

Prognostic disclosure in cancer care: a systematic literature review

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Abstract

Background: Collusion in cancer care is the diplomatic concealment of information between a triad of the health care professional (HCP), patient, and caregiver. Free and expressive communication is determined by multiple factors, which establishes a healthy balance between 'patient-centric' and 'family-centric' decision making. The lack of a universal approach to prognostic disclosure techniques emphasizes the need for a systematic review of contemporary practice.

Methods: A systematic review of the literature was conducted till June 2020 using themes based on cancer, communication, prognostic disclosure, and collusion by using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Results: Fifty-three studies involving 10,569 subjects were studied for their utility on prognostic disclosure using different communication methods and interfaces. Twenty-three studies used a face-to-face interview with subjects while in-person telephonic interviews were conducted in two studies, 16 studies implicated semi-structured questionnaires, and 6 studies mentioned the development of a new technique/tool for disclosure. The duration of a session for prognosis-disclosure ranged from 22 min to 1 h. The involvement of palliative care specialists and mental health professionals was limited during the disclosure of the prognosis.

Conclusion: The findings of the review indicate that patients in cancer care are aware of their diagnosis and to a certain extent of prognosis despite nondisclosure by their family members and treating teams. This review emphasizes the assessment of 'disclosure wishes' among patients and caregivers in separate interviews rather than simply relying on one specific method of interviewing. The nonconfrontational approach and training among HCPs are of utmost importance to build therapeutic resilience among the treating team involved in cancer care. Since many factors such as family wishes, cultural dissonance, medical model, and patient perception could become barriers to prognostic disclosure, there is a need to develop a universal approach to prognostic disclosure and handling associated collusion.

Keywords: cancer, collusion, communication, disclosure, techniques

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Introduction

Communication among health care professionals (HCP), patients, and caregivers (referred to as triad) is a vital aspect of bringing a healthy recovery from disease and suffering, especially from a psychological viewpoint.¹ Striking a healthy balance between delivering adequate information without imparting excessive knowledge about the facts of an illness is an essential skill to be acquired

by clinicians practicing in the discipline of cancer, palliation, and hospice care. Collusion is known to be an established unrevealed dissonance between doctors, patients, and or caregivers frequently encountered in cancer care.² Collusion is understood as a secret agreement between doctor and patient or sometimes with the caregiver to protect the psychological health of the patient undergoing treatment for serious medical

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illnesses. In cancer care, collusion happens very frequently and attempts to troubleshoot through information sharing, and decision making has been made in the recent past by developing interview techniques. To develop an effective strategy to identify and demystify the communication gap, it is essential to realize the different needs of the patient at different stages of an illness and adapt the most effective strategies applicable to establish a healthy communication interface.³ It is appropriate to consider an individual's readiness to know about the diagnosis and prognosis of cancer including the readiness of the caregiver to share the information for healthy coping of the triad (doctor, patient, and caregiver).⁴

The prevalence of collusion varies from 30% to 70% depending on cultural context. Very few studies have looked at the interface and modules of unraveling the collusion.⁵ Therefore, this systematic review was conducted to evaluate the prognostic disclosure techniques in cancer care.

Materials and methods

The protocol of the review was registered on PROSPERO with study ID CRD42021249216.

Objective

The review identifies the evidence-based disclosure techniques used in cancer prognosis, duration of such sessions, and involvement of different health care professionals in disclosure across the world.

Inclusion and exclusion criteria

Types of studies. We included all types of original research studies (except case reports), which focused on disclosure strategies for identifying collusion, obstacles faced during the disclosure, intervention modules developed to improve the nature of disclosure between HCPs and patients, and/or caregivers, focusing on cancer prognosis.

Types of intervention. We included studies on disclosure of cancer prognosis at the time of receiving treatment or having completed the treatment. We included disclosure at any stage of palliation or hospice care irrespective of stage or bodily site of cancer. We excluded studies that deal with disclosure of cancer screening results such as genetic testing results, risk perception, vaccine prophylaxis; specific interventions disclosure such as drug cost, adverse effects of cancer treatment,

chemotherapy, radiotherapy, surgical procedure, complementary and alternative medicine (CAM) therapy; nondisclosure of symptoms by patients; ethical nondisclosure during clinical trials; voluntary information/knowledge-seeking from print media, television, social media, and other sources; population survey; survey among HCP regarding attitude toward disclosure, cancer survivors; studies on parent-child disclosure; quality assessment of communication material such as pamphlet, images, metaphors; communication methods after laryngectomy; only inter-professional communication studies and studies focusing on non-cancer life-limiting conditions.

Types of participants. We included studies with patients and/or caregivers of any age and gender who had suffered from cancer of any type and any severity, admitted, outpatient, or under community treatment being disclosed of cancer. We included all studies in which standard communication protocols were used or newly developed as a part of the research and were delivered to patients and/or caregivers by HCP or researchers. Also, we considered studies only if (1) Communication was conferred within HCP, patient and caregiver or HCP, and caregiver or HCP and patient. (2) Studies involved the clinical improvisation in face-to-face or telephonic dialogue with the HCP/researchers, and (3) studies that described the type of communication strategy.

Search strategy. A systematic literature search of the following databases was conducted on 15 June 2020 by two independent authors (RS and PC): Cochrane, PubMed, and Google Scholar. In addition, the reference lists of the pertinent literature were screened for the relevant studies.

Search keywords. The search started with the keyword collusion in cancer. Further to identify the articles of interest for this review, the search was narrowed by using the combination of following search terms as follows: ("Collusion" OR "communication" OR "communication pattern" OR "communication strategy" OR "communication methods" OR "communication techniques" OR "nondisclosure") AND ("cancer") (Supplementary file 1).

Data collections and analysis. Variables used for data extraction and further analysis constituted: Type of study/study design, Country, Age (mean and median), Type of study, Inclusion criteria, Exclusion criteria, number of Cases and Controls,

Type of cancer diagnosis, Type of communication paradigm, Scales used for measuring depression, anxiety, quality of life and stress, and any newly developed communication module for breaking bad news or disclosure strategy.

Data extraction and management. Two authors (RS and PC) independently extracted data from the selected trials using a standardized coding form prepared in Microsoft Excel. They discussed any differences in the data extraction till the resolution of conflict. The following data were extracted:

General information. Author, Year of publication, Title, Journal (title, volume, pages), If unpublished, Source, Duplicate publications, Country, and Language of publication.

Intervention information. Type of intervention (e.g. structured/semi-structured questionnaire, method of interview, survey, medical record/notes analysis, transcript analysis, and/or a combination), Time duration of interview method (detailed information if available), patient and caregiver preference (patient preferred *versus* researcher selected), Professionals involved (professional or training of nonprofessionals), Length and frequency of disclosure intervention, Intensity of intervention, and Comparison intervention if any.

Participant information. The total sample size of the study, Study setting (hospital, outpatient, palliative care, hospice care, home, community), Cancer diagnosis, Communication technique, and Patterns of collusion.

Types of outcome measures. The quality of life and patient/caregiver satisfaction is a crucial component of cancer prognostication. In end-of-life care, the communication strategies are varied due to cultural influence on the patient's autonomy. Therefore, we selected the following primary outcomes for this review: Disclosure interface between HCP, patient, and caregivers; Effective disclosure techniques and protocols evolved to date; Duration and frequency of disclosure sessions; Professionals involved in disclosure making.

