

# Effective communication in palliative care from the perspectives of patients and relatives: A systematic review

## Review Article

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### Abstract

**Objectives.** In palliative care, effective communication is essential to adequately meet the needs and preferences of patients and their relatives. Effective communication includes exchanging information, facilitates shared decision-making, and promotes an empathic care relationship. We explored the perspectives of patients with an advanced illness and their relatives on effective communication with health-care professionals.

**Methods.** A systematic review was conducted. We searched Embase, Medline, Web of Science, CINAHL, and Cochrane for original empirical studies published between January 1, 2015 and March 4, 2021.

**Results.** In total, 56 articles on 53 unique studies were included. We found 7 themes that from the perspectives of patients and relatives contribute to effective communication: (1) open and honest information. However, this open and honest communication can also trigger anxiety, stress, and existential disruption. Patients and relatives also indicated that they preferred (2) health-care professionals aligning to the patient's and relative's process of uptake and coping with information; (3) empathy; (4) clear and understandable language; (5) leaving room for positive coping strategies, (6) committed health-care professionals taking responsibility; and (7) recognition of relatives in their role as caregiver. Most studies in this review concerned communication with physicians in a hospital setting.

**Significance of results.** Most patients and relatives appreciate health-care professionals to not only pay attention to strictly medical issues but also to who they are as a person and the process they are going through. More research is needed on effective communication by nurses, in non-hospital settings and on communication by health-care professionals specialized in palliative care.

## Introduction

Palliative care should be aligned to the needs, goals, and preferences of patients and their relatives. For many patients and relatives, it is important to retain (a certain degree of) control over care. Health-care professionals can only provide appropriate care at the appropriate moment if they are aware of the needs and preferences of those involved (Hoare et al. 2015; Shin et al. 2016; Steering Committee for Appropriate End-of-Life Care (RDMA) 2015; Stegmann et al. 2021). Patients and relatives should be confident that goals and preferences discussed with a health-care professional are known throughout the care process (Back 2020; den Herder-van der Eerden et al. 2017; Van Vliet and Epstein 2014). This requires continuous effective communication between health-care professionals and patients and their relatives, because needs, goals, and preferences can change during a disease trajectory (Bergqvist and Strang 2019; Hwang et al. 2015; Shin et al. 2016). Health-care professionals from all disciplines and professions providing palliative care, both generalists and specialists, should therefore have adequate communication skills.

In the Netherlands Quality Framework for Palliative Care (Boddaert et al. 2017), which is based on international literature and guidelines (Hospice New Zealand 2012; National Coalition for Hospice and Palliative Care 2013; National Institute for Health and Care Excellence (NICE) 2011; Palliative Care Australia 2005), effective communication is defined as “a structured process between patient and healthcare professional in which bilateral information exchange and equality – with respect for the dependent position of the patient – are the basis.”

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Effective communication requires empathy and appropriate verbal and nonverbal communication techniques (Boddaert et al. 2017; Slort et al. 2012). Since 2010, there is increasing attention in the scientific literature for communication between patients and health-care professionals, in particular for communication between patients and physicians, often from the health-care professional's perspective. A widely used model to map the functions and outcomes of patient–physician communication from the health-care professional's perspective is the model of De Haes and Bensing (2009). Less is known about the functions and outcomes of effective communication from the perspectives of patients and relatives.

The Canadian Medical Education Directive for Specialists (CanMeds) model is 1 of the most adopted frameworks for competency-based education for medical students (Frank et al. 2014; Griewatz et al. 2020). In this model, being a communicator is an important professional role of physicians. However, research among patients and relatives shows that it is not self-evident that health-care professionals timely obtain essential information when caring for patients who are in the palliative phase of their illness, and their relatives (Shin et al. 2016; Stegmann et al. 2020; Zwakman et al. 2018a). Further patients may fail to continuously make their preferences known (den Herder-van der Eerden et al. 2017). Moreover, health-care professionals may not timely and adequately share information about the needs and wishes of patients and relatives with colleagues (Engel et al. 2020; Flierman et al. 2020).

The aim of this systematic review was to explore the perspectives of patients and relatives on effective communication with palliative health-care professionals, i.e. how can health-care professionals make them feel invited and safe to express their experiences, concerns, needs, and to share their goals and preferences for treatment and care.

## Method

### Design

We conducted a systematic literature review. We report on this review according to the updated systematic approach of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for reviews (Page et al. 2021).

### Definition

In consultation with palliative care experts, we developed the following definition of effective communication in palliative care:

Effective communication in palliative care is a dialogical process between the patient and/or relative and health-care professional(s) in which both informative and empathic aspects are exchanged. Exchanging informative aspects includes sharing information about prognosis/treatment/care by the health-care professional and sharing knowledge and experiences by the patient and/or relative. Exchanging empathic aspects relates to maintaining or promoting the professional–patient relationship and addressing emotions by both the health-care professional and the patient and/or relative.

Effective communication supports equality between the conversation partners, while considering the dependent position of the patient and differences in expertise and experience, and creates an atmosphere in which patients and relatives feel invited and safe to share their concerns, needs, and preferences regarding care and treatment, regardless of content, context, cultural aspects, and health literacy.

Effective communication relates to the 4 dimensions that are important in the care of patients in the last phase of life: physical, psychological, social,

and spiritual. Communication can be initiated either by the patient and/or relative as well as by the health-care professional.

Effective communication results in care that is perceived as appropriate (as much as possible) by the patient and, in addition, a feeling of safety and being supported by the patient and/or relative.

### Search strategy

The search strategy was based on PALETTE, the “Palliative care Literature rEview iTeraTive mEthod,” a method to develop search strategies in literature reviews on palliative care focused on complex concepts, such as effective communication (Zwakman et al. 2018b). We combined different information retrieval techniques, such as contacting experts, a focused initial search, pearl growing (Schlosser et al. 2006), and citation tracking (Papaioannou et al. 2010; Schlosser et al. 2006). An initial search and consultation of experts resulted in a set of 7 “golden bullet” articles. The search strategy was further developed in Embase in collaboration with an information specialist from Erasmus MC, University Medical Center Rotterdam, and optimized in an iterative validation process. Keywords were added until all 7 “golden bullets” were identified. The final search was carried out on March 4, 2021 using 5 databases: Embase, MEDLINE (Ovid), Web of Science, Cochrane, and CINAHL (EBSCOhost) (see Supplemental file 1 for search terms).

### Inclusion and exclusion criteria

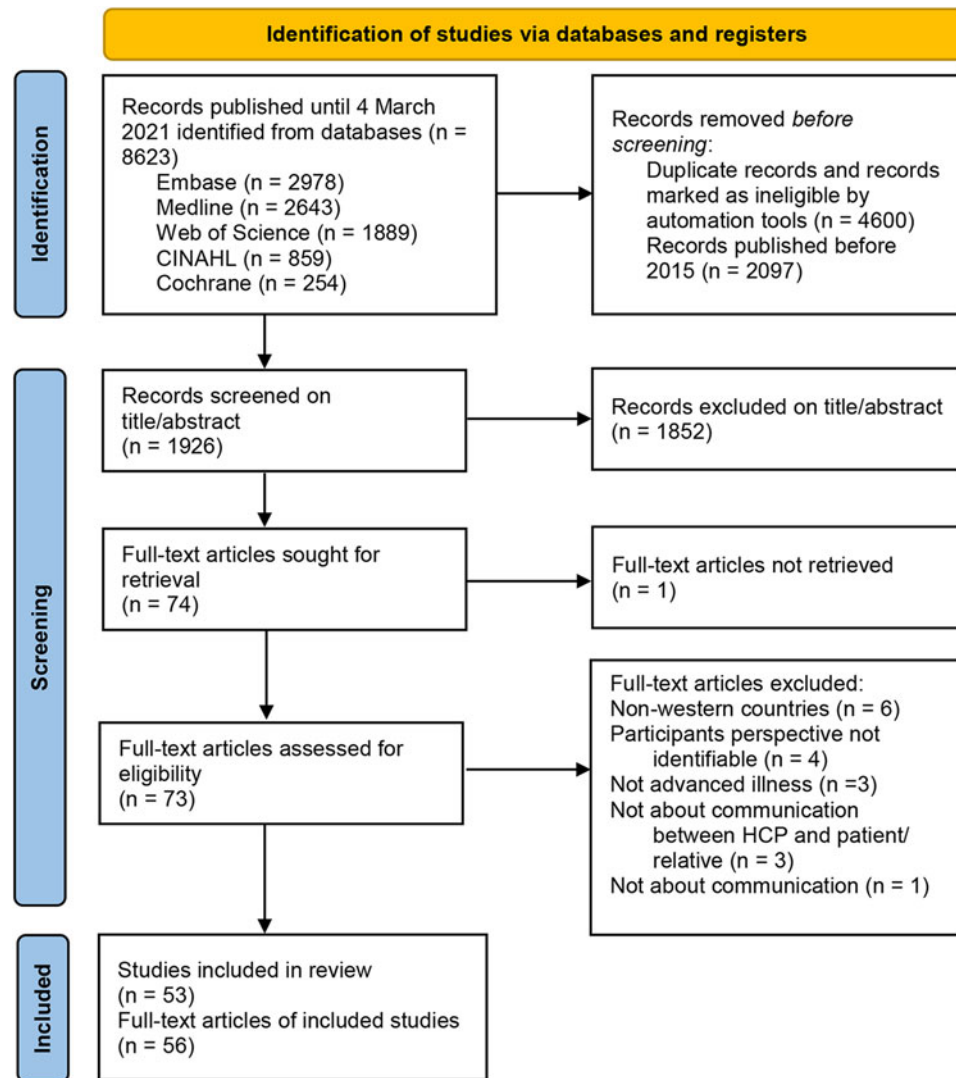
We included articles that met the following criteria: the article described an original empirical study on effective communication between patients and/or relatives with health-care professionals; the study assessed the experiences of patients diagnosed with advanced illness and/or their relatives; the article was published in English between January 1, 2015 and March 4, 2021. We chose the year 2015 as starting point, because from that time a growing patient-centered focus was found in studies on communication in palliative care (Bensing et al. 2013; De Boer et al. 2013). Studies on communication conducted in non-Western countries, in pediatric palliative care and review articles were excluded.

