

BMJ Open Protocol for an integrative review: patient and families' perspectives on telehealth in palliative care

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ABSTRACT

Introduction Increases in the use of telehealth in palliative care (telepalliative care) prior to, and during, the COVID-19 pandemic have resulted in a proliferation of studies on the topic. While knowledge is building on how providers and recipients adapt to telepalliative care, no reviews have, as of yet, examined telepalliative care from a patient and family perspective. Therefore, the aim of this integrative review is to explore patients and families' perspectives on telepalliative care. **Methods and analysis** An integrative review will be performed inspired by the methodology of Remington and Toronto from March 2022 to December 2022. Medline, Embase, PsycINFO and CINAHL will be searched for primary peer-reviewed studies that describe telepalliative care from patient and families' perspectives. Limiters will be used for age; 18 years+, time; 10 years, and language; English and Danish. Hand searches of authors of included articles and reference lists of included articles will be performed. Two reviewers will independently screen and appraise selected articles using the Mixed Method Appraisal Tool. Conflicts will be resolved through discussions with a third reviewer. Data will be extracted independently by two reviewers into a data matrix with predefined headings and analysed using thematic analysis. Findings will be reported thematically, summarised into a thematic synthesis and discussed in relation to relevant literature.

Ethics and dissemination Ethical approval is not required for this review. Results will be published in an international peer-reviewed journal and presented at a relevant international conference. Reporting of this protocol was guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses Protocol checklist and prospectively reported to PROSPERO (CRD42022301206).

INTRODUCTION

Due to a rising number of people living with multimorbidity and life-limiting diseases, the need for palliative care (PC) services is increasing worldwide.¹ A PC collaborative approach is associated with improved outcomes for patients and families and the introduction of early palliative care (EPC) is associated with improved quality of life.²⁻⁵ However, tertiary and primary care settings are falling short in achieving recommended targets for the provision of PC, especially in

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The authors aim to reduce the risk of bias and increase transparency by critically appraising included studies and prospectively publishing and reporting the protocol.
- ⇒ The authors aim to increase recall by employing multiple databases and supplementary searches.
- ⇒ Search strategies are adapted from Cochrane reviews and approved by a health librarian.
- ⇒ A potential bias exists as studies published in languages other than English or Danish will be excluded.
- ⇒ Updated database searches will be performed prior to submission to a scientific journal.

middle-income and low-income countries.⁶ One method of tackling the rising need for PC is the use of telehealth solutions, which has become increasingly integrated into specialised PC within the last decade, and, most recently, during the COVID-19 pandemic.⁷ The acceleration in use indicates that telehealth in PC is gaining more prominence. Consequently, there is a need for an exploration of the literature about; patients and families' perspectives on technologically mediated PC, methods used to incorporate telehealth into PC, and the appropriateness of how and when to introduce telepalliative care into the illness trajectory.⁸⁻¹⁷ However, sustainability beyond the COVID-19 pandemic has yet to be demonstrated. Therefore, developing new insights into current practice may assist in creating sustainable solutions that foster the adoption of telehealth in PC.

BACKGROUND

Conceptual definitions

To reduce ambiguity, conceptual definitions providing meaning on a theoretical level in this review protocol are explained below and operational definitions explaining how concepts will be applied are outlined in inclusion criteria.¹⁸



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Palliative care

WHO defines PC as: "... an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with a life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual".¹ Specialised PC teams including doctors, nurses, physiotherapists and so on, and non-healthcare workers such as priests, social workers and so on provide PC to patients and families with complex PC needs. General practitioners and healthcare staff in primary care settings more frequently provide basal PC and EPC. The term 'providers' will be applied to those who provide PC to cover both healthcare workers and non-healthcare workers who provide PC.

Telehealth, telemedicine and telepalliative care

The terms telehealth and telemedicine are used interchangeably in the literature. Where telemedicine has largely been described as a method; "... to provide and support healthcare when distance separates the participants",¹⁹ a contemporary definition of telehealth goes further stating that telehealth is used to "...to improve a patient's health".²⁰ Thus, telehealth is no longer merely a question of exchanging information and overcoming geographical distances but incorporates an overarching goal of increasing patients' health.