Results

Result of search

A total of 603 studies met the preliminary search criteria, and additionally, 10 relevant studies were

included from the hand searches of references, out of which 101 studies were duplicated. After the title, abstract, and full-text screening, 386 studies were excluded as they were not relevant while 58 studies were targeted only at physicians' responses on prognostic disclosure hence excluded. After excluding 15 more studies on disclosures emphasizing more diagnostic communication, and another 2 studies targeting video-vignette-based assessments (Supplementary file), we included 51 studies with 10,569 subjects in the final qualitative synthesis, as shown in Figure 1.

Characteristics of the included studies

Types of studies among 51 included studies involved 4 mixed-method studies, 18 qualitative studies, 12 cross-sectional studies, 2 prospective longitudinal studies, 2 retrospective studies, 1 ethnographic study, 2 randomized control trials, and 1 each including an observational pre-post design, descriptive correlational study, multicentre interpretive description study, retrospective comparison with cohort design, quasi-randomized design, and an intervention survey. Nearly one-third of the studies were from the United States and India (Supplementary file).

The reasons for poor prognostic disclosure included the emotional well-being of a patient, family reasons, the patient's personality, the longevity of the disease, barriers to communication, and disease severity in a study by Chittem *et al.*⁶ A study on detecting patients' preferences for breaking bad news emphasized the need for tailoring the communication process to the individual needs⁵ which was also supported by a study on developing a tool named Patient Communication Pattern Scale (PCPS).⁷ The probability of cancer patients being informed of their diagnosis, and prognosis found that nearly 78% of poor prognoses were disclosed by physicians.⁸ A study by Sutar *et al.*³ found that most of the patients preferred disclosure in the absence of a caregiver. In a mixed-method study from Taiwan by Tang and Lee, patients expressed a strong preference for their physicians to inform them, while lower preferences for their physicians to inform their family members.⁹ A study from Canada explored the cancer experience for older women with carcinoma of breast and found that it is a false perception that older women do not want to participate in the decision making.¹⁰ A study by Harding *et al.*¹¹ talks about a novel model to understand the stigma and accessibility of palliative care. The

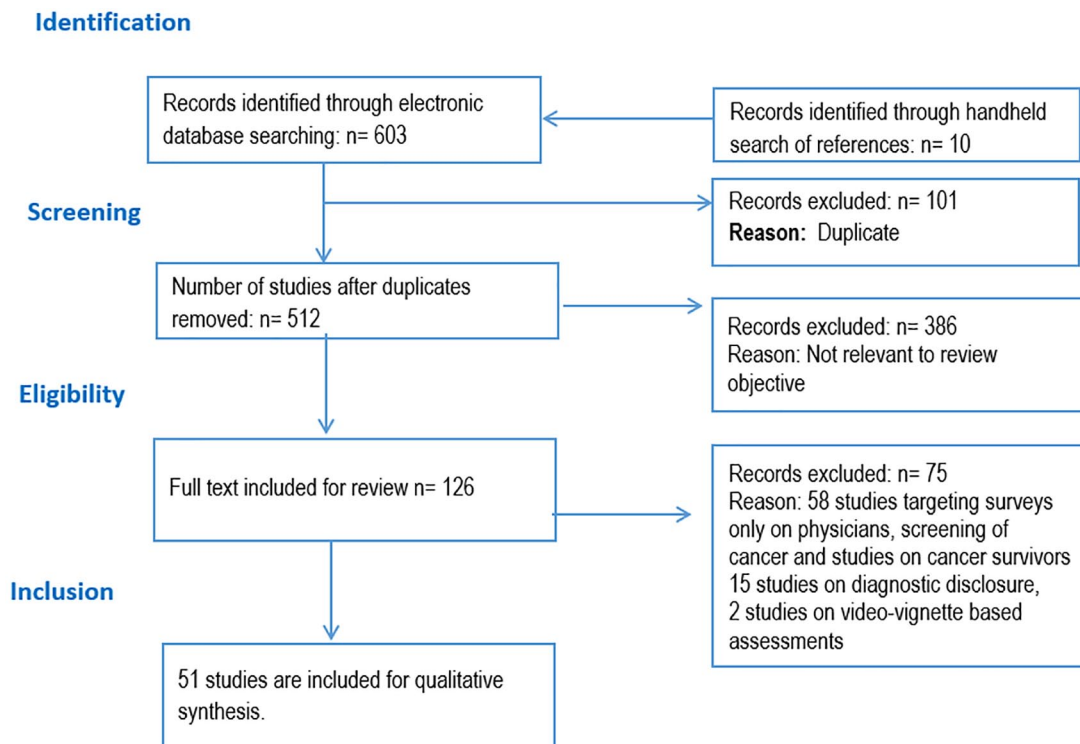


Figure 1. PRISMA flowchart of the review.

study also found that oncologists' and families' unwillingness to disclose the prognosis, and patient's concerns related to pain symptoms make clinicians view their services as under-utilized, and patients perceive palliative care as a pain management service. In a pre-post design study by Nayak *et al.*, there was a significant difference in terms of overall satisfaction, resolution of doubts, ensuring privacy, and use of clear language by physicians before and after the training in prognostic disclosure.¹²

In terms of the amount of prognostic disclosure in patients with CA breast, Bergqvist and Strang emphasized that hope is an enduring factor and the disclosure could therefore be selected for positive news, not necessarily the "whole" truth.¹³ It is also true that just including the statements of optimism did not increase the likelihood of agreement or disagreement about the chance of cure as observed by Robinson *et al.*¹⁴ The provision of selective information on chances of recovery (42.6%) was the second most common type of information sought by patients followed by the treatment-related details (26.9%) in one study.¹⁵ A qualitative study from Sweden, by Hoff and Hermerén, concluded that the physicians should not only deliver the results of each test but also explain the context to help

patients read between the lines from diagnosis to prognosis. This implies that physicians should not wait for terminally ill patients to ask for disclosure.¹⁶ According to a study by Rosenberg *et al.*¹⁷ 'following a novel approach' could be beneficial for prognostic disclosure and may include a written emotional disclosure task that can positively impact health outcomes in a cancer population. In an ethnographic study, 82.8% of patients reported false optimism about recovery varied across stages of cancer, and the maximum false optimism was seen at the third stage.¹⁸

Studies that focussed on shared decision making during prognostic disclosures mentioned an eHealth program to maximize the effects of shared decision making and found that trust in the health care system was significantly associated with the eHealth literacy of the participants.¹⁹ Similarly, according to a study by Ghoshal *et al.*,²⁰ the patients felt that knowing a diagnosis and prognosis may help them to be prepared, plan additional treatment, anticipate complications, and plan for the future and family. The strong desire among caregivers to protect the physical and psychological well-being of patients was noted by Victor *et al.*²¹ while the majority of the patients in a study by Reinert *et al.*²² expressed the need for

more information preferably through a personal, face-to-face meeting. This was supported by nearly two-thirds of patients and one-fourth of caregivers who reported that prognostic information was important according to Diamond *et al.*²³ Disclosing more detailed information to terminally ill cancer patients contributed to a better quality of communication, irrespective of the stage of disclosure as estimated by two studies.^{24,25} The study by Abdul-Razzak *et al.* describing a process of information exchange that defined 'knowing me' and 'conditional candor' appeared to play a significant role in prognostic disclosures. One study also emphasized the role of a nuanced approach to truth-telling when having end-of-life discussions with physicians.²⁶ The importance of finding the feelings of cancer avoidance, a climate of nondisclosure, and mutual concern were studied in a study by Zamanzadeh *et al.*²⁷ One observation by Nakajima *et al.*²⁸ concludes that informing more details about patients and their families including disease conditions and prognosis helps to improve the quality of terminal care. A high rate of the desired nondisclosure is found in the family-centered model as compared with the medical decision-making model which may require ethical exploration in future research.²⁹

