### RESEARCH



# Telehealth palliative care interventions for patients with advanced cancer: a scoping review

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#### **Abstract**

**Purpose** Telehealth allows patients to maintain contact with healthcare providers without necessitating travel, and is becoming increasingly utilized. The purpose of this study is to describe the components of telehealth palliative care interventions for patients with advanced cancer before the COVID-19 pandemic; identify any intervention components associated with improvements in outcomes; and evaluate reporting of interventions.

Methods This scoping review was registered on the Open Science Framework. We searched 5 medical databases from inception to June 19, 2020. Inclusion criteria were: age ≥ 18, advanced cancer, asynchronous or synchronous telehealth intervention, and specialized palliative care interventions in any setting. We assessed the quality of intervention reporting using the Template for Intervention Description and Replication (TIDieR) checklist.

**Results** Twenty-three studies met the inclusion criteria: 15 (65%) quantitative (7 randomized controlled trials, 5 feasibility trials, 3 retrospective chart reviews); 4 (17%) mixed methods, and 4 (17%) qualitative. Most quantitative and mixed methods studies were conducted in North America (12/19, 63%), reported on hybrid (in-person and telehealth) interventions (9/19, 47%), and were delivered by nurses (12/19, 63%) in the home setting (14/19, 74%). In most studies that reported improvements in patient- or caregiver-reported outcomes, the content was psychoeducational and resulted in improvements for psychological symptoms. No study provided complete reporting on all 12 TIDieR checklist items.

**Conclusion** Telehealth studies are needed that reflect palliative care's mission to provide multidisciplinary team-based care that improves quality of life in diverse settings, and that provide detailed reporting of interventions.

Keywords Palliative care · Telemedicine · Cancer · Delivery of health care · COVID-19 · Scoping review

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### Introduction

Integration of specialized palliative care into oncology care improves quality of life, reduces symptom burden, and increases satisfaction with care for patients with advanced cancer [1–3]. International cancer organizations recommend routine involvement of palliative care teams for patients with advanced cancer [4] and palliative care is increasingly being incorporated early in the course of advanced cancer through embedded or stand-alone palliative care clinics [5, 6]. Despite these benefits and recommendations, attending an in-person palliative care clinic may be challenging. Patients with advanced cancer (defined in this paper as stage III or IV disease) [3, 7–9] tend to have reduced functional status as well as many other appointments that make in-person clinic attendance impracticable [10]. In addition, telehealth may supplement in-person visits to patients in the home setting



closer to the end of life, facilitating more frequent contact with the palliative care team as patients' and caregivers' needs increase [11, 12]. Overall, telehealth may provide a convenient way for patients to maintain contact with health-care providers without necessitating travel, and is increasingly utilized in palliative care [13].

Telehealth is defined as the "delivery of health care services, where patients and providers are separated by distance." [14] Palliative care is multidisciplinary care provided by teams in outpatient, inpatient and home settings, and is relevant throughout the course of illness [15]. In oncology palliative care, telehealth interventions have been used for more than a decade to monitor symptoms and improve access to care, especially in remote areas [16, 17]. Although there have been systematic reviews of telehealth for palliative care, these reviews were not able to make conclusive recommendations due to marked heterogeneity in study designs, interventions, and outcomes [18, 19]. None of these reviews were specific to oncology and none described detailed components of telehealth interventions.

A scoping review methodology is useful to map the key concepts of a broad topic of study with a wide range of study designs [20]. The primary aim of the current scoping review was to describe the components of telehealth palliative care interventions for patients with advanced cancer available before the COVID-19 pandemic. Secondary aims were to determine whether there were particular intervention components associated with improvements in patient-reported outcomes, and to evaluate whether the reporting of interventions was of sufficient quality and detail to allow replication. A separate review will describe the telehealth palliative care interventions that were developed during the COVID-19 pandemic as a consequence of the need to maintain physical distancing.

### **Methods**

This scoping review is registered with the Open Science Framework (https://osf.io/) and reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist [21]. For this review, we followed the five stages of the scoping review framework, as defined by Arksey and O'Malley [20] and outlined in the Joanna Briggs Institute Reviewers' Manual [22]. We also conducted a critical appraisal of the quality of reporting of telehealth palliative interventions to improve the relevance and impact of our findings and to inform further research in this area [23].



A health sciences librarian developed and implemented the search strategy. The following databases were searched from inception to June 19, 2020: MEDLINE, Embase, CINAHL, PsycINFO, and Cochrane Central Register of Controlled Trials (CENTRAL). Search terms included "neoplasms," "cancer," "telehealth," "telemedicine," "internet," "palliative care," "pain," "depression," and "quality of life." The final search strategy for MEDLINE is described in Appendix 1.

### Study eligibility and screening

Studies of telehealth palliative care interventions for adult (≥18 years) patients with advanced cancer (stage III or IV, or any study that self-identified as including patients with advanced cancer) [3, 7, 8, 24] were included. Palliative care was defined as care delivered by multidisciplinary professionals with the aim of improving quality of life for patients living with serious illness and their families [15]. Telehealth could include telephone, videoconference, and asynchronous web-based communication between patient and provider; hybrid interventions, combining in-person and telehealth palliative care, were also included. Studies with any empirical methodology were included: retrospective or prospective, observational or experimental studies; descriptive studies; and qualitative or mixed-method studies. Systematic reviews were retained and their reference lists searched to identify other potential studies for inclusion. Non-Englishlanguage articles, non-empirical studies, editorials, abstracts without full papers, studies including patients with early-stage cancer, studies of mobile apps and wearable health devices, studies of online educational resources for palliative care, and studies of technology-based symptom monitoring without any palliative care intervention were excluded. Two reviewers (JJM, RC) independently screened all identified articles for inclusion. At the beginning of each level of screening, a calibration exercise was used to ensure sufficient interrater agreement. When there were disagreements, a third reviewer (CZ) was consulted to achieve consensus.