The phrase telepalliative care was first referred to in the literature in 2006 by Aoki *et al* and refers specifically to telehealth in PC²¹ enabling specialists to connect with patients and families in a virtual setting and provide PC. Reasons for employing telepalliative care include: easing access to specialists, increasing the possibility for patients to remain in their homes for as long as possible, cost-effectiveness and overcoming geographical distances.^{11 22–24} Furthermore, telepalliative care enables the active participation of patients and family members who otherwise may not have the opportunity to participate in consultations and simultaneous knowledge-sharing.²⁵

Definition of family and concept of family in PC

Wright and Leahey define family, as those who the patient says are family.²⁶ As such, family can be relatives, close friends, neighbours and so on, but what is conclusive is, that the patient defines family. Furthermore, the patient and family comprise collectively of a unit of care and the focus is on the patient and family as a unit and not on one or the other.²⁷ The importance of family within PC speaks for a conceptual lens that seeks to explain the dynamics of the family in their meeting with PC providers. Extensive research illustrates the role that families play in caring for patients with PC needs throughout their illness—a trend that will only increase in the future.^{28–31} Despite this, targeted support for family caregivers is often lacking, especially

for older caregivers and non-spouse caregivers, levels of involvement are low and families are ill-prepared for the caregiving role.^{28–31} Research that provides a family focus and the development of timely, purposeful interventions along with public health and policy initiatives is necessary.^{29–32}

Rationale and previous research

Before the COVID-19 pandemic, barriers to telehealth included resistance to change, technically challenged staff and cost and reimbursement issues.³³ However, the COVID-19 pandemic has changed the landscape of telehealth, also in the area of PC.^{8–17} The rise in use, and subsequent new knowledge on telepalliative care, solicit a review of the literature to learn from new initiatives by examining the state of the evidence of telepalliative care from a patient and family perspective.

Recent reviews have looked at: video consultations in generalised and specialised PC to various groups, advancements in the area in the USA, the scale-up, spread and sustainability of video consulting in healthcare, patient and provider acceptance, and telehealth for patients in palliative home care and rural communities.^{22 34–38} Allen Watts *et al* described some of the current telehealth programmes in PC focusing largely on settings across the USA.³⁴ They illustrated how telepalliative care programmes were developed and adopted to provide PC during the COVID-19 pandemic, highlighting pros and cons, lessons learnt and questioning sustainability beyond the pandemic.³⁴ While telepalliative care programmes were useful for a number of situations including: discussing sensitive problems, improving user satisfaction, reducing non-attendance, waiting or transportation time, and increasing access to specialists Allen Watts *et al*, also found that telepalliative care programmes created difficulties in gathering accurate information without a physical exam, technological difficulties, cultural or language barriers, extra work processes and provider stress.³⁴ Future considerations include reimbursement issues, timing the introduction of telepalliative care and developing and adapting models of telepalliative care that reduce disparity especially in low-income or middle-income areas, as what awaits on the other side of the pandemic remains to be seen.³⁴

James *et al*, who examined the scale-up, spread and sustainability of video consultations, found that evidence to support the same is lacking and therefore, stipulate the necessity of employing theoretical frameworks for the large-scale implementation of telehealth to support widespread global use during the current COVID-19 pandemic.³⁸

Cameron and Munyan examined current evidence on tele-hospice services and found that acceptance of tele-hospice services was high and that both provider and patient attitudes were generally positive.³⁵ They also highlighted the necessity of further research into the impact of technology on clinical outcomes, as

implicated by the surge in use during the COVID-19 pandemic.³⁵

In a scoping review, Steindal *et al* found that while telepalliative care seems feasible, increases access to specialists and feelings of security, and facilitates patient/provider genuine relationships, the evidence was contradictory on whether it improves burdensome symptoms and quality of life.³⁶ They conclude that more research is necessary into the experiences of patients with PC needs with non-cancer life-limiting diseases and the effectiveness of telehealth on quality of life and symptoms.³⁶ While Jess *et al* mirror these findings, they also found that further research should explore how, and when, to integrate video consultations into PC and examine the use of video consultations to integrate general and specialised PC, EPC, and in low-income and middle-income countries.²² On the other hand, Gordon *et al* found that telehealth did indeed improve quality of life and symptom management and was effective in relation to symptom monitoring, holding appointments and timesaving, but emphasised the need for further research to reinforce the feasibility and increase quality in telepalliative care.³⁹ Furthermore, they found that the existential and psychosocial aspects of telepalliative care were under-represented in research.³⁷