We started with screening titles and abstracts, and the next step was screening based on full-text articles. All steps were performed by 4 researchers using EndNote X9 (Bramer et al. 2017). Differences in the selection of potentially eligible articles were resolved by mutual agreement. When in doubt, an article was reviewed for its full text.

### Data extraction and analysis

We developed a data-extraction form that included the aim of the study, the study setting, the study design, the study population, the method of data collection, and the results of the study. Data extraction was performed by 2 researchers (M.E. and M.K.).

Since the research question appeared to be addressed by studies with both qualitative, quantitative and mixed-methods research designs, we took a convergent integrated approach to synthesize and integrate the findings (Stern et al. 2021). First, a conceptual overview of the results relevant to the review question was made of each article. In this conceptual overview, we transformed quantitative findings from included studies into a qualitative description. Second, based on the overviews of articles published in 2020 and 2021 ( $n = 17$ ), a



**Figure 1.** Flow diagram search strategy (Page et al. 2021) (2021–03-04).

first thematic structure to synthesize study results was developed. Third, remaining articles were then placed along this preliminary structure and if necessary or desirable, themes were added or existing themes were merged. This resulted in the final structure.

### Quality assessment

The quality assessment of included articles was performed independently by 2 researchers (M.E. and M.K.). Qualitative articles were assessed using the COnsolidated criteria for REporting Qualitative research (COREQ) checklist (Tong et al. 2007). Observational studies were assessed using an adapted version of the Cochrane risk-of-bias instrument, which was based on the Cochrane Bias Tool for intervention studies (Fahner et al. 2019; Higgins and Green 2011; Sondaal et al. 2016). Randomized controlled trials were assessed using the Cochrane tool for assessing risk of bias in randomized trials (Higgins et al. 2011). Given the exploratory nature of this systematic review, all articles were included in the analysis (Dixon-Woods et al. 2006).

## Results

### Characteristics of articles

The search strategy resulted in 1926 unique articles, of which 56 were included (see Fig. 1) (Abdul-Razzak et al. 2016; Adamson et al. 2018; Ahmed et al. 2015; Applebaum et al. 2018; Awdish et al. 2017; Bauman et al. 2018; Bergenholtz et al. 2020; Brom et al. 2017; Caswell et al. 2015; Chen et al. 2021; Cohen-Mansfield et al. 2017; Collins et al. 2018a, 2018b; Curtis et al. 2018; Doorenbos et al. 2016; Epstein et al. 2017; Fenton et al. 2018; Freytag et al. 2018; Garden and Seiler 2017; Gilad et al. 2022; Goebel and Mehdorn 2018; Hilário 2020; Hjelmfors et al. 2018; Houben et al. 2015; Ibañez-Masero et al. 2019; Im et al. 2019; Kim et al. 2018; Kirby et al. 2018; Kitta et al. 2021; Krawczyk and Gallagher 2016; Krug et al. 2021; Kvåle et al. 2020; Lin et al. 2018; Masefield et al. 2019; McGinley and Waldrop 2020; Melhem and Daneault 2017; Melis et al. 2021; Middleton-Green et al. 2019; Netsey-Afedo et al. 2020; O'Connor et al. 2020; Paladino et al. 2020; Pini et al. 2021; Rohde et al. 2019; Scherrens et al. 2020; Schulman-Green et al. 2018; Schulz et al. 2017; Seccareccia et al. 2015; Seifart et al. 2020; Shen et al. 2020; Steinhauser et al. 2015;

Tavares et al. 2020; Timmermann et al. 2017; Villalobos et al. 2018; Voruganti et al. 2018; Washington et al. 2019; Weerasinghe and Maddalena 2016).

An overview of the characteristics of the studies is presented in Table 1.

A classification of the included studies by study design, country, care setting, perspective studied, diagnosis, and method of data collection in addition to the characteristics in Table 1 is presented in Supplemental file 2.

In our quality assessment, for trials ( $n = 4$ ) the median quality score was 4.5 out of 7 (range, 1–5). There was no blinding of the participants in any of the trials. For observational studies ( $n = 7$ ) and the quantitative parts of mixed methods studies ( $n = 4$ ), the median quality score was 3 (range, 0–7). For qualitative studies ( $n = 41$ ) and for qualitative parts of mixed methods studies ( $n = 4$ ), the median quality score was 18.0 out of 32 (range, 4.5–21.5). A detailed presentation of the quality assessments by the researchers is provided in Supplemental file 3.

### Perspectives of patients and relatives

We identified 7 themes that from the perspectives of patients and relatives are important for effective communication in palliative care. A summary of our findings is presented in Table 2.

#### Open and honest information

Many patients wanted to be informed openly and honestly about their situation, including their diagnosis, disease, condition, treatment, side effects, disease course (metastases), and prognosis (Abdul-Razzak et al. 2016; Brom et al. 2017; Goebel and Mehdorn 2018; Masefield et al. 2019; Rohde et al. 2019; Seccareccia et al. 2015; Villalobos et al. 2018). In a few studies, patients stated that they also appreciated to be rapidly informed of results of diagnostic examinations (Goebel and Mehdorn 2018; Rohde et al. 2019; Seccareccia et al. 2015).

Several articles describe the impact of open communication. Some studies show that patients' satisfaction with communication improved when they could openly talk about the details of the disease, prognosis, or the dying process (Curtis et al. 2018; Houben et al. 2015). Open communication contributed to a stronger connection (rapport) between patient and health-care professional, which increased patients' trust (Abdul-Razzak et al. 2016; Fenton et al. 2018; Freytag et al. 2018; Paladino et al. 2020). In addition, some patients experienced more control and thus a stronger feeling of safety: being well informed about treatment options enabled them to make well-considered treatment or care decisions (Brom et al. 2017; Chen et al. 2021; Epstein et al. 2017; Paladino et al. 2020). The relationship between open communication and perceived safety was also demonstrated by the experiences of patients who (partially) missed open information. Several studies show that patients felt isolated when they had the impression that health-care professionals did not inform them adequately (Hilário 2020; Kitta et al. 2021; Rohde et al. 2019). Patients indicated that open and honest communication could help them to be better prepared to make informed decisions (Masefield et al. 2019).

When it came to feeling invited and safe to share their needs and concerns, the experiences and needs of relatives were broadly similar to patients (Ahmed et al. 2015; Caswell et al. 2015; Gilad et al. 2022; Ibañez-Masero et al. 2019; Kim et al. 2018; Masefield et al. 2019; Steinhäuser et al. 2015). However, there were also

differences between the needs and preferences of relatives and patients. Although relatives might also struggle with coping with open and honest information and might also need to hold on to hope (Applebaum et al. 2018), they generally indicated having a greater need for information than patients (Applebaum et al. 2018; Masefield et al. 2019). To provide optimal care and to be prepared for future care needs, relatives indicated that they needed timely, detailed prognostic information or information about the process of dying (Ahmed et al. 2015; Awdish et al. 2017; Bauman et al. 2018; Caswell et al. 2015; Cohen-Mansfield et al. 2017; Collins et al. 2018b; Im et al. 2019; Krawczyk and Gallagher 2016; McGinley and Waldrop 2020; Seccareccia et al. 2015; Steinhäuser et al. 2015).