#### **Data extraction**

JJM and RC used a customized form to abstract information on general study characteristics, details of the telehealth palliative care intervention, and outcome data.



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Specifically, the general study characteristics that were abstracted included author, year and journal of publication, country of origin, study design and objectives, and inclusion and exclusion criteria. Details of the telehealth palliative care intervention were abstracted using items derived from a previously described framework for reporting on palliative care interventions and items from the Template for Intervention Description and Replication (TIDieR) checklist [25, 26]. These items included: the definition of palliative care provided; professionals involved; components of care delivery; mode of care delivery (e.g. telephone, videoconference, internet, email, or hybrid [one of the above plus in-person]); setting of care delivery (defined according to where the patient or caregiver receiving care was physically located when receiving the intervention, e.g. inpatient, outpatient clinic, patient's home, palliative care unit, hospice); target population (e.g. disease, disease stage, patients/caregivers or both, age, gender, number of participants); duration (number, frequency and duration of contacts and follow-up, availability of provider after-hours); timing of intervention in the disease trajectory; tailoring of the intervention (i.e. if it was personalized, titrated or adapted, and if so, how, why and when); modifications (if the intervention was modified during the course of the study, and if so, how); and planned and actual fidelity (if adherence was assessed, whether there were strategies to maintain or improve adherence, and extent to which the intervention was delivered as planned). We also listed the domains of palliative care addressed by the interventions in each study, as defined by the National Consensus Project for Quality Palliative Care [27]. The comparator, if any, was also described (e.g. standard care, educational material, etc.). Outcomes for quantitative studies included changes in patient- or caregiver-reported outcome scores pertaining to any construct (e.g., depression, pain, quality of life), descriptive summaries of usage patterns of telehealth interventions (e.g., frequency and duration of calls, reasons for calls), as well as available data on feasibility and acceptability. We also extracted data on cost analyses and healthcare utilization (e.g., emergency room visits, hospital admissions), when available. For qualitative studies, details regarding methodology and themes were abstracted.

### **Critical appraisal**

Critical appraisal of included studies was carried out to improve the relevance and impact of our findings. Palliative care is a complex intervention (i.e. it has several interacting components) [28], that includes domains of

symptom control, coping, decision-making, and future planning [29]. We used the TIDieR checklist to assess the quality of reporting of each telehealth palliative care intervention [26]. The TIDieR checklist consists of 12 items including aim of the intervention (items 1–2), core content items (items 3–9), and implementation of the intervention (items 10–12). Two reviewers (JJM, RC) assessed the completeness of reporting of each checklist item; reporting was considered complete if sufficient detail was provided to allow replication [30].

### Results

Of the initial 12,065 articles that were identified and screened, 23 met the inclusion criteria (see Fig. 1 for PRISMA flowchart). Of these, 15 (65%) were quantitative studies (7 randomized controlled trials, [7, 31–36] 5 feasibility trials [17, 37–40], 3 retrospective chart reviews) [41–43], 4 (17%) were mixed methods studies [44–47], and 4 (17%) were qualitative studies (including two case studies) [48–51].

## Study characteristics and components of telehealth interventions

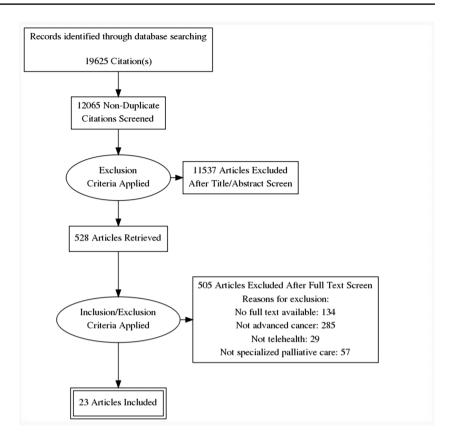
Study characteristics and intervention components are described in Table 1 (quantitative and mixed method studies) and Table 2 (qualitative studies). In all, the 23 studies targeted 1559 patients with advanced cancer, 535 family caregivers, and 961 patient-caregiver dyads. More than half (13/23, 57%) were conducted in North America, 4/23 (17%) in Europe, and only 2/23 (8%) in low- and middle-income countries [46, 50].

Of the 19 studies that used quantitative or mixed methods to report on interventions, 9 (47%) targeted patients [17, 32, 33, 35, 37, 41–43, 46], 4 (21%) family caregivers [34, 36, 39, 40], and 6 (32%) patient-caregiver dyads [7, 31, 38, 44, 45, 47]. Six studies (32%) reported on interventions provided by a specialized palliative care physician-led team [17, 33, 35, 38, 44, 46], 12 (63%) reported on interventions provided by specialized palliative care nurses [7, 31, 32, 34, 36, 37, 39–41, 43, 45, 47], and one (5%) reported on an intervention provided by a counselor [42]. In terms of mode of care delivery, five studies (26%) reported on telephone-based interventions [32, 33, 39, 41, 43], 4 (21%) videoconference-based interventions [17, 38, 40, 44], 1 (5%) an asynchronous web-based intervention [45], and 9 (47%) hybrid (inperson and telehealth) interventions [7, 31, 34-37, 42,



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Fig. 1 Flow diagram



46, 47]. In terms of setting of care, 14 studies (74%) were conducted exclusively in the home setting [32, 33, 35–41, 43–47], 4 (21%) in the home and outpatient clinic setting [7, 31, 34, 42], and 1 (5%) in the outpatient setting (the patient attended a rural telehealth facility and was linked to a virtual multidisciplinary palliative care clinic) [17]. For 4 studies (21%), providers were available 24/7 [38, 41, 44, 47], for 3 (16%) during office/clinic hours [17, 37, 43], and for 12 (63%) availability was not specified [7, 31–36, 39, 40, 42, 45, 46].