Few of the current reviews have examined patients and families' perspectives' on telepalliative care. Although some have touched on the topic while examining the quality of life of patients and increased patient and caregiver satisfaction,³⁵⁻³⁷ none addressed the topic specifically from a patient and family perspective. As displayed, the bulk of previous reviews have focused mainly on organisational aspects, PC provider or patient or caregiver perspectives, and facilitators and barriers. There is a dearth of knowledge on how telepalliative care is understood and experienced from within the family unit. Our research group has previously demonstrated how the preferences of family members influence patients' perceptions of how they would like to receive PC in the future.⁴⁰ Understanding the role that families play in telepalliative care is pivotal in understanding how or why some barriers or facilitators exist and how they present in the context of family telepalliative care. Therefore, by carrying out an integrative review (IR) on the topic from a patient and family perspective, this study will provide a new understanding of evidence, identify gaps, form a base for further research, and ultimately, may assist in increasing adoption and sustainability in telepalliative care for patients both with and without cancer illnesses and their families throughout the illness trajectory.

Aim

This IR aims to explore current literature on the perspectives of patients and families on telepalliative care to

expand the understanding of the concept of telepalliative care.

Research question

What are the perspectives of patients and families with PC needs on telepalliative care?

METHODS AND ANALYSIS

For narrow topics such as patient and families' perspectives on telepalliative care, an IR performed systematically to explore studies with various study designs will be employed. The steps involved in an IR are: problem identification, literature search, data evaluation, data analysis and drawing conclusions.¹⁸ This IR will be performed from March 2022 to December 2022.

Theoretical background

Family systems (FSs) will provide a theoretical background for this review, allowing exploration of the relationship of the patient and the family as a unit of care, rather than as individuals.⁴¹ By looking at the family as a unit of care, the focus is on how the family members interact with each other and respond to one another simultaneously on both an individual and a family level.⁴²

Reporting methods

The updated Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) will guide reporting of the review and its findings thus, increasing transparency of the review.⁴³ The PRISMA-P checklist was used to develop this protocol⁴⁴ and is available as online supplemental appendix 1. The setting, perspective, intervention, comparison, evaluation (SPICE) framework was used to develop the research question, scope of the review and inclusion/exclusion criteria.⁴⁵ An example of the elements of the SPICE framework and inclusion/exclusion criteria is displayed in table 1.

Setting

The setting of interest for this review is virtual and will not distinguish between studies undertaken in any location; either low-income, middle-income or high-income countries or care settings; either tertiary or primary. Wright and Leahey's definition of family and the applicability of FS is broad and inclusive and, as such, can be applied across cultures and settings.²⁷ Therefore, no geographical limiters will be applied.

Perspective/participants

Studies eligible for inclusion must describe patients and families' perspectives on telepalliative care. Perspectives are understood as expressions that indicate what a person thinks or feels is important in relation to a particular topic and can be conveyed as attitudes, experiences, viewpoints, perceptions and so on. The included studies may include adult patients

Table 1 Setting, perspective, intervention, comparison, evaluation (SPICE) framework used to develop the review question and scope of the review, and inclusion/exclusion criteria for an integrative review on patient and family perspectives on telepalliative care

SPICE framework		Inclusion criteria	Exclusion criteria and limiters
Setting	All healthcare settings: Home, nursing home, hospital/hospice, primary care or other clinical environments in which patients and families, and PC providers engage in telepalliative care, thus creating a virtual consultation room.	Studies from all healthcare settings	
Perspective/participants	Adult patients—both cancer and non-cancer diagnoses—and their families who engage in telepalliative care—both general and specialised PC. Family can be relatives, neighbours, friends etc.	Studies including patients 18 years and over and their families with all life-threatening diagnoses in all phases of PC throughout their illness trajectory	Studies including patient perspective only or family perspective only or PC provider perspective only
Intervention	Telepalliative care includes, but is not limited to synchronous contacts, such as video consultations or telephone consultations, or asynchronous contacts, such as email or text messages, patient-reported outcome measurements, remote wireless monitoring, online platforms, etc,	Studies must involve use of telepalliative care	
Comparison	No direct comparisons to other interventions		
Evaluation	A thematic synthesis of critically appraised literature on patient and family perspectives of telepalliative care.	Studies that are original, peer-reviewed and of various designs	
			Studies published in languages other than English or Danish Studies older than 10 years on the date of inclusion

PC, palliative care.