#### Aligning to the process of uptake and coping with information

Although many patients expressed a desire for open and honest communication, many studies also show that patients often found it difficult to cope with information about their deteriorating health (Abdul-Razzak et al. 2016; Goebel and Mehdorn 2018; Ibañez-Masero et al. 2019; Im et al. 2019; Masefield et al. 2019; Rohde et al. 2019; Seccareccia et al. 2015; Shen et al. 2020; Weerasinghe and Maddalena 2016). There were many potentially defining moments in the palliative trajectory that could be threatening, such as being diagnosed with a severe illness, the failure of treatment, the transition from curative to palliative or comfort care, transfer to another care organization, etc. (Collins et al. 2018a; Goebel and Mehdorn 2018; Hilário 2020; Hjelmfors et al. 2018; Im et al. 2019; Kitta et al. 2021; Kvåle et al. 2020; Masefield et al. 2019; Melis et al. 2021; Netsey-Afedo et al. 2020; Pini et al. 2021; Schulman-Green et al. 2018; Schulz et al. 2017; Tavares et al. 2020; Villalobos et al. 2018). Although patients indicated that they preferred open and honest information about these topics, such information confronted patients with their deterioration, their "running out" of treatment options and thus with the threat of increasing dependence and the approaching end of life. This could result in fear, stress, and existential disruption, inducing feelings of insecurity and loss of control. For many patients who thought they were willing to face their end of life and the series of decisions that came with it, arriving at the moment where they had to do so turned out to be a heavy task (Im et al. 2019; Krug et al. 2021; Masefield et al. 2019; Netsey-Afedo et al. 2020; Pini et al. 2021; Rohde et al. 2019; Schulz et al. 2017). This tension between wanting to be openly informed and feeling safe, and how patients and relatives found their way in this, looked different for each patient and relative. Some patients were open for detailed information about end-of-life issues while others indicated that they preferred to stay away from the discussion about their prognosis or future care (Bergenholtz et al. 2020; Hjelmfors et al. 2018; Kirby et al. 2018; Krug et al. 2021; Schulman-Green et al. 2018; Seifart et al. 2020; Shen et al. 2020). This required customization and a person-centered approach. Patients preferred the physician to assess which and how much information they appreciated (Abdul-Razzak et al. 2016; Bergenholtz et al. 2020; Goebel and Mehdorn 2018; Lin et al. 2018). Patients and relatives stated that they sometimes found it difficult to ask for more information: they often did not know what to ask and liked to be explicitly invited to ask questions during or after a conversation with a health-care professional (Awdish et al. 2017; Collins et al. 2018a; Goebel and Mehdorn 2018; Kitta et al. 2021; O'Connor et al. 2020).

Patients indicated that they needed time to process the information provided (Abdul-Razzak et al. 2016) and wanted health-care

Table 1. Characteristics of the included studies

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
<b>Qualitative studies</b>						
Adamson et al. (2018) <b>US</b>	To explore how cancer patients' interpretations of the physician's role as information giver affect the communication relationship with the physician and their information-seeking behavior.	SHO	Qualitative study	Adult patients with cancer stages I to IV and 4 cancer types.	Ps: n = 10	Semi-structured interviews
Ahmed et al. (2015) <b>CA</b>	To explore the perceptions and preferences of lung cancer patients, their caregivers and health-care providers and the current practice and opinions on DNR discussions.	SHO	Prospective descriptive study	Patients who received a diagnosis of non-small cell and small cell carcinoma, had incurable disease, and were not to receive further curative therapy. Caregivers were nominated by the patients as primary caregiver.	Ps: n = 10 Rs: n = 9 HCPs: n = 10 <sup>a</sup>	A questionnaire with "think aloud" process when responding to items on DNR status and DNR discussions.
Bergenholtz et al. (2020) <b>DK</b>	To explore the wishes of patients and their relatives with regard to talking about the end of life (EoL) in an acute hospital setting when living with a life-threatening disease	HO	Qualitative study	Patients and caregivers from wards identified by SPICT as likely to be nearing the palliative phase of disease trajectory	Ps: n = 11 Rs: n = 6	Face-to-face semi-structured interviews
Brom et al. (2017) <b>NL</b>	To examine whether and how the steps of shared decision-making (SDM) can be recognized in decision-making about second- and third-line chemotherapy.	UHO	Longitudinal qualitative study	Adult patients with advanced cancer confronted with the decision whether or not to start secondary third-line chemotherapy, and their physicians (oncologists and other medical specialists)	Ps: n = 14 HCPs: n = 18 <sup>a</sup>	In-depth interviews with patients and physicians Observations of the patients' out-clinic visits Coding of observations was based on the steps of SDM.
Caswell et al. (2015) <b>GB</b>	To understand the factors and processes which affect the quality of care provided to frail older people who are dying in hospital and their family carers	UHO	Qualitative study: ethnographic approach	Bereaved family carers of patients who died in the hospital ward during the course of the research.	Rs: n = 13	[Non-participant observation] semi-structured interviews [and a review of case notes]
Cohen-Mansfield et al. (2017) <b>IL</b>	To classify and quantify complaints concerning EoL care.	HO	Qualitative study	Primary family caregivers of deceased patients	Rs: n = 70	Structured face-to-face interviews with 1 open question on the behavior of the doctors/nurses.
Collins et al. (2018a) <b>AU</b>	To explore patient views surrounding communication about palliative care and their responses to its discussion.	SHO & HO-OP	Cross-sectional, prospective, qualitative study	Adult patients with advanced cancer	Ps: n = 30	Narrative-style interviews
Collins et al. (2018b) <b>AU</b>	To explore caregiver perspectives on communication about death, dying, and the introduction to palliative care.	SHO & HO-OP	Cross-sectional, prospective, qualitative study	Adult caregivers of people with advanced cancer	Rs: n = 25	Narrative-style interviews

(Continued)

**Table 1.** (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Garden and Seiler (2017) <b>US</b>	To examine how people with serious illnesses communicate information they have acquired about their illness from the Internet and social or mass media to their doctors.	MIX	Qualitative study	Adult patients with different types of serious illness who sought information from other sources besides his or her doctor to learn about the nature of his or her illness.	Ps: <i>n</i> = 22	In-depth interviews.
Gilad et al. (2022) <b>IL</b>	To examine EoL conversation among patient, family, and staff during long-term hospitalization in a neurological rehabilitation department.	RD	Qualitative case study	Rehabilitation department staff and members of the patient's family. The patient was a disabled veteran, who had several hospitalizations in this department and died at age 60.	Rs: <i>n</i> = 2 HCPs: <i>n</i> = 16 <sup>a</sup>	Semi-structured face-to-face interviews and 1 auto-ethnographic account.
Hilário (2020) <b>PT</b>	To explore the extent to which the “revivalist” discourse of a good death, which promotes an awareness of dying, shapes the lived realities of palliative care patients and their families.	PCU	Qualitative study	Staff, patients and family members at palliative care units (PCUs)	Ps: <i>n</i> = 10 Rs: <i>n</i> = 20 HCPs: <i>n</i> = 20 <sup>a</sup>	In-person interviews. Field notes from interviews. Participant observation.
Hjelmsfors et al. (2018) <b>SE</b>	To describe patients' experiences of communication about their heart failure (HF) prognosis and explore how these experiences affected their preferences for future communication about the prognosis.	HO-OP	Qualitative study	Patients with New York Heart Association (NYHA) type I–III HF	Ps: <i>n</i> = 9 (individual) Ps: <i>n</i> = 15 (in 4 focus groups)	In-person interviews Focus-group audio-recorded and transcribed. Field notes
Ibañez-Masero et al. (2019) <b>ES</b>	To understand caregivers' experiences regarding health information and communication during the illness and death of family members.	HO & COM	Qualitative study	Bereaved caregivers who had accompanied a family member at the EoL.	Rs total: <i>n</i> = 123 Rs: <i>n</i> = 42 (in 5 nominal focus groups) Rs: <i>n</i> = 40 (in 5 discussion groups ) Rs: <i>n</i> = 41 (interviews)	Face-to-face focus groups In-depth interviews )
Im et al. (2019) <b>CA</b>	To explore the challenges of integrating EoL communication into HF management from the perspectives of older adults and family caregivers	SHO-OP	Qualitative study	Older patients with HF and caregivers	Ps: <i>n</i> = 12 Rs: <i>n</i> = 7	Semi structured interviews (14), individual (7), and dyads (5).
Kim et al. (2018) <b>US</b>	To describe family surrogates' experiences when engaging in Physician Orders for Life-Sustaining Treatment (POLST) discussions with primary care providers.	NH	Qualitative study	Family surrogates of individuals with advanced dementia who had a POLST discussion.	Rs: <i>n</i> = 10	In-person semi-structured interviews immediately after the POLST discussion Field notes