Of the 4 studies that used qualitative methods, 2 were case reports with qualitative description [50, 51], 1 used a grounded theory approach [48], and 1 used thematic analysis [49]. Three studies explored perspectives regarding telehealth palliative care of patients with advanced cancer and their family caregivers [49–51], and 1 explored the perspectives of specialist palliative care clinicians [48]. The mode of delivery was videoconference in 2 studies [48, 51], phone in 1 [49], and asynchronous communication in 1 [50]. The setting was home for all 4 studies; availability was only specified in 1 study, which was 24/7 [50]; the timing of intervention was only specified in one study, which was within 60 days of diagnosis of advanced cancer [49].

Appendix 2 lists the disciplines of publishing journals and definitions of palliative care provided in each article. The definition was provided in 1 [46] of 8 articles

in palliative or supportive care journals [17, 41, 43, 45, 46, 48–50], 3 of 3 papers in psychosocial oncology journals [36, 40, 42], 0 of 6 papers in oncology journals [31–34, 37, 39], and 3 [36, 40, 42] of 6 papers in medical journals [7, 35, 38]. The World Health Organization definition of palliative care was used most often (4/7 definitions) [35, 36, 38, 42]. None of the 23 studies reported on all 8 palliative care domains of the National Consensus Project for Quality Palliative Care; the most commonly included domains were structure (19/23, 82%) and psychological (18/23, 78%), while the least commonly included domains were legal (4/23, 17%) and cultural (0/23, 0%).

## Outcomes and components associated with positive outcomes

Eleven of 19 quantitative and mixed methods studies reported on patient- (7/11) [7, 17, 31–33, 35, 38] or caregiver-reported outcomes (4/11) [34, 36, 39, 40]. The most common patient- or caregiver-reported outcomes were physical and psychological symptoms (11/19, 58%) [7, 17, 31–36, 38–40], quality of life (6/19, 32%) [7, 31, 33, 34, 38, 40], and acceptability or satisfaction (5/19, 26%) [17, 35, 38, 40, 45]. Other outcomes included survival (1/19, 5%) [31], usage patterns (6/19, 32%) [41–43, 45–47], feasibility (5/19,



First author, year,	Study design	Target and timing of	Participants (N, mean	Details of telehealth intervention	ervention	Control group	Outcomes measured	Results of interest
country		intervention	age, % female)	Provider, content	Availability of provider, setting, domains of palliative care addressed		and assessment timing	
Delivery by telephone	0							
Bruera 2013, USA [32]	RCT	Patients with advanced cancer with a fatigue score ≥ 4/10, multisite Timing: not specified	N: 190 Mean age: 58 %F: 67	Provider: Research nurse with training in palliative care; Content: 4-6 nurse calls over 2 weeks; focused on symptom assessment, medication review, and psychosocial support	Availability: not specified Setting: home Domains: physical, psychological, social	Four groups: methylphenidate + nurse telephone intervention(NTI), placebo(PL) + NTI, methylphenidate + control telephone intervention(CTI), and PL + CTI	Fatigue score; on day 15	MP and NTI alone or combined were not superior to placebo
Cheville 2019, USA [33]	RCT	Patients with advanced cancer and moderate func- tional impairment, multi-site Timing: progno- sis > 6 months	N: 516 Mean age: 65 %F: 50	Provider: Nurse pain care manager supervised by palliative care physician Content: phone-based physical conditioning program by physical therapist fitness care managers; weekly pain management by nurse pain care manager	Availability: not specified Setting: home Domains: physical, structure	Three groups: control, telerehabilitation, telerehabilitation, tion+pain management	Function, pain, QoL, resource utilization; at baseline, 3 and 6 months	Improved pain in both intervention arms and outcomes not enhanced with additional pain management
Elfrink 2002, Netherlands [41]	Retrospective chart review	Review of a telehealth after-hours service for patients discharged from the palliative care unit of a cancer institute between 1997–1999 Timing: not specified	N: 124; Mean age: 54 %F: 60	Provider: Clinical nurse specialists in palliative care unit; Content: 24-h telephone palliative care consultation service	Availability: 247 Setting: home Domains: physical, structure	N/A	Usage patterns	Majority (40%) of calls were regarding pain; 97% of concerns could be addressed without hospital admission; Mean duration of calls was 16 min
Pimentel 2015, USA [43]	Retrospective chart review	Patients with advanced cancer referred to palliative care and accessing a telephone triage program Timing: not specified	N: 115 Median age: 59 %F: 55	Provider: Palliative care trained nurses; Content: Usage patterns of a supportive care telephone triage program	Availability: office hours Setting: home Domains: physical, psychological, structure	N/A	Usage patterns	Most common reasons for calls were pain, pain medication refills, and counseling



Table 1 (continued)								
First author, year,	Study design	Target and timing of	Participants (N, mean	Details of telehealth intervention	tervention	Control group	Outcomes measured	Results of interest
country		intervention	age, % remale)	Provider, content	Availability of provider, setting, domains of palliative care addressed		and assessment timing	
Walsh 2003, USA [39]	Feasibility trial without control group	Caregivers of patients with advanced cancer Timing: progno- sis > 6 weeks	N: 5 Mean age: 66 %F: 80	Provider: Nurse interventionist; Content: 4 weekly 1-h telephone intervention for caregivers of hospice patients, guided by Hogan's model of bereavement	Availability: not specified Setting: home Domains: psychologi- cal, EoL	N/A	Caregiver burden, depression, social support	Reduced depression among caregivers after receiving the intervention; late referral to hospice was a barrier to study recruitment
Delivery by video								
Aoki 2006, Japan [44]	Mixed methods	Dyad (patients with advanced cancer in a rural community and their caregivers) Timing: not specified	N: 2 Mean age: 75 %F: 50	Provider: Palliative care physician and staff; Content: Telepal-liative care through Polycom Viewstation videoconferencing;	Availability: 24×7 Setting: home Domains: physical, structure	Usual oncology care	Qualitative: Thematic analysis of quality of telepalliative care through patient interview; Quantitative: cost analysis of simulated model of admission to palliative care unit vs. in-person home visit vs. tele-palliative care	Tele-palliative care improved convenience and access and reduced costs. Telepalliative care could reduce the need for in-person visits
Nemecek 2019, Austria [38]	Feasibility trial with control	Dyad (Patients with advanced cancer and their family caregivers) Timing: not specified	N: 30 Mean age: 50 %F: 43	Provider: Palliative care physician; Content: videoconference through i Pad as needed; patientinitiated	Availability: 24×7 Setting: home Domains: physical, psychological, structure	Usual palliative care	QoL, mood, feasibility, user satisfaction, hospital admission; assessed 10 weeks after baseline	Telehealth is feasible; mood was significantly improved in the intervention group; user satisfaction was good
Washington 2018, USA [40]	Feasibility trial with control	Family caregivers of patients with advanced cancer Timing: not specified	N: 83 Mean age: 51.5 %F: 68.7	Provider: Trained research nurse; Content: a structured problem-solving therapy intervention delivered over 3 sessions, one week apart, via web-based videoconferencing or telephone per patient preference	Availability: not specified Setting: home Domains: psychologi- cal, social	Usual care	Caregiver anxiety, depression, QoL, feasibility, satisfaction	Feasibility of the intervention was demonstrated; there was less anxiety among caregivers in the intervention arm; high satisfaction scores for patients and physicians