18 years and over with both cancer and non-cancer diagnoses and their families hereunder, relatives, close friends, neighbours and so on, who receive PC at any stage in their illness trajectory.

Intervention

Included studies must involve a type of technology that can facilitate telepalliative care.

Comparison

This item of SPICE is not applicable in the IR, as there will be no direct comparison drawn to other interventions in this review.

Evaluation

An exploration of patients and families' perspectives, which will be the main outcome of the IR, will be assembled to a thematic synthesis.

Inclusion criteria

Studies eligible for inclusion are primary peer-reviewed studies of various designs from all healthcare

settings—both inpatient, outpatient, primary and tertiary care—that include adult patients 18 years and over and their families, who have participated in telepalliative care.

Exclusion criteria

Even though PC providers in their interaction with patients and families become a part of the FS,⁴¹ their perspectives are not a specific area of interest to this review. Therefore, studies involving PC providers' perspectives only on telepalliative care will be excluded. Limiters will be applied for language, age and timeframe. From a practical point of view, all languages other than English or Danish will be excluded, thus, increasing the feasibility of the review. WHO differentiates between paediatric PC and adult PC, taking into account developmental stages and relational phenomena that are unique to children.⁴⁶ Therefore, studies relating to telepalliative care in paediatric patients (under 18 years) and their families will be excluded in the screening process. A limiter to

avoid retrieval of studies published before 2011 will be applied as technological advancements and digital readiness have evolved remarkably in recent years.

Review registration

To facilitate peer reviewing and reduce the risk of bias, this protocol was prospectively reported to PROSPERO ref number: CRD42022301206.⁴⁷

Search methods and search strategy

Multiple search strategies will be employed to ensure high recall of all relevant data sources including database searches that are both specific based on key words and comprehensive to accommodate as many synonyms as possible, and supplementary searches to identify further sources.^{18 48} The search strategy was developed from the SPICE framework above. A healthcare librarian was consulted frequently to ensure the quality of the strategy and support the development of the search strings.¹⁸ The terms 'patient' and 'perspectives' were not employed as the health librarian advised that they are too unspecific. The search strategy composes of:

- ▶ Combinations of natural language including the keywords (palliative care, telehealth, telepalliative care, and family) and synonyms.
- ▶ Controlled language derived from thesaurus, for example, MeSH terms.
- ▶ Search terms inspired by and adapted from existing strategies in Cochrane reviews including a telemedicine/telehealth search string,⁴⁹ a palliative search string⁵⁰ and family search strings.^{51 52}
- ▶ A validated filter for mobile applications will be added to the search string on the Ovid platform.⁵³
- ▶ Boolean operators AND and OR and syntaxes specific to each database.

An example of the search string for Medline (Ovid) is provided in online supplemental appendix 2 table 1. The search strategy was piloted in Medline (Ovid) and further refined to ensure that it captured five key articles identified through citation searching early in the review process.

Information sources

Systematic searches will be performed for qualitative, quantitative, and mixed methods primary peer-reviewed studies in Medline (Ovid), Embase (Ovid), PsycINFO (Ovid) and CINAHL (Ebsco). All search strings will be listed in supplementary files. Database searches will take place from March 2022 to December 2022 and will be updated prior to submission to a scientific journal.

Supplementary searches to identify further sources to minimise publication bias will include: author searches of authors of identified literature included in systematic reviews on the topic from the above-mentioned databases and the Cochrane Library. The search will stop when all relevant databases have been searched, modified searches with added relevant terms have been conducted with no

new results retrieved, and author searches of authors of identified literature render no new results.¹⁸

Screening and selection process

References will be imported to Endnote,⁵⁴ duplicates will be identified and removed, and imported to Covidence, where further duplicates will be identified and removed.⁵⁵

Two reviewers will pilot inclusion criteria by screening an initial number of articles to align expectations and definitions in relation to inclusion criteria. Piloting will cease when expectations are aligned. Thereafter, two reviewers will independently screen titles and abstracts for eligibility according to predefined inclusion and exclusion criteria. Reports that do not provide adequate information in titles and abstracts for selection will go to full-text screening. Disagreements will be resolved through consensus or by consulting a third reviewer. Two reviewers will independently screen all potentially relevant reports in full text for eligibility. Disagreements will be resolved through consensus, or, if necessary, by consulting a third reviewer. If two articles published in the same study are selected, they will be included as one study. PRISMA will be used in this review.⁴³ A separate PRISMA flow diagram for each database and an overall combined PRISMA flow diagram will illustrate searches, screening and selection processes resulting in included studies.