(Continued)

Table 1. (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Kirby et al. (2018) <b>AU</b>	To develop a critical, evidence-based understanding of the experiences of people from Culturally and Linguistically Diverse (CALD) backgrounds, and their caregivers in a palliative care setting.	PCU & HO-OP	Qualitative interviews	CALD patients and their caregivers admitted who were classed as having palliative illnesses	Ps: <i>n</i> = 16 Rs: <i>n</i> = 14	Audio-recorded in-person interviews with support of professional interpreters, transcribed in English.
Kitta et al. (2021) <b>AT</b>	To examine patients' experiences of EoL discussions and to shed light on patients' perceptions of the transition from curative to palliative care.	PCU in UHO	Qualitative methodology	Adult patients with terminal cancer who were no longer under curative treatment, with a prognosis of 2–12 months life expectancy and had EoL discussion prior to admission to the PCU.	Ps: <i>n</i> = 12	Semi-structured interviews
Krawczyk and Gallagher (2016) <b>CA</b>	To explore how communicating prognostic uncertainty impacts family members, and why prognostic forecasts should focus on raising awareness that a patient is sick enough to die.	HO & PCU	Qualitative study	Relatives of patients 4–6 months after the patient's death.	Rs: <i>n</i> = 90	Phone interviews Field notes
Krug et al. (2021) <b>DE</b>	To explore patients' and informal caregivers' salutogenetic experiences with the Milestone Communication Approach (MCA).	UHO	Qualitative study	Advanced lung cancer patients and informal caregivers, participating in a larger evaluation study and randomized into receiving the intervention MCA	Ps: <i>n</i> = 13 Rs: <i>n</i> = 12	Face-to-face, semi-structured interviews after having had at least two encounters within the MCA.
Kvále et al. (2020) <b>NO</b>	To gain insight into the illness narratives of cancer patients, from the day they suspected that something was wrong until living with incurable cancer.	UHO	Qualitative study	Adult cancer patients receiving palliative chemotherapy with the intention of prolonging life (as informed by their oncologist), not being close to the EoL.	Ps: <i>n</i> = 13	Patients' illness narratives
Lin et al. (2018) <b>US</b>	To describe advanced cancer patients' and oncologists' perspectives about family involvement and influence on Goals of Care (GoC) conversations.	UHO, HO, & COM	Qualitative study	Patient with advanced cancer and their oncologists	Ps: <i>n</i> = 39 HCPs: <i>n</i> = 21 (Oncologists) <sup>a</sup>	Semi-structured interviews Audio-recorded

(Continued)

Table 1. (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Masefield et al. (2019) BE, GB, IE, IT	To explore commonalities in the experience and unmet communication needs of idiopathic pulmonary fibrosis patients and their carers.	COM	Qualitative study	Idiopathic pulmonary fibrosis patients and their carers	The national patient organization from 4 countries participated (number of focus groups): GB (1) Ps: n = 5 Rs: n = 3 IT (2) Ps: n = 7 Rs: n = 4 BE (1) Ps: n = 6 IE (5) Ps: n = 23 Rs: n = 10	Focus groups
Melhem and Daneault (2017) CA	To explore the needs of cancer patients in palliative care and to determine how care providers, including family physicians, could meet these needs more fully.	HO & HO-OP	Qualitative study: GT approach	Patients in the palliative phase of cancer who had already received at least 1 treatment of chemotherapy or radiation treatment.	Ps: n = 12	Semi-structured interviews
Melis et al. (2021) IT	To understand the phenomenon of communication related to knowing the diagnosis and prognosis, by exploring the perspectives of patients with advanced cancer, their caregivers, physicians and nurses.	HO	Qualitative study: phenomenological approach	Adult cancer patients with a life expectancy of less than 1 year as estimated by the attending oncologist, their main caregiver and HCPs who cared for recruited patients.	Ps: n = 7 Rs: n = 7 HCPs: n = 13 <sup>a</sup>	In-person semi-structured interviews
Middleton-Green et al. (2019) GB	To evaluate "Gold Line," a 24/7, nurse-led telephone and video-consultation support service for patients thought to be in the last year of life.	COM	Retrospective cohort qualitative study	Patients given access to "Gold Line" because they were identified as potentially in their last year of life, carers who utilized service.  [Data on time and nature of contact was gathered from the electronic patient record (EPR)].	Ps: n = 8 Rs: n = 6	Face-to-face semi-structured interviews Data from EPR
Netsey-Afede et al. (2020) DK	To explore how patients with advanced prostate cancer (APC) experience the communication with health professionals and to explore their experiences of the decision-making processes during their course of treatment.	HO-OP	Qualitative study: phenomenological-hermeneutic approach	Adult patients with APC	Ps: n = 13	Broad open-ended interviews at 3 timepoints with (almost) all patients: 1. 3–19 days after patients were diagnosed with APC and initiated with palliative treatment. 2. After 1, 3, or 6 months after starting with palliative treatment. 3. 9–12 months later.  Report of participant observations during the diagnostic phase and preceding each interview to gain an impression of what was at stake in conversations with HCPs.

(Continued)



Table 1. (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
O'Connor et al. (2020) AU	To explore patients' perspectives of the GoC discussions in the hospital setting.	HO	Descriptive exploratory qualitative study	Adult patients from ICU, respiratory medicine, renal medicine, general medicine, geriatric medicine, internal medicine, and orthopedic surgery (elderly patients) department who had completed a GoC discussion in their current or recent episode of care in hospital.	Ps: $n = 38$	Semi-structured individual or dyadic interviews (with the carer/family member present)
Pini et al. (2021) GB	To identify current barriers, facilitators, and experiences of raising and discussing palliative care with people with advanced cancer.	SHO & PCU/HC	Qualitative study	Patients with advanced cancer and HCPs.	Ps: $n = 24$ HCPs: $n = 8^a$	In-person interviews
Rohde et al. (2019) NO	To explore the experiences of patients with incurable colorectal cancer while in palliative care and their reflections on the information provided by physicians and nurses.	HO & HO-OP	Qualitative study	Adult patients with metastatic colorectal cancer who had undergone surgery for their cancer and were referred for palliative chemotherapy	Ps: $n = 20$	In-person in-depth interviews Logs made by the researchers
Scherrens et al. (2020) BE	To understand and explain the behavior "starting a conversation about palliative care with a professional carer" from the perspective of people with incurable cancer.	MIX	Qualitative explorative study	Adult patients with incurable cancer that was diagnosed at least one month ago, not (yet) receiving palliative care or receiving palliative care	Ps: $n = 25$	Semi-structured, face-to-face interviews
Schulman-Green et al. (2018) US	To describe perceptions of the timing and content of GoC conversations among oncologists and patients with advanced cancer.	HO including 4 hospitals and community clinics	Qualitative study	Adult patients diagnosed with advanced cancer (stage IV or stage III irresectable lung, pancreatic, or biliary cancer) Oncologists (experienced in solid tumors, seeing at least 2 advanced cancer patients/month).	Ps: $n = 39$ HCPs: $n = 21^a$	Semi-structured, face-to-face interviews
Schulz et al. (2017) CA	To explore experiences and perspectives of patients with advanced HF, their caregivers, and providers, regarding conversations for patients at risk of dying from HF.	HO	Qualitative study: grounded theory	Patients with advanced HF (NYHA III or IV) and key members (professional and informal) of their healthcare team.	209 interviews (Ps, Rs, and HCPs <sup>a</sup> ) clustered into 50 team sampling units (each unit including a patient and at least to patient-identified additional team members: HCPs and/or Rs and/or community members)	Semi-structured interviews