were regarding physical issues related to

thematic analysis of questions and posts, user experience

Usage patterns,

N/A

Availability: not specified

Provider: Nurse

practitioner

N: 707 visits from 395 unique users over the 8-week study period

Dyad (Patients with pancreatic cancer and their family

Delivery by asynchronous web-based communication

Grant 2011, USA Mixed methods

[45]

for follow-up

Setting: home Domains: physical, psychological, structure, EoL

Content: Online interactive webpage, with option to initi-

Mean age: not speci-

caregivers) Timing: not specified

fied %F: 73

ate contact through email

Most (85%) questions

pancreatic cancer and

its treatment; users found the webpage

helpful and easy to use

First author, year,	Study design	Target and timing of	Participants (N, mean	Participants (N, mean Details of telehealth intervention	tervention	Control group	Outcomes measured	Results of interest
country		intervention	age, % female)	Provider, content	Availability of provider, setting, domains of palliative care addressed		and assessment timing	
Watanabe 2013, Canada [17]	Feasibility trial without control	Patients with advanced cancer Timing: not specified	N: 44 initial consults and 28 follow-up visits were com- pleted Median age: 60 %F: 41	Provider: Specialist Availability: office multidisciplinary hours palliative care team; Setting: outpatient Content: vide- Domains: physical oconference -based psychological, palliative radio- spiritual therapy for patients in rural areas; patients attended local telehalth facilities accompanied by nurses trained in symptom assessment; virtual clinic available one half-day per week; 90 min videoconference for new consult and 30 min	Availability: office hours Setting: outpatient Domains: physical, psychological, social, structure, spiritual	N/A	Feasibility, effect on symptoms, cost, satisfaction	Improved anxiety and appetite; average per visit savings through telehealth were 471.12 km, 7.96 h, and Cdn \$192.71. Feasibility and satisfaction were demonstrated

Table 1 (continued)

Delivered by hybrid platform (in-person+telehealth)

First author, year,	Study design	Target and timing of	Participants (N, mean	Details of telehealth intervention	ervention	Control group	Outcomes measured	Results of interest
country		intervention	age, % female)	Provider, content	Availability of provider, setting, domains of palliative care addressed		and assessment timing	
Bakitas 2009, USA [7]	RCT	Dyad (patients with advanced cancer attending a rural cancer center, and their caregivers) Timing: Within 8–12 weeks of diagnosis of advanced cancer, prognosis of one year	N: 322 Mean age: 65 %F: 42	Provider: Advanced practice nurse with palliative care specialty training Content: telehealth:4 initial phone-based structured educational and problemsolving sessions focused on patient self-management and empowernent, and monthly follow-up calls lin-person: monthly group appointments with palliative care physician and nurse practitioner	Availability: not specified Setting: home and outpatient Domains: physical, psychological, social, structure, spiritual, legal	usual oncology care	QoL, symptom intensity, mood, healthcare utilization; measured at baseline, I month, and every 3 months	QoL improved, Mood improved
Bakitas 2015, USA [31]	RCT	Dyad (Patients with advanced cancer and their caregivers, multi-site) Timing: Within 30–60 days of diagnosis of advanced cancer and prognosis 6–24 months; or 3 months later	N: 207 Mean age: 64 %F: 48	Provider: Advanced practice nurse with palliative care specialty training; Content: telehealth: phone-based weekly coaching for 6 sessions using a manualized curriculum (Educate, Nurture, Advise Before Life Ends intervention) and monthly follow-up. In-person: initial palliative care physical care and the coaching and monthly follow-up.	Availability: not specified Setting: home and outpatient Domains: physical, psychological, social, structure, spiritual, legal	palliative care intervention after 3-month delay	Qol., symptom impact, mood, 1-year survival, and resource use; measured at baseline, 6, 12, 18, and 24 weeks, and every 12 weeks thereafter	I-year survival



Table 1 (continued)	<u>~</u>							
First author, year,	Study design	Target and timing of	Participants (N, mean	Participants (N, mean Details of telehealth intervention	itervention	Control group	Outcomes measured Results of interest	Results of interest
country		intervention	age, % řemale)	Provider, content	Availability of provider, setting, domains of palliative care addressed		and assessment timing	
Dionne-Odom 2015, USA [34]	RCT	Family caregivers of patients with advanced cancer in a rural setting Timing: Within 30–60 days of diagnosis of advanced cancer and prognosis 6–24 months; or 3 months later	N: 122 Mean age: 62 %F: 78	Provider: Advanced practice nurse with palliative care specialty training; Content: telehealth: 3 structured weekly telephone coaching sessions (Educate, Nurture, Advise Before I ife Ends	Availability: not specified Setting: home and outpatient Domains: psychological, social, structure, spiritual	Same intervention, delayed by three months	QoL, depression, burden	Early palliative care improved caregiver depression at three months compared to control group