Critical appraisal of quality

The Mixed Methods Appraisal Tool (MMAT) V.2018 will be used to critically appraise the quality of the selected studies in the proposed review.⁵⁶ MMAT was developed to appraise the quality of empirical studies of diverse designs: qualitative, quantitative or mixed methods using design specific criteria.⁵⁷ Two reviewers will independently appraise all selected studies. The validity and reliability of MMAT are documented and guidelines for use are available.^{56 58} Hong *et al* recommend that reviewers meet to agree on indicators and train uniformity of use across the various design categories.⁵⁶ This will be achieved by reviewers meeting to agree on indicators relevant to this review, independently reviewing the first 10 studies, and meeting to discuss results to achieve a common understanding of the appraisal process. An overall score can be obtained. However, exclusion based on the overall score is discouraged.⁵⁷ Therefore, the ratings for each criteria of MMAT and related comments will be displayed in a table to provide an overview of the quality of included studies. Overall scores will be entered into the data matrix, ratings will be reported descriptively and depending on the same, may be mentioned as a limitation in the discussion. If studies are excluded, reasons for exclusion will be given. A third reviewer will be called on in the case of discrepancies.

Strategy for data extraction, analysis and synthesis

The primary goal of an IR is to create a better understanding of a topic through the synthesis of multiple sources.⁵⁹ Therefore, the analysis and synthesis aim to

create new meaning and knowledge about families' perspectives on telepalliative care through an in-depth analysis of the results of included literature. This will be performed in several steps: assembling a data matrix, performing a thematic analysis and finally, coherently synthesising and discussing results in relation to relevant theory.

Data extraction

Data extraction will be performed independently by two reviewers into a predefined data matrix in an Excel spreadsheet. The research question will be placed above the data matrix ensuring alignment of extracted data with the aim of the review. Agreement on extracted data will be established through reviewer negotiation among the two reviewers. If necessary, discrepancies will be discussed with a third reviewer until agreement is established.

Data items

Extracted data will include: author, year and country of origin, context (tertiary, outpatient, primary care etc) and sample size, study design and methodology, main findings, type of patient/family constellation, theoretical approach, type of technology, type of perspective (technology-related, or PC-related or both), type of cancer or non-cancer (diagnosis) telepalliative care, type of telepalliative care (specialist or general) and quality rating. An example of the proposed data extraction table is provided as online supplemental appendix 2 table 2.

Outcomes and prioritisation

The main outcome of the proposed review is a new understanding of patient and families perspectives on telepalliative care presented in a thematic synthesis.

Data analysis and synthesis

Data will be analysed using thematic analysis; abductively in relation to predefined elements of the data matrix during extraction, and inductively across the data matrix.⁶⁰ The steps of thematic analysis; familiarising with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report, will guide the process.⁶⁰ Furthermore, the integration of quantitative data with qualitative data will be achieved by 'qualitising' quantitative results using a convergent synthesis design; data will be extracted and coded according to vocabulary used by the original authors in description of results, integration of data will occur at the point of data extraction and using thematic analysis, results will be presented together.⁶¹ Two reviewers will independently code the extracted data across the data matrix producing initial codes, identifying patterns and grouping codes to form potential themes. At this point, the reviewers will meet to discuss themes and coded data, revisiting the data matrix when necessary and creating an overview of the analysis. Differences will be resolved through discussions and revisiting original studies. Interpretation of themes and subthemes will continue within the review team resulting

in the production of a thematic synthesis, which will be organised around the main themes. Results will also be presented in a table with themes and corresponding characteristics from included studies.¹⁸ Thematic analysis is appropriate, as it is a flexible method that can be used to identify and organise main themes or recurring patterns moving back and forth across the data matrix.¹⁸

Patient and public involvement

Patients and public were not actively involved in the design of this protocol. However, a motivating factor in performing this review was the findings of a qualitative study on patient and relatives' preferences in relation to telepalliative care performed by the authors EHB and GB.⁴⁰ This review protocol is part of a PhD project and will guide further coproduction studies with active patient and family participation.

Data statement

Data will be stored in Open Analyse, a secure data storage facility at the faculty of medicine at University of Southern Denmark in Odense, Denmark.