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**Table 1.** (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Seccareccia et al. (2015) <b>CA</b>	To identify elements of communication that are central to quality of care and satisfaction with care on palliative care units (PCUs), as described by inpatients, family caregivers, and healthcare providers.	PCU MIX	Qualitative study	Adult cancer and noncancer patients, or caregivers of patients, admitted to one of 4 inpatient PCUs and having been on the PCU for at least 48 hours.	Ps: n = 23 Rs: n = 23 HCPs: n = 39 <sup>a</sup>	Semi-structured individual interviews (Ps and Rs) Focus groups (HCPs)
Shen et al. (2020) <b>US</b>	To understand Latino-advanced cancer patients' and their caregivers' preferred methods of communicating about advance care planning (ACP).	SHO	Qualitative study	Adult Latino patients with advanced cancer and their caregivers	Ps: n = 20 Rs: n = 9	In-person semi-structured interviews Telephone interviews
Steinhauser et al. (2015) <b>US</b>	To describe what families of hospitalized patients consider central to the quality of their experience at the EoL.	SHO & UHO	Qualitative study	Bereaved family members of patients who had died of chronic disease 6-12 months prior at a Veterans Administration or private academic medical center.	Rs: n = 14	Two focus groups In-depth follow-up interviews with 2 members of each focus group.
Tavares et al. (2020) <b>GB</b>	To understand the preferences of patients with chronic obstructive pulmonary disease for discussions about palliative and advance care planning with clinicians.	MIX	Qualitative study: phenomenological approach	Adult patients with chronic obstructive pulmonary disease at different stages of their disease trajectory, recruited from GP practices, hospital outpatient clinics or Research Department.	Ps: n = 33	Semi-structured interviews
Timmermann et al. (2017) <b>DK</b>	To explore how seriously ill hospitalized patients experience and assign meaning to the health professionals' communication.	UHO	Qualitative study: phenomenological approach	Patients hospitalized due to a potential life-threatening illness	Ps: n = 12	Open interviews Reinterview to nuance previous interview
Villalobos et al. (2018) <b>DE</b>	To explore the patients' and family-caregivers' needs and preferences regarding communication, quality of life (QOL), and care over the trajectory of disease.	UHO	Qualitative study	Patients with metastatic lung cancer, their relatives, and HCPs involved in their care	Ps: n = 9 Rs: n = 9 HCPs: n = 15 <sup>a</sup>	Individual semi-structured interviews (Ps and Rs) Focus-groups (HCPs)
Voruganti et al. (2018) <b>CA</b>	To understand participant perceptions on electronic patient-HCP communication in general and the added value of a new (web based) tool in particular.	UHO	Qualitative study	Advanced cancer patients, caregivers, cancer and palliative care physicians who used a web-based tool for patient-HCP communication, the Loop intervention, for a duration of 3 months.	Ps: n = 6 Rs: n = 5 HCPs: n = 7 <sup>a</sup>	In-person interviews repeated monthly for 3 months Field notes

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**Table 1.** (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Washington et al. (2019) <b>US</b>	To explore family caregivers' perspectives on communication with oncology care providers.	UHO MIX	Qualitative study	Family caregivers of adult cancer patients receiving outpatient palliative care services (who had or had not received a problem-solving intervention for family caregivers in a parent randomized clinical trial study)	Rs: n = 63	In-person interviews Telephone interviews Questions focusing on evaluation of the intervention were omitted in this study.
Weerasinghe and Maddalena (2016) <b>CA</b>	To explore EoL caregiving experiences of South Asian immigrants during the illness trajectory (from diagnosis to death) from the perspectives of family caregivers.	COM	Qualitative study	Bereaved family caregivers of deceased South Asian immigrants.	Rs: n = 7	Semi-structured interviews
<b>Quantitative observational studies</b>						
Awdish et al. (2017) <b>US</b>	To test the feasibility of a communications bundle to facilitate skill transfer from simulation to real encounters and improve patient and/or family satisfaction with physician communication.	UHO	Prospective cohort pilot study	<p>Patients and surrogates admitted to the medical intensive care unit (MICU) with APACHE IV predicted mortality greater than 30% and/or single organ failure, and relatives.</p> <p>Intervention Receiving the communication bundle:</p> <ol style="list-style-type: none"> <li>1. Simulation communication training for MICU physicians based on VitalTalk training.</li> <li>2. Scheduling a family meeting within 72 hours of MICU admission</li> <li>3. Standardized pre- and post-meeting team huddles</li> <li>4. Documentation of a meeting in the electronic medical record (EMR)</li> </ol> <p>Control Receiving no communication bundle, in separate units of the MICU where staff did not have any prior training in communication skills within the past year.</p>	<p>Intervention Ps: n = 8 Rs (surrogates): n = 7</p> <p>Control Ps: n = 5 Rs (surrogates): n = 11</p> <p>Intervention HCPs: n = 5<sup>a</sup></p> <p>Control HCPs: n = 9<sup>a</sup></p>	<p>Questionnaire: a self-developed satisfaction survey with questions related to satisfaction with physician communication</p> <p>Report of all family meetings during the hospitalization</p>

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Table 1. (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Bauman et al. (2018) US	To assess the feasibility of an intervention to facilitate communication between oncology clinicians and caregivers of patients in hospice care.	HC	Feasibility study	<p>Adult caregivers of patients with cancer who enrolled in home hospice and had received oncology care in one of 4 participating cancer centers</p> <p>Intervention Ensuring Communication in Hospice by Oncology (ECHO) for patients who enroll in hospice:</p> <ol style="list-style-type: none"> <li>Supportive phone calls, first twice weekly decreasing to monthly until patient death, from oncology clinician to patient/IC.</li> <li>Optional clinic visit for the patient to address clinical questions</li> <li>Bereavement call tailored to the ICs needs</li> </ol>	Rs: n = 15	<p>Several assessments and exit interviews on satisfaction with the intervention</p> <p>Questionnaires:</p> <ul style="list-style-type: none"> <li>Family Appraisal of Caregiving Questionnaire-Palliative Care</li> <li>6 items from FAMCARE-20 scale</li> <li>Perceived Stress Scale</li> <li>Decision Regret Scale</li> <li>6 questions from Toolkit After-Death Bereaved Family Member Interview</li> <li>1 question from Quality of End-of-Life Care scale</li> <li>Open-ended questions</li> </ul>
Fenton et al. (2018) US	To assess whether physician discussion of prognosis is associated with detrimental changes in measures of the strength of the patient-physician relationship	SHO & UHO & HO	Longitudinal cohort study	<p>Adult patients with advanced cancer and their oncologists</p> <p>Intervention VOICE (Values and Options in Cancer Care)</p> <ol style="list-style-type: none"> <li>Oncologist received a training including a video and feedback from standardized patients portraying patients with advanced cancer and caregivers during 2 separate visits.</li> <li>Patients received a coaching session incorporating a question prompt list and up to 3 follow-up telephone calls from coaches.</li> </ol> <p>Control Oncologists received no training, patients received no coaching session.</p>	<p>Intervention Ps: n = 130 Control Ps: n = 135 38 physician clusters</p> <p>Intervention Physicians n = 19<sup>a</sup></p> <p>Control Physicians: n = 19<sup>a</sup></p>	<p>Questionnaire: Patient survey at baseline, between 2 and 7 days after audio-recorded visits and 3 months after audio-recorded visits</p> <ul style="list-style-type: none"> <li>The Human Connection (THC) Scale</li> <li>Perceived Efficacy in Patient-Physician Interactions measure (PEPPI) scale</li> </ul> <p>Report of audio-recorded visits:</p> <ul style="list-style-type: none"> <li>Assessment of prognostic discussion by coding transcribed audio-recorded visits using the Prognostic and Treatment Choices (PTCC) scale</li> </ul>

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Table 1. (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Freytag et al. (2018) US	To identify predictors of participation of patients with advanced cancer in clinical encounters with oncologists and to assess the impact of patient and caregiver participation on perceptions of physician support	HO & UHO	Quantitative study	Adult patients with stage IV solid or stage III cancer and caregivers selected by the recruited patients and their physicians	Data collected prior to randomization phase in randomized controlled trial study (Epstein et al. 2017) Ps: $n = 119$ Rs: $n = 83$ Physicians: $n = 38^a$	Questionnaires pre-consultation visit (completed by patients and caregivers): <ul style="list-style-type: none"> <li>• THC Scale</li> <li>• The 5-item Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE) scale</li> <li>• An assessment of general physical well-being taken from the FACIT measurement system</li> <li>• 11 questions of the McGill Quality of Life questionnaire</li> <li>• Short form PEPPI.</li> </ul> Questionnaires post-consultation visit (completed by patients and caregivers): <ul style="list-style-type: none"> <li>• Health Care Communication Questionnaire (HCCQ);</li> <li>• A 5-item self-reported measure of the patient's sense of support of their autonomy by their physician.</li> </ul> Report of audio-recorded visits: <ul style="list-style-type: none"> <li>• Transcripts were coded for active patient/caregiver participation behaviors and for physicians' facilitative communication.</li> </ul>
Goebel and Mehndorn (2018) DE	To assess the patients' perspective regarding the content of bad news, patients' preferences for the communication of bad news, and clinical consequences of mismatch of patients' communication preferences.	UHO	Cross-sectional observational study	Adult patients after the first neuro-surgical treatment for an intracranial neoplasm.	Ps: $n = 42$	Questionnaires Communication preferences <ul style="list-style-type: none"> <li>• German version of the Measure of Patients' Preferences questionnaire; to assess patients' communication preferences regarding patient-physician communication</li> <li>• Patients rated for each item being a preference whether the physician had (yes or no) acted according to this preference in the situation in which they had received the worst news.</li> </ul> Psychosocial burden <ol style="list-style-type: none"> <li>1. Distress Thermometer</li> <li>2. Hospital Anxiety and Depression Scale (HADS)</li> <li>3. Illness-Specific Social Support Scale</li> <li>4. Short-Form Health Survey (SF-8)</li> <li>5. Patients' estimation of their need for illness-related information as well as their satisfaction with their level of information</li> </ol>

