specific telehealth barriers far outweighed the facilitators. Identified barriers to implementation included multiple logistical pieces required to implement the intervention; inflexibility of palliative care providers to meet NH needs; and a lack of leadership buy in. The participants reported system level barriers among NH staff and the palliative care specialist, including challenges coordinating telehealth visits, lack of teamwork between NH staff and the palliative care provider, and staff not prioritizing consults. The nurse practitioner reported, "There's just so many layers. It's very challenging to coordinate the timing of the telehealth visit, the staff to be able to assist." Staff also reported competing priorities that prevent them from collaborating with the palliative care specialist, "it could be a lack of staffing for the day. Majority of the time, every time you come, uhm, it's all these various amounts of things because we have different types of patients on one floor. It could be a trach patient, you could get 3 trach people, you know, couple bedbound people who

need eating. You know, just things like that, so we always try to put hands together to help one another out as much as possible" (social worker). Additionally, some telehealth representative participants cited that often NHs lack buy in for using telehealth due to existing hierarchies and territorial providers, "I will say there's always the, the skilled nursing and the assisted facilities, things like that or where we get, you know, sometimes no buy in. That's a good way of putting it. Sometimes you would, you will have locations where the nurse will tell them outright, 'The primary care provider doesn't want us working with you'" (chief product officer).

Facilitators included convenient, user-friendly and readily available telehealth equipment, and NH staff and family presence during visits. For example, NH staff participants reported "Yeah, yeah, it's an easy. It's an easy platform to use." NH staff engagement, family presence, and personal connections were seen as essential for successful telehealth visits: "we always have a nurse, a unit manager present or myself" (social worker); "I'm a good asset and tool to help them understand difficult situations" (care partner); and "having someone be able to communicate on behalf of the residents is even more powerful" (advocate). Participants also reported that palliative care aligns with their goals, "Well, for me professionally it it, it really aligns and it's what I've done for the last 27 years. And so it really does align, and it it aligns with my professional goals and my personal goals as well" (nurse practitioner).

Discussion

In this qualitative study, we used key informants' feedback to better understand implementation of a NH telehealth palliative care intervention for PLWD. Participants reported that telehealth reaches PLWD in NHs earlier in the disease course and reaches those who may otherwise lack access to palliative care services. They identified benefits of palliative care consultation to include support, resources, and education. However, we found the barriers far outweighed the facilitators for uptake during implementation. General implementation barriers included stigma surrounding dementia, palliative care, and NHs. Specific to telehealth, barriers were multiple logistical pieces required to implement the intervention; inflexibility of the palliative care nurse practitioner to meet NH needs; NH competing priorities, and inability to assess residents in person.

These barriers are wide ranging and require not only addressing challenges to telehealth, but the misunderstandings people hold about palliative care, inadequate dementia education, and the unique NH environment. Despite NHs in this study having existing telehealth equipment, staff and the nurse practitioner still reported challenges connecting—primarily due to scheduling difficulties. Persistent workforce issues prevented the staff

from being available to assist with visits. This could be due to the non-urgent nature of telehealth palliative visits or possibly their perceived value to the NH. In a NH telehealth quality improvement project during the pandemic, Okamoto et al., report similar logistical barriers that included inconsistent routines for scheduling appointments and direct care staff's inability to accommodate provider's needs and vice versa [24].

Key informants also described potential inequities in access to telehealth palliative care. Recent research investigating barriers to telehealth palliative care has raised the same concerns [25]. For example, key informants commented that a family care partner who may want to be a part of the palliative care visit or could help facilitate it might not have the technological capability. Inequities could also include the technology infrastructure in a NH facility with poor wireless internet where some rooms have access and others do not [24].