DISCUSSION

This proposed IR aims to explore telepalliative care from the perspective of patients and families. An IR is considered useful for the purpose of this review, as it includes material from multiple designs. The review will be guided and developed by the methods provided by Toronto and Remington.¹⁸ A summary of major findings will be presented and discussed using the key concepts of the theoretical framework and in relation to previous literature. Implications or recommendations for future research, practice, education, theory/and or policy, as appropriate will be made. The proposed IR may contribute to a heightened awareness of the importance of patients and families' role in the interdisciplinary team, becoming mutually involved in caring for the patient and family members in a more meaningful, respectful and empathetic way that honours their wishes to care.

Ethics and dissemination

Ethical approval is not relevant to this review. Results will be published in an international peer-reviewed journal and presented at a relevant international conference. Findings will be reported locally and applied clinically, where relevant. Furthermore, the research team will endeavour to report and cite authors in a respectful manner in relation to original findings.

Limitations

According to Toronto and Remington, limitations of IRs can entail flaws in selected studies, weakness of the review itself or a combination of both.¹⁸ In this review, critical appraisal using MMAT along with prospectively reporting to PROSPERO (CRD42022301206) and publishing the protocol aims to reduce the risk of bias and increase transparency. Potential limitations of the

review may include: the exclusion of potentially relevant papers and grey literature due to the exclusion of non-English or non-Danish studies, non-peer-reviewed studies and limiting the searches to the chosen databases.

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Contributors All authors contributed to the design and methodology of the protocol. EHB performed background searches and is responsible for writing the protocol. EHB and ANØS developed the attached search strategy in collaboration with a health librarian. All authors have read and approved the final protocol manuscript prior to submission. EHB submitted the manuscript.