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**Table 1.** (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Houben et al. (2015) NL	To examine the quality of EoL care communication during 1 year follow-up of patients with advanced chronic organ failure.	UHO-OP & HO-OP	Observational study	Patients with advanced chronic organ failure (COPD, CHF or CRF) and their closest relatives (in case the patient died within two years after baseline).	Ps: <i>n</i> = 265 (at baseline) Ps: <i>n</i> = 206 (at 12 months)	Questionnaires at baseline: <ul style="list-style-type: none"> <li>• HADS</li> <li>• Satisfaction with medical treatment (a score ranging from 0 (not satisfied) to 10 (very satisfied))</li> <li>• Medical Outcomes Study 36-Item Short-Form Health Survey).</li> <li>• EoL subscale of the Quality of Communication questionnaire (QOC-EoL).</li> </ul> Questionnaires at 4, 8, and 12 months: <ul style="list-style-type: none"> <li>• QOC-EoL.</li> </ul>
Seifart et al. (2020) DE	To investigate gender differences in cancer patients regarding preferences concerning content, optimal time point, mode of initiation, and dialog partners for EoL discussions.	UHO and SHO	Cross-sectional study	Adult female and male cancer patients in a palliative in- and outpatient setting and in a rehabilitation clinic.	Ps: <i>n</i> = 186	Semi-structured interviews with questions about 6 topics related to EoL discussions with Likert scale answer options and other closed answer options.  Questionnaire: <ul style="list-style-type: none"> <li>• 12-item Short-Form Health Survey (SF-12)</li> </ul>

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Table 1. (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Randomized controlled trials						
Curtis et al. (2018) US	To evaluate the efficacy of a patient-specific pre-conversation communication priming intervention (Jumpstart-Tips) targeting both patients and clinicians and designed to increase GoC conversations compared with usual care	MIX	Cluster-randomized clinical trial	<p>Adult patients with advanced cancer or other advanced illness and their clinicians</p> <p>Intervention</p> <ol style="list-style-type: none"> <li>Pre-visit, patients filled in a survey designed to identify their individual preferences, barriers, and facilitators for communication about EoL care</li> <li>An algorithm was used to (a) create an abstracted version of the patient's preferences; (b) identify the most important communication barrier or facilitator.</li> <li>Provide communication tips based on VitalTalk curricular material tailored to patient responses.</li> </ol> <p>The 1-page Jumpstart-Tips was sent to clinicians 1 or 2 working days prior to the patient's visit.</p> <p>Patients also received patient-specific 1-page Jumpstart-Tips forms with suggestions for their GoC conversation.</p> <p>Control</p> <p>Patients completed the same surveys, but no information from the surveys was provided to patients or clinicians.</p>	<p>Intervention Ps <math>n = 249</math></p> <p>Control Ps <math>n = 288</math></p> <p>132 clinician clusters</p> <p>Intervention Clinicians <math>n = 65^a</math></p> <p>Control Clinicians <math>n = 67^a</math></p>	<p>Pre-visit questionnaire (intervention and control):</p> <ul style="list-style-type: none"> <li>See participant information: step 1. (intervention and control)</li> </ul> <p>Post-visit questionnaires at 2 weeks, 3 months and 6 months:</p> <ul style="list-style-type: none"> <li>Patient report of occurrence of GoC Communication (yes/no)</li> <li>QOC-EOL;</li> <li>Patient assessments of goal-concordant care at 3 months with 2 questions from SUPPORT (1. Defining patient's preference for either extending life or ensuring comfort; 2. Patient's perceptions of their current treatment);</li> <li>Symptoms of depression and anxiety</li> </ul> <p>Report in electronic health record</p> <ul style="list-style-type: none"> <li>GoC discussions, advance care planning, and discussions about palliative or hospice care were coded as absent or present.</li> </ul>

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**Table 1.** (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Doorenbos et al. (2016) <b>US</b>	To determine the effects of the "provider GoC intervention" compared to usual care on the number of GoC conversations and QOC between HF patients and providers	UHO-OP	Randomized study	<p>Patients with 1 diagnosis of HF with reduced ejection fraction (EF) with EF 40% or with preserved EF with EF &lt; 50%) 2 completion of an outpatient (HF) visit within the past 6 months and a scheduled follow-up visit.</p> <p>Patient GoC intervention</p> <ol style="list-style-type: none"> <li>1. Telephone based pre-visit coaching session</li> <li>2. One sheet patient activation outline constructed from pre-visit coaching that was shared with both the patient and their HF provider</li> <li>3. Patient activation, skills enhancement, and role playing conversation openers to initiate a GoC conversation with the provider at the next upcoming HF clinic visit. At the conclusion of telephone coaching, participants were asked to rate desire and confidence to engage in a GoC conversation with their HF provider, using a 0–10 scale (0 = definitely no – 10 = definitely yes), and to designate their desired role in SDM.</li> </ol> <p>Provider GoC intervention</p> <ol style="list-style-type: none"> <li>1. Receipt of the patient activation outline that was constructed during pre-visit coaching and given to the provider on the day of the planned HF clinic visit.</li> <li>2. Providers received patient-specific mortality estimates, information about the patient's desire for involvement in SDM, and coaching communication tips specific to this patient.</li> <li>3. Provider was asked to facilitate a GoC discussion.</li> </ol> <p>Control</p> <p>Usual care, patients completed questionnaires, but providers did not receive the GoC activation outline and were not told that patients were participating in the study.</p>	<p>Intervention Ps: n = 39</p> <p>Control Ps: n = 41</p>	<p>Questionnaires</p> <ul style="list-style-type: none"> <li>• QOC questionnaire</li> <li>• Anxiety (GAD-7)</li> <li>• Depression (PHQ-9)</li> </ul> <p>Report/medical file</p> <ul style="list-style-type: none"> <li>• Number of GoC conversations after intervention</li> <li>• Referrals to palliative care</li> <li>• Completion of advance directives</li> </ul>

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Table 1. (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Epstein et al. (2017) US	To determine whether a combined intervention involving oncologists, patients with advanced cancer, and caregivers would promote patient-centered communication, and to estimate intervention effects on shared understanding, patient-physician relationships, QOL, and aggressive treatments in the last 30 days of life	MIX	Cluster randomized clinical trial	Community-dwelling adult patients (with caregivers) with advanced non-hematologic cancer and their medical oncologists  Intervention VOICE 1. Oncologists received individualized communication training using VOICE Physician Standardized Patient-Instructors 2. Patients (with caregivers) participated in pre-visit (VOICE) individualized communication coaching session with follow-up telephone calls.  Control Oncologists received no training, patients received no coaching session.	Intervention Ps: $n = 130$ with enrolled Rs: $n = 101$  Control Ps: $n = 135$ with enrolled Rs: $n = 93$ 38 physician clusters  Intervention Physicians: $n = 19^a$  Control Physicians: $n = 19^a$	Audio-recorded office visit after patient coaching session (for intervention) or after study entry (for control) 4 measures for recorded visits: 1. Engaging patients in consultation (APPC); 2. Responding to patients' emotions (Verona VR-CoDES); 3. Informing (PTCC, Informing patients about prognosis and treatment choices subscale); 4. Balanced framing of decisions (PTCC, Balanced Framing subscale)  Pre-visit and post-visit questionnaires: • THC scale • HCCQ • PEPI scale • Physicians and patients were also asked to estimate 2-year survival and curability of the patient's cancer  QOL questionnaires at 3-month intervals from study entry for up to 3 years: 1. McGill QOL scale single item; 2. McGill Psychological Well-Being subscale; 3. McGill Existential Well-Being subscale; 4. FACT-G Physical Functioning subscale, and 5. FACT-G Social Functioning subscale
Paladino et al. (2020) US	To evaluate the patient and clinician experience of a conversation using a Serious Illness Conversation Guide (SICG).	SHO	Cluster-randomized clinical trial	Adult patients with cancer identified by their oncology clinician with a "no" response to the surprise question: Would you be surprised if this patient died in the next year?, and their oncology clinician  Intervention 1. Clinical tools including SICG for clinicians and materials to prepare patients 2. Clinician training and coaching 3. Systems-changes including an email reminder and a medical record documentation template  Control Clinicians received no SICG, training or systems-changes	In this study only data from intervention group Ps: $n = 118$ Physician clusters Intervention Physicians: $n = 41^a$	Questionnaires • Patient and clinician experience were measured with self-designed surveys administered to patients after their SICG conversation and to clinicians after the first SICG conversation they had with a patient. • Clinician experiences were measured with self-designed surveys again at the end of the study.