	Patients who par- ticipated in telehealth outreach counseling had significantly more encounters and shorter interval between initial and follow-up visits than those who received in-person outpatient counseling	Telemedicine improved access to palliative care and reduced the utilization of emergency services; web conferencing can complement inperson care
	Usage patterns	Usage patterns, qualitative descrip- tion of symptoms, audio and video quality, caregiver satisfaction
	Y.Y.	ΚΆ
	Availability: not specified Setting: home and outpatient Domains: psychological, social, structure, spiritual	Availability: not specified Setting: home Domains: physical, psychological, social, structure, legal, EoL
before Life Ends intervention), monthly follow-up, and bereavement call; in-person: palliative care consultation	Provider: Licensed professional counselors; Content: Remote psychosocial counseling via videoconference or telephone to complement in-person care	Provider: Multidisciplinary palliative care team; Content: telehealth: weekly web conferences, and as needed telephone calls, emails; inperson: monthly consultation
	N: 452 Median age: 58 %F: 65	N: 12 Mean age: 68 %F: 41
5 HOHIBS FARET	Patients with advanced cancer Timing: not specified	Patients with advanced cancer in a LMIC Timing: not specified
	Retrospective chart review	Mixed methods
	Guzman 2020, USA [42]	Hennemann- Krause 2015, Brazil [46]



First author, year,	Study design	Target and timing of	Participants (N, mean	Details of telehealth intervention	itervention	Control group	Outcomes measured	Results of interest
country		intervention	age, % remale)	Provider, content	Availability of provider, setting, domains of palliative care addressed		and assessment timing	
Hochstenbach 2016, The Neth- erlands [37]	Feasibility trial without control group	Patients with advanced cancer with moderate to severe cancer pain Timing: progno- sis > 3 months	N: 11 Mean age: 53 %F: 55	Provider: Registered nurses specialized in pain and palliative care Content: telehealth: Daily pain education, and advice through mobile application in iPad with text messaging functionality. weekly overview and graphical display of symptoms for nurses with colored risk flags; nurses had the option to call patients and escalate to palliative care physician if needed; in-person: baseline assessment of pain, medication usage, and pain education provided by nurse at the content of pain.	Availability: office hours Setting: home Domains: physical, structure	N/A	Feasibility and patients adherence; qualitative description of patient and provider experience	Feasibility of the intervention was demonstrated; adherence was 76% for pain monitoring and 100% for education sessions. The intervention enables patients with cancer pain to practice self-management and for nurses to support them remotely



First author, year,	Study design	Target and timing of	Participants (N, mean	Participants (N, mean Details of telehealth intervention	tervention	Control group	Outcomes measured	Results of interest
country		intervention	age, % female)	Provider, content	Availability of provider, setting, domains of palliative care addressed		and assessment timing	
Hoek 2017, The Netherlands [35]	RCT	Patients with advanced cancer Timing: not specified	N: 74 Mean age: 62 %F: 34	Provider: Hospital-based specialized palliative care consult team; Content: telehealth: weekly videoconferencing using ipad with the nurse practitioner. The patient's general practitioner was also invited to join; in-person: Usual care, which in the palliative care clinic as needed; 12-week study period	Availability: not specified Setting: home Domains: physical, psychological, structure	Usual care	Symptom burden, satisfaction, caregiver burden, hospital admission	Total distress score and anxiety score were significantly higher in the intervention group; possible explanations include supply-driven (not need-based) care delivery and high level of specialized palliative care involvement in the control group
Hudson 2014, Australia [36]	RCT	Family caregivers of patients with advanced cancer receiving home palliative care Timing: within 2 weeks of referral to palliative care	N: 298 Mean age: 59 %F: 70	Provider: Family caregiver support nurse; Content: One-on-one psychoeducational intervention over four weeks; Three groups: One in-person visit plus three phone calls vs. two phone calls vs. standard care	Availability: not specified Setting: home Domains: psychologi- cal, EoL	Usual care	Caregiver psychological distress at one-week post-intervention and eight-weeks post-death of patient	Significantly less worsening in caregiver distress at eight-weeks post-death of patient in the one-visit plus three phone call group, compared to control and two-visit group

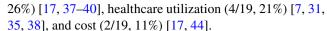
Table 1 (continued)



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Table 1 (continued)								
First author, year,	Study design	ming of	Participants (N, mean Details of telehealth intervention	Details of telehealth in	tervention	Control group	Outcomes measured Results of interest	Results of interest
country		intervention	age, % female)	Provider, content	Availability of provider, setting, domains of palliative care addressed		and assessment timing	
Stern 2012, Canada [47]	Mixed methods	Dyad (Patients with N: 5 patient-cadvanced cancer dyads and 7 and their family bereaved fa caregivers receiving caregivers tele-palliative care) Mean age: 61 Timing: not specified %F: 36	N: 5 patient-caregiver Provider: Specialdyads and 7 is palliative care bereaved family nurses; caregivers Content: telehealth Mean age: 61 able as needed for videoconferenci with patients, with patients, with patients, with patients, with patients, with patients, with patients optional remote monitoring of vitals; there were also telephone as in-person visits and page 1.	Provider: Specialist palliative care nurses; Content: telehealth: nurses were available as needed for videoconferencing with patients, with optional remote monitoring of vitals; there were also telephone and in-person visits as needed	Availability: 24×7 Setting: home Domains: physical, psychological, structure	N/A	Qualitative interview Patients, family with patients and bereaved family tele-nurses fel caregivers; quantitative analysis of enabled family usage patterns access to care calls were relapin and symphysis of care relaping and symphysis of calls were relaping and symphysis o	Patients, family caregivers and tele-nurses felt that tele-palliative care enabled family car- egiving and improved access to care; most calls were related to pain and symptom management





Of 11 studies reporting on symptoms, 7 (64%) were randomized controlled trials [7, 31-36], of which 4 reported statistically significant improvements [7, 33, 34, 36]. Targets for these 4 studies were family caregivers [34, 36], patients [33], and dyads [7]; mode of delivery included telephone [33], and hybrid delivery [7, 34, 36]. Three of the 4 interventions were based on psychoeducational content focusing on problem-solving and/or bereavement care delivered by nurses [7, 34, 36]. Three studies reported on improved psychological symptoms (anxiety, mood/depression, or psychological distress): 2/3 in caregivers [34, 36] and 1/3 in patients [7]. One randomized controlled trial reported improvements in patients' physical symptoms [33]. Of note, this study was a 3-arm randomized controlled trial of telephone-based rehabilitation, with or without pain management [33]; improvements in pain were noted in both intervention arms compared to usual care, but there was no difference between intervention arms.