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

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REFERENCES

- 1 WHO. *Planning and implementing palliative care services: a guide for programme managers*. 91. Switzerland: WHO pres, 2016.
- 2 Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363:733–42.
- 3 Temel JS, Greer JA, El-Jawahri A, et al. Effects of early integrated palliative care in patients with lung and Gi cancer: a randomized clinical trial. *J Clin Oncol* 2017;35:834–41.
- 4 Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet* 2014;383:1721–30.
- 5 Lukas Radbruch SPatBoDotE, European Association for Palliative Care. White paper on standards and norms for hospice and palliative care in Europe. Part 1 and part 2. *Eur J Palliat Care* 2009;16.
- 6 World Health O. *Assessing national capacity for the prevention and control of noncommunicable diseases: report of the 2019 global survey*. 2020. Geneva: World Health Organization, 2020.
- 7 Webb M, Hurley SL, Gentry J, et al. Best practices for using telehealth in hospice and palliative care. *J Hosp Palliat Nurs* 2021;23:277–85.
- 8 Ritchey KC, Foy A, McArdel E, et al. Reinventing palliative care delivery in the era of COVID-19: how telemedicine can support end of life care. *Am J Hosp Palliat Care* 2020;37:992–7.
- 9 Chávarri-Guerra Y, Ramos-López WA, Covarrubias-Gómez A, et al. Providing supportive and palliative care using telemedicine for patients with advanced cancer during the COVID-19 pandemic in Mexico. *Oncologist* 2021;26:e512–5.
- 10 Calton B, Abedini N, Fratkin M. Telemedicine in the time of coronavirus. *J Pain Symptom Manage* 2020;60:e12–14.
- 11 Calton B, Shibley WP, Cohen E, et al. Patient and caregiver experience with outpatient palliative care telemedicine visits. *Palliat Med Rep* 2020;1:339–46.
- 12 Broglio K, Kirkland KB. Rural palliative care patients' attitudes toward telemedicine visits during the COVID-19 pandemic: a descriptive study. *J Palliat Med* 2021;24:1126–7.
- 13 Calton BA. Communication strategies for providing palliative care via telemedicine #406. *J Palliat Med* 2021;24:135–6.
- 14 Atreya S, Kumar G, Samal J, et al. Patients'/Caregivers' perspectives on telemedicine service for advanced cancer patients during the COVID-19 pandemic: an exploratory survey. *Indian J Palliat Care* 2020;26:40–4.
- 15 Silva MD, Schack EE. Outpatient palliative care practice for cancer patients during COVID-19 pandemic: benefits and barriers of using telemedicine. *Am J Hosp Palliat Care* 2021;38:842–4.
- 16 Biswas S, Adhikari SD, Gupta N, et al. Smartphone-based telemedicine service at palliative care unit during nationwide lockdown: our initial experience at a tertiary care cancer Hospital. *Indian J Palliat Care* 2020;26:S31–5.
- 17 Miller KA, Baird J, Lira J, et al. The use of telemedicine for home-based palliative care for children with serious illness: a scoping review. *J Pain Symptom Manage* 2021;62:619–36.
- 18 Toronto CE, Remington R. *A step-by-step guide to conducting an integrative review*. Springer Nature Switzerland AG, Gewerbstrasse 11, 6330 Cham, Switzerland: Springer, 2020.
- 19 Institute of Medicine Committee on Evaluating Clinical Applications of T. The National Academies Collection: Reports funded by National Institutes of Health. In: Field MJ, ed. *Telemedicine: a guide to assessing telecommunications in health care*. Washington (DC): National Academies Press (US) Copyright © 1996, National Academy of Sciences, 1996.
- 20 Tuckson RV, Edmunds M, Hodgkins ML. Telehealth. *N Engl J Med* 2017;377:1585–92.
- 21 Aoki N, Ohta S, Yamamoto H, et al. Triangulation analysis of tele-palliative care implementation in a rural community area in Japan. *Telemed J E Health* 2006;12:655–62.
- 22 Jess M, Timm H, Dieperink KB. Video consultations in palliative care: a systematic integrative review. *Palliat Med* 2019;33:942–58.
- 23 Funderskov KF, Boe Danbjørg D, Jess M, et al. Telemedicine in specialised palliative care: healthcare professionals' and their perspectives on video consultations-A qualitative study. *J Clin Nurs* 2019;28:3966–76.
- 24 Calton BA, Rabow MW, Branagan L, et al. Top ten tips palliative care clinicians should know about Telepalliative care. *J Palliat Med* 2019;22:981–5.
- 25 Funderskov KF, Raunkjær M, Danbjørg DB, et al. Experiences with video consultations in specialized palliative home-care: qualitative study of patient and relative perspectives. *J Med Internet Res* 2019;21:e10208.
- 26 Wright & Leahey's Nurses and families. *A guide to family assessment and intervention*. 7th ed. Philadelphia: F.A. Davis, 2019: 380 s.
- 27 Bell JM, Care FC. Family centered care and family nursing: three beliefs that matter most. *Pflege* 2014;27:213–7.
- 28 Hudson P, Payne S, Caregivers F. Family caregivers and palliative care: current status and agenda for the future. *J Palliat Med* 2011;14:864–9.
- 29 Tarberg AS, Kvangarsnes M, Hole T, et al. Silent voices: family caregivers' narratives of involvement in palliative care. *Nurs Open* 2019;6:1446–54.