In terms of not disclosing prognostic information, a study by Roscoe *et al.*³⁰ found that patients perceived an absence of communication about key end-of-life topics. This can be avoided by improving the delivery of information by framing information positively, gradually disclosing information, and separating family consultations as noted by Mitchison *et al.*³¹ In a qualitative study by Valizadeh *et al.*,³² the participants wanted basic information about their prognosis and treatments from their treating physicians, but did not receive this information, and encountered difficulty accessing information elsewhere. In another study, it was noted that 65% of families did not want to disclose information to their children while decision making about treatment.³³

Communication interface and data collection method used for prognostic disclosure

The interface of prognostic communication or disclosure of information related to cancer prognosis was assessed in 53 studies. A face-to-face interview setting was used in 23 studies as described in Table 1. Two retrospective studies retrieved the prognostic communication details while in-person telephonic interviews were

conducted in two studies using medical records.^{34–36} In comparison, the combination of methods such as interviews and records or interviews and ward observation or interview and home visits was used in five studies.^{8,18,37,38} Almost all the studies with face-to-face or telephonic interviews used audiotaped recordings of verbatim of the triad involved, and subsequently, most of the qualitative studies used grounded theory procedures for analysis of the transcripts.¹⁰ All included studies had participants from either or both genders with ages more than 18 years except one study that included children.³⁹

Communication modules and techniques used for prognostic disclosure

As described in Table 1, the module of the disclosure was semi-structured questionnaire in 16 studies,^{3,8,9,11,14,16,19,26,29,34,39–41,43,55–58} self-reported questionnaire in 5 studies,^{12,19,42,59} and structured questionnaire in 11 studies. Writing-based expressive communication¹⁷ and video vignette-based interface^{55,58} were used as an alternative interface for prognostic disclosure in two studies (Supplementary data). Mail-based submission of disclosure-related information was noted in three studies.^{43–45} Information disclosure associated with data collection was indirectly supplemented through behavioral observation of patients in five studies.¹⁸ Focused group discussion was a part of disclosure in two studies.^{8,37} Significant heterogeneity was noted in terms of the stepwise approach to disclosing the prognosis. Sixteen studies explicitly described the communication techniques used during interviews.

These included efforts to disclose information through certain questionnaire and protocols during the study such as SPIKE protocol,²⁴ VOICE protocol (Views of Informal Carers – Evaluation of Services),⁸ STAS-J (Support Team Assessment Schedule-Japanese),²⁸ CCAT-F Disclosure subscale and perception of the patients' degree of disclosure regarding cancer-relevant topics caregiver strain (CSI), and unmet needs (SCNS-P&C),²⁵ Attitude Toward Truth-Telling of Cancer,⁶⁰ National Comprehensive Cancer Network (NCCN),⁴⁶ Distress Thermometer and Problem List and University of Washington School of Medicine Quality of Communication Questionnaire (QOC),³⁰ Prognosis and Treatment Perceptions Questionnaire (PTPQ),²³ Cancer Patient's World Questionnaire (CPWQ),⁴² Cancer behavior inventory,^{45,61} University of Washington School

Table 1. Characteristics of the studies included in the systematic review.

Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
1. Sutar <i>et al.</i> ³	South India, Palliative care	Observational mixed method	124	Multiple cancer	A newly developed 14 items collusion questionnaires (patient version and caregiver version) was administered using a FRIENDS protocol (30 min, 2 sessions)	Psychiatrists	Identify reservations about disclosing information to patients and caregivers and identify collusion. Perceived ill effects of information on patient and caregiver from vice versa perspectives. Around 50% of collusions were unraveled systematically using FRIENDS protocol. The majority of the patients preferred to be interviewed in the absence of a caregiver and was statistically significant with the existence of collusion in the family. It is worthwhile to talk about 'end-of-life issues,' the dying process, and unfinished work with patients and caregivers rather than keeping it. (62 patients and 62 caregivers)
2. von Blanckenburg <i>et al.</i> ⁵	Germany, Inpatient and outpatient of a university hospital	Qualitative study	336	Multiple	Interviews leading to the development of The Marburg Breaking Bad News Scale (MABBAN) (60 min)	NS	To develop a questionnaire based on the SPIKES protocol to detect patients' preferences for breaking bad news communication. Physicians should improve the setting, share knowledge in all clarity, involve the patients in further planning, and consider demographic variables. It is important to emphasize the individual preferences beyond the six steps and tailor the communication process to the individual.
3. Chittem <i>et al.</i> ⁶	India, Outpatient, Hospital	Mixed-method study	15	Multiple	Interview with semi-structured tool – digital audio recording. (25 min)	NS	To explore the reasons and experience of caregivers on disclosure <i>versus</i> nondisclosure to patients about their cancer diagnosis. Six main reasons for disclosing: emotional well-being, lack of control, preparing the patient, family reasons, patient's personality, and longevity/curability of the disease. Six main reasons for not disclosing: emotional well-being, family reasons, patient's personality, longevity/curability of the disease, barriers to communication, and disease severity. Disclosing families used an asset-based approach, and nondisclosing families used a deficits-based approach to their role.
4. Ilan and Carmel ⁷	Israel, Community clinics	Cross-sectional study	251	Not specified	Face-to-face interview 14 item Patient Communication Pattern Scale (PCPS) (NS)	NS	To develop a tool for evaluating patients' communication patterns. PCPS is a reliable tool for patient's communication patterns which is 14 items with five domains: Providing information, Questioning; requesting clarification; Initiating requests for information; Reporting Preferences, and Reporting emotions

(Continued)

Table 1. (Continued)

Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
5. Costantini <i>et al.</i> ⁸	Italy, Community	Retrospective mortality follow-back survey	1271	Digestive, respiratory, or genitourinary system cancer	Semi-structured interview with the caregiver guided by Adapted version of the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire (NS)	Physicians, nurses, social workers, and psychologists	Estimating the probability of cancer patients being informed of their diagnosis, prognosis, and exploring circumstances around the disclosure. 80% diagnosis and 78% of poor prognosis were disclosed by physicians as compared with 0.5% and 0.9% of other paramedical professionals. 14% and 16% received diagnostic and prognostic information from friends and relatives. Nearly 37% of people who died of cancer had received information about diagnosis and 13% about poor prognosis. 29% and 50% were aware of diagnosis and prognosis without any disclosure.
6. Tang and Lee ⁹	Taiwan, Multicenter, Inpatient, Hospital	Mixed-method study	364	Not specified	Semi-structured interviews, developed a new Interview schedule for diagnosis and prognosis associated collusion (NS)	Medical and surgical oncologist	To explore preferences of information and attitudes toward disclosing information related to diagnosis and prognosis from health care professionals to family and from family to patient from the patient's point of view. The vast majority (93.7%) of patients reported being aware of their cancer, but only 58.4% of patients were aware of the curability of their disease. Patients expressed a strong preference for their physicians to inform them. In contrast, subjects reported significantly lower preferences for their physicians to inform their family members.
7. Crooks ¹⁰	Canada, Outpatient, Hospital	Review of literature with qualitative study	20	Women with stage I or II breast cancer diagnosed after age 65	Interview (1-h, multiple sessions)	Researcher, clinician	Contributions of grounded theory research to new understandings of the cancer experience for older women. To understand patients' experiences, concerns, and strategies used in dealing with breast cancer diagnosis and treatment. Patients should be informed and their concerns must be addressed. It is a false perception that older women do not want to participate in decision making. Physicians were noted to keep positive collusion.
8. Harding <i>et al.</i> ¹¹	South India, Palliative care	Cross-sectional qualitative study	20	Advanced cancer	Semi-structured questionnaire (30 and 45 min)	Oncologists, psychiatric social workers, and clinical psychologist	To develop an explanatory evidence-based model of stigma, communication, and access to cancer palliative care in India that can be used to develop, test, and implement future interventions. Oncologists' and families' unwillingness to disclose the prognosis, and patient's focus on pain due to their lack of insight makes clinicians view their services as under-utilized, and patients perceive palliative care as a pain management service. Talks about a novel model to understand the stigma and accessibility to palliative care. 10 patients and 10 caregivers

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Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
9. Nayak <i>et al.</i> ¹²	India, Outpatient, Hospital	Intervention study and a Survey	400	Not specified	8 item questionnaires prompting yes and no answers. (NS)	Trained nurses	To assess cancer patients' perception of the quality of communication before and after the implementation of a communication strategy. Doubts cleared by the doctor in 105 patients (26%) versus 225 patients (56%) Following a new communication strategy resulted in major improvements in patients' perceptions of quality of communication. There was a significant difference in terms of overall satisfaction, resolution of doubts, ensuring privacy, and use of clear language by physicians before and after the training.
10. Bergqvist and Strang ¹³	Sweden, Palliative care	Cross-sectional qualitative study	20	Metastatic breast cancer	Semi-guided face-to-face interviews (tape-recorded and transcribed verbatim) (30- to 46-min interviews)	Oncologist, pathologist	To explore breast cancer patients' preferences and perceptions of patient-doctor communication regarding continuous late lines of palliative chemotherapy. Doctors need to individualize information, help patients make sense of their life, and allow hope to endure without further chemotherapy. Disclosure could be selective for positive news, not necessarily the 'whole' truth.
11. Robinson <i>et al.</i> ¹⁴	USA, Multicenter, Outpatient, Hospital	Cross-sectional study	198	Not specified	Audiotaped recordings of communication between oncologists and patients [19 min 52 s (SD: 13 min 51 s)]	Oncologists (Medical, hematological, gynecological, radiotherapy)	To identify the communication factors that influence patient-oncologist concordance about the chance of cure [baseline phase of the Studying Communication in Oncologist Patient Encounters (SCOPE) trial]. Oncologists disclosed information on treatment (94.3%) and test results (77.3%) in the majority of their visits to patients, while prognosis was discussed in 50.4% of visits. Statements of optimism did not increase the likelihood of agreement or disagreement about the chance of cure. (147 patients, 51 oncologists)
12. Piredda <i>et al.</i> ¹⁵	Italy, Inpatient, Hospital	Cross-sectional survey	120	NS	11-item structured questionnaire covering information about the disease, chances of recovery, possible treatments, a side effect of chemotherapy, and the trajectory of illness (NS)	Researchers	To assess patients' attitudes toward disclosure of information. The information ranked as most important by respondents was information about illness (65.7%) followed by information about the chance of recovery (42.6%), treatments (26.9%), side effects of chemotherapy, and how to deal with them (22.4%), and the trajectory of illness (20.4%). No one wanted to receive information or less information as possible about the possibility of recovery and possible treatments. Health professionals' awareness should be raised.

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Table 1. (Continued)

Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
13. Hoff and Hermerén ¹⁶	Sweden, Inpatient, Hospital	Qualitative study	12	7 patients with malignant hematological diseases, 5 patients with inoperable lung cancer diseases.	Semi-structured interview NS	Researcher	To study obstacles and awareness of information disclosure. Four kinds of obstacles were studied: (1) Physician obstacle – Reluctance to talk with patients about their approaching death. (2) Patient Obstacle – Denial (3) The physician and patient are in collusion. (4) Neither physician nor the patient but the insidious way in which lung cancer and hematological malignancies progress. Physicians should not only deliver the results of each test but also explain the context to help patients read between the lines from diagnosis to prognosis. Physicians should not wait for terminally ill patients to ask for disclosure.
14. Rosenberg <i>et al.</i> ¹⁷	USA, Outpatient, Hospital	RCT	30	Prostate cancer	Expressive disclosure through writing (30 min for 4 days)	Oncologist	To explore the feasibility and the efficacy of a brief, well-defined psychosocial intervention (expressive disclosure) and compare with controls. Patients in the expressive disclosure condition showed improvements in the domains of physical symptoms and health care utilization. A written emotional disclosure task can positively impact health outcomes in a cancer population.
15. The <i>et al.</i> ¹⁸	Netherlands, Inpatient, Hospital	A qualitative observational (ethnographic) study	35 patients	Small cell lung cancer	Full-time observation of the patient during ward admission, home visits, and formal interviews (NS)	Doctor and nurses	To discover and explore the factors that result in 'false optimism about recovery'. 82.8% of patients reported false optimism about recovery varied across stages of cancer such as existential crisis at first diagnosis, focus on therapy during the first treatment, the relative peace of mind during tumor invisibility on X rays, the existential crisis at recurrence, and a crisis when 'no cure' was informed. The maximum false optimism was seen at the third stage.
16. Nejati <i>et al.</i> ¹⁹	Taiwan, Four teaching hospitals	Prospective longitudinal study	276	Multiple myeloma	Self-reported pattern using eHealth Literacy Scale (eHEALS), Multidimensional Trust in Health Care Systems Scale (MTHCSS), Patient Communication Pattern Scale (PCPS), and 9-Item Shared Decision-Making Questionnaire (SDM-Q-9), Family Decision-Making Self-Efficacy (FDMSE) (NS)	Physician	To identify determinants of shared decision making in patients with multiple myeloma (MM) to facilitate the design of a program to maximize the effects of shared decision making. Patient communication and eHealth literacy were found to be important determinants of shared decision making. The proposed model showed that trust in the health care system was significantly associated with the eHealth literacy of the participants.