Of the 6 studies that reported on quality of life, 4 were randomized controlled trials [7, 16, 33, 34], and of these, 1 (25%) reported improvement [7]; the intervention targeted dyads, was provided by specialized nurses through a hybrid mode of delivery, included psychoeducational content, and was timed early in the disease trajectory of advanced cancer. One randomized controlled trial by the same research team measured one-year survival, and reported improvement [31]; the intervention targeted dyads, was provided by specialized nurses through a hybrid mode of delivery, included psychoeducational content, and was timed early in the disease trajectory of advanced cancer. Of the 5 feasibility studies, 4 (80%) concluded that the intervention was feasible; one reported that late referral to hospice was a barrier to study recruitment [39].

### Critical appraisal of completeness of reporting of interventions

Completeness in reporting for the 23 included studies is summarized in Fig. 2. No study provided complete reporting on all 12 TIDieR checklist items. All studies provided a clear description and rationale for the telehealth palliative care intervention, and reporting on the relevant materials used (such as telephone or videoconferencing equipment) and procedures followed for the interventions (items 1-4). Similarly, all studies provided details of the country and setting of the intervention (item 7). Most studies (20/23, 87%) reported on the details of how the palliative care intervention was provided (item 6), including mode of delivery of telehealth and hybrid interventions. Similarly, most (18/23, 78%) specified who provided the intervention (such as a



First author, year, country	Qualitative method	Study objectives; inter-	Participants (N, mean	Details of telehealth intervention	rention	Main themes
		vention target and timing (if relevant)	age, % female)	Provider, mode of delivery	Availability of provider, setting, domains of palliative care addressed	
Collier 2016, Australia [48]	Focus groups and analysis by realistic evaluation and grounded theory approach	Exploring perspectives of clinicians delivering community specialist telehealth palliative care Timing: N/A	N: 10 Mean age: not specified %F: 83	Provider: Specialist physician, nurse practi- tioner, and community nurses Mode of delivery: Vide- oconference	Availability: not specified Setting: home Domains: physical, psychological, social, legal, structure	Telehealth challenges current models of care; can support remote and rural patients; can save time for clinicians; can be complementary to in-person care; can be associated with technological troubles and alertoverload. Video consults can help make better connection with patients than phone calls. Clinicians felt they should be involved in the design of the telehealth service
Dhiliwal 2015, India [50]	Case series with qualitative description	Description of the experience of patients with advanced cancer, and their family caregivers, of telepalliative care in a LMIC setting Timing: not specified	N: 2 Mean age: 62 %F: 50	Provider: Palliative care physician Mode of delivery: Asynchronous smartphone based communication, including SMS, WhatsApp, Email, as well as video calls	Availability: 24×7 Setting: home Domains: physical, psychological, social, structure, EoL	Telehealth supported access to consultative palliative care for patient and family, family was able to share imaging and laboratory reports through telehealth, telehealth helped to avoid hospitalization at end-of-life and supported home-based care
Dionne-Odom 2018, USA [49]	Qualitative formative evaluation with a thematic analysis approach	Exploring perspectives of rural-dwelling patients with advanced cancer, their family caregivers, and lay patient navigators, regarding a telehealth palliative care intervention for family caregivers Timing: Within 60 days of diagnosis of advanced cancer	N: 18 patients, 20 family caregivers, 26 lay patient navigators Patient mean age: 58 %F: 33.3 Caregiver mean age: 56 %F: 95	Provider: not specified Mode of delivery: phone	Availability: not specified Setting: home Domains: psychologi- cal, social, structure, spiritual	Telehealth palliative care is acceptable but in-person care is preferred to establish relationships; rural patients may not be techsavy or have adequate internet access; sessions should be a minimum of 20 min long and content should be flexible based on need



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First author, year, country Qualitative method	Qualitative method	Study objectives; inter-	Participants (N, mean	Details of telehealth intervention		Main themes
		vention target and timing age, % female) (if relevant)	age, % female)	Provider, mode of delivery	Availability of provider, setting, domains of palliative care addressed	
Morgan 2017, Australia [51]	Morgan 2017, Australia Case report with qualita- Exploring perspectives [51] tive interview of a single patient wit advanced cancer in a trial of telehealth community palliative care Timing: not specified	Exploring perspectives of a single patient with advanced cancer in a trial of telehealth community palliative care Timing: not specified	N: 1 age: 57 sex: male	Provider: Community Availability: not spepalliative care nurse Setting: home and general practitioner Domains: physical, Mode of delivery: Vide-social, structure coonference using iPad; Telehealth self-reporting of symptoms and automatically triggered videoconference based on symptom alerts	Availability: not specified Telehealth is feasible and acceptable to patients Domains: physical, and family; videoconfer social, structure encing saves travel time and costs and empowers patients to inform clinicians about their symptoms	Telehealth is feasible and acceptable to patients and family; videoconferencing saves travel time and costs and empowers patients to inform clinicians about their symptoms

specialized palliative care nurse or physician) with sufficient details to allow replication (item 5). Only 6 of 23 studies (26%) reported when telehealth or in-person visits were initiated, the duration of the visits, frequency of follow-up, and whether providers were available afterhours (item 8). Less than half of the studies reported on items 9–12: tailoring or personalization of the intervention, modification to the telehealth intervention during the study, assessment of intervention fidelity, and reporting of fidelity. Of note, items 10-12 were assessed as not applicable for 10 studies, either because they were qualitative studies (n=4) or quantitative studies reporting only on usage patterns (n=6).