- 30 Coyne E, Heynsbergh N, Dieperink KB. Acknowledging cancer as a family disease: a systematic review of family care in the cancer setting. *Eur J Oncol Nurs* 2020;49:101841.
- 31 Hodson AR, Peacock S, Holtslander L. Family caregiving for persons with advanced heart failure: an integrative review. *Palliat Support Care* 2019;17:720–34.
- 32 Applebaum AJ, Buda KL, Schofield E, *et al.* Exploring the cancer caregiver's journey through web-based meaning-centered psychotherapy. *Psychooncology* 2018;27:847–56.
- 33 Scott Kruse C, Karem P, Shifflett K, *et al.* Evaluating barriers to adopting telemedicine worldwide: a systematic review. *J Telemed Telecare* 2018;24:4–12.
- 34 Allen Watts K, Malone E, Dionne-Odom JN, *et al.* Can you hear me now?: improving palliative care access through telehealth. *Res Nurs Health* 2021;44:226–37.
- 35 Cameron P, Munyan K. Systematic review of Telehospice telemedicine and e-health. *Telemed J E Health* 2021;27:1203–14.
- 36 Steindal SA, Nes AAG, Godskesen TE, *et al.* Patients' experiences of telehealth in palliative home care: scoping review. *J Med Internet Res* 2020;22:e16218–e.
- 37 Gordon B, Mason B, Smith SLH. Leveraging telehealth for delivery of palliative care to remote communities: a rapid review. *J Palliat Care* 2022;37:213–225.
- 38 James HM, Papoutsi C, Wherton J, *et al.* Spread, scale-up, and sustainability of video consulting in health care: systematic review and synthesis guided by the NASSS framework. *J Med Internet Res* 2021;23:e23775.
- 39 Gordon B, Mason B, Smith SLH. Leveraging telehealth for delivery of palliative care to remote communities: a rapid review. *J Palliat Care* 2022;37:213–25.
- 40 Hayes Bauer E, Ørsted Schultz AN, Brink A, *et al.* Patients' and relatives' preferences for a Palliative/Oncology day ward and out-of-hours Telemedicine-An interpretive description. *Healthcare* 2021;9. doi:10.3390/healthcare9060758. [Epub ahead of print: 18 06 2021].
- 41 Bell JM. Family systems nursing: re-examined. *J Fam Nurs* 2009;15:123–9.
- 42 Wright LM, Leahey M. Trends in nursing of families. *J Adv Nurs* 1990;15:148–54.
- 43 Page MJ, McKenzie JE, Bossuyt PM, *et al.* The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Syst Rev* 2021;10:89.
- 44 Moher D, Shamseer L, Clarke M, *et al.* Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev* 2015;4:1.
- 45 Booth A, Sutton A, Papaioannou D. *Systematic approaches to a successful literature review*. 2nd ed. Los Angeles: Sage, 2016: ix. 326 sider.
- 46 WHO. *Integrating palliative care and symptom relief into paediatrics: a who guide for health care planners, implementers and managers*. 1st ed. 20, Avenue Appia 1211 Geneva 27 Switzerland: World Health Organisation, 2018: 96.
- 47 Page MJ, Shamseer L, Tricco AC. *Registration of systematic reviews in prospero: 30,000 records and counting. (2046-4053 (Electronic))*.
- 48 Whittemore R, Knaf K. The integrative review: updated methodology. *J Adv Nurs* 2005;52:546–53.
- 49 Xyrichis A, Iliopoulou K, Mackintosh NJ, *et al.* Healthcare stakeholders' perceptions and experiences of factors affecting the implementation of critical care telemedicine (CCT): qualitative evidence synthesis. *Cochrane Database Syst Rev* 2021;2:Cd012876.
- 50 Horey D, Street AF, O'Connor M, *et al.* Training and supportive programs for palliative care volunteers in community settings. *Cochrane Database Syst Rev* 2015;2015:CD009500.
- 51 Mackintosh NJ, Davis RE, Easter A, *et al.* Interventions to increase patient and family involvement in escalation of care for acute life-threatening illness in community health and hospital settings. *Cochrane Database Syst Rev* 2020;12:Cd012829.
- 52 Treanor CJ, Santin O, Prue G, *et al.* Psychosocial interventions for informal caregivers of people living with cancer. *Cochrane Database Syst Rev* 2019;6:Cd009912.
- 53 Ayiku L, Hudson T, Glover S, *et al.* The NICE Medline and Embase (Ovid) health apps search filters: development of validated filters to retrieve evidence about health apps. *Int J Technol Assess Health Care* 2021;37:e16.
- 54 . Endnote20-Guiden - Referencesoftware [University library homepage information on reference management tools]. Campusvej 55,5230 Odense M, Denmark SDU; 2021. <https://libguides.sdu.dk/endnote20> [Accessed 12 Oct 2021].
- 55 CochraneCommunity. About Covidence [Webpage], 2020. The Cochrane collaboration. Available: <https://community.cochrane.org/help/tools-and-software/covidence/about-covidence>
- 56 Hong QN, Gonzalez-Reyes A, Pluye P. Improving the usefulness of a tool for appraising the quality of qualitative, quantitative and mixed methods studies, the mixed methods appraisal tool (MMAT). *J Eval Clin Pract* 2018;24:459–67.
- 57 Pluye P, Gagnon M-P, Griffiths F, *et al.* A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *Int J Nurs Stud* 2009;46:529–46.
- 58 Souto RQ, Khanassov V, Hong QN, *et al.* Systematic mixed studies reviews: updating results on the reliability and efficiency of the mixed methods appraisal tool. *Int J Nurs Stud* 2015;52:500–1.
- 59 Torraco RJ. Writing integrative literature reviews: using the past and present to explore the future. *Hum Resour Dev Rev* 2016;15:404–28.
- 60 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- 61 Thomas J, Harden A. *Methods for the thematic synthesis of qualitative research in systematic reviews. (1471-2288 (Electronic))*.