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Table 1. (Continued)

Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
17. Ghoshal et al. ²⁰	India, Outpatient, hospital	Qualitative	500	Not specified	Pre-validated, close-ended preference questions and were interviewed for open-ended attitude questions (NS)	Two research assistants	To understand the preferences and attitudes of patients and family caregivers on disclosure of cancer diagnosis and prognosis in an Indian setting. The patients felt that knowing a diagnosis and prognosis may help them be prepared, plan additional treatment, anticipate complications, and plan for future and family. (250 patients and 250 caregivers)
18. Victor et al. ²¹	India, Palliative care	Cross-sectional qualitative	200	Not specified	Semi-structured questionnaire guided by European Organization for research and treatment of cancer QOL Questionnaire-C30 (NS)	Treating physician	To determine the prevalence of collusion and its influence on the quality of life (QOL) among patients in palliative care Caregivers restrained doctors from disclosing the diagnosis. There is a strong desire among caregivers to protect the physical and psychological well-being of patients. Collusion was independently associated with poor QOL when adjusted for demographic variables. (100 patients and their caregivers)
19. Reinert et al. ²²	Germany, Hospital	Cross-sectional study	314	Brain tumor	Self-assessment questionnaire ranged into five clusters (diagnosis, treatment, living with cancer, additional support, and legal issues) (NS)	NS	To evaluate and investigate the information needs, information behavior, level of information on patients and their relatives. The majority of patients and their relatives wished to receive maximum information about diagnosis, prognosis, and treatment. Many expressed the need for more information preferably through a personal, face-to-face meeting.
20. Diamond et al. ²³	USA, Inpatient, Hospital	Mixed-methods exploratory study	82	Malignant glioma	Audio-recorded semi-structured assessment in a private, quiet, and uninterrupted setting. Prognosis and Treatment Perceptions Questionnaire (PPQ) (NS)	One of the three trained members of the study team	To explore associations between neurocognitive function and patterns of prognostic awareness and communication preferences. Less than half of patients and nearly two-thirds of caregivers already had full prognostic awareness. Nearly two-thirds of patients and one-fourth of caregivers reported that prognostic information was extremely or very important. (50 patients and 32 paired caregivers)

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Table 1. (Continued)

Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
21. Nakajima <i>et al.</i> ²⁴	Japan, Sapporo, Hokkaido In patient, Hospital	Observational pre-post design	91	Multiple	More detailed information based on the SPIKES and Support Team Assessment Schedule (Japanese version) (At admission and 1 week after this approach)	Researchers	To examine whether disclosing more detailed information about disease progression to terminally ill patients could improve the quality of communication. Cancer disclosure into 4 groups: A: Nondisclosure (n = 8), B: Disclosure of cancer diagnosis (n = 25), C: Disclosure of life-threatening disease (n = 40), D: disclosure of poor prognosis (n = 18) Disclosing more detailed information of cancer for terminally ill cancer patients contributed to improving the quality of communication, irrespective of the stage of disclosure.
22. Haun <i>et al.</i> ²⁵	Germany, Inpatient or Outpatient, University hospital	Cross-sectional survey	378	Multiple	Distress (OSC-R10), Perception of the patients' degree of disclosure regarding cancer-relevant topics (CCAT-F Disclosure subscale), caregiver strain (CSI), and unmet needs (SCNS-P&C) (NS)	Physician	To assess the impact of caregivers' perceived nondisclosure by the patients. 33% of the caregivers and 25% of the patients exhibited significant anxiety, with a tendency toward a higher frequency in the caregivers. The prevalence of depression was lower but equally high in caregivers and patients. The caregivers' perceived nondisclosure by the patients was primarily associated with their anxiety and disease-specific distress (189 pairs of cancer and their partners)
23. Abdul-Razzak <i>et al.</i> ²⁶	Canada, Palliative care	Multicenter interpretive description study	16	NS	Semi-structured, one-on-one interviews (22–70 min)	Researcher	To understand patients' preferences for physician behaviors during end-of-life communication. Two major themes emerged: (1) 'knowing me', which reflects the importance of acknowledging the influence of family roles and life history on values and priorities expressed during end-of-life communication, and (2) 'conditional candor', which describes a process of information exchange that includes an assessment of patients' readiness, being invited to the conversation, and sensitive delivery of information. Patients prefer a nuanced approach to truth-telling when having end-of-life discussions with their physicians. (5 cancer patients and 11 noncancer patients)
24. Zamanzadeh <i>et al.</i> ²⁷	Iran, East Azerbaijan Province, Community	Qualitative	38	NS	Semi-structured, in-depth interviews which were tape-recorded and transcribed verbatim (32–71 min, mean 46 min)	Researcher	To describe the experiences of cancer disclosure by cancer patients, their family members, and physicians. A climate of nondisclosure predominated because patients were the last to know their diagnosis, they were unaware of their prognosis, and family members and physicians employed strategies to conceal this information. Three categories were identified: cancer avoidance, a climate of nondisclosure, and mutual concern. 20 patients, 10 family members, and 8 (physicians)

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Table 1. (Continued)

Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
25. Nakajima et al. ²⁸	Japan, Palliative care	Retrospective	87	NS	Support Team Assessment Schedule-Japanese (STAS-J), a tool for palliative care audit NS	Physician and nurses	To examine the relationship between informing patients of cancer and the quality of terminal care. Four categories defined: 'nondisclosure of cancer diagnosis', 'disclosure of the cancer diagnosis', and 'disclosure of the life-threatening diagnosis', and 'disclosure of poor prognosis'. The results of this study demonstrated that informing patients and their families of more specific information, including disease conditions and prognosis, helps improve the quality of terminal care.
26. Back and Huak ²⁹	Singapore, Outpatient, Hospital	Prospective audit	369	Multiple	Therapeutic interview (two interviews were conducted in case of incomplete data) (NS)	Single radiation oncologist, patient, and caregivers	To study the extent of nondisclosure and factors associated with it in cancer patients. Discussion of therapeutic options and informed consent for treatment was ideally sought through a shared decision-making model incorporating physician, patient, and family 17.6% of new patients encountered nondisclosure of diagnosis of their malignancy. A high rate of the desired nondisclosure is found in the family-centered model as compared with the medical decision-making model which requires ethical exploration in future research.
27. Roscoe et al. ³⁰	USA, South Florida, Head and neck oncology clinic	Qualitative	14	End-stage head and neck cancer	In-person/telephonic interview based University of Washington School of Medicine Quality of Communication Questionnaire (QOC) based structured questionnaire (30 min)	Researcher	To find the ability to communicate with patients and their willingness to discuss specific aspects of end-of-life care. Patients perceived an absence of communication about key end-of-life topics.
28. Mitchison et al. ³¹	Australia, Outpatient, Hospital oncology clinic	Qualitative exploratory study	73	Metastatic cancer	Structured interview guided by questions based on the prognostic literature (NS)	Doctors	To describe the pattern of communication between oncologists and migrant cancer patients. To elicit migrant cancer patients' personal experiences of communication during the consultations and their preferences for prognostic communication How much information to disclose was based on variation in pattern: Complete prognostic disclosure, nondisclosure, disclosing later, the disparity between family and patient, asking permission first making a capacity judgment first. Manner of information delivery was based on: framing information positively, gradually disclosing information, separate family consultations (31 Anglo Australians, 20 Chinese, 11 Arabic, and 11 Greek migrants)

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Table 1. (Continued)

Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
29. Valizadeh <i>et al.</i> ³²	Iran, Inpatient, outpatient clinics, and physicians' offices, hospital	Qualitative	20	Breast cancer	The in-depth semi-structured interview which was audiotaped and transcribed in verbatim (32–66 min, mean 47 min)	Researcher	To understand and assess the need for changes in current patient and health care provider education. Four themes emerged: the atmosphere of nondisclosure, eventual disclosure, distress in knowing, and the desire for information. The participants wanted basic information about their prognosis and treatments from their treating physicians, but did not receive this information, and encountered difficulty accessing information elsewhere.
30. Seth ³³	North India, Palliative care hospital	Qualitative study-survey	25	Acute lymphoblastic leukemia (NS)	Simple questionnaire formulated using WHO guidelines (NS)	Health care provider	To evaluate parental views on the participation of children in prognostic disclosure, decision making for treatment, and beliefs and practices for palliative care. Parents of patients interviewed together in the absence of patient. 65% of families did not want to disclose information to their children while decision making about treatment, etc. 95% of parents felt that child should not take any decision about treatment.
31. Jeba <i>et al.</i> ³⁴	South India, Palliative care hospital	Retrospective study	306	Not specified	Health care records (NS)	Researcher	To study factors contributing to collusion in patients who had visited palliative care OPD at least 3 times with follow-up until death. Collusion was present in 40% of cases and addressed in 35% of cases. 18% Collusion regarding diagnosis and 40% regarding prognosis. Collusion is higher among females, patients, manual workers, and those not accompanied by the spouse.
32. Kao and Goh ³⁵	Singapore, Hospice home care	A retrospective comparison with the cohort of Tay <i>et al.</i>	100	Advanced cancer	Chart review using Eastern Cooperative Oncology Group (ECOG) performance status (NS)	Physician	To determine the rate of nondisclosure to patients. The rate of nondisclosure was 23%. There was no significant association between nondisclosure and gender or ethnicity.
33. Kirwan <i>et al.</i> ³⁶	The United Kingdom, Inpatient, Hospital	Cross-sectional observational study	359 patients	Epithelial ovarian cancer	Hospital record of patients regarding communication of the cancer diagnosis and treatment. (NS)	NS	To understand how doctors record-breaking bad news in ovarian cancers. Collusion was present in 33 % of patients. Collusion was recorded 3 times more in elderly patients (>65 years).

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Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
34. Huang <i>et al.</i> ³⁷	Australia, Teaching hospitals, and cancer support organization	Qualitative	48	Multiple	Focused group discussion, telephonic interviews guided by Rissel Acculturation Scale (NS)	Psychiatrist	To identify attitudes toward cancer and associated information and communication needs of Chinese patients and their relatives in Sydney. Nondisclosure of a poor prognosis was more acceptable by family members. Patients preferred a confident and clear diagnosis and treatment recommendation. (36 patients and 12 relatives)
35. Schroy <i>et al.</i> ³⁸	USA, Boston, Community	Quasi-randomized design	315	Colorectal adenoma	Brief, computer-based educational program (CBEP) after polypectomy, or in combination with a personalized letter (PL), and generic letter (standard care). A phone survey was conducted 3 months after post-polypectomy. (NS)	Research assistant	To determine whether a brief, computer-based educational program (CBEP) administered alone after polypectomy, or in combination with a personalized letter (PL), was more effective than standard care (SC) for heightening awareness and improving risk communication. The CBEP + PL intervention is an effective strategy for improving knowledge, risk perception, and risk communication among adenoma patients. [CBEP + PL (<i>n</i> = 99), CBEP (<i>n</i> = 96), or SC (<i>n</i> = 120) arms]
36. Claffin and Barbarin ³⁹	USA, Community	Qualitative longitudinal	43 children	Multiple	Children were interviewed after completion of a group family interview. (45–60 min)	NS	To address the information disclosure from the perspective of children diagnosed with cancer. 62.8% of children were told nothing at the time of diagnosis. Over time, young children reported experiencing as much disruption and distress from the illness as did their older and more informed counterparts.
37. Clemente ⁴⁰	Spain, Inpatient, Hospital and house	Qualitative/ethnographic	17	Not specified	Daily participant observation of medical and social activities, biographical questionnaires, unstructured and semi-structured interviews, and video recording (NS)	Clinicians and nurses	To explore clinicians' practices of partial information disclosure to adolescents with cancer. Clinician responses were categorized as contingent answers, narrow answers, nonanswer responses, and question forestalling. Nurses' observation is important in strategic communication development. Combining participatory methods of interviewing children with other methods, such as conversation analysis.

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38. Liu <i>et al.</i> ⁴¹	China. Tertiary hospital	Prospective cohort study	248	Not specified	A self-designed questionnaire following a semi-structured interview. (NS)	Clinician	To investigate the disclosure incidence of cancer diagnosis to patients before chemotherapy, to survey the attitudes of the patients and their families and related influencing factors toward disclosure of cancer diagnosis, and to compare the anxiety and depression levels between the disclosure and nondisclosure patients. More than half of the patients did not know their exact diagnosis. Patients and their family members had different preferences toward diagnosis disclosure. Higher anxiety level was found in the diagnosis nondisclosure group. (124 pairs of the patient and family members)
39. Ross <i>et al.</i> ⁴²	Denmark, Outpatient, Hospital	Cross-sectional study	61	Multiple	Telephonic interview using 8-item Cancer Patient's World Questionnaire (CPWQ) NS	Psychologist, trained interviewer, and medical professionals	To develop and validate a short instrument assessing the patients' perception of communication with health care staff. This communication scale, the CPWQ-com, performed well and proved to be a valid and highly reliable measure of satisfaction with the communication with health care staff.
40. Marwit and Datson ⁴³	USA, Community	Survey	26 women and 86 male	Not specified	Mail questionnaire packet containing Social Support Appraisals Scale, Miller Behavioral Style Scale, The Costello-Comrey Anxiety Scale, Hardiness Scale, short form and Belief in Personal Control Scale (NS)	NS	To find out the disclosure preferences and pathways through a stepwise disclosure protocol to break barriers to collusion. The majority of the participants expressed a desire for full disclosure and no one endorsed nondisclosure. 64.3% indicated the presence of a loved one present during the disclosure of a terminal prognosis, while 32.1% preferred it alone; and 3.6% preferred information be conveyed exclusively to a loved one.
41. Morita <i>et al.</i> ⁴⁴	Japan, Palliative care and Hospital	Multicenter questionnaire survey	318	Not specified	Questionnaires mailed to bereaved family members (NS)	NS	To clarify the family-reported degree of emotional distress and the necessity for improvement in communication methods when communicating about the ending of anticancer treatment, and to identify factors contributing to the levels of emotional distress and the necessity for improvement. 19% reported 'considerable' or 'much' improvement was necessary for the information about ending anticancer treatment, a considerable number of families felt a need for improvement of the communication methods.