### **Discussion**

This scoping review identified 23 studies that reported on telehealth palliative care interventions for patients with advanced cancer before the COVID-19 pandemic. More than half of the studies were conducted in North America, and most used quantitative methods, though only seven were randomized controlled trials. Most interventions were psycho-educational (included information giving, problem-solving, coping skills training, or emotional and social support) [52], were delivered by nurses, and were assessed using psychological outcomes. Reporting of the intervention was generally inadequate to allow replication.

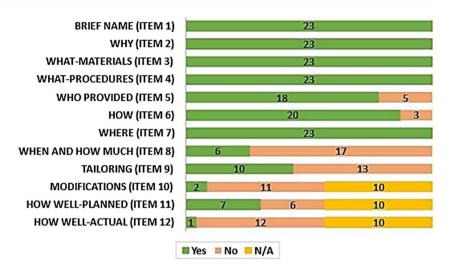
Our main aim in this scoping review was to provide a comprehensive account of telehealth interventions that were developed for cancer palliative care before the COVID-19 pandemic. These fell mainly into three categories - video, telephone, and hybrid – with approximately half of the studies using either video or telephone and the other half using hybrid interventions. Most of these interventions were delivered by nurses to patients who were in the home setting, and were psychoeducational in nature; the timing of the intervention in the disease course was often not provided. In response to the COVID-19 pandemic, telehealth delivery by multidisciplinary palliative care teams increased markedly [53, 54], including in low- and middle-income countries [55]. It will be important to report on changes in the nature of telehealth interventions after the pandemic and potential implications for patient care. For example, while our pre-pandemic review identified no telehealth palliative care interventions for inpatients, there are reports of inpatient telehealth palliative care during the pandemic. [56–58]

Due to the paucity of randomized controlled trials, it was not possible to conclusively determine components of telehealth palliative care interventions associated with improvements in outcomes. In most studies that reported



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Fig. 2 Number of studies with each TIDieR checklist item assessed as complete (n=23)



improvements in patient- or caregiver-reported outcomes [7, 33, 34, 36], improvements were for psychological symptoms, but this is likely due to the nature of the interventions, which were mostly psychoeducational, and focused on problem-solving and/or bereavement care. Most improvements were reported in hybrid interventions [7, 34, 36], with only one study reporting on a telephone-based intervention [33]; there were no randomized controlled trials reporting on improved outcomes from a video-based intervention. Of the seven trials reviewed, three (of which two were by the same authors) assessed successful hybrid models of early palliative care [7, 34, 36]. Additional studies are needed to determine whether the improvements in quality of life demonstrated with early in-person palliative care interventions can also be achieved using telehealth interventions [1-3]. This is especially important given the increased delivery of outpatient telehealth palliative care as a consequence of the pandemic [59–61].

Usage of the TIDieR checklist allowed for a critical appraisal of the completeness of description of each intervention and its replicability for future studies to improve the quality of future research in telehealth palliative care and improve its translation into practice [62, 63]. Although there was generally a description of how and by whom the intervention was provided, information was usually missing regarding the timing of interventions in the disease trajectory, their duration, frequency of follow-up, and whether providers were available after-hours. Details regarding tailoring or personalization of the intervention, modifications to the intervention during the study, and intervention fidelity were also infrequently reported. In addition, defining palliative care should be the first step in describing a palliative care intervention, since palliative care is an evolving field

that has been variably defined [64]; only 30% of included studies provided a definition of palliative care.

### Strengths and limitations

Strengths of this review were the thorough search strategy, use of two independent reviewers to extract data, and use of the TIDieR checklist to assess completeness of reporting for telehealth palliative care interventions, which have become highly topical during the COVID-19 pandemic and beyond. Limitations include that our aim of describing components of telehealth palliative care interventions was hampered by lack of complete reporting; similarly, our aim of determining which components were associated with positive outcomes was limited by the small number of randomized controlled trials. Finally, all the studies were completed prior to the COVID-19 pandemic; however, this was explicitly the focus of this study, which we believe provides a useful overview of the pre-pandemic state of the science on telehealth palliative care. We are planning a further review that will focus specifically on the rapid rise in telehealth palliative care interventions during the COVID-19 pandemic.

### Conclusion

Telehealth has long been an important means of increasing access to palliative care. This scoping review reported on telehealth palliative care interventions for patients with advanced cancer before the COVID-19 pandemic. Most interventions were hybrid models delivered by nurses in the home setting, included mainly psychosocial content, and



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reported improvements in psychological outcomes. In addition, most were conducted in North America and studies in low- and middle-income countries are needed. Future studies should move beyond description to examine the feasibility and efficacy of telehealth palliative care interventions delivered by palliative care teams in diverse settings and should include assessment of physical as well as psychosocial symptoms. These studies should provide detailed reporting of the telehealth palliative care interventions to improve their reproducibility and implementation in routine practice. The COVID-19 pandemic has provided an impetus for the rapid expansion of telehealth palliative care interventions. Further research is needed to describe these interventions, compare them to the pre-pandemic literature, and determine their potential to improve outcomes for patients with advanced cancer and their families.