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**Table 1.** (Continued.)

Authors (year) Country	Aim	Setting	Study design	Sample	Number of participants studied	Method of data collection
Studies with mixed-methods design						
Abdul-Razzak et al. (2016) CA	To understand patient perspectives on physician behaviors during EOL communication.	UHO (n = 3)	Mixed methods: Quantitative study: cross-sectional design Qualitative study: interpretative study	Seriously ill patients, aged ≥ 55 years, with an estimated 6- to 12-month mortality risk of 50%.	Quantitative Ps: n = 132 Qualitative Ps: n = 16	QOC questionnaire (including QOL-EOL) Social demographic questionnaire Semi-structured, face-to-face interviews
Applebaum et al. (2018) US	To understand what informal caregivers know about their loved one's prognosis and to understand their preferences for communication of prognostic information.	SHO	Prospective, mixed-methods study	Adult informal caregivers of patients with malignant glioma.	Rs: n = 32	Semi-structured assessment and interviews with open follow-up questions
Chen et al. (2021) US	To examine patient perceptions of discussions, decision-making, and psychosocial burdens related to receiving palliative radiotherapy.	SHO	Mixed methods study: Survey Qualitative study	Patients with cancer receiving their first course of palliative radiotherapy for lung or bone metastases	Ps: n = 17	Face-to-face interviews Questionnaire (oral) based on the Consumer Assessment of Healthcare Providers and Systems Survey for Cancer Care
McGinley and Waldrop (2020) US	To explore how communication, advance care planning, and care in the later stages of advanced illness influence family caregivers' well-being in bereavement.	HC	Mixed methods study	Adult bereaved caregivers from a single hospice provider agency.	Rs: n = 108	Quantitative data: <ul style="list-style-type: none"> <li>• Frequency of in-person family meetings concerning the end stage of the illness</li> <li>• Perceived QOC with HCPs</li> </ul> Qualitative data: Semi-structured interviews. This paper focuses on data derived at Time 1 (4 months following the death of their relative in hospice care)

BE = Belgium, COM = community, DNR = Do Not Resuscitate, FACT = Functional Assessment of Chronic Illness Therapy, FAMCARE = measures Family Satisfaction with Advanced Cancer Care, GAD = General Anxiety Disorder, GB = United Kingdom of Great Britain and Northern Ireland; HC = hospice care, HCPs: Health Care Professionals, HO = hospital, HO-OP = hospital outpatient, ICs = informal caregivers, ICU = intensive care unit, IE = Ireland, IT = Italy, MIX = a mixture of settings, NH = nursing home, PCU = Palliative Care Unit, PHQ = Patient Health Questionnaire, Ps = Patients, RD = Rehabilitation Department, Rs: Relatives/Informal Caregivers/Family Caregivers, SHO = Diseased Specialized Hospital, SPCT = Supportive and Palliative Care Indicator Tool, UH = University Hospital, UHO-OP = University Hospital Outpatient.  
 \*For this study, we focused on the perspectives of patients and relatives.

**Table 2.** Effective communication from the perspectives of patients and relatives, overview of themes found

Themes
1. Open and honest information
2. Aligning to the process of uptake and coping with information
3. Empathy
4. Clear and understandable language
5. Leaving room for positive coping strategies
6. Committed health-care professionals taking responsibility
7. Recognition of relatives in their role as caregiver

professionals to give them time and space to do so and to acknowledge their suffering (Melhem and Daneault 2017; Schulman-Green et al. 2018). Most patients and relatives wanted health-care professionals to share the information sensitively to the life-changing impact a diagnosis or prognosis could have (Adamson et al. 2018; Caswell et al. 2015; Goebel and Mehdorn 2018; Krawczyk and Gallagher 2016; Kvåle et al. 2020; Netsey-Afedo et al. 2020; Rohde et al. 2019; Schulz et al. 2017). Aligning information to the process the patient was going through, connecting to where the patient was in terms of information uptake, and offering understanding and room for questions were found to be helpful strategies. Patients and their relatives experienced that physicians, after giving bad news, often rapidly turned to positive aspects or to proposing another examination (Kitta et al. 2021). Patients sometimes felt pressured to quickly agree to a (non-)treatment decision (Abdul-Razzak et al. 2016). Patients indicated that they preferred health-care professionals to show that they saw and understood what bad news meant for the patient and for his life (Masefield et al. 2019; Netsey-Afedo et al. 2020; Seifart et al. 2020). They should see the patient as a person, not as their disease. Some patients experienced that conversations with the physician were bound by rules, that the focus had to be on symptoms and treatment, and that there was little room for talking about impending death (Collins et al. 2018a). Various studies also show that patients found it important that health-care professionals at the end of a conversation offered them the opportunity for a follow-up contact (Goebel and Mehdorn 2018; Kvåle et al. 2020).

### Empathy

Most patients and relatives expressed the need for empathic communication (Abdul-Razzak et al. 2016; Adamson et al. 2018; Awdish et al. 2017; Bergenholtz et al. 2020; Caswell et al. 2015; Chen et al. 2021; Cohen-Mansfield et al. 2017; Garden and Seiler 2017; Gilad et al. 2022; Goebel and Mehdorn 2018; Ibañez-Masero et al. 2019; Kim et al. 2018; Kvåle et al. 2020; Masefield et al. 2019; McGinley and Waldrop 2020; Melhem and Daneault 2017; Netsey-Afedo et al. 2020; O'Connor et al. 2020; Rohde et al. 2019; Scherrens et al. 2020; Schulz et al. 2017; Seccareccia et al. 2015; Steinhauser et al. 2015; Timmermann et al. 2017; Villalobos et al. 2018; Voruganti et al. 2018; Washington et al. 2019). Patients emphasized that effective communication required that health-care professionals had the right skills and empathy (Garden and Seiler 2017; Rohde et al. 2019; Scherrens et al. 2020; Seccareccia et al. 2015). They indicated that empathy was reflected in the behavior and attitude of health-care professionals and that it was partly unrelated to the content of what was being discussed (Awdish et al.

2017; Garden and Seiler 2017; Goebel and Mehdorn 2018; Kvåle et al. 2020; Melhem and Daneault 2017; O'Connor et al. 2020; Rohde et al. 2019; Seccareccia et al. 2015; Steinhauser et al. 2015; Timmermann et al. 2017; Villalobos et al. 2018; Voruganti et al. 2018; Washington et al. 2019). Body language suggesting that professionals were busy made patients feel ignored and as if they were a burden (Timmermann et al. 2017). For most patients and relatives, the informative side of effective communication was inextricably linked to the empathic side (Goebel and Mehdorn 2018; Kvåle et al. 2020; Melhem and Daneault 2017; Rohde et al. 2019; Scherrens et al. 2020; Seccareccia et al. 2015; Voruganti et al. 2018). In addition, patients appreciated continuity of care providers, which allowed them to develop rapport with and trust in health-care professionals (Middleton-Green et al. 2019; Voruganti et al. 2018).

### Clear and understandable language

Both patients and relatives indicated that they wanted information to be presented in clear and understandable language (Awdish et al. 2017; Caswell et al. 2015; Collins et al. 2018b; Garden and Seiler 2017; Krawczyk and Gallagher 2016; Krug et al. 2021; O'Connor et al. 2020; Steinhauser et al. 2015). If health-care professionals used veiled terms, for example avoiding the word cancer (Villalobos et al. 2018), this could lead to patients feeling insecure or isolated (Hilário 2020; Kitta et al. 2021; Rohde et al. 2019). For relatives, unclear language could lead to tension and uncertainty (Caswell et al. 2015; Collins et al. 2018b; Krawczyk and Gallagher 2016). Because they could not properly interpret the signals from the health-care professionals they could feel overwhelmed by the seriousness of the situation (Collins et al. 2018b; Krawczyk and Gallagher 2016). The use of euphemisms could also hamper patients' and relatives' understanding of the patient's condition (Caswell et al. 2015; Collins et al. 2018a, 2018b; Villalobos et al. 2018). For example, using terms like "seriously (ill)" could provide patients with a limited understanding of the time they had left (Masefield et al. 2019). An example of a signal from health-care professionals in a hospital that pointed to a patient's impending death, but was not understood as such by the relatives of the patient was: moving the patient to a room for 1 person during hospitalization (Caswell et al. 2015). Relatives indicated that it was important that the patient and the relative, by using clear language to inform the patient, were offered the opportunity to discuss and finalize things with each other (Caswell et al. 2015; Krawczyk and Gallagher 2016; Steinhauser et al. 2015).