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Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
42. Ruland <i>et al.</i> ⁴⁵	Norway, Community	Randomized control trial	325	Breast cancer and prostate cancer	Mailed questionnaire Cancer behavior inventory (3, 6, 9, and 12 months of the study with flexible duration)	NS	To examine the effects of WebChoice on symptom distress (primary outcome), depression, self-efficacy, health-related quality of life, and social support (secondary outcomes). The experimental group had access to WebChoice and the control group received URLs of publicly available cancer Web sites. Participants in the experimental group showed significant within-group improvements in depression. In the control group, self-efficacy and health-related quality of life deteriorated significantly over time.
43. Jones <i>et al.</i> ⁴⁶	Australia, Victoria, Community	Cross-sectional study	154	NS	Supportive care interviews followed by experiential interviews guided by National Comprehensive Cancer Network (NCCN) Distress Thermometer and Problem List (Few minutes to 30 min)	Clinician and researcher	To evaluate the role of supportive care interviews in terms of improving the communication gap. The majority of patients interviewed for this study felt that the supportive care process enhanced communication, completing the supportive care process encouraged them to reflect upon and clarify unmet needs, assisted them to seek assistance rather than 'soldiering on' by themselves.
44. Gan <i>et al.</i> ⁴⁷	China, Hospital and Community	Mixed-method study	2183	Not specified	In-depth interview guided by Disclosing Diagnosis Questionnaire (DDQ) (NS)	Oncologist, researchers	To explore attitudes toward truth-telling practice among physicians, patients, patients' family members, and the general population, and reasons for nondisclosure. Quantitative data indicated that physicians were the least, and patients the most, in favor of disclosure. Qualitative data among physicians and follow-up surveys among cancer patients revealed five reasons for the concealment of cancer diagnoses by physicians, including lack of awareness of patients' right to knowledge, cultural influences, insufficient medical resources and training, families' financial concerns, and the need to protect doctors from violence. (212 physicians, 143 patients with cancer, 413 family members, 1415 members of the general population)
45. Buzaglo <i>et al.</i> ⁴⁸	USA, Outpatient, Fox Chase Cancer Center, a National Cancer Institute	Qualitative Cross-sectional survey	46	Metastatic solid tumor	New tool (web-based) developed based on Quality and Quantity of life (NS)	NS	A pilot study to develop an Internet-based method to assess cancer patient information needs and enhance doctor-patient communication. 22% preferred the physician to assume final decision-making responsibility. Satisfaction was observed among patients in terms of information presentation (87%), manner of information presentation (89%), and matching of communication with patient preferences (83%). 100% were at least 'moderately satisfied' with the survey

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Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
46. Ingersoll <i>et al.</i> ⁴⁹	USA, palliative care	Cross-sectional study	282	Multiple advanced cancer	Audio recorded interview and consultation (NS)	Palliative care clinicians and nurses	To examine whether conversations involving Black or Latino patients with advanced cancer differ in the presence or characteristics of prognosis communication. Prognosis communication was more common among patients who identified as neither Black nor Latino compared with those who identified as either. Prognosis communication was less than half as likely to occur during conversations with Black or Latino patients compared with others (231 patients, 51 clinicians)
47. Bachner <i>et al.</i> ⁵⁰	Israel, Home hospice unit	Descriptive correlational study	77	Multiple	Illness and Death Scale, General Self-Efficacy Scale, Maslach Burnout Inventory, Short Geriatric Depression Scale (NS)	NS	To compare the level of open communication between caregivers from two ethnic groups and examine the contribution of different caregiver characteristics and situational variables to the explanation of open communication. A significant negative association was found between the duration of caregiving and open communication, Spouses of Ashkenazi origin communicated more with their loved ones about illness and death compared with their Sephardi counterparts. Ethnic origin accounted for 16.6% of the explained variance, caregiver characteristics added 20.3%, and situation variables lent a modest contribution of 3.5%
48. Thorne <i>et al.</i> ⁵¹	Canada, Outpatient, Hospital	Qualitative longitudinal	125	Multiple	Face-to-face initial individual interviews followed by an ongoing series of bimonthly face-to-face or telephone interviews (NS)	NS	To understand helpful and unhelpful communication from the patient perspective and to document changes in patient needs and priorities over time. Patient accounts reveal 3 types of poor communication. 'Ordinary misses' are everyday missteps for which maturation and socialization may be an adequate solution. 'Systemic misunderstandings' are assumptive gaps between patients and professionals, which may be addressed through qualitative research. 'Repeat offenders' are a subset of clinicians whose communication patterns become a particular source of patient distress.

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Authors	Country and setting	Study design	Sample size	Cancer diagnosis/site	Disclosure tools/techniques used/developed (time duration, length, and details of disclosure technique)	Professionals involved in the disclosure	The objective of the study and key information obtained regarding prognostic disclosure
49. Ross <i>et al.</i> ⁵²	Denmark, Community	Cross-sectional survey	1490	Multiple	Self-reported 8-item Cancer Patient's World Questionnaire, CPWQ (NS)	NS	To access how communication with health care staff is perceived by cancer patients and to categorize those patients who report a problem in communication. Prognosis communication was more common among patients who identified as neither Black nor Latino compared with those who identified as either. A high proportion (24%) of patients reported one or more problems with the communication.
50. Hack <i>et al.</i> ⁵³	Canada, Vancouver, Calgary, Winnipeg, Outpatient	Qualitative	173	Prostate cancer	Audiotaped clinical encounter MIPS – Medical Interaction Process System and Patient Perception Scale-9 items applied after consultation (NS)	Clinical research nurse	To explicate the content of primary adjuvant treatment consultations in breast oncology and examine the predictive relationships between patient and oncologist consultation factors and patient satisfaction with communication The most frequent oncologist mode was 'gives information to the patient'; an average of 222.9 utterances per consultation (71.3 % of the total utterances of the oncologist). The second and third most common modes for the oncologist were 'directs/advises' (20.6 utterances per consult; 6.6% of oncologist utterances), followed by 'registers information' (15.2 utterances per consult; 4.9% of oncologist utterances). The most common mode for patients was 'registers information' (46.8 utterances per consult; 41% of patient utterances), followed by 'gives information' (39.7 utterances per consulting; 34.8% of patient utterances).
51. Miura <i>et al.</i> ⁵⁴	Japan, Inpatient, Hospital	Qualitative study	229	Primary lung cancer	Interview (NS)	Patient, caregiver, and physician	To assess current trends in disclosure of lung cancer to patients. 98.0% of surgical patients and 75% of nonsurgical patients have disclosed their illness. Reasons for nondisclosure to nonsurgical patients ranged from rejection by family members (29 patients) to a lack of ability to understand (3 patients). Reasons for nondisclosure to nonsurgical patients ranged from rejection by family members (29 patients) to a lack of ability to understand (3 patients). (101 surgical patients and 128 nonsurgical patients)

of Medicine Quality of Communication Questionnaire (QOC)-based structured questionnaire,³⁰ Disclosing Diagnosis Questionnaire (DDQ),⁴⁷ and Rissel Acculturation Scale.³⁷

Newer methods for disclosure balanced patient autonomy and family-centric disclosure. One of the studies developed 14 items of collusion questionnaires (patient version and caregiver version) administered using a 'FRIENDS' protocol (Find-Feelings, Reason-Reason out-Reassure, Identify-Intention, Effect of Escaping, Now or Never, Discuss-Deterioration-Damage and Stabilize)³ which is similar to conventional methods of breaking bad news; however, it is developed by a team of psychiatrists and emphasizes more on the dealing with the escaping attitude of patients and caregivers and handling the distress in separate interviews. The semi-structured interview schedule for diagnosis and prognosis associated collusion,⁹ The Marburg Breaking Bad News Scale (MABBAN)⁵ gives more emphasis on individual preferences and tailoring the communication process to the individual needs, based on SPIKES protocol. The web-based tool⁴⁸ emphasizes the awareness of the values associated with quality and length of life, a crucial component for health delivery. The 14-item Patient Communication Pattern Scale (PCPS)⁷ addresses the dimensions of information, clarification, initiation, preferences, and emotions required for more open and collaborative decision making in cancer care, while the 'WebChoice' preferences⁴⁵ allow the consolidated analysis of questionnaires, system logs, and digital messages. Moreover, digital platforms such as computer-based educational programs (CBEP) and personalized letters (PL) are being developed to cater to patient-centric disclosure about their cancer prognosis which gives feedback to the patient as well as the treating team about their emotional processing.⁴¹