### **Appendix 1: Search strategy for MEDLINE**

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) < 1946 to June 19, 2020 >

Search Strategy:

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- 1. exp Neoplasms/ (3331305)
- 2. (cancer\* or neoplasm\*).mp. (3339802)
- 3. or/1-2 (3882700)
- 4. exp Telemedicine/ (28295)
- 5. exp Cell Phone/ (10598)
- 6. exp Telephone/ (22323)
- 7. exp Electronic Mail/ (2675)
- 8. exp User-Computer Interface/ (37090)
- 9. exp Internet/ (78862)
- 10. exp Internet-Based Intervention/ (130)
- 11. ((remote or telephone\* or tele\* or phone\* or cell\* or cellphone\* or tablet\* or smartphone\* or smart phone\* or mobile or wireless or technology or internet or web) adj1 (monitor\* or intervention\* or deliver\* or support\*

- or based or app\* or software\* or program\* or consult\*)).mp. (208331)
- 12. (telemedicine or telemedical\* or telehealth or virtual or telehospice or telemonitor\* or e-health or ehealth or mobile health or video conferenc\* or videoconferenc\*).mp. (99589)
- 13. (email\* or e-mail\*).ti,ab. (16248)
- 14. or/4–13 (395343)
- 15. exp Palliative Care/ (53811)
- 6. exp Terminal Care/ (51074)
- 17. exp Hospice Care/ (6453)
- 18. ((palliative or terminal or end-of-life or hospice) adj1 (care or intervention\* or management or medicine or therap\*)).mp. (93403)
- 19. exp Pain/ (393774)
- 20. exp Pain Management/ (33691)
- 21. ((pain or symptom\*) adj1 manage\*).mp. (58651)
- 22. exp Mental Health/ (37919)
- 23. exp Mental Disorders/ (1233411)
- 24. mental.mp. (540980)
- 25. exp Depression/ (118157)
- 26. exp Depressive Disorder, Major/ (29885)
- 27. depress\*.mp. (541522)
- 28. exp Anxiety/ (84505)
- 29. exp Anxiety Disorders/ (79038)
- 30. anxiety.mp. (234754)
- 31. exp Stress, Psychological/ (130427)
- 32. ((psychological or mental) adj1 stress).mp. (124635)
- 33. exp "Quality of Life"/ (193391)
- 34. quality of life.mp. (329896)
- 35. exp Cognitive Behavioral Therapy/ (28279)
- 36. (cognitive behavioral therap\* or cognitive behavioural therap\*).mp. (30934)
- 37. or/15-36 (2636194)
- 38. 3 and 14 and 37 (3297)
- 39. limit 38 to english language (3185)



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### Appendix 2

 Table 3
 Journal disciplines and definitions of palliative care provided

Author, journal, year	Journal discipline	Definition of palliative care provided	Source referenced
Aoki, Telemed J E Health 2006 [44]	Medicine	not specified	N/A
Bakitas, JAMA 2009 [7]	Medicine	Multidimensional assessment to identify, prevent, and alleviate suffering, interdisciplinary team evaluation and treatment in selected cases, effective communication skills and assistance with medical decision-making, skill in care of dying and bereaved, continuity of care, equitable access, and commitment to continue improvement and excellence	Palliative Care [27]
Bakitas, J Clin Oncol 2015 [31]	Oncology	not specified	N/A
Bruera, J Clin Oncol 2013 [32]	Oncology	not specified	N/A
Cheville, JAMA Oncol 2019 [33]	Oncology	not specified	N/A
Collier, Palliat Med 2016 [48]	Palliative Care	not specified	N/A
Dhiliwal, Indian J Palliat Care 2015 [50]	Palliative Care	not specified	N/A
Dionne-Odom, J Clin Oncol 2015 [34]	Oncology	not specified	N/A
Dionne-Odom, J Pain Symptom Manage 2018 [49]	Palliative Care	not specified	N/A
Elfrink, J Palliat Care 2002 [41]	Palliative Care	not specified	N/A
Grant, J Palliat Med 2011 [45]	Palliative Care	not specified	N/A
Guzman, Psychooncology 2020 [42]	Psychosocial oncology	Palliative care aims to improve the quality of life of patients and families who are facing problems associated with termina illnesses by providing prevention and relief of suffering	•
Hennemann-Krause, Palliat Support Care 2015 [46]	Supportive care	Palliative care aims to control symptoms at any stage of the disease and follow patients and their family members until the end of the patients' lives, reducing suffering and improving quality of life	Johnston 2012 [65]
Hochstenbach, Eur J Oncol Nurs 2016 [37]	Oncology	not specified	N/A
Hoek, BMC Med 2017 [35]	Medicine	Palliative care intends to improve the qual ity of life of patients facing life-threaten- ing illnesses and their families	
Hudson, Psychooncology 2014 [36]	Psychosocial oncology	Support for family caregivers is a core aspect of palliative care provision	World Health Organization [15]
Morgan, Healthcare 2017 [51]	Medicine	not specified	N/A
Nemecek, Cent Eur J Med 2019 [38]	Medicine	Palliative care is the active total care of patients whose disease is not responsive to curative treatment	World Health Organization [15]
Pimentel, J Pain Symptom Manage 2015 [43	3]Palliative Care	not specified	N/A
Stern, J Telemed Telecare 2012 [47]	Medicine	not specified	N/A
Walsh, Cancer Nurs 2003 [39]	Oncology	not specified	N/A
Washington, Psychooncology 2018 [40]	Psychosocial oncology	palliative oncology, defined as the integra- tion into cancer care of therapies to address the multiple issues that cause suffering for patients and their families and impact their quality of life	
Watanabe, Support Care Cancer 2013 [17]	Supportive care	not specified	N/A

Legend: N/A Not applicable



**Supplementary Information** The online version contains supplementary material available at https://doi.org/10.1007/s00520-023-07907-z.

**Author contributions** Camilla Zimmermann conceptualized the idea for the study. Jean Jacob Mathews and Ronald Chow performed the literature search and data analysis. Jean Jacob Mathews wrote the first draft of the manuscript and all authors critically revised the work. All authors read and approved the final manuscript.

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**Data Availability** The data of this study are available from the corresponding author upon reasonable request.

#### **Declarations**

**Competing interests** The authors declare no competing interests.

**Conflict of interests** The authors declare that there is no conflict of interest.

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