### Leaving room for positive coping strategies

In several studies, it was suggested that both patients and relatives needed positive thinking and a perspective of hope, in addition to honest information (Applebaum et al. 2018; Doorenbos et al. 2016; Goebel and Mehdorn 2018; Im et al. 2019). Many patients and relatives indicated that they felt more secure when the physician showed understanding that they hold on to what was still important in life, despite bad news (Abdul-Razzak et al. 2016; Applebaum et al. 2018; Curtis et al. 2018; Houben et al. 2015; Ibañez-Masero et al. 2019; Masefield et al. 2019).

### Committed health-care professionals taking responsibility

The involvement of numerous health-care professionals could lead to uncertainty among patients and relatives about whether

someone felt responsible for them and deprived patients of a fundamental sense of security and trust, i.e. knowing that they were not only in good hands with regard to medical-technical care but also that their health-care professional cared about them as a person (O'Connor et al. 2020; Voruganti et al. 2018). Continuity of health-care professionals prevented patients from having to tell the same story over and over again, but also facilitated a human connection, that could appeal to health-care professionals' sense of responsibility and commitment (Brom et al. 2017; Middleton-Green et al. 2019; Voruganti et al. 2018). If several health-care professionals were involved, patients indicated that consistent reporting about their illness and test results was important (McGinley and Waldrop 2020; Steinhäuser et al. 2015). Patients and relatives further preferred a proactive attitude from health-care professionals (Ahmed et al. 2015; Tavares et al. 2020; Voruganti et al. 2018), unless the patient indicated otherwise (Ibañez-Masero et al. 2019; McGinley and Waldrop 2020; Steinhäuser et al. 2015; Washington et al. 2019).

### **Recognition of relatives in their role as caregiver**

In several studies, relatives emphasized that patients often largely relied on their caregiving and that they considered themselves the backbone of the patient's support system. Many felt heavily burdened and believed that their role as caregiver deserved explicit attention and recognition from health-care professionals (Masefield et al. 2019; Washington et al. 2019). Patients and relatives indicated that health-care professionals should take time to "really" listen to their concerns and needs and where possible provide personalized support (Awdish et al. 2017; Caswell et al. 2015; Collins et al. 2018b; Masefield et al. 2019; Seccareccia et al. 2015; Steinhäuser et al. 2015).

Sometimes, the relative felt the need to protect the patient from threatening information, for example about the prognosis, so that the patient continued to have hope (Melis et al. 2021) and did not suffer too much from knowing the truth (Ibañez-Masero et al. 2019; Weerasinghe and Maddalena 2016). Although this could be the case especially in non-Western cultures, relatives indicated that they preferred to receive understandable information themselves to be able to care for their family member (Weerasinghe and Maddalena 2016). Applebaum et al. (2018) found that relatives did not ask their own questions out of respect for the patient, who might not want to know everything. On the other hand, some patients indicated that they preferred to keep relatives not informed, especially if the disease progressed and the burden or fear and worry of the relatives might increase (Lin et al. 2018; Melis et al. 2021). Relatives indicated that the key to open communication lied with the health-care professional, she/he could set the example (Ibañez-Masero et al. 2019).

### **Discussion**

The aim of this systematic review was to synthesize existing knowledge about the perspectives of patients with advanced illness and their relatives on effective communication in palliative care. We found that many patients and relatives wanted to be informed openly and honestly about their situation and that this brought a feeling of security. However, patients and relatives also wanted health-care professionals to align to their process of uptake and coping with information, because honest information also could induce fear, stress and existential disruption. For effective communication, patients and relatives further indicated that they

preferred the following elements: empathy, clear and understandable language, leaving room for positive coping strategies, committed health-care professionals taking responsibility, and recognition of relatives in their role as caregiver.

Our study brings to light that the dynamics of patients and relatives in communication with health-care professionals have their own process, and that health-care professionals must align with this process. Guidance of patients and relatives in their process over time is important, while research on communication by health-care professionals is often done once after, for example, a communication training program in a following conversation with a real or simulated patient (Selman et al. 2017). Our finding that for patients and relatives the informative side was inextricably linked to the empathic side of communication underlines the findings of a recent systematic review of Van der Velden et al. (2020). Their systematic review on the effect of prognostic communication on patient outcomes in palliative cancer care showed the benefit for most patients of explicit information in combination with empathic communication strategies by health-care professionals, although literature studying longer-term outcomes of prognostic communication was limited (Van der Velden et al. 2020). Westendorp et al. (2022) found that patients considered a lack of empathy in the communication by the oncologist as potentially harmful whereas they considered the exploring of patient's needs and preferences by the oncologist as helpful communication. Our review emphasizes that patient-centered communication is essential for high-quality palliative care. Such awareness should be expressed by physicians as well as nurses in planned or goal-directed communication, but also in unplanned communication.

We also found that patients and relatives preferred a proactive attitude from health-care professionals. However, numerous studies show that physicians often feel hampered in discussing prognosis and palliative care issues with patients with advanced illness and therefore do not communicate about needs, goals, and preferences regarding treatment and care in an adequate and timely manner with patients and relatives (Horlait et al. 2016; Stegmann et al. 2020; Udo et al. 2018). Physicians often act reactively rather than proactively (Udo et al. 2018). Over the last decade, several communication skills training programs for health-care professionals on communication with palliative care patients have been developed and evaluated (Fujimori et al. 2014; Paladino et al. 2019; Slort et al. 2014); however, there is little consensus on their effectiveness and how to evaluate their added value (Back 2020; Bos-van den Hoek et al. 2019). In evaluation studies of such communication skills training programs in palliative care, gradually more attention is paid to their effectiveness on the broader experiences of patients and relatives in quantitative studies (Curtis et al. 2018; Doorenbos et al. 2016) as well as in qualitative studies (Kim et al. 2018; Krug et al. 2021), although comparing studies can be difficult because of the wide diversity of outcomes in included studies (Van der Velden et al. 2020). The most promising communication skills training interventions for high-quality palliative care point to the training of professionals' communication skills in teams (Back 2020).

In addition to shared preferences of a patient and her/his relative for communication in palliative care, health-care professionals should be aware of possible differences in their preferences in conversations. Sometimes, relatives want more prognostic information. While it may be complicated, for legal privacy reasons, to have an additional conversation with the relative, for example in case the patient has no limited capacity for communication, health-care professionals should be sensitive to the needs of relatives and support relatives to discuss their concerns.

Most studies in this review focused on communication with physicians in a hospital setting, although many studies also emphasize the important role of general practitioners, nursing home physicians, and nurses in different care settings in palliative care (Gilissen *et al.* 2017; Sekse *et al.* 2017; Van der Plas *et al.* 2018). Therefore, more attention should be paid to the experiences of patients and relatives with communication with nurses in all care settings and physicians in nonhospital care settings. From the studies in this review, it is unclear whether there is a difference in effective communication as perceived by patients and/or relatives between generalists and in palliative care specialized professionals.

### Limitations of the study

Some limitations of this systematic review should be taken into account. First, most studies included no information about the level of expertise in palliative care of the health-care professionals involved. This limits the opportunity to explore the potential added value of in palliative care specialized professionals. Second, most studies concerned planned conversations with physicians, whereas also other health-care professionals communicate with patient and relatives in planned as well as unplanned conversations. Third, only 3 studies have been found in which diversity of patients and relatives is given attention. Besides those about patients or relatives from a non-Western culture, we did not find any studies that paid attention to other diversity in Western countries, for example, in religion, socio-economic background, sexual orientation, or health skills.

### Conclusion

Our systematic review demonstrates that, for effective communication, patients and their relatives, besides open and honest information, want health-care professionals to pay attention not only to the patient's disease and symptoms but also to who the patient is beyond the illness and to the role of the relative. Such attention can give patients and relatives a sense of safety within the uncertainty of experiencing a trajectory of advanced illness. Tailored information, empathy, and clear language are the basic elements of effective communication. Our review also shows that additional research is needed on effective communication by nurses, in nonhospital settings and on the added value of in palliative care specialized professionals. More research is also needed in the natural setting of clinical practice (e.g., ethnographic research) and on diversity of patients and relatives.

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