Duration of prognostic disclosure session and frequency of such sessions

Around 13 studies have described the time required for disclosure of the information using the respective methodology of the research framework. The duration of the prognostic disclosure session ranged from 7 min to 1 h. However, six studies mentioned the required time as less than 30 min, such as 22 min²⁶ and a few minutes to 30 min,^{3,6,14,30,46} while six studies mentioned required duration of more than 30 min to 1 h.^{5,10,11,13,17,27,32,39,59,62} Time constraint is an important indicator that

should be focused on while developing disclosure modules in cancer prognostication. There was no consensus on the frequency of disclosure sessions; however, newly developed protocols have suggested having face-to-face interviews, at least twice, to deliver the information on prognostic disclosure.^{3,10}

Health care professional involved in prognostic disclosure

Professionals involved in actual prognostic disclosure were assessed in all the studies. Around 43 studies had explicitly stated the professionals or treating team members who were involved in prognostic disclosure. Four studies involved mental health professionals^{3,8,25,42} of which three studies exclusively involved psychiatrists in disclosure-related research^{3,8,25} while assistance from the clinical psychologist and psychiatric social worker was noted in other studies. As described in Table 1, the prognostic disclosure was carried out by trained researchers or research assistants in 14 studies but not clarified on their professional qualifications, treating physicians in 10 studies, treating oncologists in 5 studies, and nurses in 1 study¹² as compared with a combination of multiple HCPs in 9 studies as shown in Table 1. Very few studies indicated the direct involvement of medical or surgical oncologists in disclosure. This also highlights the difficulty in handling prognostic disclosure by oncologists. What factors determine such a discrepancy could be a topic of future research.

Discussion

This is the first review of its kind which has focussed on the communication methods used to unravel the collusion and systematically analyzed the techniques of prognostic disclosure among HCP, patients, and caregivers. Factors determining the collusion could be associated with any of the three persons involved in the triad of information exchange. From HCP's perspective, oncologists were found to be least involved in direct prognostic disclosure.³ This could be related to the perceived therapeutic nihilism and inadequacy in handling difficult questions posed by patients and caregivers during treatment. Physicians and other HCP are also worried about the deleterious effects of disclosing facts related to the bad prognosis of cancer and anticipatory non-compliance to further treatment and decisions about palliative care by patients and caregivers.

Only two studies involved psychiatrists in prognostic disclosure raise a critical question of inconsistent involvement of mental health professionals in collusion with associated researchers that should be emphasized in future palliative services. Another aspect of prognostic disclosure is the average time required for such sessions ranges from 22 min to 60 min while requiring multiple sessions for a few patients and families. Thus, a significant amount of dedication is expected from a treating team; therefore, having a team of regular palliative care specialists or mental health professionals could help in managing the collusion.² Since palliative care specialists and mental health professionals can address collusion as well as train fellow HCP with relative certainty, it is wise to expect them to develop consistent disclosure modules fitting the needs of end-of-life care. This would undoubtedly improve the quality of life of patients with cancer.^{2,3} One of the critical barriers in prognostic disclosure is the absence of uniform communication modules and training programs for HCP dealing with cancer patients, which may be explained by their limited utility to replicate the research findings across the world.

Unlike in developed countries, relatively sparse dedication and importance are given to the assessment and management of psychological concerns arising in the aftermath of cancer diagnosis and prognosis in developing countries. There is also a paucity of palliative care professionals in developing countries. The striking differences among decision-making models of west and east are also responsible for halting the progress of uniform training of HCPs to systematically assess individual factors in disclosure making. Recent decades have witnessed the shift among disclosure techniques from the 'patient's autonomy' to the 'family-centric model' in many countries.⁴⁹⁻⁵² This overlap is a result of cultural diversity and view of life and death from the family perspective. The transition from different stages of cancer and facing the end-of-life situation may not be an ordinary circumstance to be catered to by the medical model of 'patient autonomy'. Instead shared disclosure could be preferred by some patients and caregivers, which is substantiated by common family values in eastern countries. Although maintaining patient privacy and autonomy is of prime importance in the medical model, the shared caring and decision-making model of the family should equally be given priority. Therefore, sequential disclosure techniques maintaining

patient and family values could be perceived as the best disclosure modules in the future.⁵³

HCPs involved in the care of cancer patients play a significant role in navigating the disclosure preferences that eventually result in a systematic unraveling of collusion.⁵⁴ It is essential to have a face-to-face or video conferencing-based module starting with open-ended questions funneling into close-ended statements through the development of separate and structured protocols for patients and caregivers. Alternately routine evaluation of self-rated questionnaires can assist HCPs and caregivers in understanding the mental health trajectory of patients and readiness for disclosure. It is customary to believe that HCP should receive professional training to carry out such communication signaling within the triad effectively. This could also mitigate the burnout among HCP who are not equipped with the required disclosure tools.

Conclusion

Improvement in treatment adherence after healthy disclosure could be the ultimate success on the part of treating teams in palliative or hospice care. Nonreluctance to participate in a treatment and psychological breakdown process could be addressed by the uniform disclosure module with the help of palliative care specialists or mental health professionals. Currently, enough evidence substantiates the fact that prognostic disclosure does less harm than expected and future protocols should take care of patients' and caregivers' feelings of 'being understood'. It can be concluded that an average time required for any session of prognostic disclosure should be at least 30 min with a patient alone. Finally, considering the cultural diversity across the world, it is yet to see if the development of a universal disclosure module could fit well for a 'family-centric' as well as 'patient's autonomy oriented' approach than simply finding the best among the two.

Limitations

The review is limited to a few databases; hence, other methods of disclosure in other databases and the gray literature could have been missed, though a hand-search of the references was carried out. The review is not able to weigh the benefits of one communication practice over another because of limited studies on the evidence of effectiveness. Few studies have considered

diagnostic as well as prognostic collusion together, and therefore, it is difficult to see them separately as cancer care involves the continuum of care across several stages of the disease.

Implications

The review can provide a one-stop check on the available communication techniques and protocols used among cancer and palliative care services for prognostic disclosure. This could enable clinicians to keep up to date with evidence-based information about various communication methods and protocols followed during disclosure. The review also highlights the importance of developing the uniform communication paradigm as a potential area for future research.

Ethics approval and consent to participate

Not applicable as this is a systematic review of published literature.

Consent for publication

Not applicable for patient's consent. Both the authors give consent for the publication.

Author contribution(s)

Roshan Sutar: Conceptualization; Data curation; Investigation; Methodology; Project administration; Resources; Software; Supervision; Visualization; Writing – original draft; Writing – review & editing.

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Availability of data and materials

The data and material is available on request to corresponding author.

Supplemental material

Supplemental material for this article is available online.

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