Facilitators included convenient, user-friendly and readily available telehealth equipment, and NH staff presence during visits. Past research shows that NH staff are generally enthusiastic about the potential of telehealth [7]. Telehealth also addresses workforce shortages and provider burnout [26]. In recent years, NHs accelerated wide adoption of telehealth to connect NH residents to their healthcare providers [7]. Reimbursement, policy changes, and published clinical practice standards have facilitated the use of telehealth in NHs [13, 27]. Further growth in telehealth was fueled by the COVID-19 pandemic; its use rose from 0.15% in 2019 to 15% in early 2020 [28]. However, by 2022, telehealth use dropped again to 2%. The rapid expansion of services demonstrated that implementation and use of telehealth services are feasible for NHs to connect residents to providers unable to visit the facility in person; however, it is unclear how to implement these services in a way that maintains their success. In our study, we engaged NHs that had pre-existing telehealth services available 24 h/day, but they were most often used for acute care visits (e.g., resident change in condition/urgent care) and it was challenging to adapt its use for routine care. One way to address how NH can successfully adapt existing telehealth for palliative care is to conduct a needs assessment prior to implementing services and address specific requirements that are unique to each NH setting [29].

We found that key informants believed that improved access to providers who could assist with goals of care conversations was an important outcome of telehealth palliative care. Similarly, The Centers for Medicare Services has advocated use of telehealth for advance care planning, counseling, and access to specialists. This is especially important for PLWD and other forms of cognitive impairment who are at risk for receiving treatments that do not match their care goals [30]. Other outcomes most relevant to the

key informants included improved symptom management, quality of life, and decreased health care utilization. Reducing hospitalizations is a common clinical outcome chosen by researchers conducting clinical trials for PLWD and it has been shown to be important to PLWD and their care partners as well [31].

Suggested adaptations included increased family engagement in the logistics of the intervention and strong NH staff involvement in palliative care consults. Family care partners of PLWD are essential to include in palliative care consultations [32]. They often provide background information for the clinician, inform symptom assessment and management, and make decisions about treatment preferences based on personal knowledge about the PLWD [33]. As such, ensuring they are involved in a NH consult is essential although it may be burdensome to ask their assistance in technology set up. To address both the logistical issues and NH advocacy, future iteration of this intervention will incorporate a navigator or outreach specialist who will serve as an NH and palliative care intermediary to facilitate telehealth visits.

We acknowledge the limitations of the findings of this study and its limited generalizability. The sample included a NH setting of low organizational readiness to engage in practice change with insufficient and inflexible staffing and unclear leadership buy in. It is possible in NH settings with a higher level of readiness to change that implementation of palliative telehealth for PLWD would be successful. While the NH expressed willingness to engage in this trial, the SW champion was not supported by peers or leadership during implementation, which is thought to influence champion performance [34]. In addition, streamlined referral processes using the electronic medical record with direct notification to palliative care specialist and the primary care provider for referral would eliminate this workload from the SW.

Conclusions

In this study, key informants who participated in this study reported barriers to uptake while implementing a NH telehealth palliative care far outweighed the facilitators. Future work will focus on addressing additional supports needed for palliative care telehealth implementation (e.g. additional palliative care and/or NH staff presence), the unique NH dementia context (e.g., need for staff and family education), and user-centered design to fit NH workflow and dementia-specific needs.

Abbreviations

NH	Nursing Homes
PLWD	People Living with Dementia
PRISM	Practical Implementation Sustainability Model
RE-AIM	Reach, Effectiveness, Adoption, Implementation and Maintenance

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Author contributions

JC, GD, LH, NH, and ME conceptualized the study design. JC collected and analyzed study data. All authors were major contributors to development of the manuscript. All authors read and approved the final manuscript.

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Data availability

The dataset generated and analyzed during the current study are not publicly available due to confidentiality reasons.

Declarations

Ethics approval and consent to participate

The study was approved by the Advarra Institutional Review Board. All participants included in this analysis reported in this manuscript provided informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Human ethics approval and consent to participate

IRB approval from Advarra Institutional Review Board was obtained prior to beginning data collection. Verbal informed consent was obtained from all participants included in the analysis reported in this manuscript. This study adhered to the Declaration of Helsinki.

Author details

¹University of Maryland School of Nursing, Baltimore, USA

²Corporal Michael J. Crescenzo Veterans Affairs Medical Center, Philadelphia, USA

³Division of Geriatric Medicine and Palliative Care Program, University of North Carolina Chapel Hill, North Carolina, USA

⁴University of Pennsylvania School of Nursing, Philadelphia, USA

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